Doctor of Nursing Practice Project

Titled

A Quality Improvement Project to Increase Advanced Practice Registered Nurse Self-Efficacy for Specialty Referrals of Patients with Early Symptoms of Dementia

by

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Abstract

Introduction: Dementia is a global issue that affects more than 55 million people yearly, with approximately 5-6% of these cases being classified as early dementia. Early dementia symptoms present as vague complaints, including memory loss, difficulty concentrating, an inability to carry out daily tasks, struggle to find the correct word in a conversation, confusion, and mood changes. Early recognition of these symptoms by advanced practice registered nurses (APRNs) and other healthcare providers can improve patient outcomes by offering them appropriate referrals and treatment.

Purpose: This project aimed to increase provider knowledge and self-efficacy surrounding early dementia symptoms by educating APRNs about early symptoms of dementia, its clinical significance, and how to manage the condition. The goal was to increase provider self-efficacy for early patient referrals for appropriate diagnosis and treatment as per the recommendations from the online training.

Methods: An educational module from the U.S. Department of Health and Human Services Health Resources and Services Administration was utilized with a pre-test post-test format in Qualtrics.

Results: Thirty-one participants completed the project in its entirety. Using the Wilcoxon signed rank test, both the dementia knowledge and the self-efficacy scores showed significant improvement after watching the educational module, with significance scores of $p= .025$ and $p= .029$, respectively.

Conclusion: Based on the results of this project, a simple evidence-based educational module has the potential to enhance APRN learning, thus improving patient management. Early and

complete evaluation by a specialty provider for those who have early dementia symptoms helps minimize delays in diagnosis and optimize patient care.

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A Quality Improvement Project to increase Advanced-Practice Registered Nurse Self-Efficacy for Specialty Referrals of Patients with Early Symptoms of Dementia

Dementia affects more than 55 million people globally, with approximately 10 million new cases diagnosed each year. The estimated annual cost of caring for these patients is $1.3 trillion US dollars (World Health Organization, 2023). Early dementia is a condition that involves symptoms that begin before the formal diagnosis of dementia (Spreadbury & Kipps, 2018). An estimated 5-6% of patients presenting with dementia present with symptoms before age 65 (Mayo Clinic, 2022). Symptoms of early dementia include memory loss, difficulty concentrating, an inability to carry out daily tasks, struggling to find the correct word in a conversation, confusion, and mood changes. Memory loss is frequently not the first symptom (Alzheimer’s Society, 2021). Typically, these patients will present with changes in personality or an inability to concentrate, visual difficulties, or language problems. Symptoms are often attributed to physiological changes or stress (Lo, 2017). Patients’ ages and health histories may cause providers to overlook dementia as a potential diagnosis, leading to misdiagnosis and improper management.

Early recognition, referral, and treatment by a provider, including APRNs, can yield improved patient outcomes and quality of life by allowing patients to preserve cognitive functioning and reserves to maintain optimal health (Cations et al., 2021). One way to help ensure improved outcomes is through educating APRNs on how to appropriately refer patients for appropriate medical management (Lawler et al., 2020). Early referrals will allow neurology and other specialty providers to order and receive approval for appropriate testing (including labs, CT scans, and MRIs).

The four-phase Outcomes Management Model guided this evidence-based quality improvement (QI) project and hoped to improve patient outcomes with early dementia symptoms (Melnyk & Fineout-Overholt, 2019).

Outcomes Management Model Phase One

Clinical Problem

Dementia is an organic, progressive disease of the brain that affects intellectual functioning impairs memory and leads to personality changes. Diagnosis typically occurs after age 65 but may develop as early as age 30 to 64 years. The broad nature of symptoms is often attributed to age-related changes or stress, meaning that early symptoms of dementia are often underdiagnosed or misdiagnosed (Spreadbury & Kipps, 2018; Lo, 2017). Diagnosis of early dementia is often delayed, leading to poorer patient outcomes and a decrease in the patient's quality of life (Cations et al., 2021).

Structure and Process/Background

Early recognition, referral, and treatment of dementia by a provider can yield improved patient outcomes by allowing the patient to preserve cognitive functioning and reserves and maintain optimal health (Couzner et al., 2022). One way to help ensure improved outcomes is through educating primary care advanced practice registered nurses (APRNs) on early dementia symptoms and how to appropriately refer patients for appropriate medical management (Lawler et al., 2020). The APRN can refer patients to neurologists and specialty providers, who can order and receive approval for appropriate testing (including labs, CT scans, and MRIs) more rapidly than a general-care provider (Cations et al., 2021). Increasing referrals for appropriate services can improve the patient's quality of life (Kimura et al., 2020).

Purpose and Goals of Project

The goal of this project was to increase provider knowledge and self-efficacy. The purpose was twofold: 1) to educate APRNs about early symptoms of dementia, its clinical significance, and how to manage the condition, with the goal of 2) increasing provider self-efficacy for early patient referrals for appropriate diagnosis and treatment as per the recommendations from an online training module.

PICOT Question

For APRNs (P), does completing a one-hour educational module on early symptoms of dementia (I) compared to no formal education or guidelines for practice (C) increase provider knowledge and self-efficacy for specialty referral rates of adults experiencing symptoms (O) throughout the module (T)?

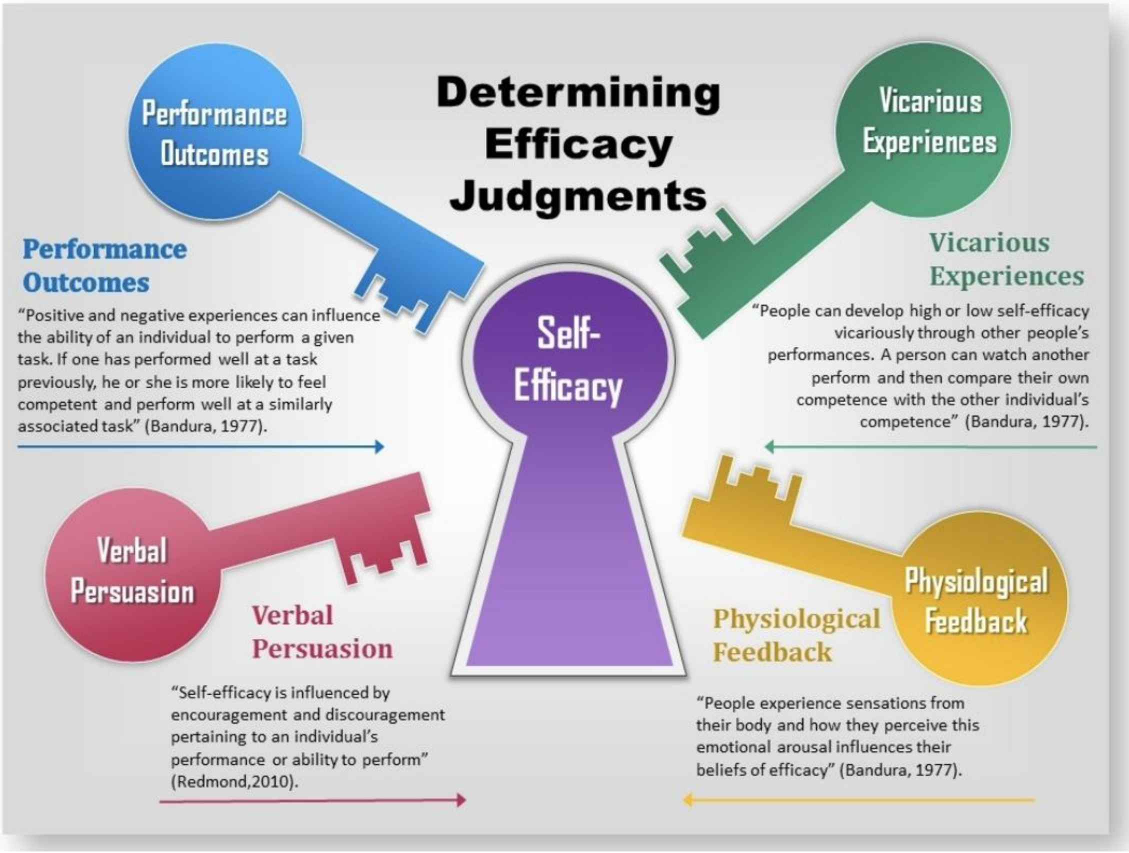
Outcome Target: Self-Efficacy

Self-efficacy is an individual's belief in their capacity to complete behaviors necessary to achieve specific behaviors and influences how individuals motivate themselves to behave a certain way (Bandura, 1994). Self-efficacy is an essential concept within health care and has been used as an effective strategy to improve outcomes for both patients and providers (Youngwanichsetha, 2022). Self-efficacy promotes initiating, adopting, and maintaining behaviors that yield positive outcomes in people's lives (Shorey & Lopez, 2021). Adequate knowledge and skills also influence behavioral patterns (Bandura, 2011).

Figure 1 depicts four components to achieving self-efficacy: verbal persuasion, physiologic feedback, vicarious experiences, and performance outcomes. Verbal persuasion and encouraging an individual's ability to complete tasks affect self-efficacy (Bandura, 1977; Bandura, 1994). For this evidence-based project, participants will be persuaded to take the initiative to refer patients with early dementia symptoms through an enhanced learning opportunity that benefits their practice. Physiological feedback is how the individual's body feels while taking initiative in behaviors promoting self-efficacy. Participants in the evidence-based project will have positive physiological feedback through the knowledge they are gaining from patients and promoting health outcomes.

Self-efficacy can develop vicariously through other people's experiences and by comparing their behaviors to those of others. Through their peers' participation in this project, advanced practice registered nurses (APRNs) promoted their self-efficacy and learned and improved their practice in treating patients with early-stage dementia.

Figure 1.
Self-efficacy Theoretical Model



"Positive and negative experiences can influence the ability of an individual to perform a given task. If one has performed well at a task previously, he or she is more likely to feel competent and perform well at a similarly associated task" (Bandura, 1977).

"People can develop high or low self-efficacy vicariously through other people's performances. A person can watch another perform and then compare their own competence with the other individual's competence" (Bandura, 1977).

"Self-efficacy is influenced by encouragement and discouragement pertaining to an individual's performance or ability to perform" (Redmond,2010).

"People experience sensations from their body and how they perceive this emotional arousal influences their beliefs of efficacy" (Bandura, 1977).

Note: The various components of Bandura's Self-Efficacy Theory. Adapted from Pennsylvania State University. (n.d.). *Self-efficacy theory*. Self-Efficacy Theory.

Performance outcomes are measures of how successful an individual was at a task; if an individual is successful in completing a similar task previously, they will be more likely to believe they will be successful on a new, similar task. The project participants completed a pre-test, a web-based learning module, and a follow-up test. The proposed format allowed the APRNs to advocate for their learning and allowed them to complete the task successfully due to its familiar format.

This evidence-based QI project promoted provider self-efficacy by educating APRNs about early dementia and its management. Education was accomplished by utilizing four strategies of the self-efficacy model: verbal persuasion, physiological feedback, vicarious experiences, and performance outcomes (Bandura, 1977).

Evidence-Based Quality Improvement Model

This evidence-based QI project was based on the four-phase Outcomes Management Model (Figure 2) as described in Melnyk and Fineout-Overholt (2019). Phase one involved identifying the clinical problem, the outcome targets, instruments, and data sources to prepare for baseline data measurement.

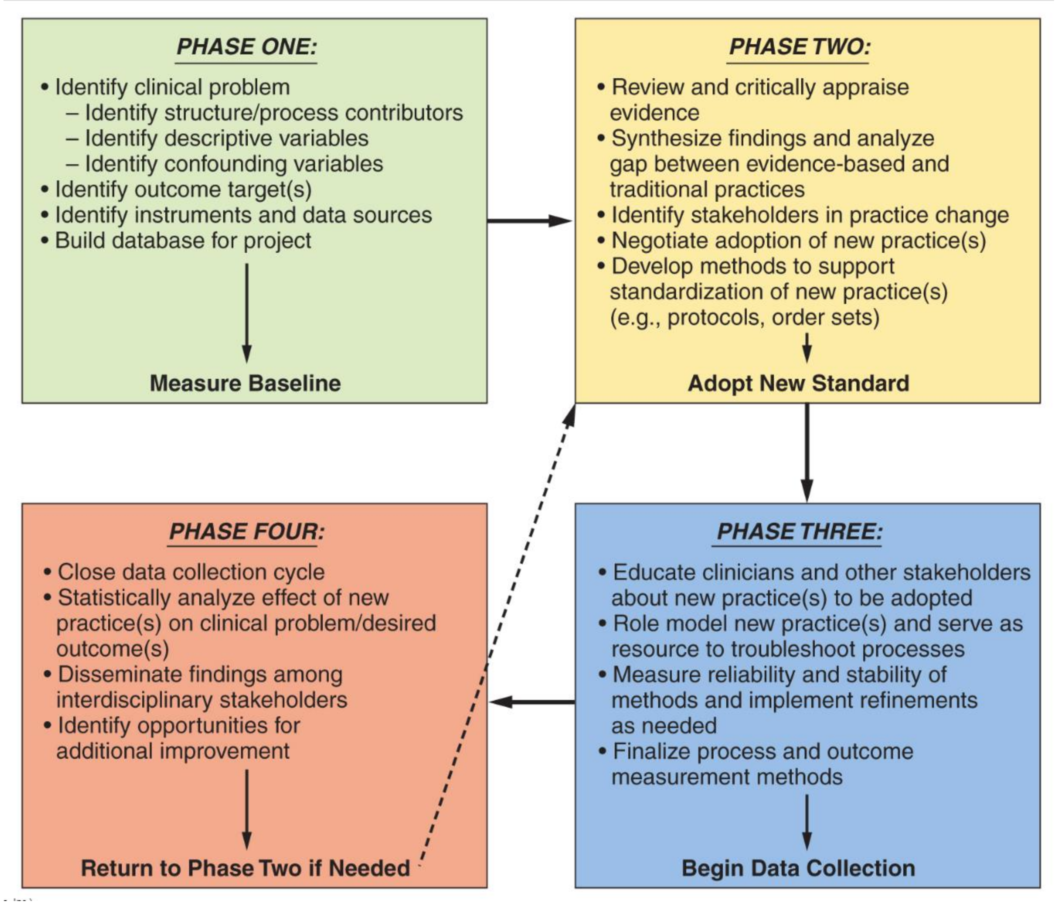
Phase two involved reviewing, appraising, and synthesizing the evidence, identifying stakeholders, and developing methods to support the standardization of new practices, with the goal of having the new standard adopted.

Phase three involved educating clinicians and stakeholders about the proposed evidence-based practice change, having them role model the new practices, and having the clinicians serve as resources to manage the processes better.

Phase four included dissemination of findings and an opportunity to make changes that will lend to stakeholder acceptance and sustainability of the new proposed process.

Figure 2.

Outcomes Management Model



Note: The phases of the Outcomes Management Model. Adapted from Melnyk, B.M., & Fineout-Overholt, E. (2019). *Evidence-Based Practice in Nursing and Healthcare: A Guide to Best Practice.*

Outcomes Management Model Phase Two

Literature Review

The literature demonstrated a need for evidence-based care changes in practice to improve the early diagnosis and treatment of dementia. Current literature supported the need for educating healthcare providers on young and early dementia symptoms; however, there was limited information on interventions specifically for APRNs. This is important to note because APRNs are a growing force in healthcare and significantly influence patient outcomes.

The overarching theme discovered in the literature is that there is a lack of knowledge among healthcare professionals on what proper care for patients with early dementia entails. There has been agreement between healthcare providers regarding the information that is crucial for healthcare providers to understand in treating these patients, but this knowledge needs to be more well-known and well-spread across disciplines (Couzner et al., 2022). Due to the neurologically and physically degenerative nature of this condition, the quality of life for the patient became another theme within the literature (Baptista et al., 2016). Awareness of disease, prognosis, and plan of care are associated with an improved quality of life must keep this in mind when providing care for these patients (Hvidsten et al., 2019).

The University's nursing librarian assisted in finding an educational module to use for this project. An advanced search in both CINAHL and MEDLINE databases with the main search of dementia, including the keywords of education, train, or learn; program, module, or course; nursing; and diagnose, detect, or screen. Additional research was completed in these databases to search for an appropriate self-efficacy definition and measurement tool.

Search Strategies

The databases used for the literature and evidence search were CINAHL, Ovid Nursing Database, ProQuest Nursing and Allied Health Source, and Health Source: Nursing/Academic Edition. Keywords to find evidence included: young-onset dementia (with screening, diagnosis, and treatment for some of the searches), evidence-based provider education, APRN education, quality of life dementia, self-efficacy model, and provider self-efficacy. Only evidence from academic journals written in English discussing early dementia from 2017 to 2023 were used.

The total number for the combined searches included more than 500 articles. Over 100 articles were reviewed, and a total of more than 25 were considered for the project (Figure 3). A year limit was not placed on theoretical and evidence-based model searches due to the theories being original works of the authors (Table 1).

Figure 3.
Search Strategies

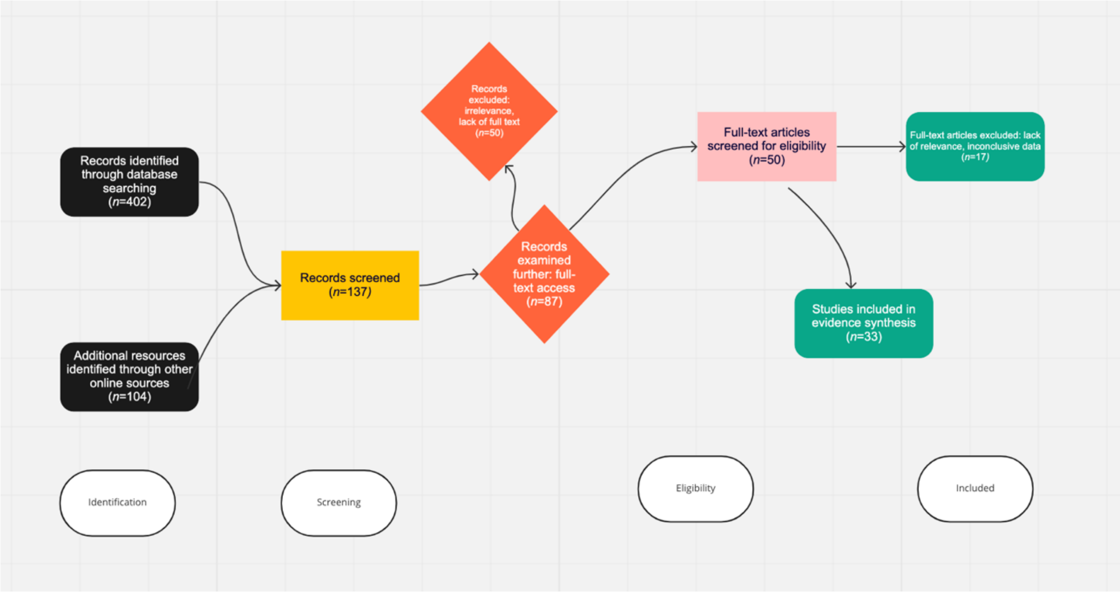


Table 1.

Literature Search Table

Search Date	Keywords combined with Boolean Phrases (AND, OR, NOT)	Limits/Filters/Qualifiers	Database	Total	Reviewed	Potential for Usage
01/18/2023	Dementia screening	Past 5 years; all journals; English language	Ovid Nursing Database	300+	15	3
01/18/2023	Early dementia diagnosis	Last 5 years; scholarly journals; English language	ProQuest Nursing and Allied Health Source	63	15	3
01/18/2023	Early dementia treatment	None	Health Source: Nursing/Academic Edition	1	1	1
01/19/2023	APRN education dementia	Last 5 years; scholarly journals; English language	ProQuest Nursing and Allied Health Source	4	3	1
01/19/2023	Evidence based provider education	2015-present; academic journals; English language; nurse practitioner	CINAHL Plus	1	1	0
01/19/2023	Evidence based provider education	Past 5 years; all journals; English language	Ovid Nursing Database	11	3	1
01/19/2023	Evidence based education	2018-present academic journals; English language; evidence-based education; evidence-based nursing	Health Source: Nursing/Academic Edition	25	7	3

01/21/2023	Quality of life dementia	2017-present; academic journals; English language	CINAHL Plus	11	11	1
01/21/2023	Quality of life early dementia	Last 5 years; scholarly journals; English language	ProQuest Nursing and Allied Health Source	24	4	2
06/09/2023	Self-efficacy model	None	Google Search	100+	3	3
06/09/2023	Self-efficacy model	English language	CINAHL Plus	100+	3	1
06/09/2023	Provider self-efficacy	English language	ProQuest Nursing and Allied Health Source	23	5	1
06/20/2023	Alzheimer’s Association	None	Google	1	1	1

Critical Appraisal and Evaluation of Evidence

Rapid critical appraisal tables and checklists from the text by Melnyk and Fineout-Overholt (2019) were used. The specific tools utilized included rapid critical appraisals and checklists for systematic reviews and meta-analyses of clinical intervention questions, descriptive studies, cohort studies, and qualitative evidence (Figure 4).

Figure 4.
Rapid Critical Appraisal Checklist for Systematic Reviews and Meta-Analyses of Clinical Intervention Question

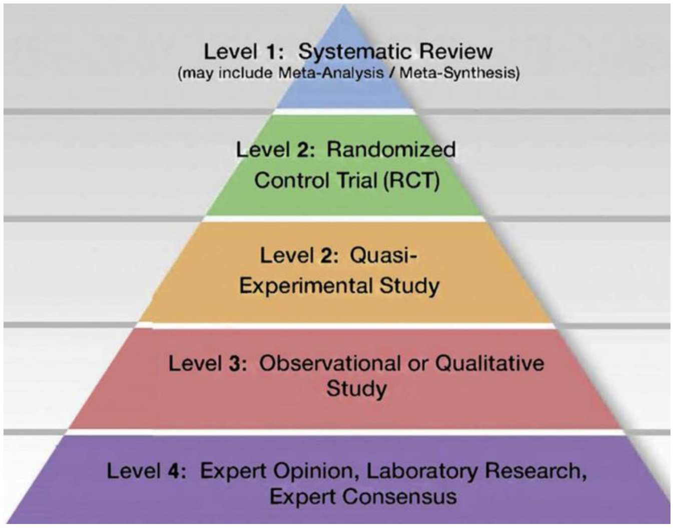
RAPID CRITICAL APPRAISAL QUESTIONS FOR SYSTEMATIC REVIEWS AND META-ANALYSES OF CLINICAL INTERVENTIONS QUESTION

VALIDITY			
1. Are the results of the review valid?			
a. Are the studies contained in the review randomized controlled trials (RCTs)?	Yes	No	Unknown
b. If not, were all relevant studies included in the review?	Yes	No	Unknown
c. Does the review include a detailed description of the search strategy to find all relevant studies?	Yes	No	Unknown
d. Does the review describe how validity of the individual studies was assessed (e.g., methodological quality, including the use of random assignment to study groups and complete follow-up of the participants)?	Yes	No	Unknown
e. Were the results consistent across studies?	Yes	No	Unknown
f. Were individual patient data or aggregate data used in the analysis?	Individual Aggregate		
g. Does the review include a description of how studies were compared using statistical analysis?	Yes	No	Unknown
RELIABILITY			
2. What were the results?			
a. How large is the intervention or treatment effect (OR, RR, effect size)?			
b. How precise is the intervention or treatment (CI)?			
APPLICABILITY			
3. Will the results assist me in caring for my patients?			
a. Are my patients similar to the ones included in the review?	Yes	No	Unknown
b. Is it feasible to implement the findings in my practice setting?	Yes	No	Unknown
c. Do the pooled or combined results of the studies support the hospital's values and goals of service delivery? (i.e., Is it feasible to implement the findings in my practice setting?)	Yes	No	Unknown
d. Were all clinically important outcomes considered, including risks and benefits of the treatment?	Yes	No	Unknown
e. What is my clinical assessment of the patient and are there any contraindications or circumstances that would inhibit me from implementing the treatment?	Yes	No	Unknown
f. What are my patient's and his or her family's preferences and values about the treatment that is under consideration?	Yes	No	Unknown
Would you use the study results in your practice to make a difference in patient outcomes? - If yes, how? - If yes, why? - If no, why not?			
Additional Comments/Reflections:			
Recommendation for article use within a body of evidence:			

Adapted from Melnyk, B.M., & Fineout-Overholt, E. (2019). Evidence-Based Practice in Nursing and Healthcare: A Guide to Best Practice.

Based on these assessments, the evidence was evaluated for reliability, validity, and applicability to the clinical question being asked. Further evaluation of the literature was completed using the Hierarchy of Evidence (Figure 5). This grades literature from I to IV, with I as the highest level of evidence (meta-analyses and systematic reviews) and IV being the lowest (expert opinion) (Melnyk & Fineout-Overholt, 2019).

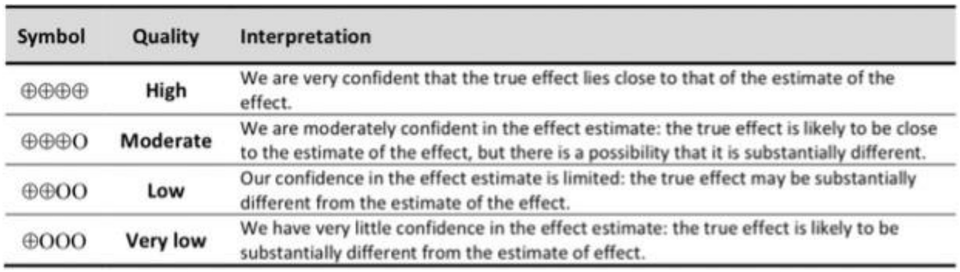
Figure 5.
Heirarchy of Evidence



Adapted from Melnyk, B.M., & Fineout-Overholt, E. (2019). Evidence-Based Practice in Nursing and Healthcare: A Guide to Best Practice.

After evaluating the literature for evidence levels, the evidence was examined using the Grading Recommendations Assessment, Development, and Evaluation (GRADE) system (Figure 6). This system evaluates the outcomes for quality of evidence. Ratings are based on an article's structure, including its design, consistency, directness, and variables used. Ratings range from "high" to "very low" (Ryan & Hill, 2016).

