



**U.S. Department of Health and Human Services
Assistant Secretary for Planning and Evaluation
Office of Disability, Aging and Long-Term Care Policy**

EXAMINING MODELS OF DEMENTIA CARE:

FINAL REPORT

September 2016

Office of the Assistant Secretary for Planning and Evaluation

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ACRONYMS

The following acronyms are mentioned in this report and/or appendices.

ABC	Antecedent-Behavior-Consequence
ACCESS	Alzheimer's Disease Coordinated Care for San Diego Seniors
ACT	Advanced Caregiver Training
ADC program	Alzheimer's and Dementia Care program
ADL	Activity of Daily Living
AICT	Advanced Illness Care Team
ANSWERS	Acquiring New Skills While Enhancing Remaining Strengths
ASPE	HHS Office of the Assistant Secretary for Planning and Evaluation
BPSD	Behavioural and Psychological Symptoms of Dementia
BRIA	Benjamin Rose Institute on Aging
CAM therapy	Complementary Alternative Medicine therapy
CCIS	Care Consultation Information System
CD	Compact Disc
CDSS	Clinical Decision Support System
CMS	HHS Centers for Medicare and Medicaid Services
COPE	Care of Persons with Dementia in their Environment
CSB	Caregiver Skill Building
CT	Computed Tomography
DBT	Dialectical Behavior Therapy
DSM-IV-R	Diagnostic and Statistical Manual of Mental Disorders Fourth Edition Revision
DVD	Digital Versatile Disc
ECHO-AGE	Extension for Community Outcomes-AGE
EEG	Electroencephalogram
EFNS	European Federation of Neurological Sciences
ENS	European Neurological Society
ERCC	Enhanced Respite Control Condition
ESML	Early-Stage Memory Loss
FAST	Functional Assessment Staging Test
FITT-C	Family Intervention: Telephone Tracking-Caregiver
HABC	Healthy Aging Brain Care
HEDIS	Healthcare Effectiveness Data and Information Set

HHS HIV	U.S. Department of Health and Human Services Human Immunodeficiency Virus
IADL INTERACT	Instrumental Activity of Daily Living Interventions to Reduce Acute Care Transfers
MDS MMSE MRI	Minimum Data Set Mini-Mental State Examination Magnetic Resonance Imaging
NCCA NIA NICE-SCIE	National Center for Creative Aging HHS National Institute on Aging National Institute for Health and Clinical Excellence-Social Care Institute for Excellence
NITE-AD NYUCI	Nighttime Insomnia Treatment and Education for Alzheimer's Disease New York University Caregiver Intervention
PACSLAC	Pain Assessment Checklist for Seniors with Limited Ability to Communicate
PAINAD scale PCP PEACE PHQ PLST PQRS Project CARE PT	Pain Assessment in Advanced Dementia scale Primary Care Provider Palliative Excellence in Alzheimer Care Efforts Patient Health Questionnaire Progressively Lowered Stress Threshold Physician Quality Reporting System Caregiver Alternatives to Running on Empty Project Physical Therapy
RCI RDAD REACH RN	Rosalynn Carter Institute for Caregiving Reducing Disability in Alzheimer's Disease Resources for Enhancing Alzheimer's Caregiver Health Registered Nurse
SSRI STAR-C	Selective Serotonin Reuptake Inhibitor Staff Training in Assisted-living Residences-Caregivers
TAP TCARE TCM TEP	Tailored Activity Program Tailored Caregiver Assessment and Referral Transitional Care Model Telehealth Education Program

UCLA
UCSF
UNMC

University of California, Los Angeles
University of California, San Francisco
University of Nebraska Medical Center

VA

U.S. Department of Veterans' Affairs

EXECUTIVE SUMMARY

A growing number of programs to help persons with dementia and their family caregivers are being developed, tested, and implemented in the United States. To learn more about whether and how models of dementia care meet practice standards, 14 components of comprehensive dementia care were identified and site visits conducted to a small sample of programs to assess how they are implemented.

The dementia care components were identified through a detailed analysis of 37 existing clinical guidelines and practice recommendation documents. The 14 identified components differ from most of the clinical guidelines and practice recommendation documents in that they encompass aspects of care for people in all stages of dementia and their families, in multiple care settings, from home to nursing home and medical care settings, and provided by a wide array of medical, social, and allied health care professionals, paraprofessionals, and direct care workers. The project postulated that most of the activities required to address the components could be performed by various types of trained professional, paraprofessional, and direct care workers. An exception to this assumption is medical management activities that can only be performed by a physician or other medical care provider who is authorized to perform them under state law and regulations for particular public programs and settings (e.g., prescribing medications). From a perspective of possible quality or assessment measures, these components are structural or process measures; they are not outcome measures.

Table ES-1 presents high-level principles of normative care derived from the review of the guidelines.

TABLE ES-1. Dementia Care Framework Components	
1. Detection of Possible Dementia	Examine for cognitive impairment when there is a decline from previous function in daily activities, occupational ability, or social engagement.
2. Diagnosis	Obtain a comprehensive evaluation and diagnosis from a qualified provider when cognitive impairment is suspected.
3. Assessment and Ongoing Reassessment	Assess cognitive status, functional abilities, behavioral and psychological symptoms of dementia, medical status, living environment, and safety. Reassess regularly and when there is a significant change in condition.
4. Care Planning	Design a care plan that will meet care goals, satisfy the person's needs, and maximize independence.
5. Medical Management	Deliver timely, individualized medical care to the person with dementia, including prescribing medication and managing comorbid medical conditions in the context of the person's dementia.

TABLE ES-1 (continued)	
6. Information, Education, and Informed and Supported Decision Making	Provide information and education about dementia to support informed decision making including end-of-life decisions.
7. Acknowledgement and Emotional Support for the Person with Dementia	Acknowledge and support the person with dementia. Allow the person's values and preferences to guide all aspects of the care. Balance family involvement with individual autonomy and choice.
8. Assistance for the Person with Dementia with Daily Functioning and Activities	Ensure that persons with dementia have sufficient assistance to perform essential health-related and personal care activities and to participate in activities that reflect their preferences and remaining strengths; help to maintain cognitive, physical, and social functioning for as long as possible; and support quality of life. Provide help as needed with medication management and pain control.
9. Involvement, Emotional Support, and Assistance for Family Caregiver(s)	Involve caregiver in evaluation, decision making, and care planning and encourage regular contact with providers. Provide culturally sensitive emotional support and assistance for the family caregiver(s).
10. Prevention and Mitigation of Behavioral and Psychological Symptoms of Dementia	Identify the causes of behavioral and psychological symptoms, and use nonpharmacological approaches first to address those causes. Avoid use of antipsychotics and other medications unless the symptoms are severe, create safety risks for the person or others, and have not responded to other approaches. Avoid physical restraints except in emergencies.
11. Safety for the Person with Dementia	Ensure safety for the person with dementia. Counsel the person and family as appropriate about risks associated with wandering, driving, and emergency preparedness. Monitor for evidence of abuse and neglect.
12. Therapeutic Environment, Including Modifications to the Physical and Social Environment of the Person with Dementia	Create a comfortable environment, including physical and social aspects that feel familiar and predictable to the person with dementia and support functioning, a sustained sense of self, mobility, independence, and quality of life.
13. Care Transitions	Ensure appropriate and effective transitions across providers and care settings.
14. Referral and Coordination of Care and Services that Match the Needs of the Person with Dementia and Family Caregiver(s) and Collaboration Among Agencies and Providers	Facilitate connections of persons with dementia and their family caregivers to individualized, culturally and linguistically appropriate care and services, including medical, other health-related, residential, and home and community-based services. When more than 1 agency or provider is caring for a person with dementia, collaborate among the various agencies and providers to plan and deliver coordinated care.

Five dementia care programs were selected for site visits from more than 50 possible programs. With only five programs, it is not possible to represent the full array of existing programs to help persons with dementia and their family caregivers. Nevertheless, the five programs were chosen to represent various program settings and ways of implementing the 14 identified dementia care components.

One of the five programs was based in a medical clinic, one was based in a residential care setting, and three were based in community agencies. The five programs were:

- BRI Care Consultation™ in Cleveland, Ohio;

- Comfort Matters™ in Phoenix, Arizona;
- Healthy Aging Brain Center in Indianapolis, Indiana;
- MIND at Home in Baltimore, Maryland; and
- RCI REACH, in the Rosalynn Carter Institute for Caregiving in Americus, Georgia.

In-person site visits were conducted for four of the programs, and telephone interviews were conducted for one program because of the travel distances involved. The purpose of the site visits was to examine how the programs were addressing each of the care components. Structured discussion guides were prepared for each site visit.

Findings from the site visits include the following:

- None of the five programs had procedures in place to detect possible dementia in general populations.
- None of the five programs directly addressed all 14 components, but most of the programs addressed most of the components. Program administrators indicated that some of the components are out of the scope of their program.
- The five programs used at least three ways to address the components: direct provision of the needed assistance; referral to another agency or individual that could provide the needed assistance; and information, education, skills training, and encouragement to help family caregivers provide the needed assistance.
- All five programs conducted assessment, reassessment, and care planning activities that facilitated the provision of individualized, person-centered care.
- There are similarities and differences in exactly how the programs interacted with persons with dementia and family caregivers.
- Programs with physicians or other primary care providers on staff were able to provide diagnostic evaluations leading to a formal diagnosis of dementia. Other programs were able to refer for diagnostic evaluations, but a formal diagnosis was not a prerequisite for participation in any of the programs.
- All five programs provided assessment and ongoing reassessment, but the assessment instruments and procedures they used vary.
- Some of the programs provided medical management, and others did not.
- All five programs had assembled information on many relevant topics to educate persons with dementia and family caregivers and support informed decision making.

- The four programs that were working with community-living people with dementia and their family caregivers interacted less often and less directly with persons with dementia than with family caregivers.
- At least two of the five programs have been disseminated to other sites across the country.

As the number of people with dementia grows larger over time, it will be increasingly important to better understand what different models of care provide and how effective they are in meeting the needs of persons with dementia and their caregivers.

1. INTRODUCTION

More than 5 million Americans are living with dementia, and the number is projected to increase to 13.8 million by 2050 (Hebert et al., 2013; NIH, 2016). Dementia affects a person's cognitive function, behavior, and ability to perform everyday activities such as shopping, paying bills, and managing medications (Alzheimer's Association, 2016; NIH, 2016). Over time, individuals require more assistance from others to meet basic needs, and quality of life is adversely affected. People with dementia and their caregivers receive care through a range of programs that provide care and support. Adult day services, special care units in assisted living and nursing homes, and caregiver support programs are just a few of the types of programs for people with dementia.

Currently, there are no pharmacological treatments that significantly slow or stop the progression of Alzheimer's disease, the most common cause of dementia (Cummings, 2014; NIH, 2016). However, many nonpharmacological approaches and care practices have been shown to have some positive effects for people with Alzheimer's disease or other dementias who live in the community and family caregivers (Maslow, 2012), such as decreased caregiver burden, stress, depression, and anxiety (Nichols, 2014; Smith, 2005; Teri, 2005); decrease in behavioral symptoms of people with dementia (Gitlin, 2016; Nichols, 2014), and a decrease in negative reactions to behavioral symptoms by caregivers (Gaugler, 2016; Gitlin, 2009; Teri, 2005). Relative few studies have examined "harder" outcomes, such as the impact on hospitalization and emergency department use.

Despite the existence of evidence-based interventions that are effective for some outcomes and populations, the availability of these services for people with dementia and their family caregivers is limited. Although a few models of dementia care are available in some communities across the country, none are widely accessible, and it has been difficult to achieve sufficient sustainable funding to make them available to the number of people with dementia and family caregivers who could benefit from them (Gitlin, 2015; Maslow, 2012).

Relatively little is known about the scope of services that programs for people with dementia and their caregivers actually supply, the quality of care provided, or the outcomes of those programs. For example, of the many guidelines available on services for people with Alzheimer's disease and their caregivers, none specify actual outcomes of care that should be measured or outcome targets. All of the guidelines specify either structural or process activities.

This project sought to add to knowledge about programs serving people with dementia by defining care components of dementia programs that can be used to assess a wide variety of dementia care providers, care settings, and stage of dementia

and then assessing how a small sample of dementia care programs addressed these components. More specifically, this project:

- Synthesized existing dementia care guidelines into a set of care components with normative standards of care.
- Developed a catalog of dementia care interventions, emphasizing evidence-based programs.
- Selected five currently operating dementia care programs from the catalog of interventions for case studies to assess how they addressed the dementia care guidelines.
- Conducted cross-case study site analyses and drew implications for dementia care and future research.

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2. DEMENTIA CARE COMPONENTS

2.1. Methodology for Developing Dementia Care Components

2.1.1. *Review of Existing Care Guidelines*

In developing best practice components of dementia care, the project team reviewed existing clinical guidelines and practice recommendations for home and community-based care, primary care, assisted living, nursing home, and hospice care. Clinical guidelines and practice recommendations draw on available research evidence and expert opinion to determine practice standards. Dementia care guidelines and recommendations from the U.S. Department of Health and Human Services (HHS) Agency for Healthcare Research and Quality National Guidelines Clearinghouse, the clinical practice literature, discipline-specific professional associations, and Alzheimer's Association recommendations for health care professionals were reviewed. Guidelines were selected only if they were published within the last 10 years. In addition, the team reviewed quality indicators from the National Committee for Quality Assurance, Healthy People 2020, Nursing Home Compare, and the Physician Quality Reporting System. A total of 37 sources were selected for review representing a variety of disciplines and areas of dementia care.

The guideline review initially identified 16 key domains of dementia care, which were later modified to 14 key domains after incorporating the findings of the five site visits. Once these broad domains were identified, the guidelines were analyzed in detail to place specific detailed recommendations or standards from each guideline within the relevant domain. Each component was then analyzed to develop an overview statement that reflected the recommendations or standards supplemented by detailed dementia care standards that represent the recommendations and standards from the selected guidelines. Throughout the process, the team recognized that a particular standard could be placed under more than one component and tried to select the most logical placement. When selecting where to place a standard, the team focused on the overall intent of the guideline authors, but readers may feel that some standards should be placed in different components.

In addition, some standards--for example, standards with respect to the importance of involving the person with dementia directly in care discussions and decisions, and using that person's expressed preferences to guide care--were stated in strikingly different words in different standards. The team noted the broad range of wording and attempted to represent accurately the core concepts. In this report, the term "family" includes the primary caregiver, other relatives, and close friends and neighbors who know the person well and can represent his or her best interests.