Figure 6.
GRADE: Quality of Evidence Based on Ratings and Interpretation

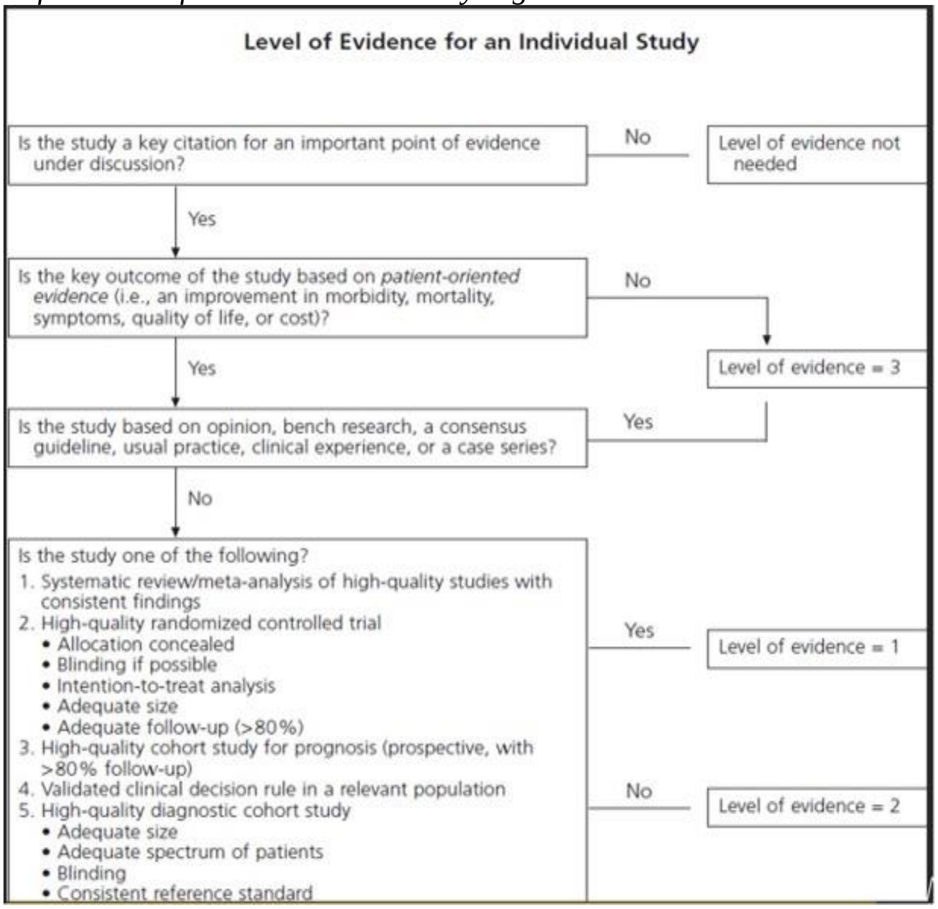


Symbol	Quality	Interpretation
⊕⊕⊕⊕	High	We are very confident that the true effect lies close to that of the estimate of the effect.
⊕⊕⊕O	Moderate	We are moderately confident in the effect estimate: the true effect is likely to be close to the estimate of the effect, but there is a possibility that it is substantially different.
⊕⊕OO	Low	Our confidence in the effect estimate is limited: the true effect may be substantially different from the estimate of the effect.
⊕OOO	Very low	We have very little confidence in the effect estimate: the true effect is likely to be substantially different from the estimate of effect.

Note: This table is used for assessing the quality of evidence based on GRADE ratings and their explanation. Adapted from Ryan, R. & Hill, S. (2016). How to GRADE the quality of evidence. *Cochrane consumers and communication group.*

Once the GRADE system was completed, the SORT Level of Evidence for an Individual Study Algorithm was used to determine the strength of each article (Ebell et al., 2004). As depicted in Figure 7, this system uses a rating system of A, B, or C to evaluate the strength of each article, with A being the lowest and C being the highest level of strength.

Figure 7.
SORT: Level of Evidence for an Individual Study Algorithm



Note: The algorithm used for deciding the strength of a recommendation based on a body of evidence as discussed by Strength of Recommendation Taxonomy (SORT). Adapted from Ebell, M. H., Siwek, J., Weiss, B. D., Woolf, S. H., Susman, J., Ewigman, B., & Bowman, M. (2004). Strength of recommendation taxonomy (SORT): A patient-centered approach to grading evidence in the medical literature. The Journal of the American Board of Family Practice, 69(3), 548-556.

The SORT system algorithm (Figure 8) gives the reader an appraisal recommendation, with ratings ranging from 1-3 where 1 is the highest quality of evidence and 3 is the lowest (Table 2).

Figure 8.

SORT: Strength of Recommendation Based on a Body of Evidence Algorithm

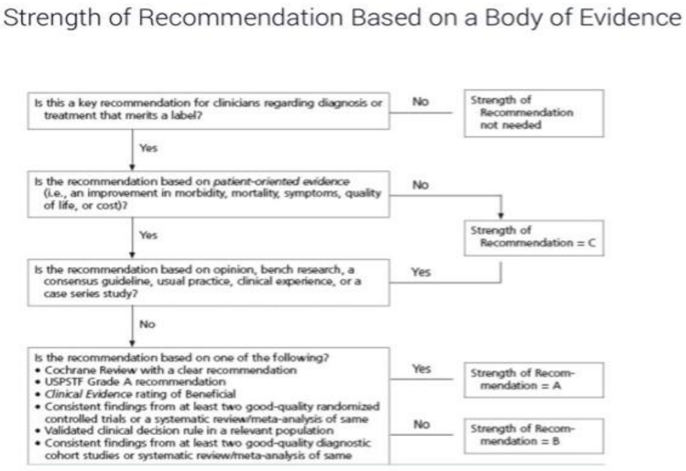


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Table 2.

Recommendations Derived from Evidence Synthesis

Recommendation	Strength of Evidence for Recommendations (SORT)	Citation in Support of Recommendation	Rationale	Level of Evidence (SORT)	Quality Rating (GRADE)
Recommends provider education to promote patient outcomes	C	Couzner et al., (2022)	People with dementia have unique needs and experiences, requiring care and support that is timely, appropriate, and accessible, meaning health professionals must have sufficient knowledge about the disease.	1	++++
	C	Lawler et al., (2020)	Educators planning dementia curriculum for allied health professionals could consider addressing areas of knowledge related to the identified items, with view to providing a foundation for excellence in dementia care.	1	++++
Recommends increased referrals to specialty services	C	Spreadbury & Kipps (2018)	Optimizing clinical care through medical management, referrals, empathy, education, and psychological support for patients and their caregivers is crucial to improve outcomes.	1	++++
	C	Kimura et al., (2020)	Quality of life was improved when patients had appropriate interventions through early referral to specialty services.	1	+++

Recommendation	Strength of Evidence for Recommendations (SORT)	Citation in Support of Recommendation	Rationale	Level of Evidence (SORT)	Quality Rating (GRADE)
Recommends education programs promote provider self-efficacy	C	Shorey & Lopez (2021)	The stronger a person's cognitive perception of self-efficacy, the higher they set their goals and commitment to achieve these goals. This helps to improve patient management and care outcomes. Educational programs should establish a sense of self-efficacy, which is crucial for acting independently and competently in the nursing profession.	1	+++
	C	Lopez-Garrido, 2020	A strong sense of efficacy promotes accomplishment by assuring individuals of their capabilities and ability to overcome challenges. Self-efficacy promotes the initiation, adoption, and maintenance of behaviors that yield positive outcomes people's lives. Adequate knowledge and skills also influence individual's behavioral pattern.	1	++++

Recommendation	Strength of Evidence for Recommendations (SORT)	Citation in Support of Recommendation	Rationale	Level of Evidence (SORT)	Quality Rating (GRADE)
Recommends identifying barriers to accessing care	C	Cations et al., 2021	It is important for everyone involved in healthcare decision-making to collaborate to effectively facilitate access to seamless care for patients and their families.	1	++++
	B	Dixit et al., 2021	In providing care and support for patients, factors such as burden, depression, and anxiety should be targets for intervention to improve access to care.	2	+++
Recommends implementing evidenced-based practice into patient care	C	O’Malley et al., 2020	Understanding the uniquely personal experience of people going through the process of diagnosis for dementia is essential to provide appropriate services. Patient’s values and experiences should be used to support and guide clinical decision-making.	1	++++

Synthesis of Evidence

Early Dementia Defined

Early dementia is a condition that involves symptoms of dementia that begin before the formal diagnosis of dementia (Spreadbury & Kipps, 2018). The most common source of early and young-onset dementia is frontal-temporal dementia, but can also be caused by vascular causes, genetic causes, Alzheimer's, and alcohol. Those with learning disabilities or cognitive impairments (namely Down Syndrome) are more likely to be affected (Alzheimer's Society, 2021).

Dementia may rapidly progress, cause physical problems with coordination and balance, and may contain a genetic component than other forms of dementia (Alzheimer's Society, 2021). Key early cognitive symptoms of dementia include memory loss, challenges with solving problems, confusion, misplacing items, difficulty completing daily tasks, the inability to retrace steps, and mood changes (O'Malley et al., 2020). Symptoms are progressive and non-curable but are manageable with proper care.

There is no cure for dementia of any form, but there are both drug and non-drug treatment options available for those suffering from symptoms of the condition. Medication treatments include antidepressants, cholinesterase inhibitors, and NDMA receptor antagonists. Donepezil (Aricept), a cholinesterase inhibitor, and memantine (Namenda), an NDMA receptor antagonist, are typical first-line medications used to treat symptoms of dementia (Cations et al., 2021). Although they work in different ways, both donepezil and memantine work to improve memory, attention, and the ability to perform daily tasks. Non-medication options include supportive care (physical, occupational, and speech therapies), counseling services, staying active, and more experimental treatments including deep brain stimulation. Effective treatment for early symptoms is a combination of medication therapy and supportive care that is begun early in diagnosis.

Testing for Early Dementia

Diagnostic tests for dementia include mental ability tests, blood work, and brain scans (Alzheimer’s Society, 2021). Mental ability tests are readily available in any primary care provider’s office and include the Mini-Mental Status Exam (MMSE) and the Montreal Cognitive Assessment (MoCA). Lab work should be focused on eliminating any causes for the patient’s symptoms, such as vitamin deficiencies or infection. Genetic testing may also be useful in certain forms of dementia. Brain scans are the most crucial tool in diagnosing early symptoms of dementia. Computerized tomography (CT) scans and magnetic resonance imaging (MRI) provide an in-depth look at the brain, its structures, and any other disease processes that may exist (e.g., strokes or tumors) and cause symptoms like those found in early dementia (Alzheimer’s Society, 2021; Elhusein et al., 2018).

Significance of Early Dementia

Negative changes in quality of life due to mismanaged care is the largest complaint from dementia patients and their caregivers (Dixit et al., 2021). Patients with dementia often find that their employment, finances, and interpersonal relationships all suffer due to their illness being mismanaged due to delayed diagnosis. Further, costs of care increase exponentially for those suffering from dementia that is not well managed (Alzheimer’s Association, 2023). These costs include medications, therapies, healthcare provider visits, and potentially at-home or skilled facility nursing care. Many of these costs can be delayed with prompt patient management.

Provider Education and Importance of Referral

While specific baseline data on referral numbers is not available, data suggests that early referral is important for improved patient outcomes. Much of the literature focuses on physicians, excluding the importance of interdisciplinary and collaborative care. The significance of proper healthcare provider education about early dementia symptoms includes treatment and prognosis. Proper early management of the patient includes the referral to appropriate services for diagnostic testing and prompt intervention (Baptista et al., 2016; Cations, 2021).

There are three main stages in which providers need to be educated to optimize care for patients, demonstrating the overarching theme of proper education for care for providers. The stages are pre-diagnosis, diagnosis, and post-diagnosis (Spreadbury & Kipps, 2018). In the pre-diagnosis stage healthcare providers recognize symptoms as organic and refer patients to appropriate specialties. During the diagnosis stage, the patient undergoes testing using a variety of diagnostic tools. Tools for diagnosis include in-office mental status exams, blood work, and brain imaging. In the post-diagnosis stage, coping and adjusting to the diagnosis occurs. Optimizing clinical care through medical management, empathy, education, and psychological support for patients and their caregivers also occurs during the post-diagnosis.

There is a lack of literature specifically focused on the care of advanced practice registered nurses (APRNs) and the care of patients with early dementia. There are however studies aimed at general healthcare provider knowledge related to the topic (Couzner et al., 2022). Due lack of peer-reviewed evidence-based literature, it is appropriate to appraise studies highlighting learning interventions for healthcare providers and apply them to the education preparation of APRNs.

The APRN and Early Dementia Care

APRNs are increasing in number and more patients are seeking care from APRNs as their primary provider (Norful et al., 2019). Dementia is a cognitively, neurologically, and physically debilitating condition at every stage, providers must be adept in the diagnosis and treatment of patients (Elhusein et al., 2018). Nurses and APRNs are unique in their approach to care in that they treat the patient holistically, not just their disease state. The literature has demonstrated the value of using APRNs across a variety of health specialties. In terms of managing dementia care, APRNs have been instrumental in managing patients and improving their outcomes; further, APRN-led educational initiatives have demonstrated satisfaction among stakeholders, and they felt like their care was being appropriately managed (Fortinsky et al., 2014). There was no literature regarding the Doctor of Nursing Practice (DNP) prepared APRN and dementia care.

Methods to Promote Standardization of New Care Practices

The methods for this evidence-based QI project are based on the Outcomes Management Model as described in Melnyk and Fineout-Overholt (2019). The first started with a robust literature search related to the clinical problem related to early symptoms of dementia and identifying the outcome targets. The data sources were APRNs known to the student, members of the Ohio Nurse Practitioner Facebook Group, members of the OAAPN, and American Medical Directors Association/The Society for Post-Acute and Long-Term Care Medicine (AMDA/PALTC) conference attendees participating in the project and the baseline data will be their survey responses.

The goal of phase two was to adopt the evidence-based standard practice change. The literature search and review for this phase has begun with the evidence synthesis table as seen in Appendix A.

Stakeholders for this project were identified as APRNs who were members of the above organizations. APRNs who known to the student were sent the Qualtrics link, those who were members of the Facebook Group were invited to participate in this project through a series of posts, members of the OAAPN were invited through an email blast from the OAAPN board and through a QR code at local meetings, and business cards containing a QR code to the project were handed out at the AMDA/PALTC conference (Appendix B). The invitation contained the link to the survey, with the opening page being the informed consent (Appendix C). APRNs of all specialties were allowed to participate and were asked to identify their area of practice in the pre-survey for demographic data (Appendix D). Providers were not excluded based on areas of practice. A second group of stakeholders included the project committee, comprised of PhD-and DNP-prepared nurses to guide the project, and a DNP-prepared APRN in neurology served as a content expert.

Phase three measured the reliability and stability of methods, and implements any changes as needed. The educational module was completed in this phase. The educational module was from the U.S. Department of Health and Human Services Health Resources and Services Administration (U.S. DHHS HRSA).

Data collection occurred before and after the intervention. Data sources included answers from participant survey responses both before and after the module. Qualtrics software was used to obtain data from participants. The educational module was held online. It consisted of a PowerPoint with a visual and auditory format to promote participant learning. Proper and improper management was discussed, providing the APRNs with a more comprehensive example of how patients should be managed.

Phase four consisted of final data collection and to measure outcomes and determine if perceived-self efficacy increased and whether APRN knowledge was enhanced through the learning module. SPSS software was used for data analysis.

Outcomes Management Model Phase Three

Educate Clinicians about the New Practices to be Adopted

The need for educating providers on early dementia symptomatology and management has been well documented. As the population in the United States ages, symptoms of dementia must be recognized early on to properly manage care for many people. Educating APRNs on the early symptoms of dementia and how to promote self-efficacy in proper management for patients is a crucial step for improved clinical outcomes. The U.S. DHHS HRSA has provided free educational and evidence-based guidelines for healthcare professionals to help promote education on dementia-related topics, including early symptom management. These guidelines were published in 2018 and promote self-efficacy for managing care by appropriately educating providers on what to do to help patients presenting with early dementia symptoms.

The DNP student formed a team of a chair and two committee members and found a content expert in the form of a DNP in neurology. The project was completed over two months, February through March of 2024.

The project consisted of four sections. The first portion was recruitment, which happened through the student, the Ohio Nurse Practitioner Facebook Group, the OAAPN, and those attending the AMDA/PALTC conference. The DNP student directly sent the Qualtrics project link to APRNs known to the student. Facebook posts were made visible to members asking them to participate in the evidence-based project. The OAAPN sent an email to members notifying them that the project was available on their website, with a link directing them to the project;

they were also presented with a QR code at local chapter meetings. Business cards with QR codes linked to the project were utilized at the conference. Once participants agreed and completed consent to participate held within the project on Qualtrics, there was a questionnaire consisting of a knowledge pre-check and demographic information, including how long the practitioner has been practicing and what their area of expertise is.

An important component of the intake process was to determine if participants had seen patients with symptoms of dementia previously and how they managed their care. All information was anonymously stored in a secure online repository, managed only by the study's primary investigator and the project chair.

The third section was the educational online module about the clinical management of patients with the condition. Education was completed by APRNs who were known to the DNP student, who were members of the Ohio Nurse Practitioner Facebook Group, the OAAPN, and who attended the American Medical Directors Association/The Society for Post-Acute and Long-Term Care Medicine (AMDA/PALTC) conference in March of 2024

The final section of the project included having participants complete an online follow-up questionnaire that followed the educational module. The follow-up questionnaire was used to measure participant knowledge about early dementia symptoms, and the self-efficacy evaluation of participants using general knowledge questions from the HRSA module and Chen's self-efficacy scale.

Sample

A convenience sample of APRNs completed the QI project. This included APRN colleagues of the student, the Ohio Nurse Practitioner Facebook Group, the OAAPN, and those who attended the AMDA/PALTC conference in March of 2024. There were various ways to access the project survey. Social media and the OAAPN website posts contained a Qualtrics link that took participants directly to the project. The QR code allowed for participants to access the project through their mobile devices.

Eligibility requirements included participants who: 1.) were at least 18 years of age, 2.) could provide voluntary implied consent, and 3.) held a current APRN license.

Role Modeling New Practices

The intervention was in the form of an online questionnaire and educational module from the U.S. DHHS HRSA (Appendix E). There were immediate pre- and post-tests in Qualtrics to determine if APRN self-efficacy and early dementia knowledge improved after the module (Appendix F).

Role Responsibilities

Implementing the evidence-based project required participation from APRNs colleagues of DNP student, members of the Ohio Nurse Practitioner Facebook Group, the OAAPN, and those who attended the AMDA/PALTC conference. The DNP student posted the project at various times over the span of the eight-week timeframe. The intervention took place online, and participants completed the questionnaires and module when they chose to.

Barriers

Potential barriers for this project included a lack of participants and responders, the limited timeframe to complete the project, internet connectivity issues, and if someone did not have a smart device or computer.

Facilitators

The doctoral project chair and committee helped the DNP student by guiding them through the processes and procedures needed to be successful. A nurse practitioner specializing in neurology served as a mentor and content expert, providing tools and resources related to the content of the project. Other facilitators included the DNP student, the APRNs who volunteered to take the survey, the members of the Ohio Nurse Practitioner Facebook Group, the OAAPN, and the participants at the AMDA/PALTC conference.

Approvals

Approval was obtained from the Ohio Nurse Practitioner Facebook Group chairperson (Appendix G). The University's IRB granted approval and exempt status on January 31, 2024. The project population was not considered a vulnerable population and had minimal associated risks. The OAAPN application to distribute the project to members was completed on February 5, 2024, and approval was given on February 19, 2024, and the organization posted the project to their website and emailed a link to all members.

Project Implementation Timelines

A project implementation timeline (Table 3) was designed and utilized to help ensure the project was completed in a timely fashion.

Table 3.
Planning for Implementation Timeline

Planning for Implementation	Timeline
1. Assess the Need for Change in Practice PICOT: For APRNs (P), does completing a one-hour educational module on early symptoms of dementia (I) compared to no formal educational or guideline for practice (C) increase provider knowledge and self-efficacy for specialty referral rates of adults experiencing symptoms (O) over the course of the module (T)?	January 2022
2. Locate the Best Evidence • Literature Search • Literature Review	January 2022 through August 2022

Planning for Implementation	**Timeline**
3. Critically Analyze the Evidence Critical Appraisal of Literature Rapid Critical Appraisal Hierarchy of Evidence Strength of Evidence Strength of Recommendation Literature Synthesis	January 2022 through August 2022
4. Design Practice Change	
Select outcomes to be measured	May 2022
Design Evidence-Based Practice Project	May 2022
Select chair	May 2022
Select committee members	May 2022
Obtain study site permission	November 2023
Defend proposed Evidenced-Based Practice Project	December 2023
5. Implement and Evaluate Change in Practice	
Obtain IRB approval	January 2024
Implement Evidence-Based Practice Project	February 2024
Data Collection and Analysis	March 2024
Evaluate Processes and Outcomes	March 2024
6. Defend DNP Scholarly Project and Integrate and Maintain Change in Practice	April 2024

Project Implementation

Approval from the University's Institutional Review Board was granted on January 31, 2024. Upon receiving approval, various methods to gather participants were utilized between February 5 and March 23, 2024. During this time, the student reached out directly to APRNs to complete the project. Other recruitment strategies were through the OAAPN, the Ohio Nurse Practitioners Facebook group, and the American Medical Directors Association/The Society for Post-Acute and Long-Term Care Medicine (AMDA/PALTC). The OAAPN application to distribute the project to members was completed on February 5, 2024, with approval given on February 19, 2024. At this time, OAAPN posted the project to their website and emailed a link to all members of the organization. Social media posts were made to the Ohio Nurse Practitioners

Facebook group between February and March of 2024. Two hundred fifty business cards containing a QR code linked to the project on Qualtrics were ordered, and approximately 125 were distributed at the AMDA/PALTC national annual conference between March 9 and 11, 2024 in San Antonio, Texas.

Begin Data Collection

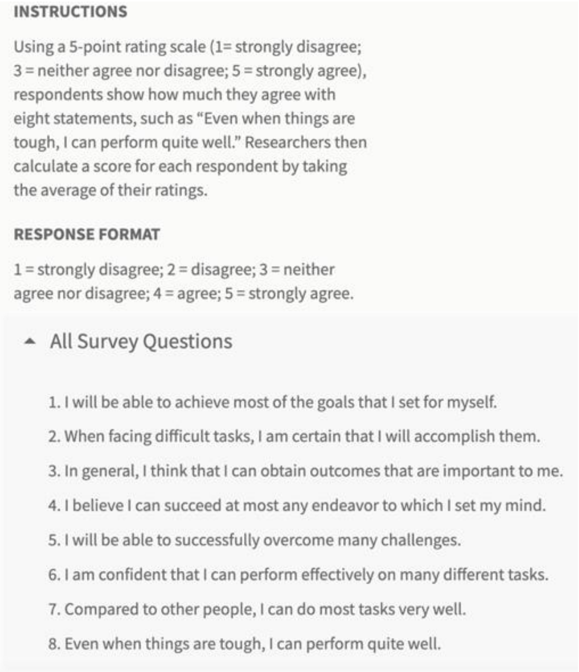
Outcome Measure One

The first outcome measure assessed knowledge of care for patients with early dementia symptoms. The four questions appeared in the QI presentation titled *Understanding the Early Stage of Dementia for an Interprofessional Team*, as received by the U.S. Department of Health and Human Services. They were extracted from the presentation and used to assess knowledge of managing care for patients with early dementia symptoms.

Outcome Measure Two

The second outcome measure was self-efficacy, which was assessed with the New General Self-Efficacy Scale (NGSES, Figure 9) developed by Chen and associates (2001). This scale is an eight-item questionnaire that measures how much people believe they can accomplish goals in the face of difficulty (Chen et al., 2001). It takes less than three minutes to complete, was written at an accessible level, and is available for use to the public (Stanford University, n.d.). The NGSES has been demonstrated as a valid and reliable tool to measure self-efficacy in multiple studies and is useful in assessing APRNs’ belief in their ability to follow guidelines for early dementia symptoms (Chen et al., 2001). The scale itself was not changed, but rather APRNs were asked to think about their self-efficacy related to managing care for and referring patients with early dementia symptoms.

Figure 9.
The New General Self-Efficacy Scale



INSTRUCTIONS

Using a 5-point rating scale (1= strongly disagree; 3 = neither agree nor disagree; 5 = strongly agree), respondents show how much they agree with eight statements, such as "Even when things are tough, I can perform quite well." Researchers then calculate a score for each respondent by taking the average of their ratings.

RESPONSE FORMAT

1 = strongly disagree; 2 = disagree; 3 = neither agree nor disagree; 4 = agree; 5 = strongly agree.

▲ All Survey Questions

1. I will be able to achieve most of the goals that I set for myself.
2. When facing difficult tasks, I am certain that I will accomplish them.
3. In general, I think that I can obtain outcomes that are important to me.
4. I believe I can succeed at most any endeavor to which I set my mind.
5. I will be able to successfully overcome many challenges.
6. I am confident that I can perform effectively on many different tasks.
7. Compared to other people, I can do most tasks very well.
8. Even when things are tough, I can perform quite well.

Adapted from Chen, G., Gully, S. M., & Eden, D. (2001). Validation of a new general self *efficacy scale. Organizational Research Methods, 4(1), 62-83.*

Long-Term Target Outcome

The long-term target outcome for this project is to improve care access for people with early dementia symptoms and referral rates to neurology and specialty services, which is believed will improve patient outcomes.

Outcomes Management Model Phase Four

Data Collection and Analysis Plan

Data was collected in the University's Qualtrics software and was stored securely there until extraction. Data was then analyzed using IBM SPSS (version 29). For both the dementia knowledge screening and the self-efficacy scale, descriptive statistics were examined so that only valid cases were included. Thirty-four participants started the process, with 32 completing the demographic questionnaire, and 31 completing the project in its entirety. After examining the data and using the statistics testing decision tree provided in Grove and Cipher (2025), it was determined that the non-parametric Wilcoxon signed rank test on summed data would be appropriate to assess for change and significance for both the dementia knowledge questions and the self-efficacy scale (Appendix M). Each knowledge question on the dementia knowledge questionnaire was recorded as "correct=1" and "incorrect=0." Then, the sum of the correct responses was used to run the Wilcoxon signed rank test. For the self-efficacy scores, the non-parametric Wilcoxon signed rank test was performed to compare the scores on the tests to assess the data pairs (pre- and post-test scores) to evaluate for significance. Testing for violations of assumptions in parametric testing was not completed. The data analysis plan was discussed with the committee chair and was confirmed as appropriate by talking to a biostatistician at the University.

Outcomes of Project

Demographics

Thirty-four participants began completing the demographic portion of the survey, but only 31 completed it in its entirety. Two participants were ineligible to continue and were dismissed from continuing: one was interested in becoming an APRN and one was an APRN student, and therefore could not finish the survey. Demographic data was collected from the remaining 32 participants (Table 4).