Some of the guidelines include standards that require licensed professionals, for example, physicians and pharmacists. In general, however, the standards included in this report describe functions that could be performed by a range of disciplines and providers in a variety of settings. For example, assessment can be performed by various disciplines and providers working with the person with dementia and his or her caregivers. Even though many of the guidelines are written for or by specific professional groups, our care components are intended to identify general best practices rather than focus on the credentials of the discipline or provider that performs them. Overarching principles for these best practice standards include person-centered, interdisciplinary assessment and care, and professional and provider training about the specific needs of persons with dementia and their families.

2.1.2. Review of Draft Care Components by Subject Matter Experts

To ensure broad agreement in the field with the standards, subject matter experts with experience in evidence-based interventions, geriatric medicine, early-stage programming, end-of-life dementia care, person-centered approaches to dementia care, dementia friendly communities, family caregiver skill-building, and rehabilitation therapies were asked to review them. The experts included the following persons and others:

- Michelle Barclay, MA, Executive Co-Lead of Minnesota’s Act on Alzheimer’s and President of the Barclay Group, LLC;
- David Bass, PhD, Vice President for Research and Director of the Margaret Blenkner Research Institute, Benjamin Rose Institute on Aging;
- Christopher Callahan, MD, Director, Indiana University Center for Aging Research, and Staff Physician, Department of Medicine, Eskenazi Health;
- Maribeth Gallagher, NP, PhD, Director of the Dementia Program, Hospice of the Valley; and
- Catherine Piersol, PhD, OTR, Associate Professor, Department of Occupational Therapy, Thomas Jefferson University and Director, Jefferson Elder Care.

Overall, the subject matter experts agreed with the identified components and standards. They did not suggest that any components be added, deleted, or combined. Their comments generally focused more on providing additional detail and greater emphasis on specific topics. The team compared the experts’ comments with the content of the guidelines. When the comments were reflected in the guidelines, the team modified the draft to include them. In some instances, however, the subject matter experts’ comment was not explicitly stated in any of the selected guidelines. In those instances, these comments were not included. Comments that were not incorporated pertained to a range of topics, such as terms to use for family and other caregivers; specific safety risks, such as guns; use of specific standardized assessment

instruments; physician office practice redesign; the importance of encouraging the family caregiver to participate in the person's medical visits; the specific needs of persons with early-stage dementia; and specific recommendations on how to handle disagreements among family members.

2.1.3. Changes to Components Based on Case Studies

Following the site visits, the project team reviewed the original 16 components and decided to combine two sets of two components and modify the name of one of the components, resulting in a final list of 14 components. The two components, *Inclusion of Caregivers and Emotional Support and Assistance for Family Caregiver(s)*, were combined to form *Involvement, Emotional Support, and Assistance for Family Caregiver(s)*. The program staff at each of the sites consistently stated that the needs of family caregivers overlapped these areas and that it is not unusual for a family caregiver to seek support in each of these areas even during a single interaction with the staff. During the site visits, the project team also learned that program staff generally merged the activities involved in *Referral and Coordination of Care and Services with Collaboration among Agencies and Providers*. The program staff at the various sites shared a common vision of best practice in dementia care that involves communication and coordination across providers and agencies. The original component covering behavioral and psychological symptoms of dementia used the word *Management* and during the site visits, program staff spoke about the importance of defining in more specific terms what is required of providers responding to these challenging symptoms such as knowing the person's preferences and daily routine as a way to anticipate unmet needs to prevent or decrease behavioral and psychological symptoms. The component name was changed to *Prevention and Mitigation of Behavioral and Psychological Symptoms of Dementia*.

2.2. Final Care Components

Two tables summarize our findings regarding the principles of good dementia care. **Table 2-1** presents high-level principles of normative care. **Table 2-2** includes those broad principles but adds detailed recommendations within the identified domain.

Two appendix tables provide the raw data from which high-level principles and the detailed recommendations were derived. **Appendix A-1** presents the 14 domains and the recommendations relative to each domain found within the 37 sets of reviewed guidelines, by the source of the guideline. In **Appendix A-1**, the exact wording of the practice standards was retained to the extent possible to reflect their original intent and to capture specific clinical guidance. Citations were included with each overview statement and each detailed dementia care standard to ground the guidelines in the professional and research literature. **Appendix A-2** presents a count of the mention of each domain within the guideline recommendations, by each guideline. Thus, this table allows the reader to see how frequently each domain was addressed across the reviewed guidelines.

TABLE 2-1. Dementia Care Framework Components

1. Detection of Possible Dementia	Examine for cognitive impairment when there is a decline from previous function in daily activities, occupational ability, or social engagement.
2. Diagnosis	Obtain a comprehensive evaluation and diagnosis from a qualified provider when cognitive impairment is suspected.
3. Assessment and Ongoing Reassessment	Assess cognitive status, functional abilities, behavioral and psychological symptoms of dementia, medical status, living environment, and safety. Reassess regularly and when there is a significant change in condition.
4. Care Planning	Design a care plan that will meet care goals, satisfy the person's needs, and maximize independence.
5. Medical Management	Deliver timely, individualized medical care to the person with dementia, including prescribing medication and managing comorbid medical conditions in the context of the person's dementia.
6. Information, Education, and Informed and Supported Decision Making	Provide information and education about dementia to support informed decision making including end-of-life decisions.
7. Acknowledgement and Emotional Support for the Person with Dementia	Acknowledge and support the person with dementia. Allow the person's values and preferences to guide all aspects of the care. Balance family involvement with individual autonomy and choice.
8. Assistance for the Person with Dementia with Daily Functioning and Activities	Ensure that persons with dementia have sufficient assistance to perform essential health-related and personal care activities and to participate in activities that reflect their preferences and remaining strengths; help to maintain cognitive, physical, and social functioning for as long as possible; and support quality of life. Provide help as needed with medication management and pain control.
9. Involvement, Emotional Support, and Assistance for Family Caregiver(s)	Involve caregiver in evaluation, decision making, and care planning and encourage regular contact with providers. Provide culturally sensitive emotional support and assistance for the family caregiver(s).
10. Prevention and Mitigation of Behavioral and Psychological Symptoms of Dementia	Identify the causes of behavioral and psychological symptoms, and use nonpharmacological approaches first to address those causes. Avoid use of antipsychotics and other medications unless the symptoms are severe, create safety risks for the person or others, and have not responded to other approaches. Avoid physical restraints except in emergencies.
11. Safety for the Person with Dementia	Ensure safety for the person with dementia. Counsel the person and family as appropriate about risks associated with wandering, driving, and emergency preparedness. Monitor for evidence of abuse and neglect.
12. Therapeutic Environment, Including Modifications to the Physical and Social Environment of the Person with Dementia	Create a comfortable environment, including physical and social aspects that feel familiar and predictable to the person with dementia and support functioning, a sustained sense of self, mobility, independence, and quality of life.
13. Care Transitions	Ensure appropriate and effective transitions across providers and care settings.
14. Referral and Coordination of Care and Services that Match the Needs of the Person with Dementia and Family Caregiver(s) and Collaboration Among Agencies and Providers	Facilitate connections of persons with dementia and their family caregivers to individualized, culturally and linguistically appropriate care and services, including medical, other health-related, residential, and home and community-based services. When more than 1 agency or provider is caring for a person with dementia, collaborate among the various agencies and providers to plan and deliver coordinated care.

TABLE 2-2. Detailed Dementia Care Framework Components

<p>1. Detection of Possible Dementia</p>	<p>Examine for cognitive impairment when there is a decline from previous function in daily activities, occupational ability, and/or social engagement (3, 4, 5, 6, 8, 12, 14, 17, 18, 27, 32, 33, 37).</p> <ul style="list-style-type: none"> • Recognize signs of possible cognitive impairment (5, 8, 12, 14, 17, 18, 27, 32, 33) and communicate observation with the person and others as appropriate (3, 14, 27). • Perform a brief cognitive test when a change is observed or individual or family member or other informant reports cognitive changes (4, 5, 8, 14, 17, 18, 27, 33, 37). • Use of brief cognitive tests to identify cognitive impairment in asymptomatic persons should not be undertaken (8, 17, 27). • Consider the effects of low education, communication difficulties, cultural factors, low literacy, and sensory impairments such as hearing loss or visual acuity on inter-rater reliability of screening (6, 8).
<p>2. Diagnosis</p>	<p>Obtain a comprehensive evaluation and diagnosis from a qualified provider when cognitive impairment is suspected (5, 6, 8, 11, 12, 14, 16, 17, 18, 22, 25, 27, 30, 32, 35, 36, 37).</p> <ul style="list-style-type: none"> • Conduct a comprehensive evaluation that includes a clear history of onset and progression of symptoms (8, 12, 14, 16, 18, 27, 30, 32, 36), an interview with individual and reliable informants (when available) (6, 8, 11, 12, 14, 16, 30), a complete physical and neurological exam (12, 14, 16, 18, 22, 30, 32, 36), review of medications and other substances for adverse effects and comorbid medical and psychiatric conditions that may mimic or exacerbate dementia (8, 11, 12, 14, 18, 27, 30, 32, 36), a formal assessment of multiple cognitive domains using a validated instrument or neuropsychological testing (6, 11, 12, 14, 16, 22, 27, 30, 32, 36), assessment of ADLs (12, 14, 22, 30), brain imaging (12, 14, 16, 22, 36), and standard laboratory tests for possible reversible causes of dementia (12, 14, 16, 22, 30, 32, 36). • Consider consultation with neurologist or geriatric psychiatrist if there is diagnostic uncertainty or atypical features, the person is under 65 years of age, or there are other complicating factors (5, 8, 11, 17, 18, 25, 32). • Consult with other disciplines on the team to access full range of information to inform final diagnosis (6, 35). • Know feasible, ethical options for obtaining consent from the person with dementia (6) and obtain corroboration from knowledgeable informants (6, 8). • Communicate the diagnosis with the person and family members in a clear and compassionate manner that is consistent with their expressed wishes, values, preferences, culture, educational level, and abilities (10, 27, 37).
<p>3. Assessment and Ongoing Reassessment</p>	<p>Assess cognitive status, functional abilities, behavioral and psychological symptoms of dementia, medical status, living environment, and safety. Reassess regularly and when there is a significant change in condition (1, 2, 3, 5, 6, 7, 10, 11, 12, 13, 14, 15, 16, 17, 19, 21, 22, 23, 25, 27, 29, 30, 32, 33, 35, 36, 37).</p> <ul style="list-style-type: none"> • Use specifically designed instruments to systematically assess changes in behavioral and psychological symptoms, cognition, and function (10, 13, 14, 16, 19, 33). • Distinguish dementia from depression or delirium. (17, 19, 27, 29, 30, 33). • Assess the person's decision making capacity and determine whether a surrogate has been identified (10). • Engage the person with dementia in the assessment process and family members or others who can provide collateral information, if available (1, 10, 14, 19, 30). • Monitor for the presence of behavioral and psychological symptoms of dementia, which may indicate distress from medical, psychiatric, environmental, and social factors (2, 3, 7, 15, 19, 29, 36, 37). • Monitor for signs of neglect or abuse, such as repeated hospitalizations, multiple falls, dehydration, malnutrition, wandering from home, and medication misuse. For community-based individuals, monitor for indications that the person can no longer live alone (30).
<p>4. Care Planning</p>	<p>Design a care plan that will meet care goals, satisfy the person's needs, and maximize independence (1, 2, 3, 5, 7, 9, 10, 11, 15, 17, 18, 23, 27, 30, 35, 37).</p> <ul style="list-style-type: none"> • Involve the person, proxy decision makers, family members, and care providers in the care planning process (1, 2, 3, 7, 10). • Address quality of life by building on the person's abilities, ensuring that adequate supports are in place, and encouraging meaningful engagement in activities and socialization (1, 3, 5, 7, 15, 18, 23, 27, 30, 35). • Adapt to what can be reasonably accomplished by understanding the person's history, living situation, caregiver support, resource availability, preferences, and daily routine/patterns (3, 9, 15, 23, 27, 30). • Monitor and update care plan regularly as the person's needs, abilities, and wishes change (1, 2, 3, 5, 7, 11, 17, 18, 23, 35, 37).

TABLE 2-2 (continued)

5. Medical Management	<p>Deliver timely, individualized medical care to the person with dementia including prescribing medication and managing comorbid medical conditions in the context of the person's dementia (1, 3, 4, 5, 7, 8, 10, 11, 12, 16, 17, 22, 23, 24, 25, 26, 27, 30, 31, 32, 33, 34, 37).</p> <ul style="list-style-type: none"> • Identify and treat all comorbid conditions such as diabetes, congestive heart failure, and chronic obstructive pulmonary disease in the context of dementia (10, 11, 17, 22, 23, 25, 26, 30, 37). • Identify and treat vascular risk factors including risk for cerebrovascular events (7, 11, 12, 16). • Use nonpharmacologic and pharmacologic approaches to manage cognitive and behavioral problems in dementia (4, 7, 8, 11, 17, 22, 27, 30, 34, 37). • Simplify daily medication regimen as much as possible. Minimize number of medications (3, 8, 24, 25, 37), adjust schedule so caregiver is available to help (3, 37), monitor closely for potential side effects, review medication regimen regularly (3, 7, 8, 17, 23, 24, 25, 30, 33, 37), monitor for potential problems with over-the-counter medications (3), and document response to therapy (3, 33). • Advise about the potential benefits and risks of prescription medications for Alzheimer's disease and other dementias, and, if prescription medications are chosen, educate individuals and caregivers about use to improve adherence and clinical outcomes (7, 30). • Ease distress from symptoms, pain, and stress and maximize quality of life (1, 3, 4, 7, 10, 13, 24, 27, 32, 37). • Make early and regular use of specialized services. Refer to other providers for diagnostic consultation, rehabilitation evaluation and treatment, treatment of psychiatric disorders, pain management/palliative care, nutritional status, sensory function and social services (8, 37).
6. Information, Education, and Informed and Supported Decision Making	<p>Provide information and education about dementia to support informed decision making including end-of-life decisions (1, 2, 3, 5, 6, 7, 8, 10, 11, 13, 14, 16, 17, 20, 22, 24, 27, 29, 30, 32, 33, 37).</p> <ul style="list-style-type: none"> • Educate the person with dementia and their family about the symptoms of dementia, course and prognosis, treatments, local care and support services, support groups, government benefits, local information sources, and legal and financial options (3, 5, 10, 11, 17, 20, 27, 29, 37). • Promote decision making in a manner consistent with the values, preferences, culture, educational level, and abilities of the person with dementia (3, 10, 24). • Seek valid consent from the person with dementia by informing the person of options, checking that he or she understands care options, that the person is not coerced regarding the decision, and monitor ability to provide consent over time (27, 37). Proxy decision makers should be involved if a person lacks decision making capacity and proxy decision makers must represent the person's prior attitudes and values (33, 37). • Discuss possible safety concerns such as driving ability and reassess abilities over time (11, 22, 27, 29, 30, 36, 37). Reassessment of ability to drive should occur at least every 6-12 months (37). • Address intensity of care and end-of-life decisions with the person who has dementia and his or her caregiver and (1, 2, 3, 5, 10, 17, 24) document person's wishes (5, 29).
7. Acknowledgement and Emotional Support for the Person with Dementia	<p>Acknowledge and support the person with dementia. Allow the person's values and preferences to guide all aspects of the care. Balance family involvement with individual autonomy and choice (1, 2, 3, 5, 6, 7, 14, 15, 16, 18, 19, 21, 23, 25, 27, 30, 31, 33, 34, 35).</p> <ul style="list-style-type: none"> • Encourage participation by asking the person directly about his or her symptoms and preferences regardless of level of cognitive ability (1, 2, 3, 6, 7, 18, 19, 21, 30, 33, 35). • Recognize and support the person's selfhood throughout the course of his or her dementia (15). • Balance the person's need for protection from harmful consequences against the person's fundamental rights to autonomy, dignity, choice, and self-determination (3, 16, 42). • Provide emotional support, reassurance, and counseling as needed and appropriate, as the person addresses issues of loss and other difficulties associated with dementia (3, 14, 23, 25, 27, 30, 33).