Table 4.
Demographic Characteristics of Sample

Demographic Data (n = 32)			
Characteristic	Response	Frequency	Percent
	APRN, currently practicing	27	84.45%
	APRN, not currently practicing	5	15.6%
APRN certifications held	CNS	0	0%

	Adult-Gerontology Acute Care Nurse Practitioner	3	9.4%
	Adult-Gerontology Primary Care Nurse Practitioner	7	21.9%
	Pediatrics Acute Care Nurse Practitioner	1	3.1%
	Pediatrics Primary Care Nurse Practitioner	0	0%
	Family Nurse Practitioner	21	65.6%
	Neonatal Nurse Practitioner	0	0%
	Certified Nurse Midwife	0	0%
	Women's Health Nurse Practitioner	0	0%
	Psychiatric Mental Health Nurse Practitioner	0	0%
	Certified Registered Nurse Anesthetist	0	0%
	Multiple specialties/Other/Not listed here	0	0%
Years as an APRN	0-4	14	43.8%
	5-10	11	34.4%
	11-15	3	9.4%
	16-20	2	6.3%
	More than 21 years	2	6.3%
Ever identified early dementia symptoms	No	10	31.3%
	Yes	22	68.8%
Refer patient with early dementia symptoms to specialty provider	No	9	40.9%
	Yes	13	59.1%
Age of APRN	20-29	6	18.8%
	30-39	12	37.5%
	40-49	6	18.8%
	50-59	5	15.6%
	60-69	2	6.3%
	Over 70 years old	1	3.1%

Gender of APRN	Female	23	71.9%
	Male	4	12.5%
	Non-Binary	2	6.3%
	Prefer not to say	3	9.4%
Spanish, Hispanic, or Latino	No	27	84.4%
	Yes	5	15.6
Ethnicity of APRN	Asian or Pacific Islander	0	0%
	Black or African American	1	3.1%
	Native American or Alaskan Native	0	0%
	Native Hawaiian or Pacific Islander	1	3.1%
	White or Caucasian	25	78.1%
	Multiracial or Biracial	0	0%
	Not listed/Other	4	12.5%
	Prefer not to say	2	6.3%

Results and Findings

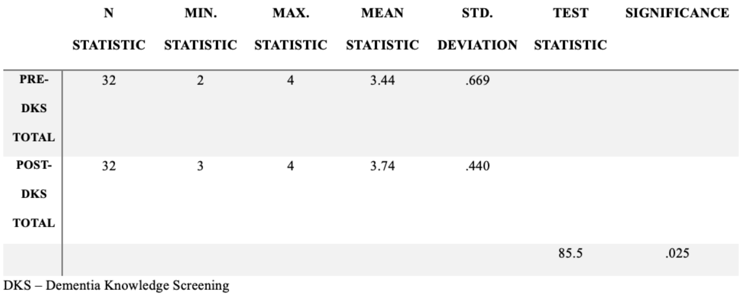
Thirty-one participants completed the pre-intervention and post-intervention questions for both dementia knowledge and self-efficacy in their entirety. This sample size was deemed adequate for the type of statistical analysis used. The dementia question responses were evaluated for correctness before and after the module. Self-efficacy for managing dementia care was evaluated to see if participants had a higher level of perceived self-efficacy to appropriately manage care for patients with early dementia symptoms.

Outcome target: Dementia knowledge

The first outcome target was to improve dementia knowledge among APRNs. The Wilcoxon signed rank test of summed pre- and post-dementia knowledge questions demonstrated a significant difference, with a value of .025 (Table 5; Figure 10).

Table 5.

Dementia Knowledge Results Table – Wilcoxon Signed Rank Test

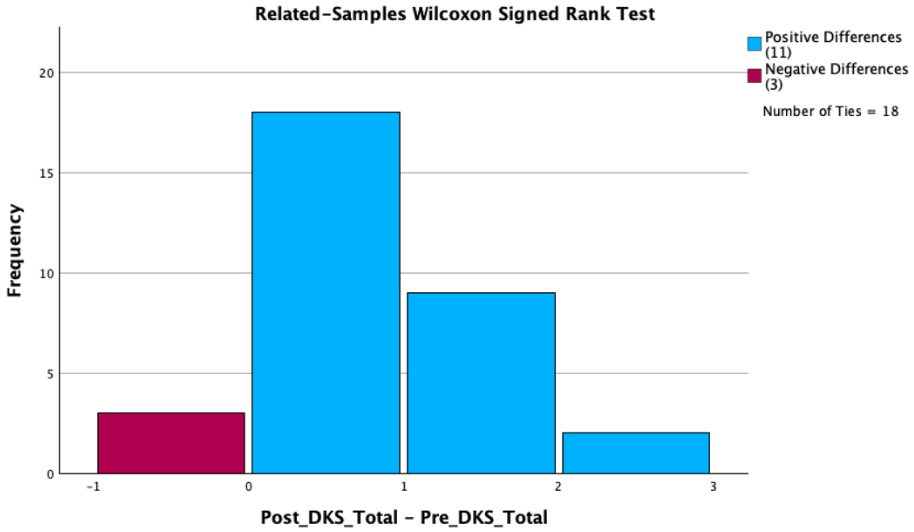


	N STATISTIC	MIN. STATISTIC	MAX. STATISTIC	MEAN STATISTIC	STD. DEVIATION	TEST STATISTIC	SIGNIFICANCE
PRE-DKS TOTAL	32	2	4	3.44	.669		
POST-DKS TOTAL	32	3	4	3.74	.440		
						85.5	.025

DKS – Dementia Knowledge Screening

Figure 10.

Dementia Knowledge Results Graph – Wilcoxon Signed Rank Test



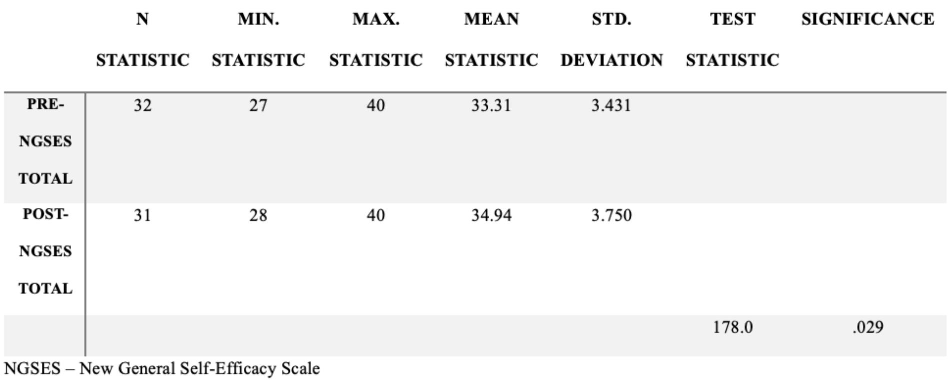
The overall knowledge about early dementia improved after the educational module.

Outcome target: Self-efficacy

The second outcome, self-efficacy, was measured before and after the educational module using the New General Self-Efficacy Scale by Chen and associates (2001). The Wilcoxon signed rank test of the pre- and post-scales demonstrated a significant difference in perceived self-efficacy for managing patients with early dementia symptoms after the module, with significance value of .029 (Table 6; Figure 11).

Table 6.

Self-Efficacy Results Table – Wilcoxon Signed Rank Test

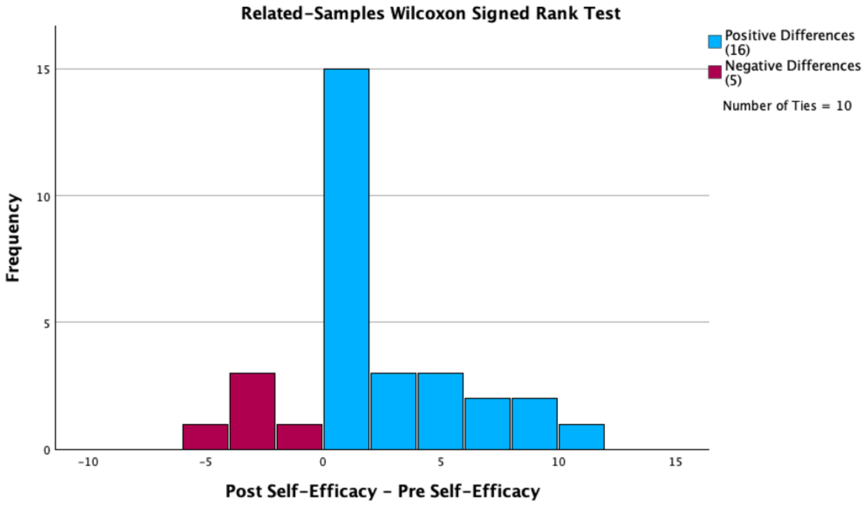


	N STATISTIC	MIN. STATISTIC	MAX. STATISTIC	MEAN STATISTIC	STD. DEVIATION	TEST STATISTIC	SIGNIFICANCE
PRE-NGSES TOTAL	32	27	40	33.31	3.431		
POST-NGSES TOTAL	31	28	40	34.94	3.750		
						178.0	.029

NGSES – New General Self-Efficacy Scale

Figure 11.

Self-Efficacy Results Graph – Wilcoxon Signed Rank Test



Based on the results, it is arguable that the educational module helped to achieve the target outcome of improving provider self-efficacy.

Significance

Results from the data analysis demonstrated that both basic early dementia knowledge and self-efficacy for managing patient care needs had a significant change after the module. The PICOT question posed was “For APRNs (P), does completing a one-hour educational module on early symptoms of dementia (I) compared to no formal educational or guideline for practice (C) increase provider knowledge and self-efficacy for specialty referral rates of adults experiencing symptoms (O) throughout the module (T)?" Although the sample size was limited, based on the project data results it can be argued that the module did help to increase both APRN knowledge and self-efficacy for specialty referral rates of adults experiencing symptoms.

Discussion

Current evidence has demonstrated a need to better educate healthcare providers about early dementia, its symptoms, and its care. Further, there was no literature specifically on how APRNs can influence care for patients with early dementia symptoms. Based on this need, this project aimed to fill a gap in education for providers. This evidence-based project provided a quick educational module for APRNs to help them feel more confident in caring for patients with these symptoms, including referring the patient to a specialty provider to ensure appropriate care is given.

This project has the potential to influence healthcare in an economic manner. Referring patients to appropriate specialty providers ensures that the patient is not using healthcare resources unnecessarily, and that only the appropriate tests are being ordered for the patient. This helps to ensure dollars are not being spent egregiously, saving the patient, the insurance company, and the healthcare system money. Appropriate and accurate testing leads to a better treatment plan and health outcome for the patient, which means dollars are not spent on unnecessary measures. Finding accurate information resources to help manage care for patients with early dementia symptoms is also easily accessible online at no cost.

This project contributed to evidence-based practice by demonstrating the effectiveness of an online module to educate APRNs. This format of education is affordable and accessible, making it an effective means of disseminating accurate information to those who need it. By providing APRNs with a quick educational module on early dementia symptoms, patient care can be improved by ensuring they receive the care they need. The data demonstrated that providers were more knowledgeable regarding basic information on early dementia symptoms, and that they felt more comfortable and had improved self-efficacy to their patient's ensure care needs were met.

Future Recommendations and Conclusions

Recommendations

Recommendations based on this project include early and complete evaluation for those who have early dementia symptoms by a specialty provider. A simple, evidence-based educational module has the potential to enhance APRN learning, thus improving patient management. This evidence-based QI project can impact APRN practice. Being aware of early symptoms of dementia can help minimize delays in diagnosis or misdiagnosis of the condition. Differential diagnoses are broad with symptoms that mimic other conditions (Couzner et al., 2022; Elhusein et al., 2018). Educating APRNs promotes their self-efficacy to manage care for patients experiencing symptoms of the condition appropriately.

Opportunities for Improvement

The limitations for this project include the limited sample size and the number of incomplete surveys that were recorded. Convenience sampling was utilized to obtain participants for this project. More recruiting measures, including email blasts, paper flyers, and the use of other social media platforms and conferences could be utilized to have a larger number of participants. This leads to the potential of a Type II error, although this is minimized by having significance in both dementia knowledge and self-efficacy improvement. To encourage participants to complete the survey in its entirety, incentives could be utilized in the forms of gift cards, or raffles for prizes. (This would mean that the format would change, and emails would need to be collected to ensure incentives reach the user upon completing the project.) Internet connectivity issues served as a limitation; the video portion of the survey was delayed or did not load for all participants, potentially influencing the low sample size. In the sample there were five APRNs who were not currently practicing, which could have affected the data in terms of dementia referrals in their current practice.

The strengths of this project include its affordability, its ease of use, and its accessibility. The information was evidence-based and readily available for APRNs to use at no cost. The information in the module was presented in a way in which it was easily available to APRNs. The information for the project as well as the project itself was web-based, free to use and accessible on any electronic device the user had available. Although the sample size was limited, there was enough data to be adequate for the type of statistical testing performed to determine significant improvement in both outcome targets.

Next Steps and Conclusions

Next steps for this project are to include other medical professionals beyond APRNs, namely physician assistants and physicians. This would help to increase sample size and to spread the survey to a larger population, making the data more reliable and valid. To further spread the survey and module, different measures can be used, including email and social media blasts across different groups, paper flyers, and targeting healthcare systems. Further, making the project design more interactive would potentially help to increase its spread and sample size.

Plans for this project include dissemination of findings. The abstract of this project was submitted to present at the annual Michigan Council of Nurse Practitioners (MICNP) conference in October of 2024. The project was also submitted to the Institute of Professional Nursing for and educational award. The survey links were left active so that data collection could continue after the project deadline so more information could be gathered. The new data will be combined and reanalyzed with the data used for this project. Once this is complete, the project will be submitted for publication.

With the increasing number of APRNs joining the workforce yearly, APRNs need to be able to recognize and manage early-stage dementia to optimize their patients’ health. APRNs are equipped to treat their patients holistically and have been proven to be a valuable resource in healthcare. Eliminating probable causes for symptoms is important, but care should not be delayed while waiting for other potential diagnoses. Early recognition and management of dementia optimizes patient outcomes.

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Appendix A.

Synthesis Evaluation Table and Comparison of Literature on Level

Citation	Conceptual Framework	Design/ Method	Sample/Setting	Major Variables Studied and Their Definitions	Outcome Measurement	Data Analysis	Findings	Level of Evidence	Quality of Evidence: Critical Worth to Practice
Author Year Title County Funding	Theoretical basis for study		Number Characteristics Exclusion criteria Attrition	Independent variables IV1 = IV2 = Dependent variables	What scales used - reliability info (alphas)	What stats used	Statistical findings or qualitative findings	Level =	Strengths Limitations Risk or harm if implemented Feasibility of use in your practice
Couzner et al. (2022); United States	-None listed -Aim of study was to determine the information that healthcare providers need to provide appropriate care for YOD patients	-An international Delphi study -Online survey platform with a panel of experts on YOD	-The panel of experts (*n* = 19) were mostly current or retired clinicians (57%, *n* = 16) -Their roles included neurologist, psychiatrist and neuropsychiatrist, psychologist, neuropsychologist and geropsychologist, physician, social worker, and nurse practitioner -The remaining respondents had backgrounds in academia, advocacy, or other areas such as law, administration, homecare or were unemployed	-Variables include characteristics of disease; causes and prevention; symptoms; diagnosis; treatments; and care management	-Very high consensus was a median score of 5, an IQR of 0 and≥80% scoring a 4 or 5 -High consensus was defined as a median score of 5, an IQR ≤1 and ≥ 80% scoring a 4 or 5 -Moderate consensus was a median score of 4–5, an IQR ≤2 and ≥ 60% scoring a 4 or 5 -No consensus (low agreement) was defined as a median score of 4–5 and either IQR ≤2 or ≥ 60% scoring a 4 or 5	-Experts in this study reached high to very high consensus on 42 statements (out of 58) that they considered to be important for health professionals to know when providing care and services to people with YOD and their families	-The panel reached a high to very high consensus on 42 (72%) statements that they considered to be important for health professionals to know when providing care and services to people with YOD and their support persons -There was agreement across all thematic categories, indicating the importance of broad professional knowledge related to YOD identification, diagnosis, treatment, and ongoing care	-Level 3	-People with young onset dementia (YOD) have unique needs and experiences, requiring care and support that is timely, appropriate, and accessible -This means health professionals must have sufficient knowledge about YOD -This study will be useful in discussing the information that is essential for health professionals to know about YOD -Limitations include small sample size

					-Statements with median scores between 2 and 4 were deemed to demonstrate no consensus				
Dixit et al. (2021); United States	-Quality of life (QoL) concept -This study aims to compare QoL self- and proxy-reports in YOD patients and their caregivers using different assessment questionnaires	-Primary measures included generic QoL (World Health Organization Quality of Life–short version [WHOQOL-BREF]), dementia-specific QoL (Quality of Life in Alzheimer's Disease Scale [QoL-AD]), health-related QoL (EQ5D), and a single-item QoL measure -Secondary measures included caregiver burden (Zarit Burden Index), mental health (Hospital Anxiety and Depression Scale), and dementia severity (Clinical Dementia Rating)	-52 participants (26 YOD patient-caregiver dyads) -Data were collected by a research nurse visiting patients and caregivers in their own homes -Responses were recorded on paper copies of scales and then transferred into an electronic platform for management and storage	-Depression, met and unmet needs, and impaired patient awareness were assessed on the various scales, all of which can have a negative influence on QoL for the patient and their caregiver -Other variables were dependent on which questionnaire was being used and analyzed (such mental health (HADS) and severity of disease (CDR))	-QoL -AD, Quality of Life in Alzheimer's Disease Scale (patient self-report or caregiver proxy report about patient) -WHOQOL-BREF, World Health Organization Quality of Life–short version (patient self-report, caregiver self-report) -Single-item QoL (patient self-report, caregiver self-report) -EQ-5D, health-related quality of life (patient self-report, caregiver self-report) -HADS, Hospital Anxiety and Depression Scale (caregiver self-report) -Zarit Burden Interview (caregiver self-report)	-Patient QoL self-reports were higher than caregiver proxy reports on the QoL-AD (P 1⁄4 .001) -Patient QoL self-reports for the WHOQOL-BREF ($P < .01$) and single-item QoL ($P < .05$) measure were significantly higher than caregiver self-reports -Dementia severity had no relationship with QoL self-reports, caregiver burden, anxiety, and depression were negatively correlated with QoL when measured using a generic and single-item measure, but not with the health-related measure	-Patients tend to self-report their QoL as higher than caregiver perceptions of patient-QoL, and caregiver self-reported QoL in most areas apart from those measuring physical health status	-Level 2	-In providing care and support for patients and caregivers, factors such as burden, depression, and anxiety should be targets for intervention -This study will guide what quality of life means for patients with YOD and what can be done to help maintain or improve QOL in this population -Limited participants is the main limitation in this study

Hendriks et al. (2021); United States	-None listed -The primary goal of the authors was to assess the global prevalence of YOD using all current available data on the disease	-Systematic review and meta-analysis	-PubMed, Embase, CINAHL, and PsychInfo databases were searched for population-based studies -A search was completed for studies containing data on the prevalence of dementia in individuals 65> years old, published between 1/1/90-3/31/20	-Age range of the patients (ages <30-64, 30-64, 40-64, 50-64, 60-64) -Sample sizes (0-499, 500-999, 1000-1999, 2000-4999, 5000<) -Study methodology (cohort, register-based) -Diagnostic criteria (ICD, Other) and type of dementia ((Alzheimer disease (AD), vascular dementia (VaD), and frontotemporal dementia (FTD)) -Socioeconomic class -Gender -These variables are all considered independent variables when run in the data analysis	-Age-standardized prevalence estimates for 5-year age bands per 100,000 people concluded that there is an age-standardized prevalence of 119.0 per 100,000 people ages 30-64	-Meta-regression showed that age range ($P < .001$), sample size ($P < .001$), and study methodology ($P = .02$) significantly influenced heterogeneity between studies -Subgroup analyses showed prevalence between men and women to be similar (estimates for men, 216.5 per 100 000 population, and for women, 293.1 per 100 000 population)	-95 studies were included; age-standardized prevalence estimates increased with age -Overall global age-standardized prevalence of 119.0 per 100,000 people ages 30-64, corresponding to 3.9 million people aged 30-64 years living with YOD globally	-Level 1	-There is a lack of data and reliable estimates of the prevalence of YOD -Such data are needed to help ensure appropriate care is given to these patients -This research provides an estimate of the prevalence of YOD globally, and demonstrates the need for more research to be done to ensure adequate care can be given for these patients
Spreadbury & Kipps (2018); United Kingdom	-N/A -In comparison with late-onset dementia, those who provide care to younger patients are likely to encounter a broader prevalence of dementia subtypes including a higher incidence of frontotemporal dementias, alongside Alzheimer's disease and vascular dementia; and interact with a more heterogeneous clinical	-The objective of this study was to use a qualitative approach with healthcare professionals with expertise in young-onset dementia to explore their perspectives on young-onset dementia care	-This study was conducted and is reported in accordance with COREQ guidelines -A purposive-sampling approach was used. The participants were six healthcare professionals with clinical expertise in young-onset dementia	-N/A -Eight overall themes were produced, two themes for each area of the dementia clinical pathway, representing important underlying issues in young-onset dementia care	-Thematic analysis, underpinned by a realist approach, was applied to interview transcripts drawing on the guide by -Codes were first applied to hard copies of transcripts by hand and then transferred to electronic copies using NVIVO version 10, refining codes in the process	-Thematic analysis was applied to interview transcripts to identify themes representing important underlying issues in care across the dementia clinical pathway (i.e., pre-diagnosis, diagnosis and postdiagnosis).	-Healthcare professionals need to recognize symptoms as organic and degenerative (rather than simply psychological) and to refer patients early to an appropriate clinical facility for assessment -Findings were organized into a paradigm surrounding issues along the dementia clinical pathway, and represent holistic YOD care to offer a structured framework for future research; however, the authors state that findings should be interpreted with	-Level 3	-The study results discuss the importance of what healthcare providers should know about YOD. -In the pre-diagnostic period, it is important for healthcare professionals to accurately recognize patient changes as more than psychological. It is important to refer to a clinician or clinical facility familiar with assessing cognitive, behavioral, and functional disorders in younger adults. -During the post-diagnostic period, there will be a care focus shift from service user requirements being addressed in clinic to being addressed more in the community. -Failure to recognize symptoms as indicative of dementia will contribute to the delay in service users obtaining an accurate diagnosis. The literature still lacks clarity as to why healthcare professionals continue to fail to recognize or misdiagnose symptoms. -A combination of factors may mislead a physician from suspecting dementia, including lack of knowledge or experience with younger onset dementia, atypical clinical features or the higher probability considering the patient's younger age that changes represent a more commonly observed mid-life neuropsychiatric disorder

	phenotype characterized by changes in behavior, functioning, personality, and communication						caution as this was an exploratory study amongst healthcare professionals		
Baptista et al. (2016); Brazil	-No theoretical model listed -Young onset dementia (YOD) develops before 65 years of age and has specific age-related adverse consequences for quality of life (QoL)	-Systematic review using the PRISMA methodology.	-Inclusion criteria for articles were as follows: cross-sectional or longitudinal studies, randomized or nonrandomized, with or without a control group, with caregivers and/or people with young onset Alzheimer's disease, vascular dementia, mixed or frontotemporal dementia, at all stages of severity	-Independent variables: Whether the patient has YOD or LOD -Dependent variables: Quality of life	-Quality of life was assessed using the Quality of Life-Alzheimer Disease scale (QoL-AD The RAND-36 Health Survey The World Health Organization Quality of Life instrument -Abbreviated version (WHOQOL-Bref) Camberwell Assessment of Need for the Elderly (CANE) Bradford Well-being Profile	-Multivariate linear regressions examined the relationship between awareness total score and its domains and all clinical variables in both YOD and LOD groups -Various statistics included Kolmogorov–Smirnov and Levene tests, Chi-square, and Mann- Whitney U test, Kruskal- Wallis and ANOVA One Way tests were used for non- parametric and parametric comparison between YOD and LOD groups separated by CDR classification	-People with YOD rated their own QoL significantly higher than their caregivers. Greater awareness of disease among people with YOD is associated with better QoL in caregivers. A relationship was found between unmet needs and daytime activities, lack of companionship and difficulties with memory. Issues associated with unmet needs were prolonged time to diagnosis, available health services and lack of caregiver's own future perspective. -Consideration should be given to conducting investigations with more homogeneous samples and use of a clear concept of QoL. The present study highlights the need for future research in a wider range of countries, using instruments specifically for YOD. It would be interesting if studies could trace	-Level 1	-Consideration should be given to conducting investigations with more homogeneous samples and use of a clear concept of QoL -The present study highlights the need for future research in a wider range of countries, using instruments specifically for YOD -It would be interesting if studies could trace parallels with late onset dementia groups

							parallels with late onset dementia groups.		
Cations et al. (2021); Australia and New Zealand	-No framework listed -Up to 10% of cases of dementia emerge prior to 65 years of age	-Eight pressing priorities for research, policy, service and advocacy which have significant potential to improve outcomes for people with YOD and their care partners and families	-Designed to address policymakers in Australia and New Zealand	-N/A	-Recommendations were made across several domains	-Data was collected from a variety of sources, including two recent Australian Royal Commission groups- the Quality and Safety of Aged Care, and Violence, Abuse, Neglect and Exploitation of People with Disability	- People with YOD and their families face complex challenges associated with their position at the intersection of multiple systems.	-Level 2	-Policymakers, researchers, clinicians and organizations within the aged, health and disability sectors must collaborate effectively to facilitate access to seamless cross-sector, family- centered care. -The eight key actions outlined here provide a roadmap to achieving this goal
Hvidsten et al. (2019); Norway	-To compare quality of life (QOL) of family carers of persons with young-(YOD) to late-onset dementia (LOD)	-Cross-sectional comparison on the QOL between the caregivers of those living with YOD and LOD	-88 carers of persons with YOD -100 carers of persons with LOD	-Independent variables: Carer of person with YOD or with LOD -Dependent variable: Answers on various scales/QOL	-The results were presented as mean QOL-AD with 95% confidence interval (CI)within YOD and LOD groups for each category of categorical characteristics	-Eleven characteristics of the persons with dementia (sex, symptom duration, scores on the CSDD, ADL, MMSE, and QOL–AD) and the carers (sex, age, relationship type with the persons with dementia dichotomized into "spousal" and "other" and scores on the GDS and RSS) were selected based on previous research on predictors of QOL, features of the study population, and assessment of correlations among covariates, where highly correlated covariates were excluded	-The QOL-AD scores of YOD-carers were significantly poorer compared to LOD-carers (mean difference 2.5 (95% CI 0.7; 4.3), $p = 0.006$). -Poorer QOL of carers was associated with more depressive symptoms (mean QOL-AD change -0.5 (-0.6; -0.3), $p < 0.001$), but with no difference between the two groups. -In contrast to LOD, QOL of carers of people with YOD was also significantly associated with symptom duration ($p = 0.002$), depressive symptoms of the	-Level 2	-YOD-carers reported significantly poorer QOL compared to LOD-carers. QOL was significantly associated with depressive symptoms in carers of both groups.