TABLE 2-2 (continued)

<p>8. Assistance for the Person with Dementia with Daily Functioning and Activities</p>	<p>Ensure that persons with dementia have sufficient assistance to perform essential health-related and personal care activities and to participate in activities that reflect their preferences and remaining strengths; help to maintain cognitive, physical, and social functioning for as long as possible; and support quality of life. Provide help as needed with medication management and pain control (1, 2, 3, 5, 9, 11, 15, 17, 30, 33, 34, 35, 37).</p> <ul style="list-style-type: none"> • Provide assistance, as needed, with basic and IADLs, including eating, bathing, dressing, elimination, movement, shopping, managing medications and pain control (1, 3, 4, 5, 15, 17, 30, 34, 35, 37). Ensure that basic needs, such as adequate nutrition, hydration, and sleep, are met. <ul style="list-style-type: none"> – Use strategies such as task breakdown to help persons with dementia complete their daily activities (1). – Support consistency and routines to maintain abilities and reduce anxiety and stress (1, 3, 15, 35). – Anticipate changes and plan ahead to provide care that meets the person’s needs (2, 3, 9). – Use vision, hearing, and other sensory aids to support health-related and personal care activities (4, 37). – Make the person as comfortable as possible (2, 3, 9). – Avoid burdensome, nonbeneficial treatments (e.g., tube feeding) (17). – Use individualized, culturally sensitive care approaches that reflect the needs and preferences of the person with dementia, build on the person’s retained abilities, and maximize his or her participation in care (1, 2, 3, 15, 17, 33, 35, 37). Do not “do for” a person who can perform an activity or part of the activity independently (1). • Use individualized care approaches to address cognitive, physical, social, and spiritual needs and increase quality of life. <ul style="list-style-type: none"> – Offer regular cognitive stimulation (11) and foster orientation (4, 37). – Provide regular physical activity and exercise to maintain strength and support physical functioning (3, 11, 15, 17, 37). – Support social relationships and social functioning and provide a sense of community, while respecting the preferences of individuals who prefers solitude (1, 3, 11, 15). • Provide and encourage participation in activities that are pleasant, enjoyable, and personally meaningful (1, 3, 15). • Consider the special needs of persons with dementia who are alone or isolated (3, 37). If needed, use technologies to monitor and communicate with persons with dementia who are alone (17).
<p>9. Involvement, Emotional Support, and Assistance for Family Caregiver(s)</p>	<p>Involve caregiver in evaluation, decision making, and care planning and encourage regular contact with providers. Provide culturally sensitive emotional support and assistance for the family caregiver(s) (2, 3, 8, 10, 11, 17, 19, 21, 22, 23, 27, 30, 32, 33, 35).</p> <ul style="list-style-type: none"> • Recognize the critical role and importance of the caregiver-care recipient dyad in dementia care (3, 11, 30). • Identify primary caregiver or decision making surrogate (10, 23). • Assess caregiver willingness and capacity to provide care, level of involvement, geographic proximity, overall health, and legal and financial concerns (3, 10, 17, 30). • Monitor caregiver strain or stress (3, 10, 16, 17, 27, 30). • Identify caregiver needs and offer education, support, and services throughout the entire course of the illness (23, 27, 32, 33, 34, 36, 37). <p>Provide culturally sensitive emotional support and assistance for the family caregiver(s) (2, 3, 4, 11, 14, 15, 17, 27, 31, 35, 37).</p> <ul style="list-style-type: none"> • Provide encouragement and reassurance for the family caregiver(s) (2, 4, 11, 14, 17, 37). • Provide family caregiver education and training to help caregivers develop skills to manage caregiving tasks (4, 17, 37). • Provide family caregivers who experience caregiving-related distress and negative psychological effects with counseling and treatments to reduce these negative effects and improve caregiver well-being (2, 15, 27, 31, 37). • Provide access to a comprehensive range of respite services and caregiving-related transportation (3, 27). • Encourage or assist in recruiting other family members, friends, and members of the caregiver’s social network to help with caregiving tasks (17, 35, 37).

TABLE 2-2 (continued)

<p>10. Prevention and Mitigation of Behavioral and Psychological Symptoms of Dementia</p>	<p>Identify the causes of behavioral and psychological symptoms and use nonpharmacological approaches first to address those causes. Avoid use of antipsychotics and other medications unless the symptoms are severe, create safety risks for the person or others, and have not responded to other approaches. Avoid physical restraints except in emergencies (1, 3, 4, 5, 7, 10, 15, 17, 22, 25, 27, 28, 29, 30, 33, 34, 36, 37).</p> <ul style="list-style-type: none">● Identify the causes of behavioral and psychiatric symptoms.<ul style="list-style-type: none">– Talk with family and other paid and unpaid caregivers to identify the causes of behavioral and psychological symptoms (27).– Consider possible causes, such as physical illness, pain, emotional distress, pain, insecurity, lack of privacy, boredom, difficulty communicating, medications, sleep disturbance, delirium, or conflict between the person with dementia and family or other unpaid or paid caregivers (5, 7, 15, 17, 22, 25, 27). Dementia-related neurochemical changes in the brain can also cause the symptoms (7).– Consider that behavioral and psychological symptoms may be a form of communication for persons who lack the ability to communicate any other way (1, 3, 15).● Plan approaches to address selected symptom(s). Do not assume that the same treatment(s) is appropriate for the wide array of behavioral and psychological symptoms (7, 17, 27, 30).<ul style="list-style-type: none">– When selecting symptoms and approaches, consider the safety and well-being of the person with dementia, family and other paid and unpaid caregivers, and others in the person's environment (37).– Document the selected symptom(s), identified causes, and planned approaches (27).● Use nonpharmacological approaches first.<ul style="list-style-type: none">– Use individualized approaches such as simplification of tasks or the environment; avoidance of situations that agitate or frighten the person or create frustration; distraction; music, pleasant activities; multisensory therapy; and massage and touch therapy (1, 10, 15, 17, 22, 25, 32, 34, 37).– Use community-based programs such as adult day care and support groups that focus on management of behavioral and psychological symptoms. Provide training for family caregivers to help them understand and manage the symptoms (3, 37).– Because people may respond better to 1 treatment than another, monitor each approach and adapt the care plan accordingly (27).● If nonpharmacological approaches are unsuccessful, consider medications to manage behavioral and psychological symptoms.<ul style="list-style-type: none">– Consider antidepressant medications if the person with dementia and depression has not responded to nonpharmacological approaches (25, 36, 37).– Consider antipsychotic medications for severe agitation, aggression, and psychosis, weighing the serious possible side effects of antipsychotics against the potential of persons with agitation, aggression, or psychosis to harm themselves or others (1, 10, 25, 36, 37).– If antipsychotic medications are started, use the lowest possible dose; reassess the need for continued use frequently, and discontinue as soon as possible (16, 22, 27, 37).– Continue nonpharmacological approaches even when using antipsychotics, antidepressants, and other medications to manage behavioral and psychological symptoms (7, 30).– Monitor the person with dementia for negative medication effects, particularly if he or she is restrained or frail (27).– Document the proportion of persons with dementia who receive antipsychotic medications and try to reduce that proportion (28, 29).● Avoid the use of physical restraints except in emergencies to prevent harm to self and others (1, 3, 4, 17, 33).● Monitor and document the effectiveness of all nonpharmacological and pharmacological approaches and adjust approaches as needed (7).
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TABLE 2-2 (continued)

<p>11. Safety for the Person with Dementia</p>	<p>Ensure safety for the person with dementia. Counsel the person and family as appropriate about risks associated with wandering, driving, and emergency preparedness. Monitor for evidence of abuse and neglect (1, 3, 10, 11, 16, 17, 29, 33, 34, 36, 37).</p> <ul style="list-style-type: none"> ● Provide information and guidance for the person with dementia and family caregiver(s) about safety and the need to modify the person's living environment to reduce risks, including falls. Assist in modifying the living environment to ensure safety, as needed, and be prepared to respond to unsafe wandering and other risky behaviors (1, 3, 11, 17, 29, 34). ● Assess and monitor driving ability and counsel the person with dementia and family caregiver(s) about the risks of driving, the likelihood that giving up driving is inevitable in progressive dementia, and alternatives to driving (11, 29, 36, 37). ● Monitor for evidence of elder abuse and neglect and report all suspicions of abuse to the appropriate authorities, as required by law (3, 10, 16). ● Respond promptly to indications of suicidal thoughts or intent to harm others (33). ● Counsel the person with dementia or the family caregiver(s) about the need for emergency preparedness, for example, to be ready for extreme weather or other emergencies. Assist the person and family caregiver in developing a plan and obtaining any needed supplies (3). ● Be sensitive to increased safety risks for people with dementia who live alone (3).
<p>12. Therapeutic Environment, Including Modifications to the Physical and Social Environment of the Person with Dementia</p>	<p>Create a comfortable environment, including physical and social aspects that feel familiar and predictable to the person with dementia and support functioning, a sustained sense of self, mobility, independence, and quality of life (1, 3, 4, 5, 9, 15, 17, 33, 34, 35).</p> <ul style="list-style-type: none"> ● Provide a physical environment that is comfortable and familiar (1, 9, 15). Accommodate adjustments in room temperatures, noise level, and lighting to increase comfort (3, 4, 9, 15, 34). In residential settings, incorporate objects from home to increase the familiarity of the physical environment (4). ● Provide a social environment that feels consistent and familiar. Involve family and friends and maintain consistency of paid and unpaid caregivers and caregiving routines (3, 4, 15, 17, 35). ● Use modifications in the physical and social environment to support optimal functioning, a sustained sense of self, mobility, independence, quality of life, and safety (1, 5, 15, 17, 34). For example, use environmental cues and monitoring systems to maximize independent movement and avoid unsafe wandering (1, 17). Provide easy, safe, and secure access to the outdoors (1). Install communication and monitoring technologies for persons with dementia who are alone (35). ● Offer opportunities for activity intended to support personal meaning, a sense of community, choices, and enjoyment (1, 15). ● Avoid both overstimulation that can cause agitation, increased confusion, and delirium and avoid understimulation that can cause sensory deprivation and withdrawal (15, 17, 33, 34).
<p>13. Care Transitions</p>	<p>Ensure appropriate and effective transitions across providers and care settings (2, 3, 4, 13, 20, 24).</p> <ul style="list-style-type: none"> ● Assess the need for a transition by considering safety, health, care needs, and level of burden associated with the transition (3, 4, 13). ● Ensure timely transfer of information about the person's cognitive and function status and coordination and communication between the care settings (2, 13). ● Avoid transitions to a hospital unless it is clearly necessary to achieve the desired goals of care (20, 24). ● Involve the person with dementia (whenever possible) and the family caregiver in planning hospital discharge and ensure that they understand the discharge plan and care instructions (3). ● Following care transitions, perform medication reconciliation to ensure that all medications are current, necessary, and unlikely to cause adverse drug interactions (3).

TABLE 2-2 (continued)

<p>14. Referral and Coordination of Care and Services that Match the Needs of the Person with Dementia and Family Caregiver(s) and Collaboration Among Agencies and Providers</p>	<p>Facilitate connections of persons with dementia and their family caregivers to individualized, culturally and linguistically appropriate care and services, including medical, other health-related, residential, and home and community-based services. When more than 1 agency or provider is caring for a person with dementia, collaborate among the various agencies and providers to plan and deliver coordinated care (3, 10, 11, 13, 17, 18, 24, 25, 30, 33, 34, 35, 37).</p> <ul style="list-style-type: none"> ● Refer the person with dementia and family caregiver(s) to sources of care and services that meet their identified needs, including: <ul style="list-style-type: none"> – Medical and health-related care and services (e.g., medication monitoring and reconciliation, specialized behavioral health services, occupational therapy, and hospice and palliative care (13, 17, 33, 35, 37)). – Residential care (17). – Nonmedical in-home and community-based services (e.g., respite care, personal care, occupational therapy, support groups, adult day services, and legal and financial planning) (3, 10, 11, 17, 24, 34, 37). ● Connect the person with dementia and family caregiver(s) to agencies and providers who can help them identify their care and service needs, including changing needs over time. Help the person and family to navigate the health care system and locate, arrange, and coordinate needed care and services. Connect them, as appropriate, to organizations that represent specific causes of dementia, such as Alzheimer’s disease, Lewy body disease, frontotemporal degeneration, and Parkinson’s disease; the local Area Agency on Aging; and social workers, care managers or other providers who are knowledgeable about local resources, treatment centers, and payment sources (10, 17, 18, 30, 34, 37). ● Be sensitive to the special issues associated with early-onset dementia, particularly about loss of employment, insurance, disability benefits, pensions, and access to support services appropriate for that group (25). ● Consider and respond to the special issues in care and service connections for persons with dementia who live alone, particularly in emergency situations (3). <p>When more than 1 agency or provider is caring for a person with dementia, collaborate among the various agencies and providers to plan and deliver coordinated care (3, 13, 16, 27, 34).</p> <ul style="list-style-type: none"> ● Involve all the agencies and providers that are caring for the person with dementia, including physicians, nurses, social workers, psychologists, medical assistants, occupational therapists, physical therapists, speech and language pathologists, community service providers and agencies, and personal care aides who are working with the person (3, 16, 27, 34). ● Conduct joint care planning involving all relevant agencies and providers and agree jointly about policies and procedures (3, 16, 27). ● Work to have 1 health care or social service provider designated to facilitate collaboration and to oversee the development and implementation of the joint care plan (13, 34). ● Use a team approach to support collaboration among professionals and other providers who work in the same care organization (13).
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NOTE: Parenthetical numbers are references and can be found in Section 2.3.