							persons with dementia (*p* = 0.030), ADL (*p* = 0.001), and carer burden (*p* = 0.002)		
Kimura et al. (2020); Brazil	-To compare the quality of life, burden, and depressive symptoms of caregivers of individuals with young-onset dementia (YOD) and late-onset dementia (LOD)	-A cross-sectional design, -The care recipients completed assessments about cognition, quality of life, and awareness of disease. -Care givers' quality of life, resilience, depressive and anxiety symptoms, hopelessness, and burden of care were assessed.	-A convenience sample of 110 dyads of individuals with dementia and their caregivers, all living in the community, was included	-Independent variable: Having YOD or being a caregiver -Dependent variable: QOL rating and depression symptoms	-For all analyses, the alpha level was set at P= .05. -There was a significant difference between individuals with LOD and YOD in cognition, depressive symptoms, functionality, and neuropsychiatric symptoms -There was a significant difference in care- giver's perspective about the QoL of individuals with dementia -The YOD group of caregivers rated the QoL of their care recipients lower.	-Initially, the descriptive analyses of all the variables were carried out by observing the means, standard deviation, and frequency -Significant results informed linear regression models. -Multivariate linear regressions were performed to determine the factors related to QoL, burden, and depressive symptoms of caregivers.	-A significant difference was found in caregivers' burden and depressive symptoms according to the age of onset -There was no difference in caregivers' quality of life between YOD and LOD groups -In the LOD group, caregivers' burden was associated with their perspective of the quality of life of care recipient, type of kinship, and presence of emotional problems	-Level 2	-Our findings suggest that the factors that affect quality of life, burden, and depressive symptoms of caregivers of individuals with LOD differ from those that affect the caregivers of individuals with YOD.
Lawler et al. (2020); Australia	-No specific framework -To evaluate the dementia knowledge of allied health professionals and identify their specific learning need	-An online survey was conducted with allied health professionals enrolled in the Understanding Dementia Massive Open Online Course, a free course open to anyone, worldwide. The primary outcome measure was the Dementia Knowledge Assessment	-The survey was completed by 1591 participants -The largest number of responses was from occupational therapists (n = 537), physiotherapists (n = 373) and social workers (n = 266). -Most were female (n = 1,406). -Most participants were from Australia (70%), with smaller numbers from Canada (7%) and Great Britain (6%).	-Independent variables: Participant demographics -Dependent variables: Responses to survey questions	-Results were reported according to profession and as an allied health cohort. -As different professions make different contributions to dementia care, statistical comparisons between professions were not conducted. -For a subgroup of the allied health cohort who completed the DKAS before and after the	-Only a participant's first attempt at the UDMOOC was included in analysis, as previous attempts may affect knowledge scores. -Mean and standard deviation were calculated for each DKAS item, and the number and percentage of responses scoring a 0, 1 or 2 were tabulated. -Mean and standard deviation were also	-The mean dementia knowledge score was 35.0 (SD 8.4), with 13% (n = 207) achieving a target score of 45/50 or above, indicating comprehensive dementia knowledge. Key knowledge gaps were in the areas of dementia onset and non-pharmacological management of	-Level 2	-Allied health professionals surveyed had significant gaps in dementia knowledge -Educators planning dementia curriculum for allied health professionals could consider addressing areas of knowledge related to the identified items, with view to providing a foundation for excellence in dementia care -The large sample size strengthened the quality and results of this survey

		Scale, assessed prior to course commencement.			MOOC, pre- and post-test scores were compared using a paired-samples t-test with 95% confidence intervals and p-value reported	calculated for the total DKAS score. -The number and percentage of participants achieving a target score of 45/50 or above are presented	behavioral and psychological symptoms of dementia.		
Lo (2017); Taiwan	-No specific framework -The AD research community has developed the idea of mild cognitive impairment (MCI) to find predementia patients who might benefit from potentially therapeutic drugs that have proven ineffective in the pas	-Systematic review	-Terms searched included mild cognitive impairment (MCI), dementia, and Alzheimer's Disease (AD)	-Independent variables within the discussed research include the type of memory loss the patient has (MCI, dementia, AD) -Dependent varibales include the built environment (physical and social) that can lead to a MCI diagnosis	-N/A	-N/A	-Several validators for clinical syndromes have been proposed: (1) identification and description by "clinical intuition" or by cluster analysis, (2) demonstration of boundaries between related syndromes by discriminant function analysis, (3) follow-up studies establishing a distinctive course or outcome, (4) therapeutic trials establishing a distinctive treatment response, (5) evidence of familial clusters, and (6) association with more fundamental abnormalities - histological, biochemical, or molecular	-Level 2	-MCI is a concept which has been used to identify patients with AD early in the disease course - Dementia of the Alzheimer type represents a referent diagnosis for MCI -Low cognitive reserve and high vascular burden may contribute to dementia through different pathways, and understanding their roles will have an enormous impact in AD prevention

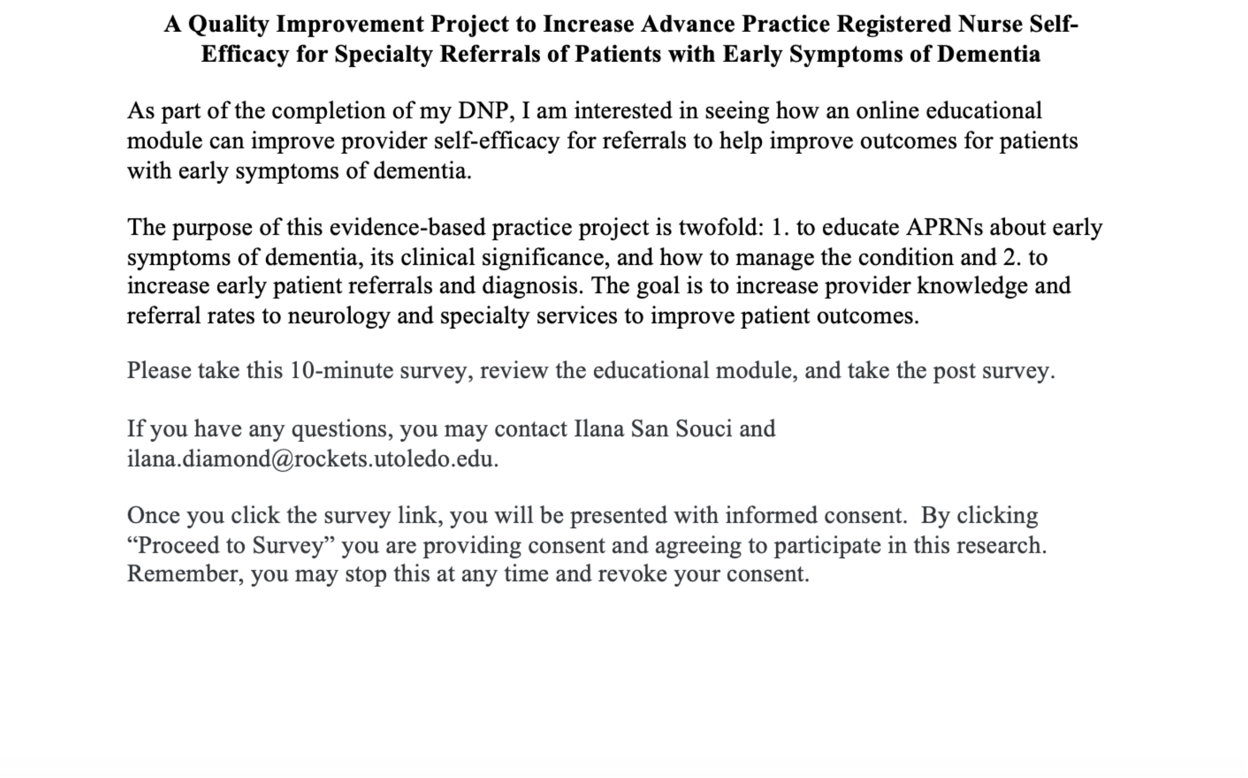
Baptista et al. (2021); Brazil	-This study is designed to investigate differences in awareness of cognitive functioning and health condition, functional activity impairments, emotional state, and social functioning and relationships among people with young onset (YOD) and late onset dementia (LOD); and examine associations between awareness and its domains with cognition, functionality, neuropsychiatric symptoms, social and emotional functioning, and quality of life (QoL) in both groups.	-Awareness of disease, dementia severity, cognition, functionality, neuropsychiatric symptoms, social and emotional functioning, and QoL were assessed	-A group of 136 people with dementia and their respective caregivers (YOD = 50 and LOD = 86) were consecutively selected -Only individuals with mild and moderate dementia according to the Clinical Dementia Rating (CDR), and with scores between 11–26 on the Mini-Mental State Examination (MMSE) were included in the study	-Independent variables: gender, age of disease onset, years of disease, mild or moderate stage of disease, educational level -Dependent variables included the scores on the assessments used in the study (ASPIDD, CDR, MMSE, PFAQ, NPI, SEQ, QoL-AD)	-The Assessment Scale of Psychosocial Impact of the Diagnosis of Dementia (ASPIDD) -The severity of dementia was measured with the clinical dementia rating scale (CDR) -Cognitive level was measured using the MMSE -The Pfeffer Functional Activities Questionnaire (PFAQ) is a caregiver-reported inventory that evaluates activities of daily living -Neuropsychiatric Inventory (NPI) to assess presence of symptoms -Quality of Life in Alzheimer's Disease scale (QoL-AD)	-Parametric variables were described by their mean and standard deviations (SD), and the non-parametric variables by their median, minimum and maximum or frequency and percent- ages for categorical variables -Chi-square and Mann- Whitney U tests were used for non-parametric and Independent *T*-tests for parametric comparation between YOD and LOD groups -Kruskal-Wallis and ANOVA One Way tests were used for non-parametric and parametric comparison between YOD and LOD groups separated by CDR classification-Multivariate linear regressions with the step-wise method were elaborated using the ASPIDD total scores and its domains as dependent variables, in order to identify the association with the independent variables (CDR, MEEM, NPI, SEQ, QOL, and PFEFFER)	-People with YOD had more neuropsychiatric symptoms than people with LOD. People with YOD were more aware of disease (total score), of their cognitive functioning and health condition and of their functional activity impairments, even if this group was more severely cognitive impaired and had a worse level of functionality than LOD group -Multivariate linear regressions showed that functionality has a wide relationship to awareness for people with YOD. While neuropsychiatric symptoms and QoL has a greater relation to awareness for people with LOD	-Level 2	-Different clinical variables are associated to different domains in YOD and LOD groups, reinforcing the heterogeneity of awareness in dementia -There was a decent sample size which contributes to strengthening the study
O'Malley et al. (2020); United Kingdom	-Better understanding of patient experience is an important driver for service improvements and can act as a lever for	-A modified Delphi approach was undertaken with 18 younger people with dementia and 18 supporters of people with young onset dementia.	-The Delphi expert panel consisted of our participants who were younger people living with dementia and family supporters of younger people living with dementia	-A recent literature review has highlighted that delays in diagnosis can be attributed to the initial delays in accessing help by the younger person and the misattribution of	-There were no statistically significant differences between statements expressed by the people with dementia and their supporters -There was a ceiling effect which	-The distributions of the ratings for all 29 statements were non-normal; therefore, a non-parametric test (Mann–Whitney test) was used for the analysis. Statistical significance was	-Statistical analyses found no difference in the scoring patterns between younger people with dementia and supporters, suggesting similar shared experiences	-Level 3	-Understanding the uniquely personal experience of young people going through the process of diagnosis for dementia is essential to provide person-centered, needs-led, and cost-effective services -Patient's values and experiences should be used to support and guide clinical decision-making

	system change -This study aims to improve the understanding of the personal experience of younger people undergoing investigation for dementia.	Questions were informed by a scoping review of the literature -The Delphi method is particularly useful in situations where existing literature is incomplete and inconsistent		symptoms by the clinician -The review also illuminated how reactions to the diagnosis can range from feelings of reassurance (in that their symptoms are now explained) to shock and destabilization. In addition, the review emphasized how unique the impact of receiving a diagnosis is to each family affected, and how vital the role of the clinician in communicating the diagnosis	effectively decreased the sensitivity of the scale -Paired analysis of the ratings of people with dementia and their supporter also did not show any statistically significant differences in ratings for any of the statements	tested at the 5% level throughout	during the diagnostic process -Twenty-seven of these statements were rated as essential or very important		-Qualitative studies involving younger people with dementia have illuminated how personal and individual the diagnostic journey is
Shorey & Lopez (2021); China	-Self-efficacy is one of the most ubiquitous term found in social, psychological, counselling, education, clinical and health literatures -Goal is to describe and evaluate self-efficacy theory and the studies most relevant to the nursing context	-Meta-analysis (it is a chapter in a book)	-The authors cited works from a variety of authors discussing the theory of self-efficacy, its various definitions, and applications, and how it can be used in nursing and health promotion	-N/A	-N/A	-N/A	-The concept of self-efficacy has been described as self-regulation, self-care, self-monitoring, self-management and self-monitoring -Self-efficacy was defined as the individual's perception of one's ability to perform particular behaviors through four processes including cognitive, motivational, affective and selection processes -The applications of self-efficacy in various nursing contexts are most beneficial to health promotion and improvement of the quality of	-Level 1	-The stronger a person's cognitive perception of self-efficacy, the higher they set their goals and commitment to achieve these goals -In terms of patient management, there is substantial evidence confirming the relationship between self-efficacy and self-management behaviors -Effective clinical trainings should establish a sense of self-efficacy among nursing students, which is a key component for acting independently and competently in the nursing profession

							health care and patient safety		

Appendix B.

Invitation to Participate in Project



A Quality Improvement Project to Increase Advance Practice Registered Nurse Self-Efficacy for Specialty Referrals of Patients with Early Symptoms of Dementia

As part of the completion of my DNP, I am interested in seeing how an online educational module can improve provider self-efficacy for referrals to help improve outcomes for patients with early symptoms of dementia.

The purpose of this evidence-based practice project is twofold: 1. to educate APRNs about early symptoms of dementia, its clinical significance, and how to manage the condition and 2. to increase early patient referrals and diagnosis. The goal is to increase provider knowledge and referral rates to neurology and specialty services to improve patient outcomes.

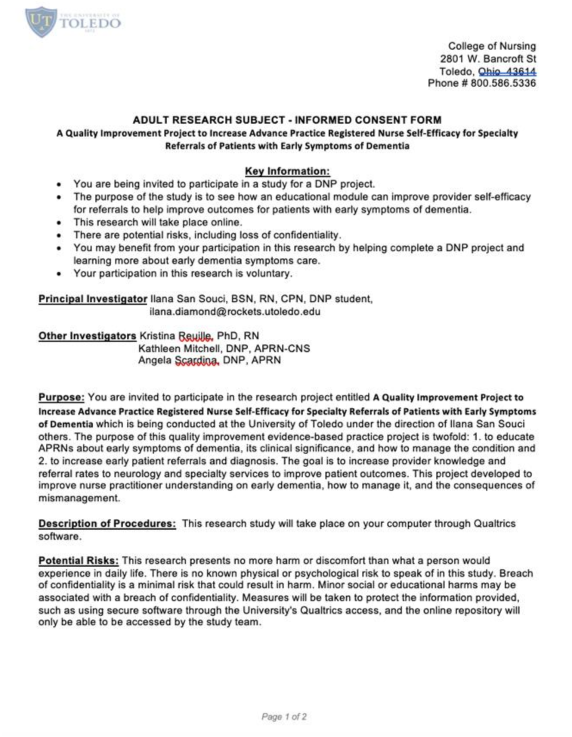
Please take this 10-minute survey, review the educational module, and take the post survey.

If you have any questions, you may contact Ilana San Souci and ilana.diamond@rockets.utoledo.edu.

Once you click the survey link, you will be presented with informed consent. By clicking "Proceed to Survey" you are providing consent and agreeing to participate in this research. Remember, you may stop this at any time and revoke your consent.

Appendix C.

Informed Consent



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ADULT RESEARCH SUBJECT - INFORMED CONSENT FORM
A Quality Improvement Project to Increase Advance Practice Registered Nurse Self-Efficacy for Specialty Referrals of Patients with Early Symptoms of Dementia

Key Information:

- You are being invited to participate in a study for a DNP project.
- The purpose of the study is to see how an educational module can improve provider self-efficacy for referrals to help improve outcomes for patients with early symptoms of dementia.
- This research will take place online.
- There are potential risks, including loss of confidentiality.
- You may benefit from your participation in this research by helping complete a DNP project and learning more about early dementia symptoms care.
- Your participation in this research is voluntary.

Principal Investigator Ilana San Souci, BSN, RN, CPN, DNP student,
ilana.diamond@rockets.utoledo.edu

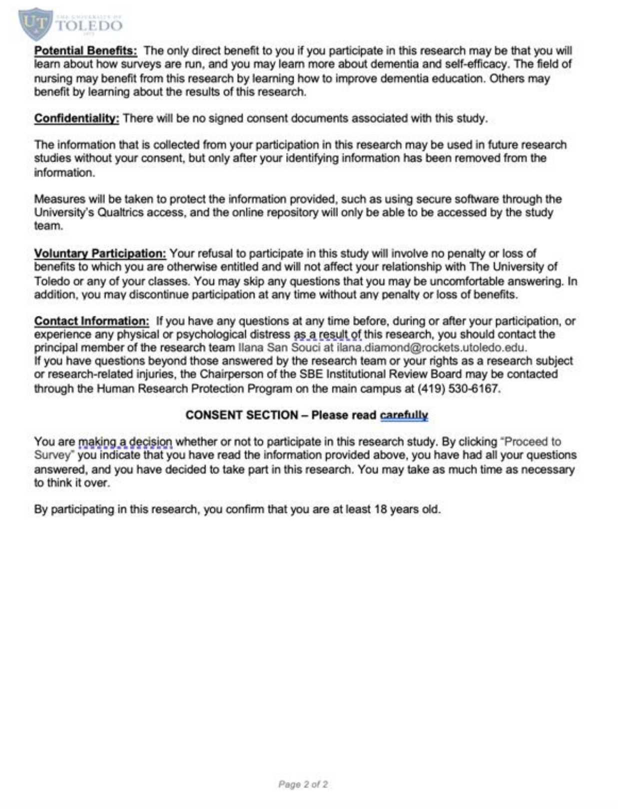
Other Investigators Kristina Reuille, PhD, RN
Kathleen Mitchell, DNP, APRN-CNS
Angela Scardina, DNP, APRN

Purpose: You are invited to participate in the research project entitled **A Quality Improvement Project to Increase Advance Practice Registered Nurse Self-Efficacy for Specialty Referrals of Patients with Early Symptoms of Dementia** which is being conducted at the University of Toledo under the direction of Ilana San Souci others. The purpose of this quality improvement evidence-based practice project is twofold: 1. to educate APRNs about early symptoms of dementia, its clinical significance, and how to manage the condition and 2. to increase early patient referrals and diagnosis. The goal is to increase provider knowledge and referral rates to neurology and specialty services to improve patient outcomes. This project developed to improve nurse practitioner understanding on early dementia, how to manage it, and the consequences of mismanagement.

Description of Procedures: This research study will take place on your computer through Qualtrics software.

Potential Risks: This research presents no more harm or discomfort than what a person would experience in daily life. There is no known physical or psychological risk to speak of in this study. Breach of confidentiality is a minimal risk that could result in harm. Minor social or educational harms may be associated with a breach of confidentiality. Measures will be taken to protect the information provided, such as using secure software through the University's Qualtrics access, and the online repository will only be able to be accessed by the study team.

Page 1 of 2



Potential Benefits: The only direct benefit to you if you participate in this research may be that you will learn about how surveys are run, and you may learn more about dementia and self-efficacy. The field of nursing may benefit from this research by learning how to improve dementia education. Others may benefit by learning about the results of this research.

Confidentiality: There will be no signed consent documents associated with this study.

The information that is collected from your participation in this research may be used in future research studies without your consent, but only after your identifying information has been removed from the information.

Measures will be taken to protect the information provided, such as using secure software through the University's Qualtrics access, and the online repository will only be able to be accessed by the study team.

Voluntary Participation: Your refusal to participate in this study will involve no penalty or loss of benefits to which you are otherwise entitled and will not affect your relationship with The University of Toledo or any of your classes. You may skip any questions that you may be uncomfortable answering. In addition, you may discontinue participation at any time without any penalty or loss of benefits.

Contact Information: If you have any questions at any time before, during or after your participation, or experience any physical or psychological distress as a result of this research, you should contact the principal member of the research team Ilana San Souci at ilana.diamond@rockets.utoledo.edu.
If you have questions beyond those answered by the research team or your rights as a research subject or research-related injuries, the Chairperson of the SBE Institutional Review Board may be contacted through the Human Research Protection Program on the main campus at (419) 530-6167.

CONSENT SECTION – Please read carefully

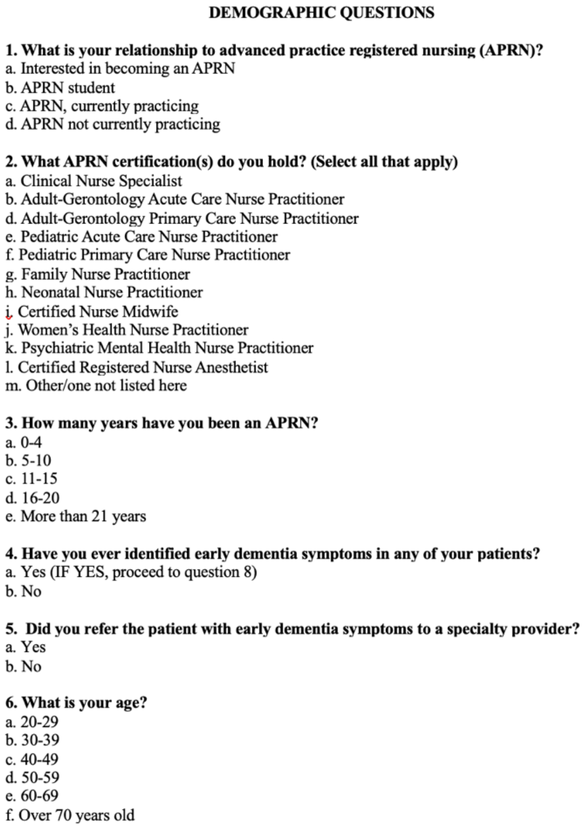
You are making a decision whether or not to participate in this research study. By clicking "Proceed to Survey" you indicate that you have read the information provided above, you have had all your questions answered, and you have decided to take part in this research. You may take as much time as necessary to think it over.

By participating in this research, you confirm that you are at least 18 years old.

Page 2 of 2

Appendix D.

Demographic Survey



DEMOGRAPHIC QUESTIONS

1. What is your relationship to advanced practice registered nursing (APRN)?
a. Interested in becoming an APRN
b. APRN student
c. APRN, currently practicing
d. APRN not currently practicing

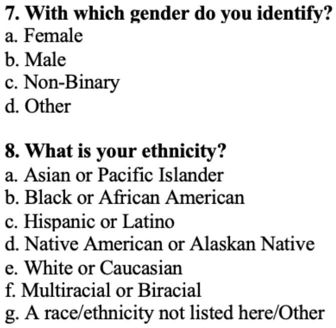
2. What APRN certification(s) do you hold? (Select all that apply)
a. Clinical Nurse Specialist
b. Adult-Gerontology Acute Care Nurse Practitioner
d. Adult-Gerontology Primary Care Nurse Practitioner
e. Pediatric Acute Care Nurse Practitioner
f. Pediatric Primary Care Nurse Practitioner
g. Family Nurse Practitioner
h. Neonatal Nurse Practitioner
i. Certified Nurse Midwife
j. Women's Health Nurse Practitioner
k. Psychiatric Mental Health Nurse Practitioner
l. Certified Registered Nurse Anesthetist
m. Other/one not listed here

3. How many years have you been an APRN?
a. 0-4
b. 5-10
c. 11-15
d. 16-20
e. More than 21 years

4. Have you ever identified early dementia symptoms in any of your patients?
a. Yes (IF YES, proceed to question 8)
b. No

5. Did you refer the patient with early dementia symptoms to a specialty provider?
a. Yes
b. No

6. What is your age?
a. 20-29
b. 30-39
c. 40-49
d. 50-59
e. 60-69
f. Over 70 years old

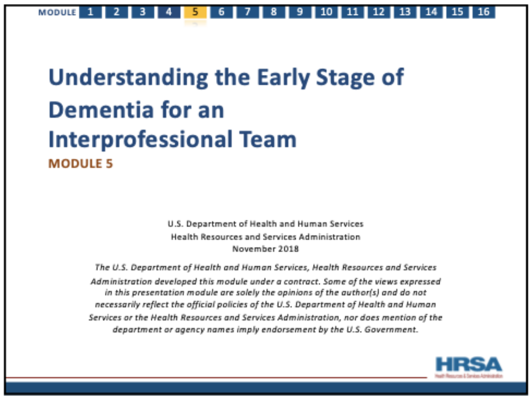


7. With which gender do you identify?
a. Female
b. Male
c. Non-Binary
d. Other

8. What is your ethnicity?
a. Asian or Pacific Islander
b. Black or African American
c. Hispanic or Latino
d. Native American or Alaskan Native
e. White or Caucasian
f. Multiracial or Biracial
g. A race/ethnicity not listed here/Other

Appendix E.

Educational Module



MODULE 1 2 3 4 5 6 7 8 9 10 11 12 13 14 15 16

Understanding the Early Stage of Dementia for an Interprofessional Team

MODULE 5

U.S. Department of Health and Human Services
Health Resources and Services Administration
November 2018

The U.S. Department of Health and Human Services, Health Resources and Services Administration developed this module under a contract. Some of the views expressed in this presentation module are solely the opinions of the author(s) and do not necessarily reflect the official policies of the U.S. Department of Health and Human Services or the Health Resources and Services Administration, nor does mention of the department or agency names imply endorsement by the U.S. Government.

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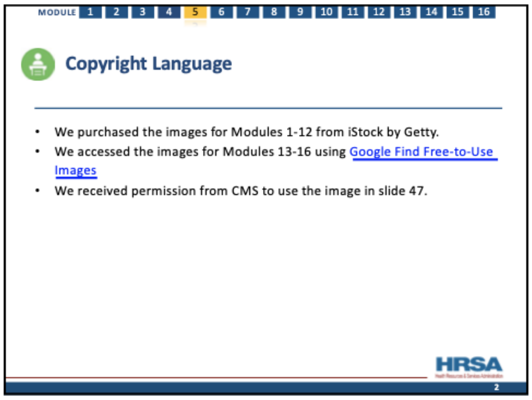

MODULE 1 2 3 4 5 6 7 8 9 10 11 12 13 14 15 16

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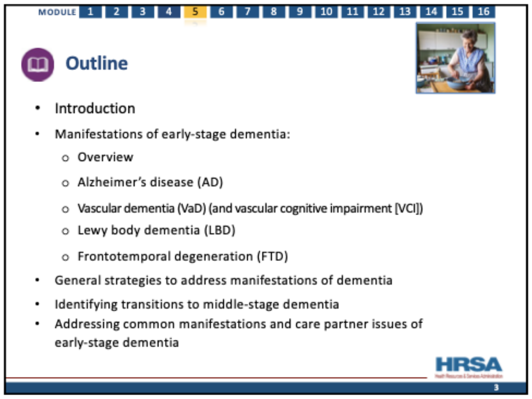

MODULE 1 2 3 4 5 6 7 8 9 10 11 12 13 14 15 16

Outline

- Introduction
- Manifestations of early-stage dementia:
  - Overview
  - Alzheimer's disease (AD)
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  - Lewy body dementia (LBD)
  - Frontotemporal degeneration (FTD)
- General strategies to address manifestations of dementia
- Identifying transitions to middle-stage dementia
- Addressing common manifestations and care partner issues of early-stage dementia

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MODULE 1 2 3 4 5 6 7 8 9 10 11 12 13 14 15 16

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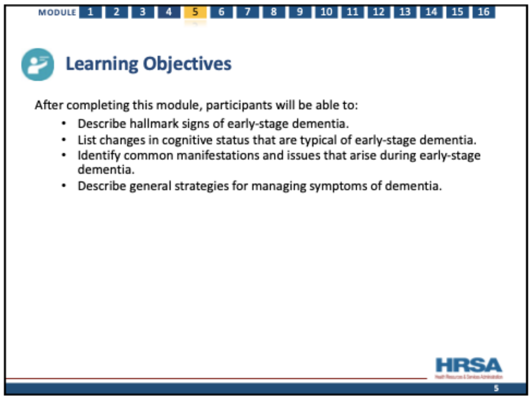

MODULE 1 2 3 4 5 6 7 8 9 10 11 12 13 14 15 16

Learning Objectives

After completing this module, participants will be able to:

- Describe hallmark signs of early-stage dementia.
- List changes in cognitive status that are typical of early-stage dementia.
- Identify common manifestations and issues that arise during early-stage dementia.
- Describe general strategies for managing symptoms of dementia.

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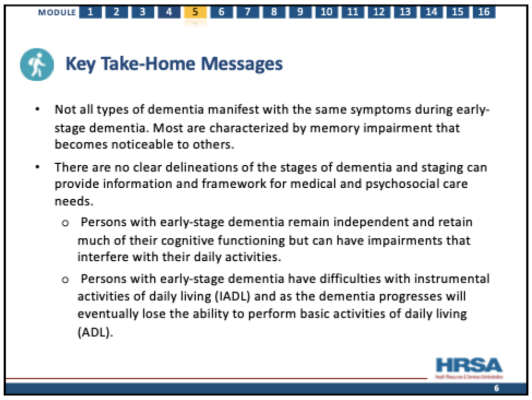

MODULE 1 2 3 4 5 6 7 8 9 10 11 12 13 14 15 16

Key Take-Home Messages

- Not all types of dementia manifest with the same symptoms during early-stage dementia. Most are characterized by memory impairment that becomes noticeable to others.
- There are no clear delineations of the stages of dementia and staging can provide information and framework for medical and psychosocial care needs.
  - Persons with early-stage dementia remain independent and retain much of their cognitive functioning but can have impairments that interfere with their daily activities.
  - Persons with early-stage dementia have difficulties with instrumental activities of daily living (IADL) and as the dementia progresses will eventually lose the ability to perform basic activities of daily living (ADL).

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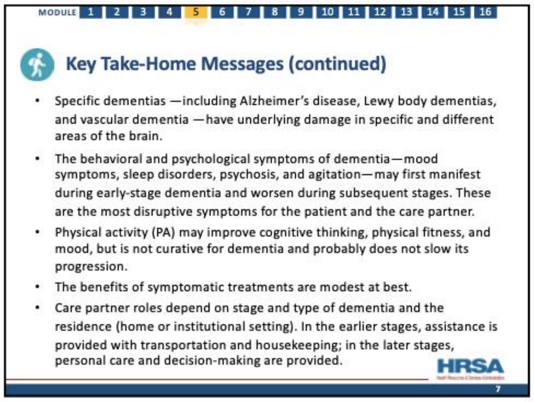

Key Take-Home Messages (continued)

- Specific dementias —including Alzheimer's disease, Lewy body dementias, and vascular dementia —have underlying damage in specific and different areas of the brain.
- The behavioral and psychological symptoms of dementia—mood symptoms, sleep disorders, psychosis, and agitation—may first manifest during early-stage dementia and worsen during subsequent stages. These are the most disruptive symptoms for the patient and the care partner.
- Physical activity (PA) may improve cognitive thinking, physical fitness, and mood, but is not curative for dementia and probably does not slow its progression.
- The benefits of symptomatic treatments are modest at best.
- Care partner roles depend on stage and type of dementia and the residence (home or institutional setting). In the earlier stages, assistance is provided with transportation and housekeeping; in the later stages, personal care and decision-making are provided.

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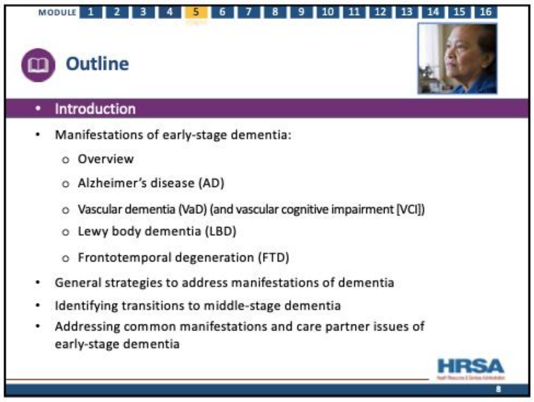

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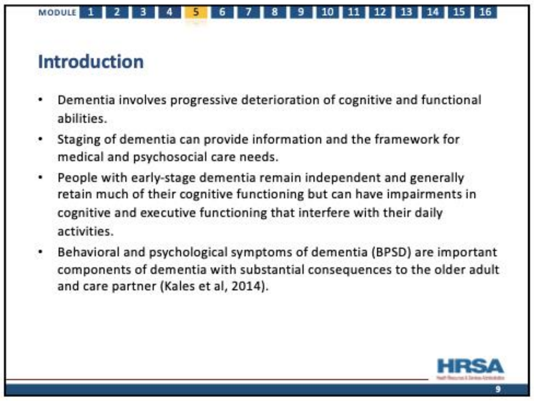

Introduction

- Dementia involves progressive deterioration of cognitive and functional abilities.
- Staging of dementia can provide information and the framework for medical and psychosocial care needs.
- People with early-stage dementia remain independent and generally retain much of their cognitive functioning but can have impairments in cognitive and executive functioning that interfere with their daily activities.
- Behavioral and psychological symptoms of dementia (BPSD) are important components of dementia with substantial consequences to the older adult and care partner (Kales et al, 2014).

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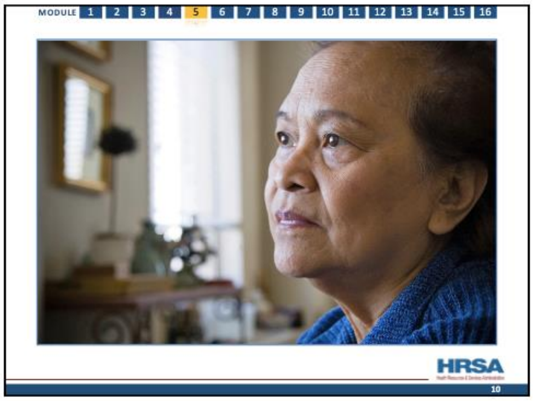

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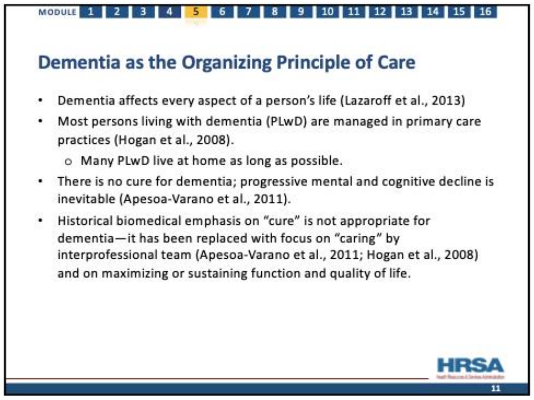

Dementia as the Organizing Principle of Care

- Dementia affects every aspect of a person's life (Lazaroff et al., 2013)
- Most persons living with dementia (PLwD) are managed in primary care practices (Hogan et al., 2008).
  - Many PLwD live at home as long as possible.
- There is no cure for dementia; progressive mental and cognitive decline is inevitable (Apesoa-Varano et al., 2011).
- Historical biomedical emphasis on "cure" is not appropriate for dementia—it has been replaced with focus on "caring" by interprofessional team (Apesoa-Varano et al., 2011; Hogan et al., 2008) and on maximizing or sustaining function and quality of life.

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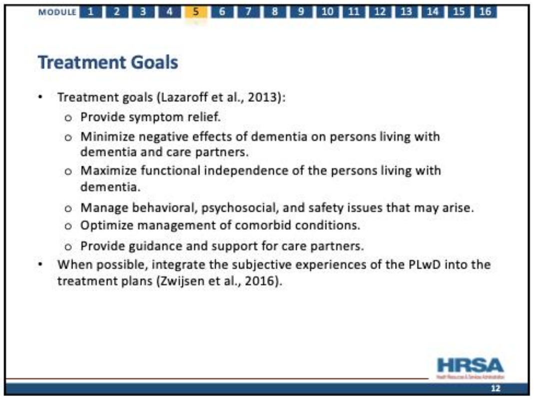

Treatment Goals

- Treatment goals (Lazaroff et al., 2013):
  - Provide symptom relief.
  - Minimize negative effects of dementia on persons living with dementia and care partners.
  - Maximize functional independence of the persons living with dementia.
  - Manage behavioral, psychosocial, and safety issues that may arise.
  - Optimize management of comorbid conditions.
  - Provide guidance and support for care partners.
- When possible, integrate the subjective experiences of the PLwD into the treatment plans (Zwijsen et al., 2016).

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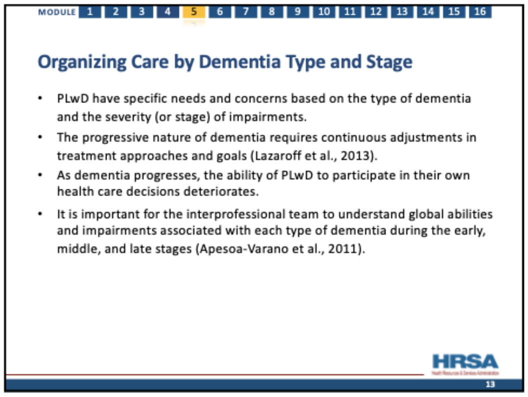

Organizing Care by Dementia Type and Stage

- PLwD have specific needs and concerns based on the type of dementia and the severity (or stage) of impairments.
- The progressive nature of dementia requires continuous adjustments in treatment approaches and goals (Lazaroff et al., 2013).
- As dementia progresses, the ability of PLwD to participate in their own health care decisions deteriorates.
- It is important for the interprofessional team to understand global abilities and impairments associated with each type of dementia during the early, middle, and late stages (Apesoa-Varano et al., 2011).

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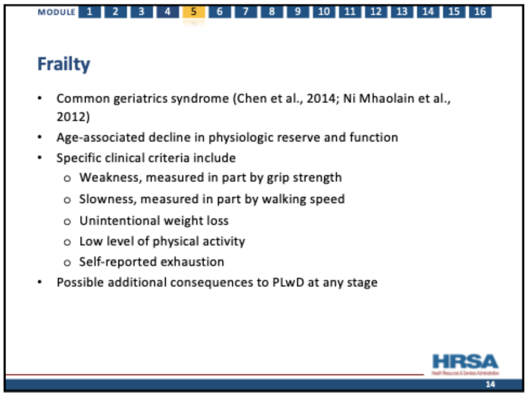

Frailty

- Common geriatrics syndrome (Chen et al., 2014; Ni Mhaolain et al., 2012)
- Age-associated decline in physiologic reserve and function
- Specific clinical criteria include
  - Weakness, measured in part by grip strength
  - Slowness, measured in part by walking speed
  - Unintentional weight loss
  - Low level of physical activity
  - Self-reported exhaustion
- Possible additional consequences to PLwD at any stage

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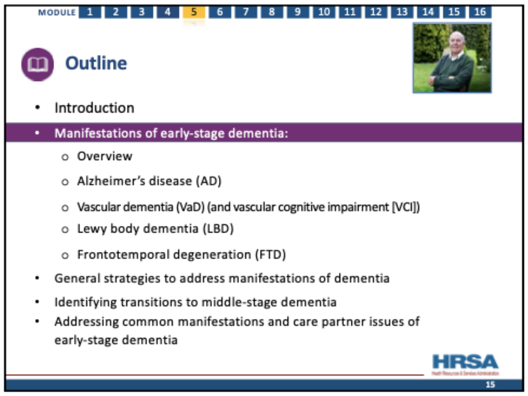

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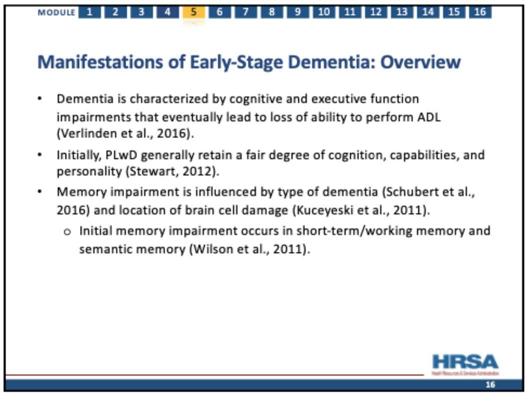

Manifestations of Early-Stage Dementia: Overview

- Dementia is characterized by cognitive and executive function impairments that eventually lead to loss of ability to perform ADL (Verlinden et al., 2016).
- Initially, PLwD generally retain a fair degree of cognition, capabilities, and personality (Stewart, 2012).
- Memory impairment is influenced by type of dementia (Schubert et al., 2016) and location of brain cell damage (Kuceyeski et al., 2011).
  - Initial memory impairment occurs in short-term/working memory and semantic memory (Wilson et al., 2011).

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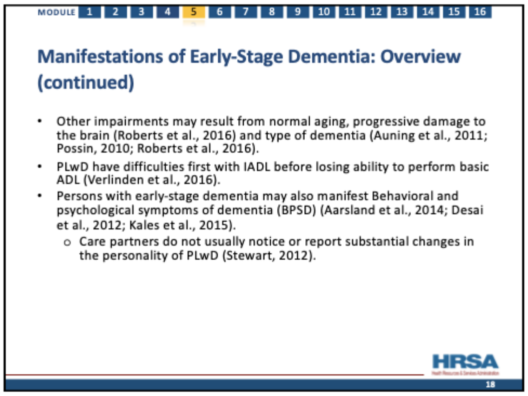

Manifestations of Early-Stage Dementia: Overview (continued)

- Other impairments may result from normal aging, progressive damage to the brain (Roberts et al., 2016) and type of dementia (Auning et al., 2011; Possin, 2010; Roberts et al., 2016).
- PLwD have difficulties first with IADL before losing ability to perform basic ADL (Verlinden et al., 2016).
- Persons with early-stage dementia may also manifest Behavioral and psychological symptoms of dementia (BPSD) (Aarsland et al., 2014; Desai et al., 2012; Kales et al., 2015).
  - Care partners do not usually notice or report substantial changes in the personality of PLwD (Stewart, 2012).

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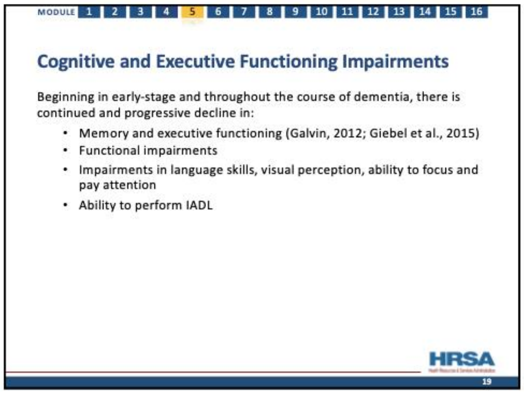
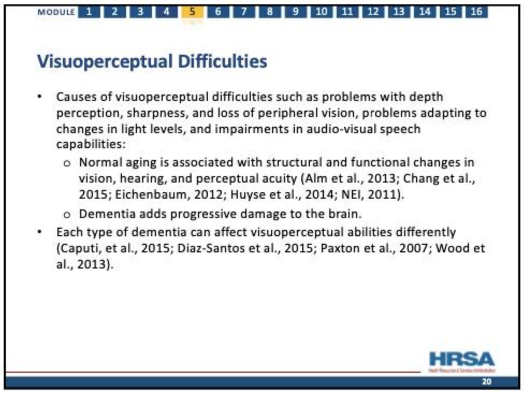


Cognitive and Executive Functioning Impairments

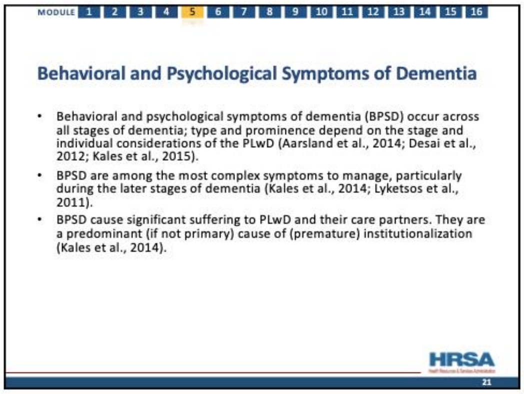
Beginning in early-stage and throughout the course of dementia, there is continued and progressive decline in:

- Memory and executive functioning (Galvin, 2012; Giebel et al., 2015)
- Functional impairments
- Impairments in language skills, visual perception, ability to focus and pay attention
- Ability to perform IADL



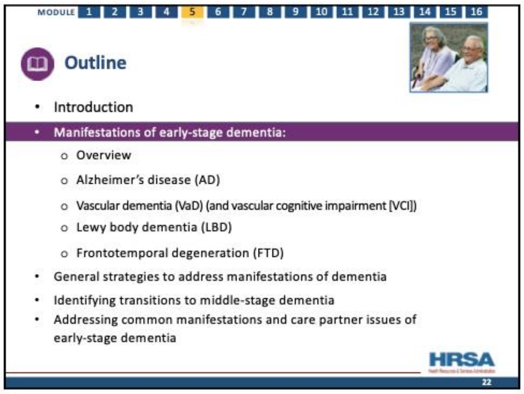
Visuoperceptual Difficulties

- Causes of visuoperceptual difficulties such as problems with depth perception, sharpness, and loss of peripheral vision, problems adapting to changes in light levels, and impairments in audio-visual speech capabilities:
  - Normal aging is associated with structural and functional changes in vision, hearing, and perceptual acuity (Alm et al., 2013; Chang et al., 2015; Eichenbaum, 2012; Huyse et al., 2014; NEI, 2011).
  - Dementia adds progressive damage to the brain.
- Each type of dementia can affect visuoperceptual abilities differently (Caputi, et al., 2015; Diaz-Santos et al., 2015; Paxton et al., 2007; Wood et al., 2013).



Behavioral and Psychological Symptoms of Dementia

- Behavioral and psychological symptoms of dementia (BPSD) occur across all stages of dementia; type and prominence depend on the stage and individual considerations of the PLwD (Aarsland et al., 2014; Desai et al., 2012; Kales et al., 2015).
- BPSD are among the most complex symptoms to manage, particularly during the later stages of dementia (Kales et al., 2014; Lyketsos et al., 2011).
- BPSD cause significant suffering to PLwD and their care partners. They are a predominant (if not primary) cause of (premature) institutionalization (Kales et al., 2014).



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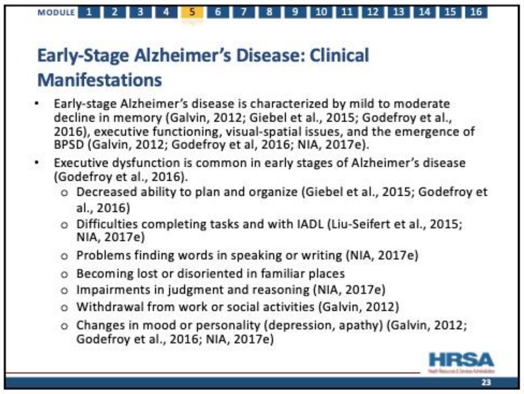
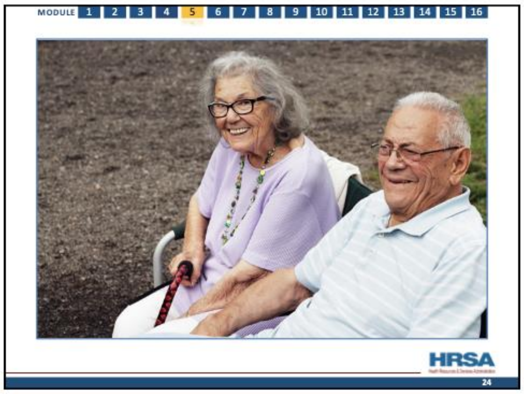
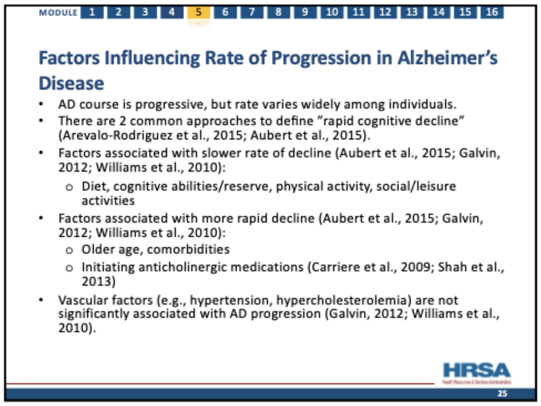


Early-Stage Alzheimer's Disease: Clinical Manifestations

- Early-stage Alzheimer's disease is characterized by mild to moderate decline in memory (Galvin, 2012; Giebel et al., 2015; Godefroy et al., 2016), executive functioning, visual-spatial issues, and the emergence of BPSD (Galvin, 2012; Godefroy et al, 2016; NIA, 2017e).
- Executive dysfunction is common in early stages of Alzheimer's disease (Godefroy et al., 2016).
  - Decreased ability to plan and organize (Giebel et al., 2015; Godefroy et al., 2016)
  - Difficulties completing tasks and with IADL (Liu-Seifert et al., 2015; NIA, 2017e)
  - Problems finding words in speaking or writing (NIA, 2017e)
  - Becoming lost or disoriented in familiar places
  - Impairments in judgment and reasoning (NIA, 2017e)
  - Withdrawal from work or social activities (Galvin, 2012)
  - Changes in mood or personality (depression, apathy) (Galvin, 2012; Godefroy et al., 2016; NIA, 2017e)





Factors Influencing Rate of Progression in Alzheimer's Disease

- AD course is progressive, but rate varies widely among individuals.
- There are 2 common approaches to define "rapid cognitive decline" (Arevalo-Rodriguez et al., 2015; Aubert et al., 2015).
- Factors associated with slower rate of decline (Aubert et al., 2015; Galvin, 2012; Williams et al., 2010):
  - Diet, cognitive abilities/reserve, physical activity, social/leisure activities
- Factors associated with more rapid decline (Aubert et al., 2015; Galvin, 2012; Williams et al., 2010):
  - Older age, comorbidities
  - Initiating anticholinergic medications (Carriere et al., 2009; Shah et al., 2013)
- Vascular factors (e.g., hypertension, hypercholesterolemia) are not significantly associated with AD progression (Galvin, 2012; Williams et al., 2010).

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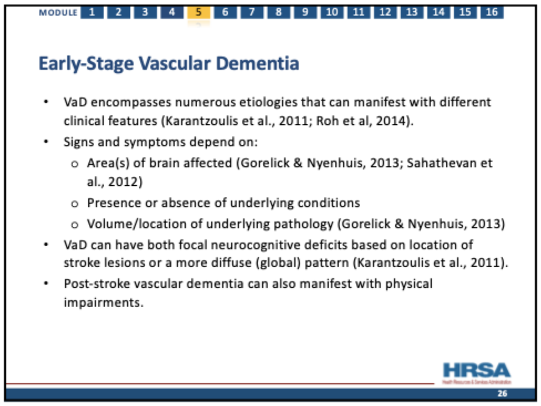

Early-Stage Vascular Dementia

- VaD encompasses numerous etiologies that can manifest with different clinical features (Karantzoulis et al., 2011; Roh et al, 2014).
- Signs and symptoms depend on:
  - Area(s) of brain affected (Gorelick & Nyenhuis, 2013; Sahathevan et al., 2012)
  - Presence or absence of underlying conditions
  - Volume/location of underlying pathology (Gorelick & Nyenhuis, 2013)
- VaD can have both focal neurocognitive deficits based on location of stroke lesions or a more diffuse (global) pattern (Karantzoulis et al., 2011).
- Post-stroke vascular dementia can also manifest with physical impairments.

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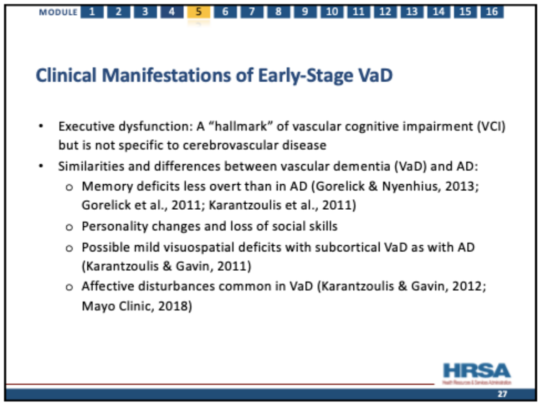

Clinical Manifestations of Early-Stage VaD

- Executive dysfunction: A "hallmark" of vascular cognitive impairment (VCI) but is not specific to cerebrovascular disease
- Similarities and differences between vascular dementia (VaD) and AD:
  - Memory deficits less overt than in AD (Gorelick & Nyenhius, 2013; Gorelick et al., 2011; Karantzoulis et al., 2011)
  - Personality changes and loss of social skills
  - Possible mild visuospatial deficits with subcortical VaD as with AD (Karantzoulis & Gavin, 2011)
  - Affective disturbances common in VaD (Karantzoulis & Gavin, 2012; Mayo Clinic, 2018)

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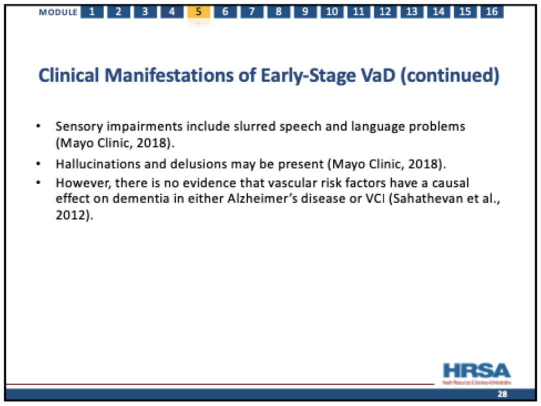

Clinical Manifestations of Early-Stage VaD (continued)

- Sensory impairments include slurred speech and language problems (Mayo Clinic, 2018).
- Hallucinations and delusions may be present (Mayo Clinic, 2018).
- However, there is no evidence that vascular risk factors have a causal effect on dementia in either Alzheimer's disease or VCI (Sahathevan et al., 2012).