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3. CASE STUDIES/SITE VISITS

To assess how programs providing dementia care services were addressing the care components that had been identified, we conducted five case studies of established programs. The five case studies were selected out of an original pool of 55 dementia care interventions that were identified, almost all of which had been shown to produce positive effects mostly in randomized controlled trials that had been published in peer-reviewed journals. **Appendix B** provides a listing of the 55 interventions and information about them, including a journal citation reporting on the effectiveness of the intervention, if available, and a high-level description of each intervention and its setting. This list was narrowed to ten possible active programs (since not all interventions were actually being used in ongoing programs), and then five sites were chosen by the HHS Office of the Assistant Secretary for Planning and Evaluation (ASPE), based on recommendations from RTI.

With only five case studies, it was not possible to represent the full array of existing programs to help persons with dementia and their family caregivers. The five sites were chosen primarily to represent the range of approaches to dementia care, especially by setting. More widely known programs were selected over less known programs, although judgments about these characteristics were based on the project team and ASPE's general knowledge about programs rather than any rigorous evaluation method. The objective in selecting highly regarded and widely known programs was to increase the likelihood that the programs would address many or most of the components. With one exception, the programs used interventions that had been found to produce some positive outcomes in randomized controlled trials.

The case studies were selected to assess a range of approaches and settings, but with only five site visits, the variability in types of programs was limited. One of the programs initially selected for a case study declined to participate, and another program was chosen to replace it. Four of the case studies were conducted in person over 2 days, and one was conducted by telephone because of the large travel distances involved. The case studies were conducted in March-May 2016 with two-person RTI teams. Structured discussion guides were developed and somewhat tailored to each program; the general domains shared ahead of time with the program administrators. **Appendix C** is an example of one of the discussion guides, which varied with each program. The guides provided a set of categories for discussion, but the actual questions asked varied greatly according to the content of the programs and the person being interviewed.

The programs at which case studies were conducted were:

- BRI Care Consultation™ in Cleveland, Ohio;
- Comfort Matters™ in Phoenix, Arizona;
- Healthy Aging Brain Center in Indianapolis, Indiana;
- MIND at Home in Baltimore, Maryland; and
- Rosalynn Carter Institute for Caregiving (RCI) Resources for Enhancing Alzheimer's Caregiver Health (REACH) in Americus, Georgia.

Four of the programs are based on at least one prior randomized controlled trial. Of those four programs, three are currently in the implementation phase and not involved in a trial. The fourth program, MIND at Home, is currently being tested in a Center for Medicare and Medicaid Innovation and HHS National Institute on Aging-funded (NIA-funded) demonstration project. The fifth program, Comfort Matters™, has not been tested in a randomized controlled trial.

Table 3-1 presents a brief description of the five case study dementia care programs. The case study programs included one medical clinic-based setting, one assisted living/nursing home setting, and three community-based programs. **Table 3-2** summarizes how the programs address the 14 care components.

TABLE 3-1. Description of Dementia Care Programs Visited

Dementia Care Program	Target Population	Setting	Number of People Served	Program Description	Statistically Significant (p= or <0.05) Outcomes from Selected Cited Articles in Appendix B
BRI Care Consultation™ (Cleveland, Ohio area)	People with dementia and family caregivers	Telephone contacts with people living at home	Over 4,000 families served through 10 research studies	Care consultants assist people with dementia and family caregivers with developing and achieving personalized goals. The program has 3 main components: initial assessment, action plan, and ongoing maintenance and support, which includes monitoring and follow-up with reassessment as needed. The CCIS is an important component of the program and contains a variety of tools to ensure fidelity to the model including the assessment trigger and follow-up questions, action step template, progress report format, and educational resources on a variety of topics.	<p>Clark et al. (2004)</p> <ul style="list-style-type: none"> • For patients with average or greater than average memory difficulties, decrease in both hospital admission and emergency department visit • Decrease in physician visits <p>Bass et al. (2003)</p> <ul style="list-style-type: none"> • Reduced caregiver depression • Reduced caregiver relationship strain <p>Partners in Dementia Care--a version of BRI Care Consultation</p> <p>Bass et al. (2015)</p> <ul style="list-style-type: none"> • Reduced relationship strain for less severely impaired veterans with dementia • Reduced depression for less severely impaired veterans with dementia • Reduced unmet needs for less severely impaired veterans with dementia <p>Bass et al. (2015)</p> <ul style="list-style-type: none"> • Reduced emergency department visits for veterans who had more difficulties with behavioral symptoms • Reduced fewer hospital admissions for some subgroups <p>Bass et al. (2013)</p> <ul style="list-style-type: none"> • Reduced caregiver depression • Increased caregiver use of support services • Reduced caregiver unmet need
Comfort Matters™ (Phoenix, Arizona)	People with dementia	Assisted living and nursing home settings	Not provided	A comfort-focused and person-directed approach to care for people with dementia that extends to any stage of dementia and engages the person as an expert in his or her own comfort. The program teaches long-term care staff, medical providers, and families about the palliative approach to dementia care with the goal of relieving physical pain, behavioral symptoms, and stress using 5 key concepts to meet the medical, physical, social, spiritual, and emotional needs of people with dementia.	No available studies provide statistical testing of the impact of the intervention. Descriptive data is available (Kuhn and Forrest, 2012).