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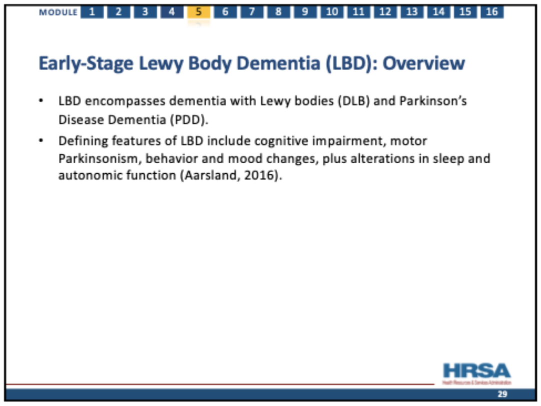

Early-Stage Lewy Body Dementia (LBD): Overview

- LBD encompasses dementia with Lewy bodies (DLB) and Parkinson's Disease Dementia (PDD).
- Defining features of LBD include cognitive impairment, motor Parkinsonism, behavior and mood changes, plus alterations in sleep and autonomic function (Aarsland, 2016).

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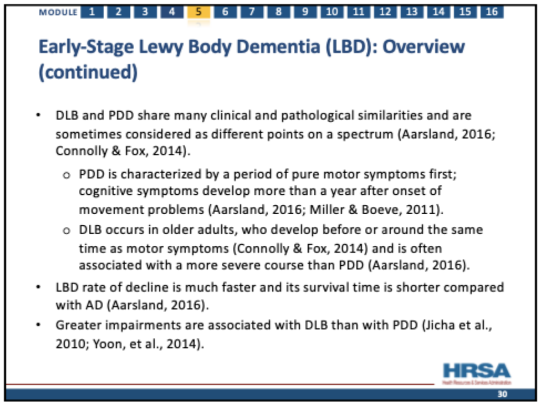

Early-Stage Lewy Body Dementia (LBD): Overview (continued)

- DLB and PDD share many clinical and pathological similarities and are sometimes considered as different points on a spectrum (Aarsland, 2016; Connolly & Fox, 2014).
  - PDD is characterized by a period of pure motor symptoms first; cognitive symptoms develop more than a year after onset of movement problems (Aarsland, 2016; Miller & Boeve, 2011).
  - DLB occurs in older adults, who develop before or around the same time as motor symptoms (Connolly & Fox, 2014) and is often associated with a more severe course than PDD (Aarsland, 2016).
- LBD rate of decline is much faster and its survival time is shorter compared with AD (Aarsland, 2016).
- Greater impairments are associated with DLB than with PDD (Jicha et al., 2010; Yoon, et al., 2014).

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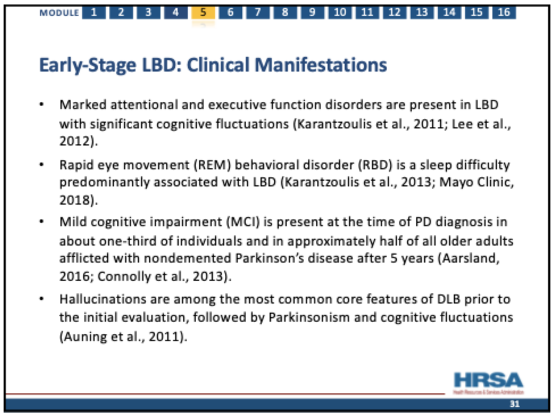

Early-Stage LBD: Clinical Manifestations

- Marked attentional and executive function disorders are present in LBD with significant cognitive fluctuations (Karantzoulis et al., 2011; Lee et al., 2012).
- Rapid eye movement (REM) behavioral disorder (RBD) is a sleep difficulty predominantly associated with LBD (Karantzoulis et al., 2013; Mayo Clinic, 2018).
- Mild cognitive impairment (MCI) is present at the time of PD diagnosis in about one-third of individuals and in approximately half of all older adults afflicted with nondemented Parkinson's disease after 5 years (Aarsland, 2016; Connolly et al., 2013).
- Hallucinations are among the most common core features of DLB prior to the initial evaluation, followed by Parkinsonism and cognitive fluctuations (Auning et al., 2011).

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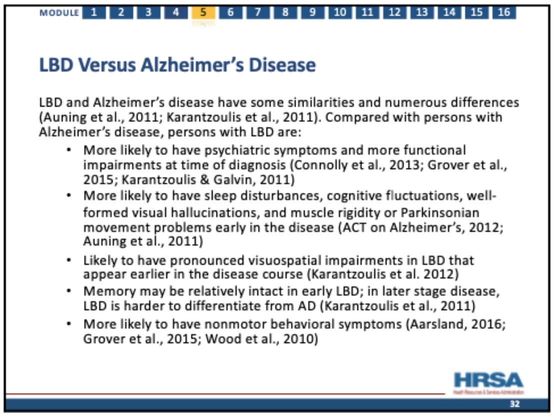

LBD Versus Alzheimer's Disease

LBD and Alzheimer's disease have some similarities and numerous differences (Auning et al., 2011; Karantzoulis et al., 2011). Compared with persons with Alzheimer's disease, persons with LBD are:

- More likely to have psychiatric symptoms and more functional impairments at time of diagnosis (Connolly et al., 2013; Grover et al., 2015; Karantzoulis & Galvin, 2011)
- More likely to have sleep disturbances, cognitive fluctuations, well-formed visual hallucinations, and muscle rigidity or Parkinsonian movement problems early in the disease (ACT on Alzheimer's, 2012; Auning et al., 2011)
- Likely to have pronounced visuospatial impairments in LBD that appear earlier in the disease course (Karantzoulis et al. 2012)
- Memory may be relatively intact in early LBD; in later stage disease, LBD is harder to differentiate from AD (Karantzoulis et al., 2011)
- More likely to have nonmotor behavioral symptoms (Aarsland, 2016; Grover et al., 2015; Wood et al., 2010)

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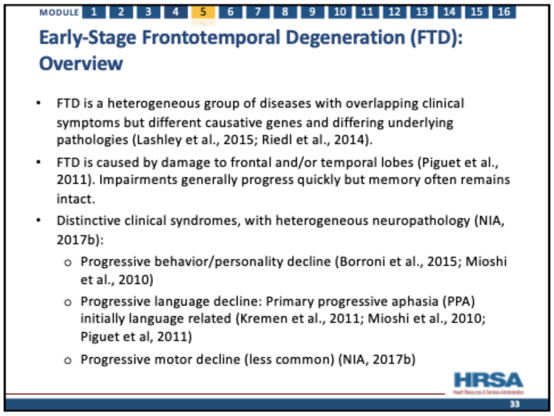

Early-Stage Frontotemporal Degeneration (FTD): Overview

- FTD is a heterogeneous group of diseases with overlapping clinical symptoms but different causative genes and differing underlying pathologies (Lashley et al., 2015; Riedl et al., 2014).
- FTD is caused by damage to frontal and/or temporal lobes (Piguet et al., 2011). Impairments generally progress quickly but memory often remains intact.
- Distinctive clinical syndromes, with heterogeneous neuropathology (NIA, 2017b):
  - Progressive behavior/personality decline (Borroni et al., 2015; Mioshi et al., 2010)
  - Progressive language decline: Primary progressive aphasia (PPA) initially language related (Kremen et al., 2011; Mioshi et al., 2010; Piguet et al, 2011)
  - Progressive motor decline (less common) (NIA, 2017b)

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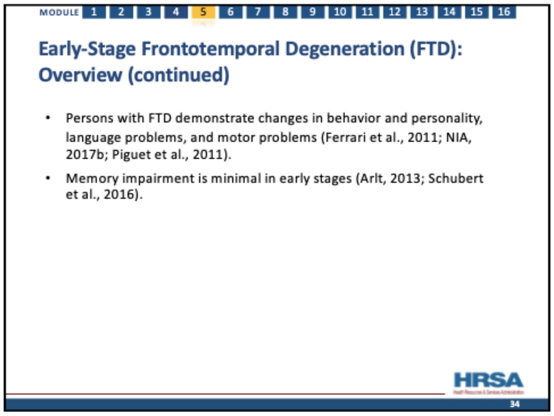

Early-Stage Frontotemporal Degeneration (FTD): Overview (continued)

- Persons with FTD demonstrate changes in behavior and personality, language problems, and motor problems (Ferrari et al., 2011; NIA, 2017b; Piguet et al., 2011).
- Memory impairment is minimal in early stages (Arlt, 2013; Schubert et al., 2016).

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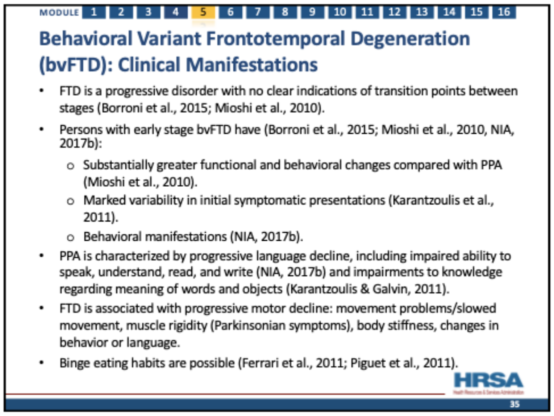

Behavioral Variant Frontotemporal Degeneration (bvFTD): Clinical Manifestations

- FTD is a progressive disorder with no clear indications of transition points between stages (Borroni et al., 2015; Mioshi et al., 2010).
- Persons with early stage bvFTD have (Borroni et al., 2015; Mioshi et al., 2010, NIA, 2017b):
  - Substantially greater functional and behavioral changes compared with PPA (Mioshi et al., 2010).
  - Marked variability in initial symptomatic presentations (Karantzoulis et al., 2011).
  - Behavioral manifestations (NIA, 2017b).
- PPA is characterized by progressive language decline, including impaired ability to speak, understand, read, and write (NIA, 2017b) and impairments to knowledge regarding meaning of words and objects (Karantzoulis & Galvin, 2011).
- FTD is associated with progressive motor decline: movement problems/slowed movement, muscle rigidity (Parkinsonian symptoms), body stiffness, changes in behavior or language.
- Binge eating habits are possible (Ferrari et al., 2011; Piguet et al., 2011).

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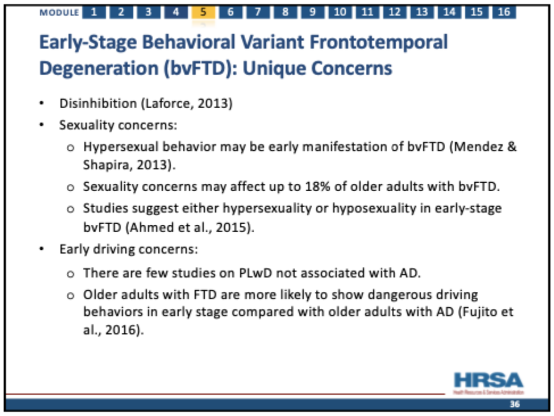

Early-Stage Behavioral Variant Frontotemporal Degeneration (bvFTD): Unique Concerns

- Disinhibition (Laforce, 2013)
- Sexuality concerns:
  - Hypersexual behavior may be early manifestation of bvFTD (Mendez & Shapira, 2013).
  - Sexuality concerns may affect up to 18% of older adults with bvFTD.
  - Studies suggest either hypersexuality or hyposexuality in early-stage bvFTD (Ahmed et al., 2015).
- Early driving concerns:
  - There are few studies on PLwD not associated with AD.
  - Older adults with FTD are more likely to show dangerous driving behaviors in early stage compared with older adults with AD (Fujito et al., 2016).

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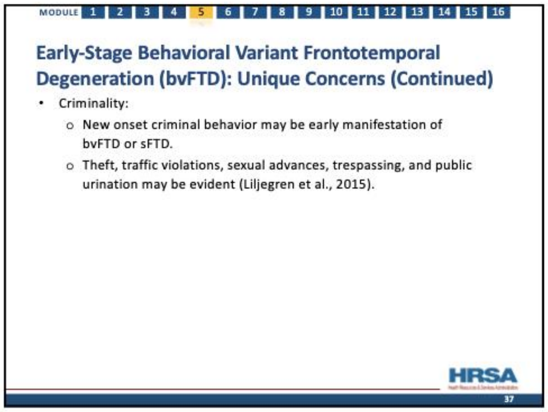
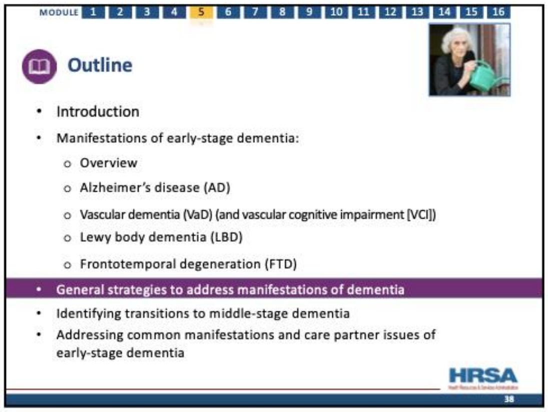


Early-Stage Behavioral Variant Frontotemporal Degeneration (bvFTD): Unique Concerns (Continued)

- Criminality:
  - New onset criminal behavior may be early manifestation of bvFTD or sFTD.
  - Theft, traffic violations, sexual advances, trespassing, and public urination may be evident (Liljegren et al., 2015).



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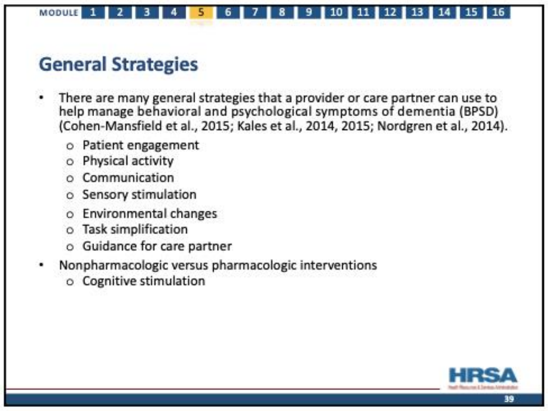
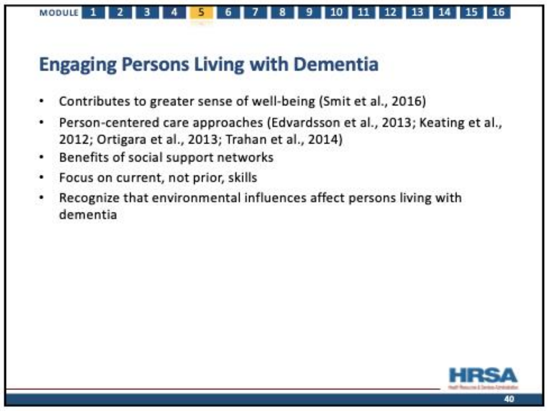


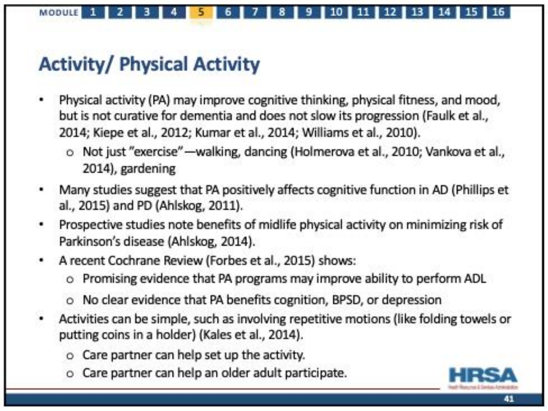
General Strategies

- There are many general strategies that a provider or care partner can use to help manage behavioral and psychological symptoms of dementia (BPSD) (Cohen-Mansfield et al., 2015; Kales et al., 2014, 2015; Nordgren et al., 2014).
  - Patient engagement
  - Physical activity
  - Communication
  - Sensory stimulation
  - Environmental changes
  - Task simplification
  - Guidance for care partner
- Nonpharmacologic versus pharmacologic interventions
  - Cognitive stimulation



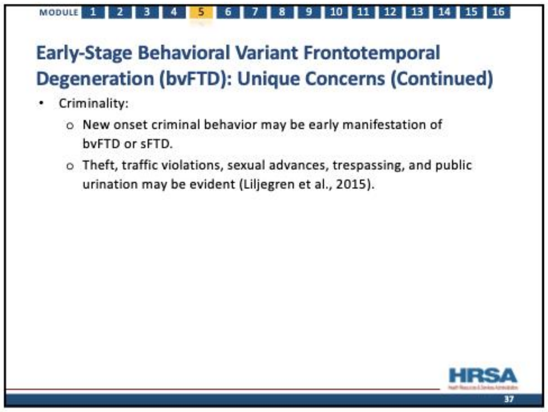
Engaging Persons Living with Dementia

- Contributes to greater sense of well-being (Smit et al., 2016)
- Person-centered care approaches (Edvardsson et al., 2013; Keating et al., 2012; Ortigara et al., 2013; Trahan et al., 2014)
- Benefits of social support networks
- Focus on current, not prior, skills
- Recognize that environmental influences affect persons living with dementia



Activity/ Physical Activity

- Physical activity (PA) may improve cognitive thinking, physical fitness, and mood, but is not curative for dementia and does not slow its progression (Faulk et al., 2014; Kiepe et al., 2012; Kumar et al., 2014; Williams et al., 2010).
  - Not just "exercise"—walking, dancing (Holmerova et al., 2010; Vankova et al., 2014), gardening
- Many studies suggest that PA positively affects cognitive function in AD (Phillips et al., 2015) and PD (Ahlskog, 2011).
- Prospective studies note benefits of midlife physical activity on minimizing risk of Parkinson's disease (Ahlskog, 2014).
- A recent Cochrane Review (Forbes et al., 2015) shows:
  - Promising evidence that PA programs may improve ability to perform ADL
  - No clear evidence that PA benefits cognition, BPSD, or depression
- Activities can be simple, such as involving repetitive motions (like folding towels or putting coins in a holder) (Kales et al., 2014).
  - Care partner can help set up the activity.
  - Care partner can help an older adult participate.



MODULE 1 2 3 4 5 6 7 8 9 10 11 12 13 14 15 16

Early-Stage Behavioral Variant Frontotemporal Degeneration (bvFTD): Unique Concerns (Continued)

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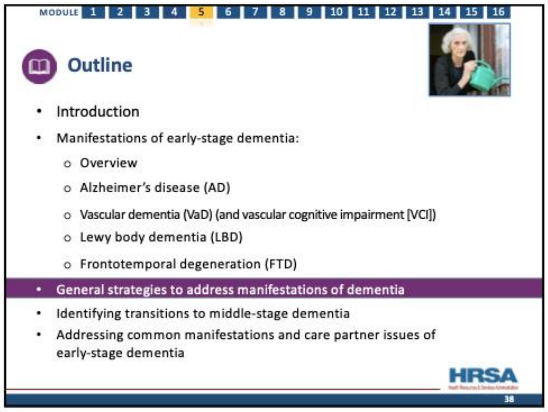

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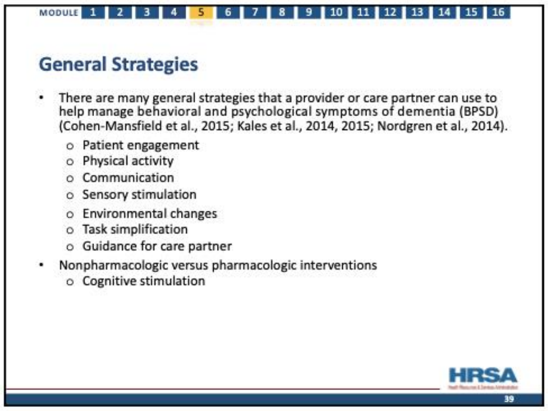

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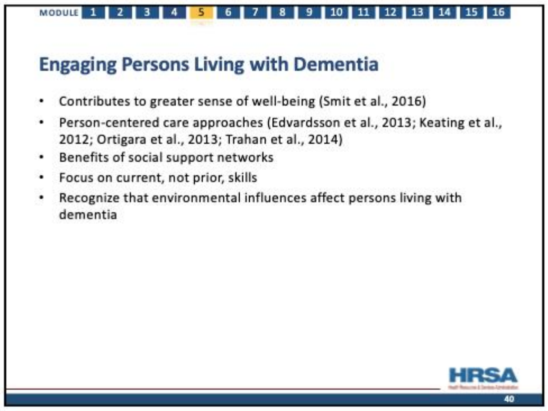

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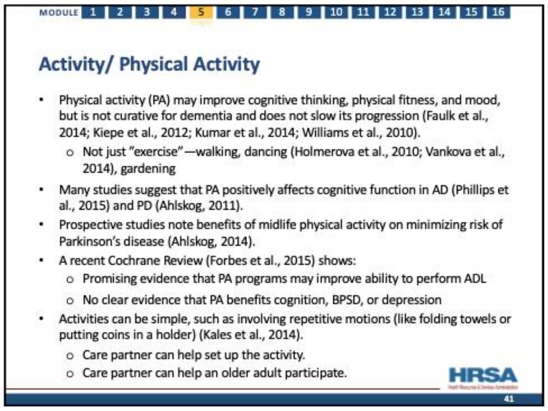

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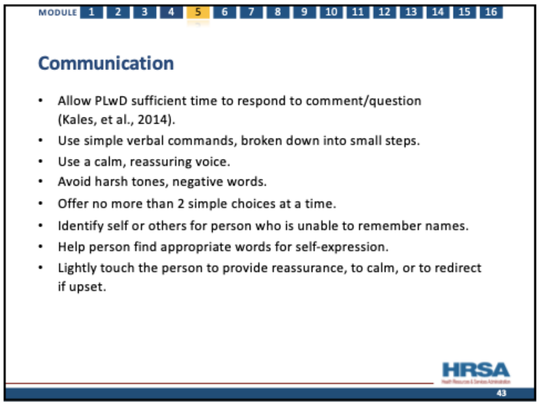

Communication

- Allow PLwD sufficient time to respond to comment/question (Kales, et al., 2014).
- Use simple verbal commands, broken down into small steps.
- Use a calm, reassuring voice.
- Avoid harsh tones, negative words.
- Offer no more than 2 simple choices at a time.
- Identify self or others for person who is unable to remember names.
- Help person find appropriate words for self-expression.
- Lightly touch the person to provide reassurance, to calm, or to redirect if upset.

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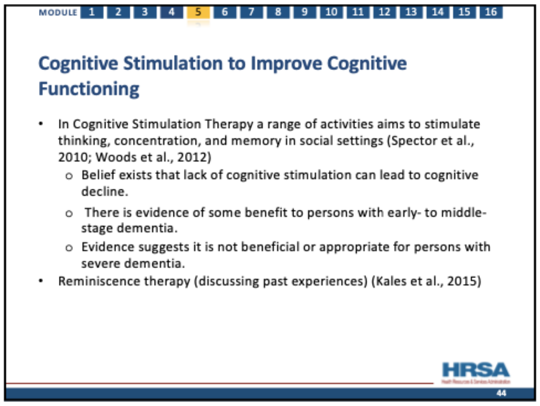

Cognitive Stimulation to Improve Cognitive Functioning

- In Cognitive Stimulation Therapy a range of activities aims to stimulate thinking, concentration, and memory in social settings (Spector et al., 2010; Woods et al., 2012)
  - Belief exists that lack of cognitive stimulation can lead to cognitive decline.
  - There is evidence of some benefit to persons with early- to middle-stage dementia.
  - Evidence suggests it is not beneficial or appropriate for persons with severe dementia.
- Reminiscence therapy (discussing past experiences) (Kales et al., 2015)

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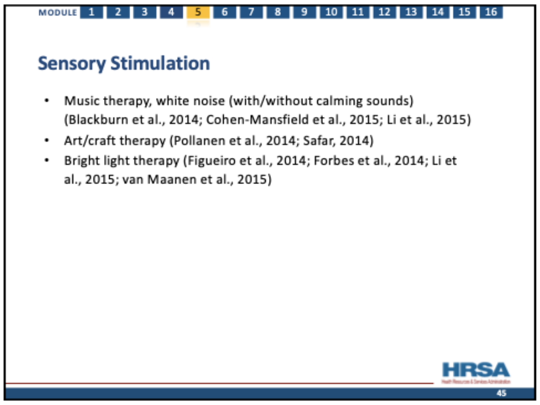

Sensory Stimulation

- Music therapy, white noise (with/without calming sounds) (Blackburn et al., 2014; Cohen-Mansfield et al., 2015; Li et al., 2015)
- Art/craft therapy (Pollanen et al., 2014; Safar, 2014)
- Bright light therapy (Figueiro et al., 2014; Forbes et al., 2014; Li et al., 2015; van Maanen et al., 2015)

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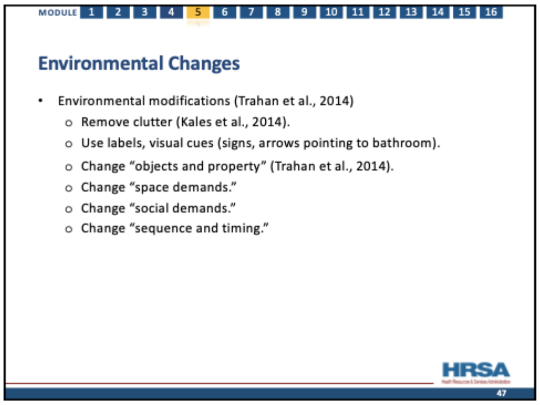

Environmental Changes

- Environmental modifications (Trahan et al., 2014)
  - Remove clutter (Kales et al., 2014).
  - Use labels, visual cues (signs, arrows pointing to bathroom).
  - Change “objects and property” (Trahan et al., 2014).
  - Change “space demands.”
  - Change “social demands.”
  - Change “sequence and timing.”

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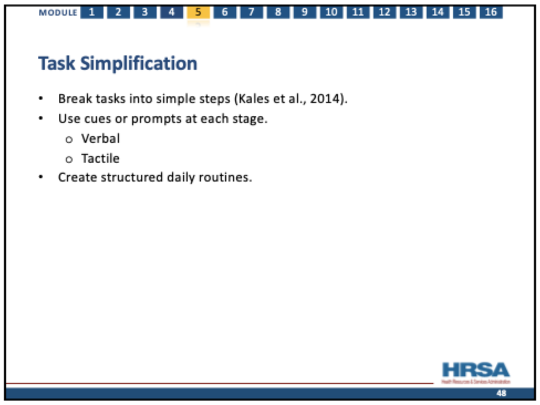

Task Simplification

- Break tasks into simple steps (Kales et al., 2014).
- Use cues or prompts at each stage.
  - Verbal
  - Tactile
- Create structured daily routines.

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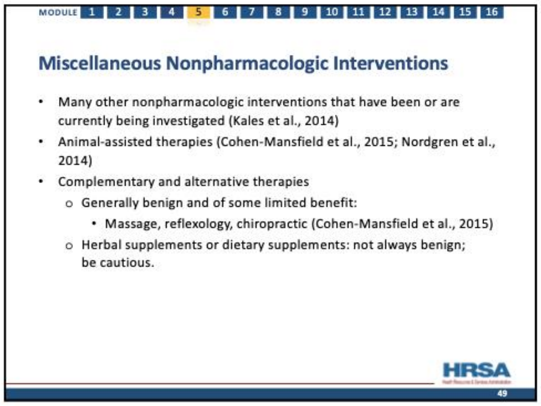

Miscellaneous Nonpharmacologic Interventions

- Many other nonpharmacologic interventions that have been or are currently being investigated (Kales et al., 2014)
- Animal-assisted therapies (Cohen-Mansfield et al., 2015; Nordgren et al., 2014)
- Complementary and alternative therapies
  - Generally benign and of some limited benefit:
    - Massage, reflexology, chiropractic (Cohen-Mansfield et al., 2015)
  - Herbal supplements or dietary supplements: not always benign; be cautious.

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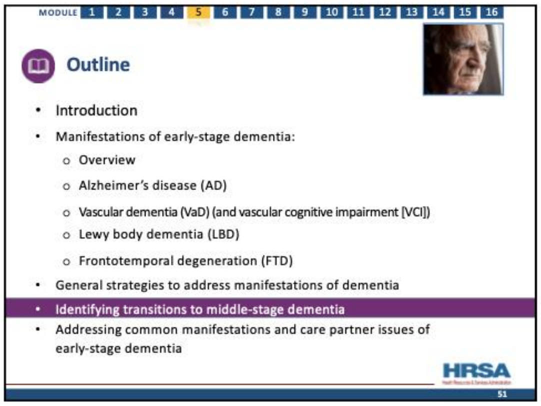

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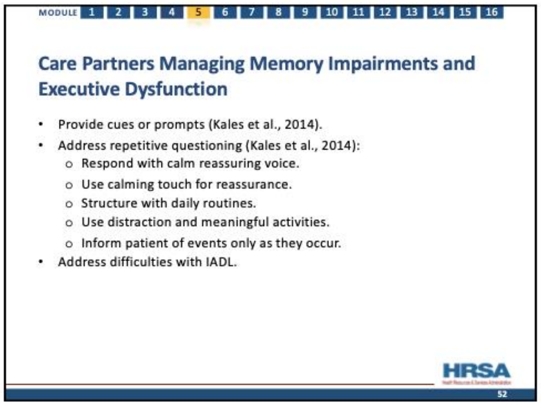

Care Partners Managing Memory Impairments and Executive Dysfunction

- Provide cues or prompts (Kales et al., 2014).
- Address repetitive questioning (Kales et al., 2014):
  - Respond with calm reassuring voice.
  - Use calming touch for reassurance.
  - Structure with daily routines.
  - Use distraction and meaningful activities.
  - Inform patient of events only as they occur.
- Address difficulties with IADL.

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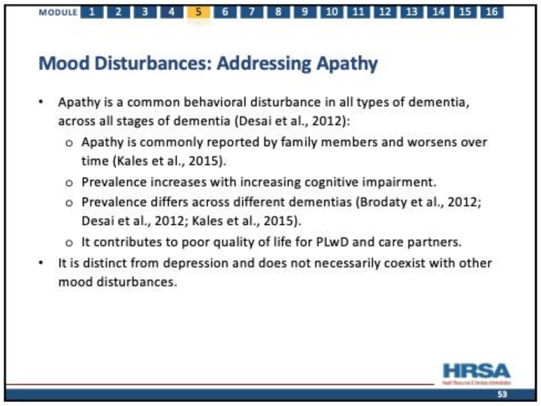

Mood Disturbances: Addressing Apathy

- Apathy is a common behavioral disturbance in all types of dementia, across all stages of dementia (Desai et al., 2012):
  - Apathy is commonly reported by family members and worsens over time (Kales et al., 2015).
  - Prevalence increases with increasing cognitive impairment.
  - Prevalence differs across different dementias (Brodaty et al., 2012; Desai et al., 2012; Kales et al., 2015).
  - It contributes to poor quality of life for PLwD and care partners.
- It is distinct from depression and does not necessarily coexist with other mood disturbances.

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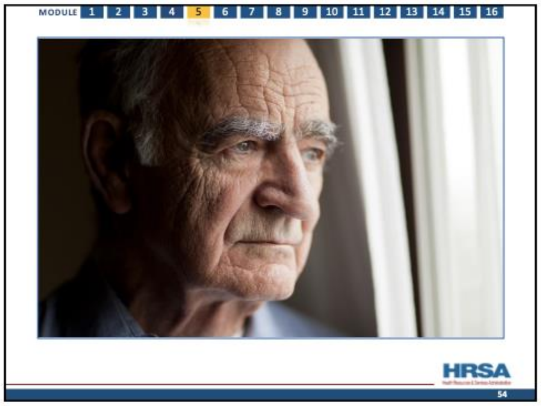

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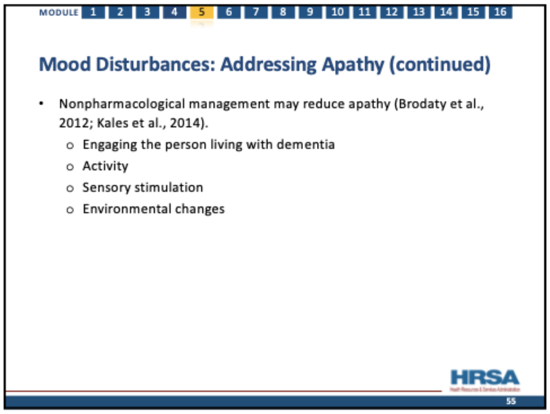

Mood Disturbances: Addressing Apathy (continued)

- Nonpharmacological management may reduce apathy (Brodaty et al., 2012; Kales et al., 2014).
  - Engaging the person living with dementia
  - Activity
  - Sensory stimulation
  - Environmental changes

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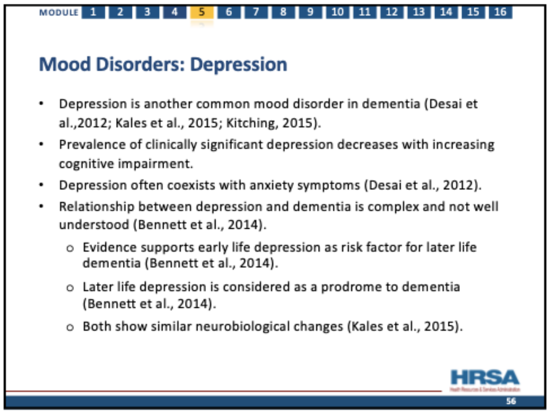

Mood Disorders: Depression

- Depression is another common mood disorder in dementia (Desai et al.,2012; Kales et al., 2015; Kitching, 2015).
- Prevalence of clinically significant depression decreases with increasing cognitive impairment.
- Depression often coexists with anxiety symptoms (Desai et al., 2012).
- Relationship between depression and dementia is complex and not well understood (Bennett et al., 2014).
  - Evidence supports early life depression as risk factor for later life dementia (Bennett et al., 2014).
  - Later life depression is considered as a prodrome to dementia (Bennett et al., 2014).
  - Both show similar neurobiological changes (Kales et al., 2015).

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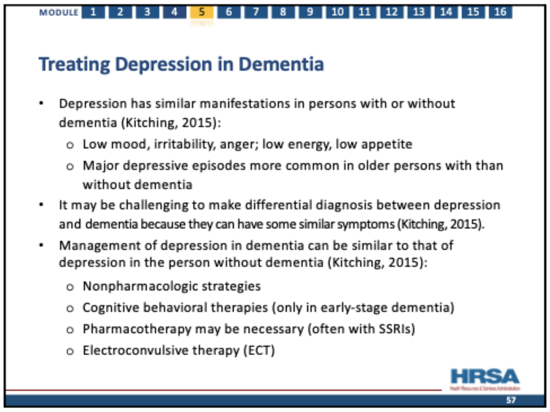

Treating Depression in Dementia

- Depression has similar manifestations in persons with or without dementia (Kitching, 2015):
  - Low mood, irritability, anger; low energy, low appetite
  - Major depressive episodes more common in older persons with than without dementia
- It may be challenging to make differential diagnosis between depression and dementia because they can have some similar symptoms (Kitching, 2015).
- Management of depression in dementia can be similar to that of depression in the person without dementia (Kitching, 2015):
  - Nonpharmacologic strategies
  - Cognitive behavioral therapies (only in early-stage dementia)
  - Pharmacotherapy may be necessary (often with SSRIs)
  - Electroconvulsive therapy (ECT)

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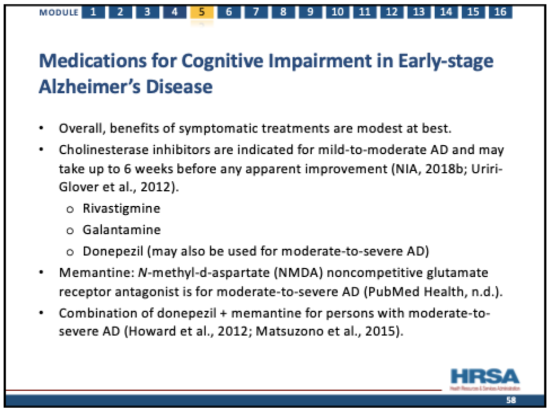

Medications for Cognitive Impairment in Early-stage Alzheimer's Disease

- Overall, benefits of symptomatic treatments are modest at best.
- Cholinesterase inhibitors are indicated for mild-to-moderate AD and may take up to 6 weeks before any apparent improvement (NIA, 2018b; Uriri-Glover et al., 2012).
  - Rivastigmine
  - Galantamine
  - Donepezil (may also be used for moderate-to-severe AD)
- Memantine: *N*-methyl-d-aspartate (NMDA) noncompetitive glutamate receptor antagonist is for moderate-to-severe AD (PubMed Health, n.d.).
- Combination of donepezil + memantine for persons with moderate-to-severe AD (Howard et al., 2012; Matsuzono et al., 2015).

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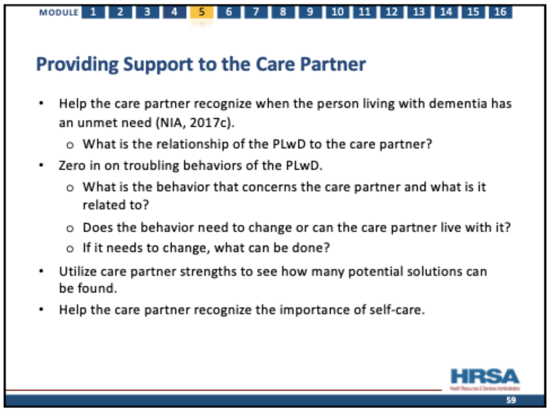

Providing Support to the Care Partner

- Help the care partner recognize when the person living with dementia has an unmet need (NIA, 2017c).
  - What is the relationship of the PLwD to the care partner?
- Zero in on troubling behaviors of the PLwD.
  - What is the behavior that concerns the care partner and what is it related to?
  - Does the behavior need to change or can the care partner live with it?
  - If it needs to change, what can be done?
- Utilize care partner strengths to see how many potential solutions can be found.
- Help the care partner recognize the importance of self-care.

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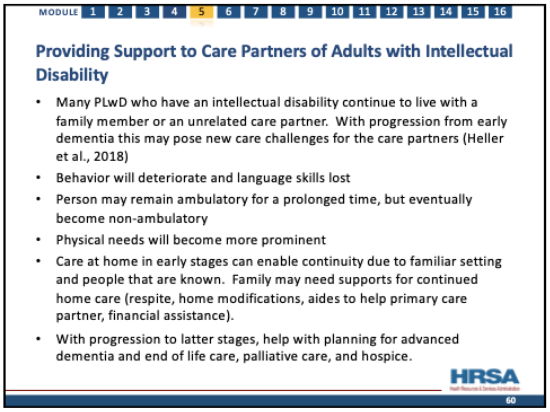

Providing Support to Care Partners of Adults with Intellectual Disability

- Many PLwD who have an intellectual disability continue to live with a family member or an unrelated care partner. With progression from early dementia this may pose new care challenges for the care partners (Heller et al., 2018)
- Behavior will deteriorate and language skills lost
- Person may remain ambulatory for a prolonged time, but eventually become non-ambulatory
- Physical needs will become more prominent
- Care at home in early stages can enable continuity due to familiar setting and people that are known. Family may need supports for continued home care (respite, home modifications, aides to help primary care partner, financial assistance).
- With progression to latter stages, help with planning for advanced dementia and end of life care, palliative care, and hospice.

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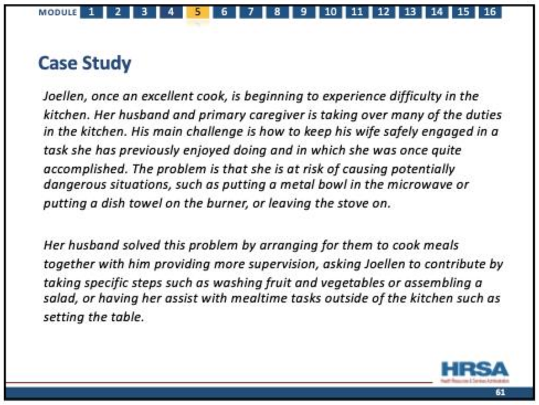
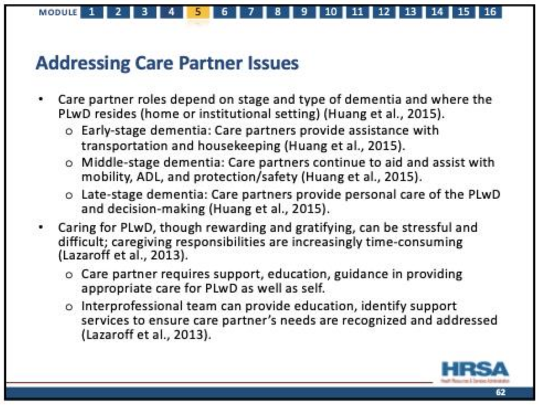


Case Study

Joellen, once an excellent cook, is beginning to experience difficulty in the kitchen. Her husband and primary caregiver is taking over many of the duties in the kitchen. His main challenge is how to keep his wife safely engaged in a task she has previously enjoyed doing and in which she was once quite accomplished. The problem is that she is at risk of causing potentially dangerous situations, such as putting a metal bowl in the microwave or putting a dish towel on the burner, or leaving the stove on.

Her husband solved this problem by arranging for them to cook meals together with him providing more supervision, asking Joellen to contribute by taking specific steps such as washing fruit and vegetables or assembling a salad, or having her assist with mealtime tasks outside of the kitchen such as setting the table.

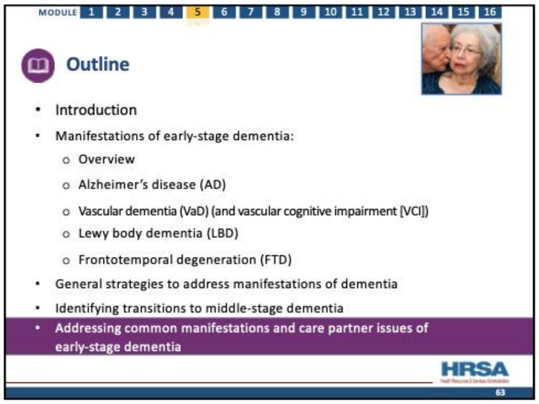
61



Addressing Care Partner Issues

- Care partner roles depend on stage and type of dementia and where the PLwD resides (home or institutional setting) (Huang et al., 2015).
  - Early-stage dementia: Care partners provide assistance with transportation and housekeeping (Huang et al., 2015).
  - Middle-stage dementia: Care partners continue to aid and assist with mobility, ADL, and protection/safety (Huang et al., 2015).
  - Late-stage dementia: Care partners provide personal care of the PLwD and decision-making (Huang et al., 2015).
- Caring for PLwD, though rewarding and gratifying, can be stressful and difficult; caregiving responsibilities are increasingly time-consuming (Lazaroff et al., 2013).
  - Care partner requires support, education, guidance in providing appropriate care for PLwD as well as self.
  - Interprofessional team can provide education, identify support services to ensure care partner's needs are recognized and addressed (Lazaroff et al., 2013).

62



Outline

- Introduction
- Manifestations of early-stage dementia:
  - Overview
  - Alzheimer's disease (AD)
  - Vascular dementia (VaD) (and vascular cognitive impairment [VCI])
  - Lewy body dementia (LBD)
  - Frontotemporal degeneration (FTD)
- General strategies to address manifestations of dementia
- Identifying transitions to middle-stage dementia
- Addressing common manifestations and care partner issues of early-stage dementia

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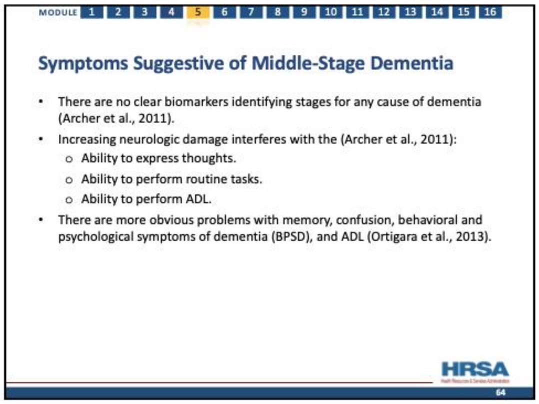

Symptoms Suggestive of Middle-Stage Dementia

- There are no clear biomarkers identifying stages for any cause of dementia (Archer et al., 2011).
- Increasing neurologic damage interferes with the (Archer et al., 2011):
  - Ability to express thoughts.
  - Ability to perform routine tasks.
  - Ability to perform ADL.
- There are more obvious problems with memory, confusion, behavioral and psychological symptoms of dementia (BPSD), and ADL (Ortigara et al., 2013).

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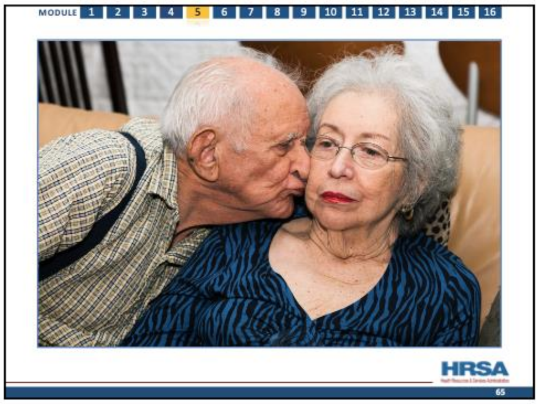

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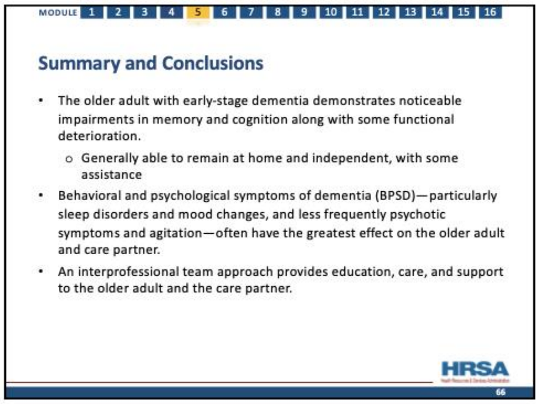

Summary and Conclusions

- The older adult with early-stage dementia demonstrates noticeable impairments in memory and cognition along with some functional deterioration.
  - Generally able to remain at home and independent, with some assistance
- Behavioral and psychological symptoms of dementia (BPSD)—particularly sleep disorders and mood changes, and less frequently psychotic symptoms and agitation—often have the greatest effect on the older adult and care partner.
- An interprofessional team approach provides education, care, and support to the older adult and the care partner.

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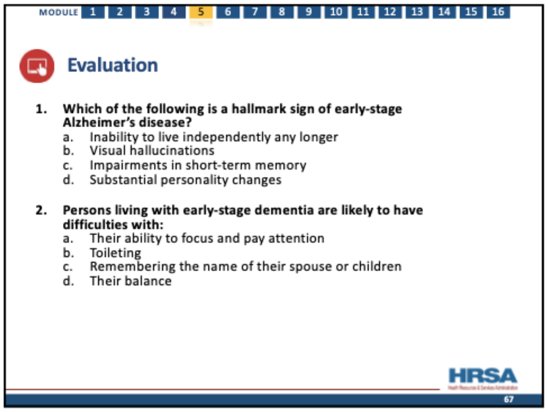

Evaluation

1. **Which of the following is a hallmark sign of early-stage Alzheimer's disease?**
   a. Inability to live independently any longer
   b. Visual hallucinations
   c. Impairments in short-term memory
   d. Substantial personality changes
2. **Persons living with early-stage dementia are likely to have difficulties with:**
   a. Their ability to focus and pay attention
   b. Toileting
   c. Remembering the name of their spouse or children
   d. Their balance

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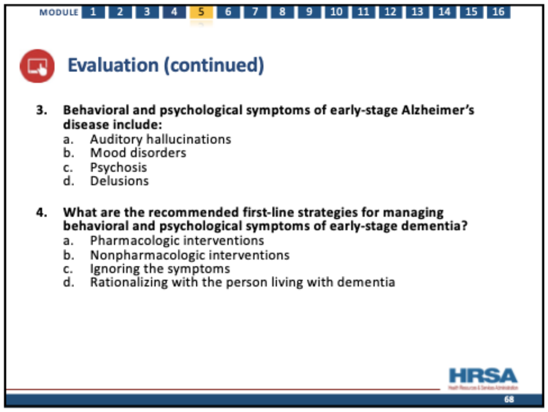

Evaluation (continued)

3. **Behavioral and psychological symptoms of early-stage Alzheimer's disease include:**
   a. Auditory hallucinations
   b. Mood disorders
   c. Psychosis
   d. Delusions
4. **What are the recommended first-line strategies for managing behavioral and psychological symptoms of early-stage dementia?**
   a. Pharmacologic interventions
   b. Nonpharmacologic interventions
   c. Ignoring the symptoms
   d. Rationalizing with the person living with dementia

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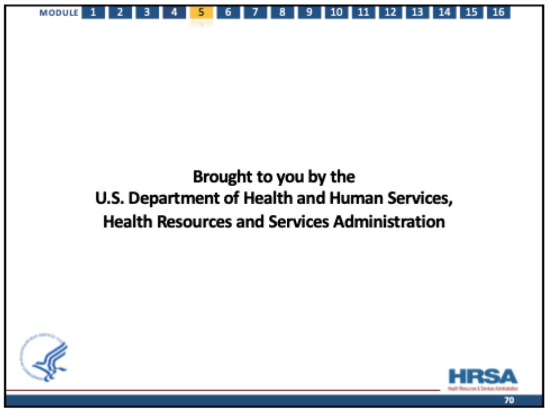
Acknowledgements

This module was prepared for the U.S. Department of Health and Human Services (HHS), Health Resources and Services Administration (HRSA), by The Bizzell Group, LLC, under contract number HHSH25034002T/HHSH250201400075I.
The dementia and education experts who served on the Dementia Expert Workgroup to guide the development of the modules included: **Alice Bonner, PhD, RN, FAAN**, Secretary Elder Affairs, Massachusetts Executive Office of Elder Affairs, Boston MA; **Laurel Coleman, MD, FACP**, Kauai Medical Clinic -Hawaii Pacific Health, Lihue, HI; **Cyndy B. Cordell, MBA**, Director, Healthcare Professional Services, Alzheimer's Association, Chicago, IL; **Dolores Gallagher Thompson, PhD, ABPP**, Professor of Research, Department of Psychiatry and Behavioral Sciences, Stanford University School of Medicine, Stanford, CA; **James Galvin, MD, MPH**, Professor of Clinical Biomedical Science and Associate Dean for Clinical Research, Florida Atlantic University, Boca Raton, FL; **Mary Guerriero Austrom, PhD**, Wesley P Martin Professor of Alzheimer's Disease Education, Department of Psychiatry, Associate Dean for Diversity Affairs, Indiana University-Purdue University Indianapolis, Indianapolis, IN; **Robert Kane, MD**, Professor and Minnesota Chair in Long-term Care & Aging, Health Policy & Management, School of Public Health, University of Minnesota; **Jason Karlawish, MD**, Professor of Medicine, Perelman School of Medicine, University of Pennsylvania; **Helen M. Matheny, MS, APR**, Director of the Alzheimer's Disease Outreach Program, Blanchette Rockefeller Neuroscience Institute, Morgantown, WV; **Darby Morhardt, PhD, LCSW**, Associate Professor, Cognitive Neurology and Alzheimer's Disease Center and Department of Preventive Medicine, Northwestern University Feinberg School of Medicine, Northwestern University, Chicago, IL; **Cecilia Rokusek, EdD, MSc, RDN**, Assistant Dean of Research and Innovation, Professor of Family Medicine, Public Health, Nutrition, and Disaster and Emergency Preparedness, College of Osteopathic Medicine, Nova Southeastern University, Fort Lauderdale, FL. Additional expertise in the development of the modules was provided by **Meg Kabat, LCSW-C, CCM; Eleanor S. McConnell, PhD, MSN, RN, GCNS, BC; Linda O. Nichols, PhD, MA, BA; Todd Semla, MS, PharmD, BCPS, FCCP, AGSF; Kenneth Shay, DDS, MS**, from the U.S. Department of Veterans Affairs and **Seth Keller, MD** and **Matthew P. Janicki, PhD**, National Task Group on Intellectual Disabilities and Dementia Practices.

69



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U.S. Department of Health and Human Services,
Health Resources and Services Administration

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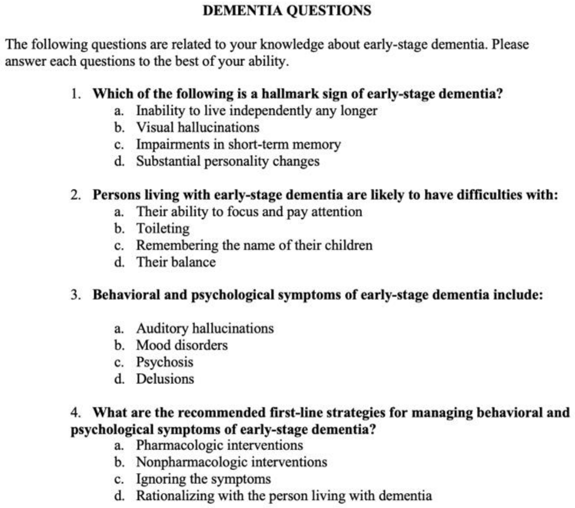
Appendix F.

Dementia and NGSE from Pre- and Post-Educational Intervention Test



DEMENTIA QUESTIONS

The following questions are related to your knowledge about early-stage dementia. Please answer each questions to the best of your ability.

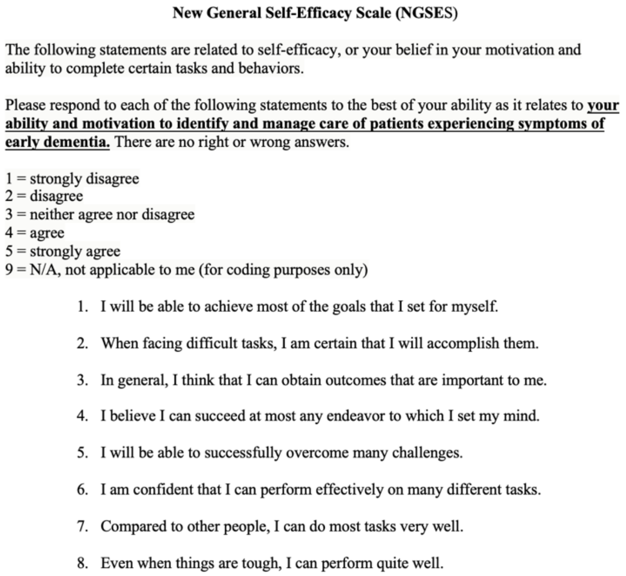
1. **Which of the following is a hallmark sign of early-stage dementia?**
    - a. Inability to live independently any longer
    - b. Visual hallucinations
    - c. Impairments in short-term memory
    - d. Substantial personality changes

2. **Persons living with early-stage dementia are likely to have difficulties with:**
    - a. Their ability to focus and pay attention
    - b. Toileting
    - c. Remembering the name of their children
    - d. Their balance

3. **Behavioral and psychological symptoms of early-stage dementia include:**

    - a. Auditory hallucinations
    - b. Mood disorders
    - c. Psychosis
    - d. Delusions

4. **What are the recommended first-line strategies for managing behavioral and psychological symptoms of early-stage dementia?**
    - a. Pharmacologic interventions
    - b. Nonpharmacologic interventions
    - c. Ignoring the symptoms
    - d. Rationalizing with the person living with dementia



New General Self-Efficacy Scale (NGSES)

The following statements are related to self-efficacy, or your belief in your motivation and ability to complete certain tasks and behaviors.

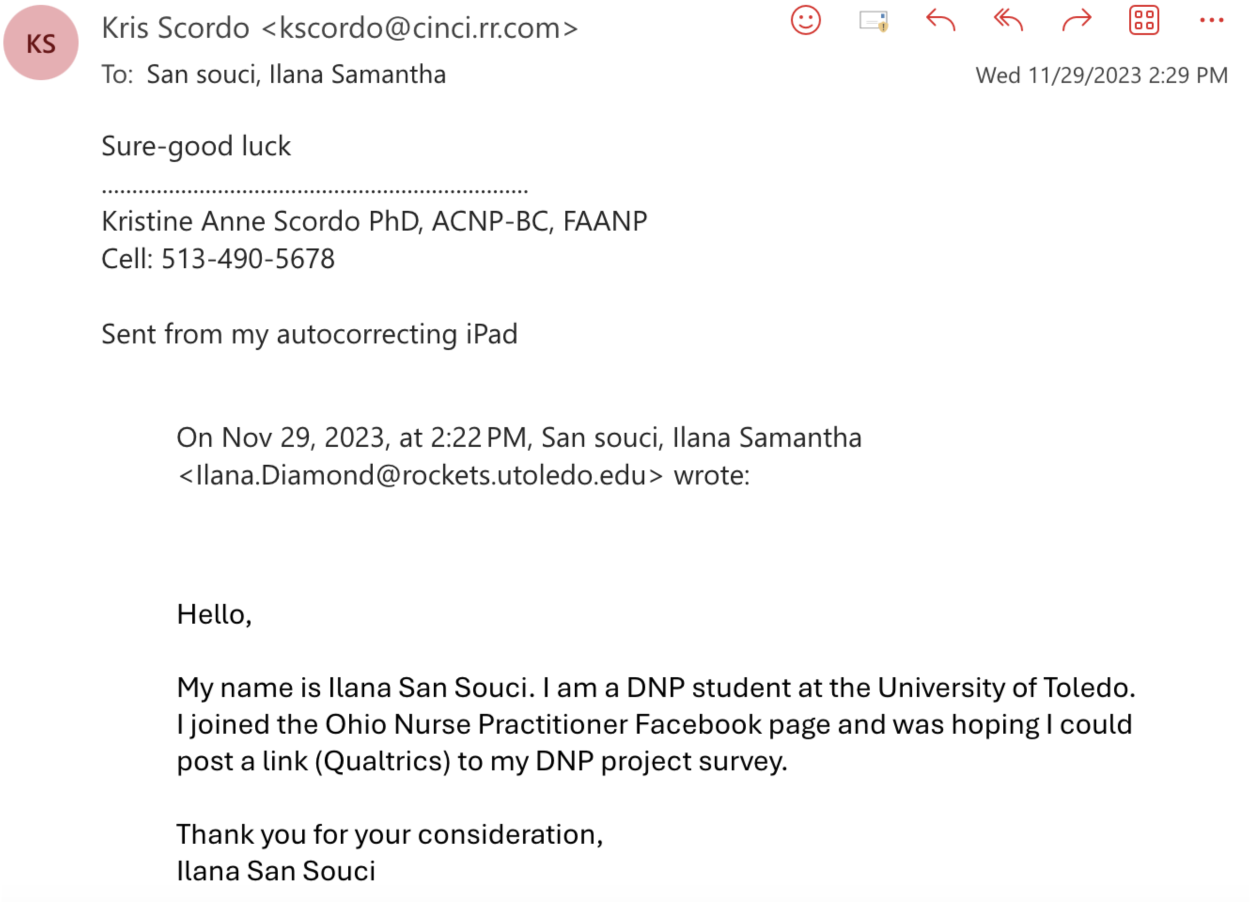
Please respond to each of the following statements to the best of your ability as it relates to **your ability and motivation to identify and manage care of patients experiencing symptoms of early dementia.** There are no right or wrong answers.

1 = strongly disagree
2 = disagree
3 = neither agree nor disagree
4 = agree
5 = strongly agree
9 = N/A, not applicable to me (for coding purposes only)

1. I will be able to achieve most of the goals that I set for myself.
2. When facing difficult tasks, I am certain that I will accomplish them.
3. In general, I think that I can obtain outcomes that are important to me.
4. I believe I can succeed at most any endeavor to which I set my mind.
5. I will be able to successfully overcome many challenges.
6. I am confident that I can perform effectively on many different tasks.
7. Compared to other people, I can do most tasks very well.
8. Even when things are tough, I can perform quite well.

Appendix G.

Permission to Post Project to Facebook Group



KS

Kris Scordo <kscordo@cinci.rr.com>

To: San souci, Ilana Samantha

Wed 11/29/2023 2:29 PM

Sure-good luck

……………………………………………………………

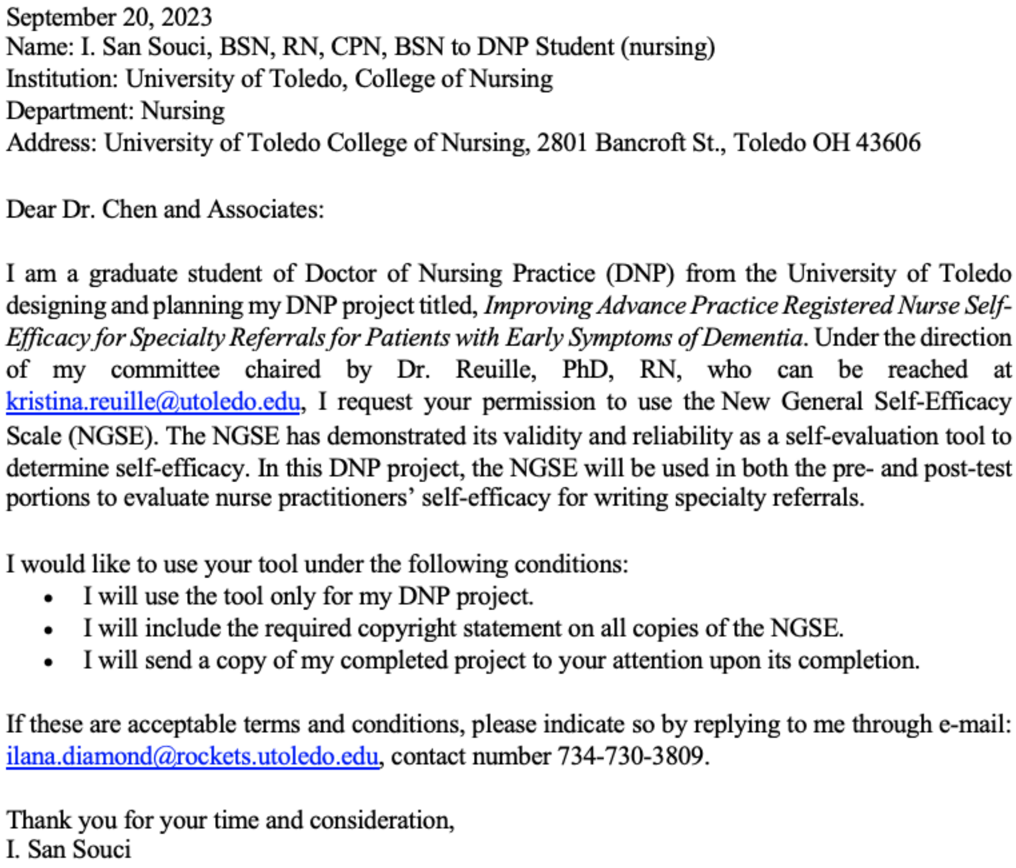
Kristine Anne Scordo PhD, ACNP-BC, FAANP
Cell: 513-490-5678

Sent from my autocorrecting iPad

> On Nov 29, 2023, at 2:22 PM, San souci, Ilana Samantha <Ilana.Diamond@rockets.utoledo.edu> wrote:
>
> Hello,
>
> My name is Ilana San Souci. I am a DNP student at the University of Toledo. I joined the Ohio Nurse Practitioner Facebook page and was hoping I could post a link (Qualtrics) to my DNP project survey.
>
> Thank you for your consideration,
> Ilana San Souci

Appendix H.

Letter for Permission to Use NGSE



September 20, 2023
Name: I. San Souci, BSN, RN, CPN, BSN to DNP Student (nursing)
Institution: University of Toledo, College of Nursing
Department: Nursing
Address: University of Toledo College of Nursing, 2801 Bancroft St., Toledo OH 43606

Dear Dr. Chen and Associates:

I am a graduate student of Doctor of Nursing Practice (DNP) from the University of Toledo designing and planning my DNP project titled, *Improving Advance Practice Registered Nurse Self-Efficacy for Specialty Referrals for Patients with Early Symptoms of Dementia*. Under the direction of my committee chaired by Dr. Reuille, PhD, RN, who can be reached at kristina.reuille@utoledo.edu, I request your permission to use the New General Self-Efficacy Scale (NGSE). The NGSE has demonstrated its validity and reliability as a self-evaluation tool to determine self-efficacy. In this DNP project, the NGSE will be used in both the pre- and post-test portions to evaluate nurse practitioners' self-efficacy for writing specialty referrals.

I would like to use your tool under the following conditions:

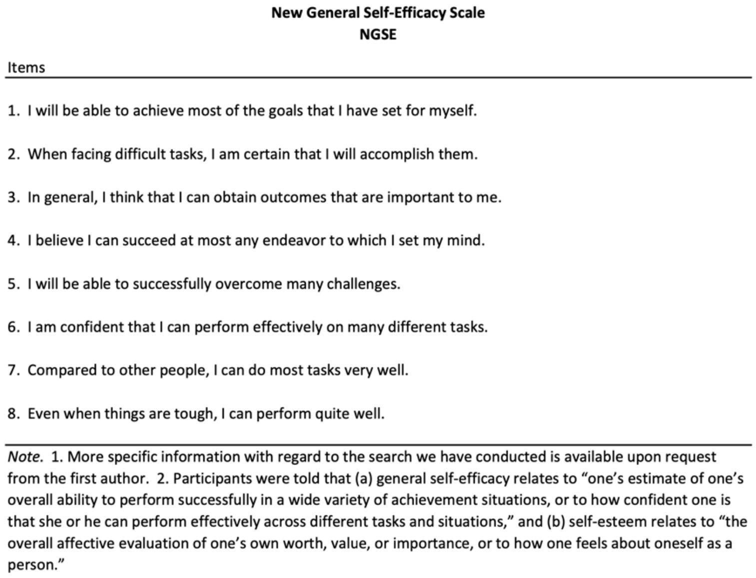
- I will use the tool only for my DNP project.
- I will include the required copyright statement on all copies of the NGSE.
- I will send a copy of my completed project to your attention upon its completion.

If these are acceptable terms and conditions, please indicate so by replying to me through e-mail: ilana.diamond@rockets.utoledo.edu, contact number 734-730-3809.

Thank you for your time and consideration,
I. San Souci

Appendix I.

Letter Permitting Use of NGSE

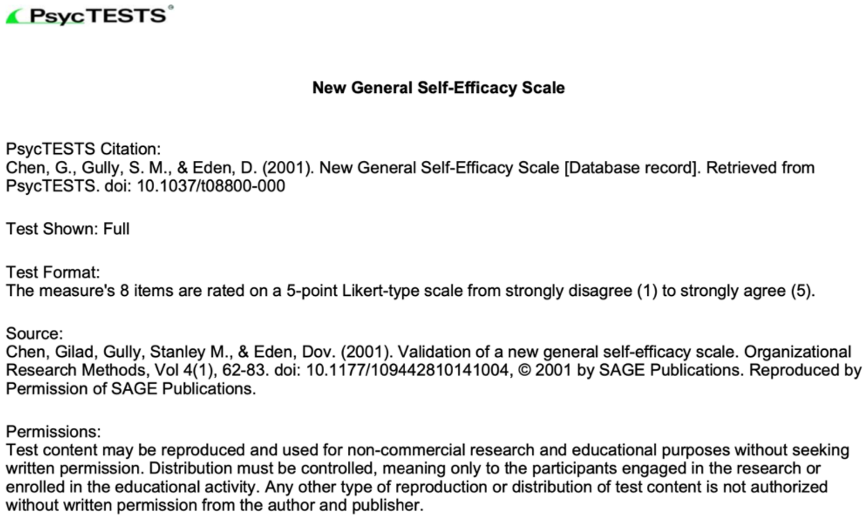


New General Self-Efficacy Scale
NGSE

Items

1. I will be able to achieve most of the goals that I have set for myself.
2. When facing difficult tasks, I am certain that I will accomplish them.
3. In general, I think that I can obtain outcomes that are important to me.
4. I believe I can succeed at most any endeavor to which I set my mind.
5. I will be able to successfully overcome many challenges.
6. I am confident that I can perform effectively on many different tasks.
7. Compared to other people, I can do most tasks very well.
8. Even when things are tough, I can perform quite well.

Note. 1. More specific information with regard to the search we have conducted is available upon request from the first author. 2. Participants were told that (a) general self-efficacy relates to "one's estimate of one's overall ability to perform successfully in a wide variety of achievement situations, or to how confident one is that she or he can perform effectively across different tasks and situations," and (b) self-esteem relates to "the overall affective evaluation of one's own worth, value, or importance, or to how one feels about oneself as a person."



PsycTESTS

New General Self-Efficacy Scale

PsycTESTS Citation:
Chen, G., Gully, S. M., & Eden, D. (2001). New General Self-Efficacy Scale [Database record]. Retrieved from PsycTESTS. doi: 10.1037/t08800-000

Test Shown: Full

Test Format:
The measure's 8 items are rated on a 5-point Likert-type scale from strongly disagree (1) to strongly agree (5).

Source:
Chen, Gilad, Gully, Stanley M., & Eden, Dov. (2001). Validation of a new general self-efficacy scale. Organizational Research Methods, Vol 4(1), 62-83. doi: 10.1177/109442810141004, © 2001 by SAGE Publications. Reproduced by Permission of SAGE Publications.

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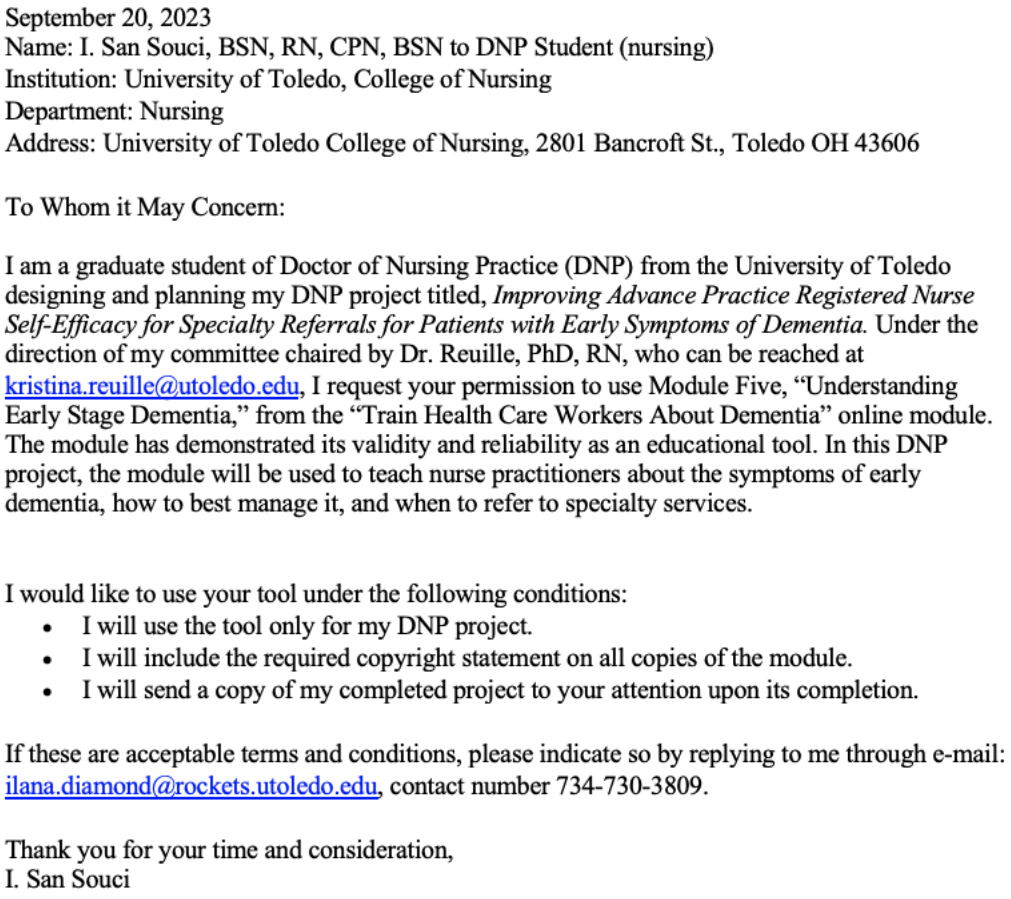
Appendix J.

Letter for Permission to Use Early-Stage Dementia Module



September 20, 2023
Name: I. San Souci, BSN, RN, CPN, BSN to DNP Student (nursing)
Institution: University of Toledo, College of Nursing
Department: Nursing
Address: University of Toledo College of Nursing, 2801 Bancroft St., Toledo OH 43606

To Whom it May Concern:

I am a graduate student of Doctor of Nursing Practice (DNP) from the University of Toledo designing and planning my DNP project titled, *Improving Advance Practice Registered Nurse Self-Efficacy for Specialty Referrals for Patients with Early Symptoms of Dementia.* Under the direction of my committee chaired by Dr. Reuille, PhD, RN, who can be reached at kristina.reuille@utoledo.edu, I request your permission to use Module Five, "Understanding Early Stage Dementia," from the "Train Health Care Workers About Dementia" online module. The module has demonstrated its validity and reliability as an educational tool. In this DNP project, the module will be used to teach nurse practitioners about the symptoms of early dementia, how to best manage it, and when to refer to specialty services.

I would like to use your tool under the following conditions:

- I will use the tool only for my DNP project.
- I will include the required copyright statement on all copies of the module.
- I will send a copy of my completed project to your attention upon its completion.

If these are acceptable terms and conditions, please indicate so by replying to me through e-mail: ilana.diamond@rockets.utoledo.edu, contact number 734-730-3809.

Thank you for your time and consideration,
I. San Souci

Appendix K.

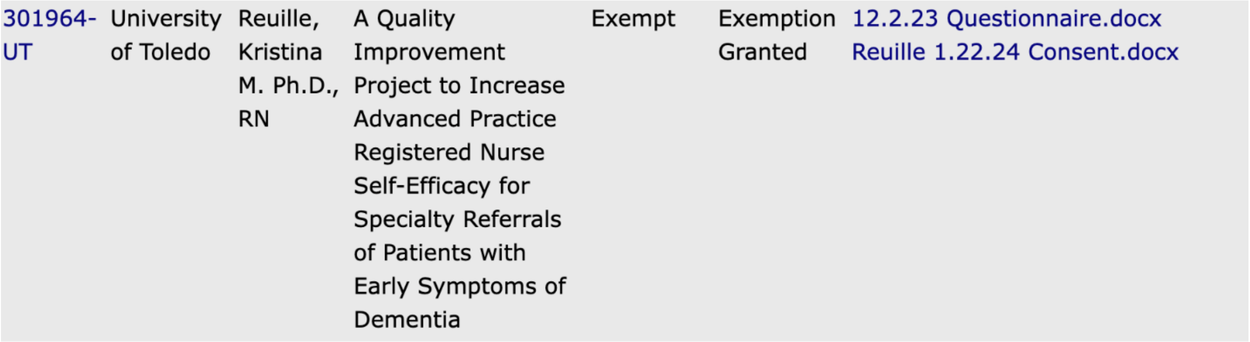
Permission to Use Early-Stage Dementia Module

Freedom of Information Act (FOIA)

The Freedom of Information Act (FOIA) allows you to access information from the federal government. HRSA, like all federal agencies, must disclose information under the FOIA, unless it falls under one of nine exemptions.

Appendix L.

IRB Approval



301964-UT	University of Toledo	Reuille, Kristina M. Ph.D., RN	A Quality Improvement Project to Increase Advanced Practice Registered Nurse Self-Efficacy for Specialty Referrals of Patients with Early Symptoms of Dementia	Exempt	Exemption Granted	12.2.23 Questionnaire.docx Reuille 1.22.24 Consent.docx

Appendix M.

Statistics Decision Tree

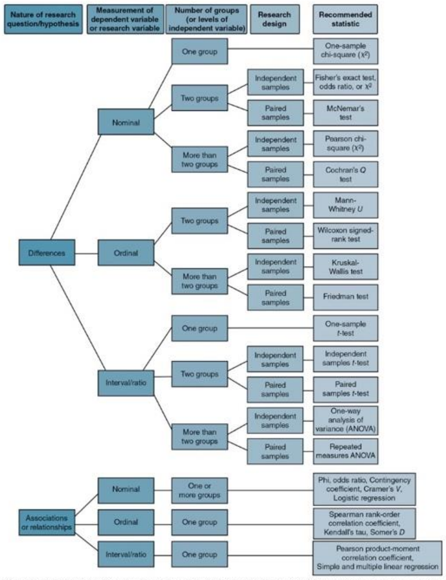
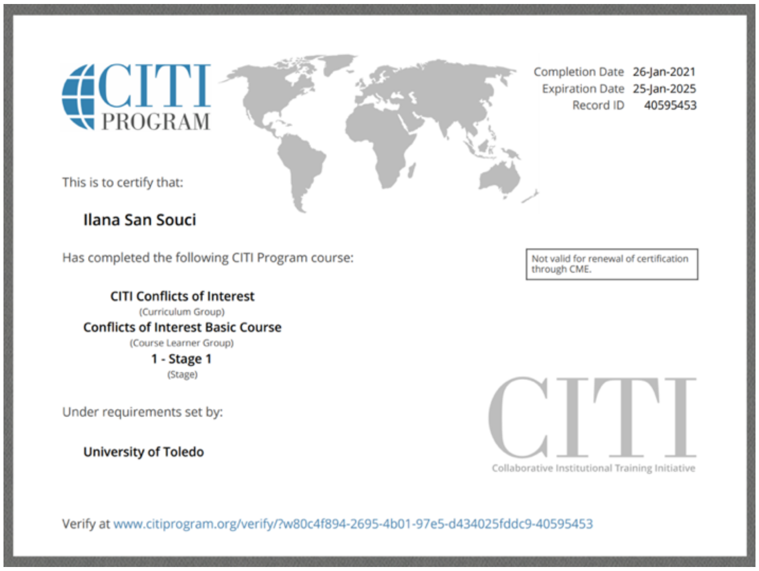


FIG. 12.1 • ALGORITHM OR DECISION TREE FOR DETERMINING APPROPRIATE STATISTICAL TECHNIQUES FOR NURSING STUDIES. *Source:* Redrawn from Gray, J. R., & Grove, S. K. (2021). *The practice of nursing research: Appraisal, synthesis, and generation of evidence* (9th ed., p. 532). St. Louis, MO: Elsevier.

(Grove & Cipher, 2025)

Appendix N.

CitiProgram Human Research Subject Research Certificate



CITI PROGRAM

Completion Date 26-Jan-2021
Expiration Date 25-Jan-2025
Record ID 40595453

This is to certify that:

Ilana San Souci

Has completed the following CITI Program course:

Not valid for renewal of certification through CME.

CITI Conflicts of Interest
(Curriculum Group)
Conflicts of Interest Basic Course
(Course Learner Group)
1 - Stage 1
(Stage)

Under requirements set by:

University of Toledo

CITI
Collaborative Institutional Training Initiative

Verify at www.citiprogram.org/verify/?w80c4f894-2695-4b01-97e5-d434025fddc9-40595453

CITI PROGRAM

Completion Date 30-Jan-2021
Expiration Date N/A
Record ID 40595512

This is to certify that:

Ilana San Souci

Has completed the following CITI Program course:

Not valid for renewal of certification through CME.

Biomedical Responsible Conduct of Research
(Curriculum Group)
Biomedical Sciences RCR
(Course Learner Group)
1 - Basic Course
(Stage)

Under requirements set by:

University of Toledo

CITI
Collaborative Institutional Training Initiative

Verify at www.citiprogram.org/verify/?wb35036d1-276d-4e55-86ab-d7f624623eb4-40595512