TABLE 3-1 (continued)

Dementia Care Program	Target Population	Setting	Number of People Served	Program Description	Statistically Significant ($p=$ or <0.05) Outcomes from Selected Cited Articles in Appendix B
Healthy Aging Brain Center (Indianapolis, Indiana)	People with dementia and family caregivers	Clinic and home	703 in the home portion of the program and 1,500 in the clinic portion of the program	The Healthy Aging Brain Center was developed as a dementia and depression care program that aims to reduce dementia-related burden among individuals with dementia and their caregivers. The program operates within Eskenazi Health System, a safety-net integrated health care system in Indianapolis, Indiana and delivers services through clinic-based and home-based approaches. The program was initiated in 2008 as a clinic-based program, designed to serve individuals with dementia and their caregivers in the clinic. In 2012, with support from a Health Care Innovation Award from the Center for Medicare and Medicaid Innovation, the program expanded to serve persons with dementia or depression in their homes (LaMantia et al., 2015).	<p>LaMantia et al. (2015)</p> <ul style="list-style-type: none"> • For participants in the home component, reduced dementia and depression symptoms • For participant in the home component, reduced symptom burden <p>Callahan et al. (2006)</p> <ul style="list-style-type: none"> • Fewer behavioral and psychological symptoms of dementia • Improvements in distress for person with dementia • Caregivers showed improvement in depression
MIND at Home (Baltimore, Maryland)	People with dementia and family caregivers	Telephone, e-mail, mail, and in-person contacts with people living at home	408 individuals were enrolled, approximately 27% of people initially referred	MIND at Home is 2 closely related studies funded by the NIA and the CMS. The care coordination intervention is primarily provided by noncredentialed memory care coordinators, but there is substantial RN involvement and a geropsychiatrist plays a prominent medical role and is available for consultations. The manualized care coordination protocol consist of 4 key components: identification of needs and individualized care planning based on the Johns Hopkins Dementia Care Needs Assessment to address unmet needs and to match the priorities and preferences of the patient and family; provision of dementia education and skill-building strategies; coordination, referral, and linkage to services; and care monitoring. Following a detailed assessment, a care plan is developed with the caregiver and the person with dementia. A key component of the program is the use of a computerized resource system that is able to identify resources and recommendations for identified problems. Following the establishment of the care plan, care coordinators work with the caregiver and person with dementia to implement the plan, with most contact being by telephone, mail and e-mail. In-person meetings can occur at any time, but are built into the protocol at 9 months and 18 months.	<p>Samus et al. (2014)</p> <ul style="list-style-type: none"> • Delay in time to all-cause transition from home • Decreased hazard of leaving the home • Reduced unmet needs in safety and legal/advance care domains • Improved self-reported quality of life

TABLE 3-1 (continued)

Dementia Care Program	Target Population	Setting	Number of People Served	Program Description	Statistically Significant ($p=$ or <0.05) Outcomes from Selected Cited Articles in Appendix B
RCI REACH (Georgia)	Family caregivers of people with dementia	In-person or telephone meetings for people living at home	No exact number provided--RCI provides REACH training to over 20 agencies in the United States that are implementing the program	RCI REACH is a 6-month, 12-session intervention that focuses on the overall well-being of family caregivers for people with dementia. Caregiver coaches serve as the interventionists for the program and meet with caregivers in individualized sessions to provide them with information and techniques to manage their caregiving activities. Interventionists conduct a risk appraisal assessment related to caregiver depression, burden, health, social support, self-efficacy and desire to institutionalize, and any behavioral issues of the person with dementia. The results of the risk assessment guide the remainder of the intervention sessions with each session focused on assisting the caregiver with an issue identified in the risk assessment.	<p>Easom et al. (2013)</p> <ul style="list-style-type: none"> • Reduced caregiver depression • Reduced caregiver burden • Improved caregiver health • Reduced behavioral problems of care recipient <p>Nichols et al. (2008)</p> <ul style="list-style-type: none"> • Reduced number of hours caregivers provided care <p>Belle, et al. (2006)</p> <ul style="list-style-type: none"> • For Hispanic or Latino and White or Caucasian caregivers, improved quality of life • For Black or African-American spouse caregivers, improved quality of life • Reduced clinical depression among caregivers

TABLE 3-2. Summary of How the Dementia Care Models Address the Care Components

Care Components	BRI Care Consultation™	Comfort Matters™	Healthy Aging Brain Center	MIND at Home	RCI REACH
1. Detection of Possible Dementia	There is no specific protocol for screening or detection of possible dementia.	MMSE is used at admission. A formal cognitive screen, the Montreal Cognitive Assessment, and comprehensive diagnostic evaluation is conducted if change in status is observed.	MMSE is used for individuals enrolled in the home portion of the program. Protocols for clinic portion of the program include standardized intake interview and clinic visit for diagnostic evaluation, and second clinic visit to provide the diagnosis.	Initial screening for the program is conducted using a simple screening tool administered over the phone by students. A comprehensive assessment of cognitive status using the MMSE and other instruments is part of the initial assessment.	FAST® Scale is used to determine a person's stage of dementia.
2. Diagnosis	Care consultants ask about memory problems and provide referrals to health care providers trained in diagnosis.	Geriatrician on staff works with the interdisciplinary team and family to conduct a comprehensive diagnostic evaluation.	Diagnostic tests and evaluation are conducted in the clinic, and some form of problem identification has already been made for patients prior to their entry into the program; for a small proportion of clinic patients who are referred from the home-based program, the diagnosis is made in the clinic. Home-based program is not involved in the diagnosis of dementia.	The clinical team will refer the participant to their primary care physician for a more thorough workup or to the Johns Hopkins University memory clinic if there is an usual presentation of the disease or if there is a question about the diagnosis, but a formal diagnosis is not required to participate in the program.	Does not directly get involved in the diagnosis of dementia; caregiver coaches encourage obtaining a formal diagnosis from a physician.
3. Assessment and Ongoing Reassessment	Initial assessment is completed over a 4-month period to allow for building rapport and trust and addressing immediate concerns. Periodic reassessment every 6 or 12 months or more often if there is a persistent problem.	Person's care needs are assessed through a pre admission meeting, MMSE, nursing assessment, medical record review, dietary screening, social work assessment, inventory of activities, medication review, and medical history and physical exam.	For the home portion of the program, a care coordinator assistant meets with the individual, caregiver, or both to conduct an initial assessment. In the clinic portion of the program, the first assessment is conducted during the intake interview over the phone with the caregiver.	A comprehensive initial assessment of the person with dementia and his or her caregiver is conducted by a nurse and a memory care coordinator in the home setting. In addition to a social assessment of the person with dementia and the caregiver, a physical exam is conducted by the nurse or other medical clinician. Another full assessment is conducted at 9 and 18 months.	Assess caregiver risks through a Risk Priority Inventory--examines caregiver depression, burden, health, social support, self-efficacy, desire to institutionalize, and behavioral problems of the person with dementia, also includes a home safety assessment; no formal assessment of the person with dementia.

TABLE 3-2 (continued)

Care Components	BRI Care Consultation™	Comfort Matters™	Healthy Aging Brain Center	MIND at Home	RCI REACH
4. Care Planning	Person living with dementia or their caregiver identifies medical and nonmedical concerns during the initial assessment and the care consultant helps with formulating goals with action steps.	Program conducts a care planning meeting within 14 days of new admission; care plans are updated quarterly and whenever there is a significant change in medical condition or cognitive status.	For the home portion of the program, care planning meetings are conducted following the home visits. For the clinic portion of the program, care planning starts with the family conference, which is aimed to educate the family about the patient's dementia and help caregivers understand more about the disease, including how the disease likely will progress, and to identify treatment goals.	After the care plan is developed, a detailed letter with the recommendations of the care team is sent to the caregiver. In developing their recommendations, the care team relies heavily on a web-based care management database that contains actions log and an electronic library of available resources for each need. The care coordinator meets with the caregiver and person with dementia discuss the recommendations and establish a plan of action.	No formal care planning process for the person with dementia; program designed around 5 main issues, which are addressed by the coach: safety, caregiver health, problem-solving, caregiver well-being, and social support.
5. Medical Management	Does not directly address medical management issues.	Medical management is overseen by the interdisciplinary team, which includes a licensed geriatrician.	Medical management usually defaults to the individual's primary care physician, who is usually within the Eskenazi Health System.	Medical management is an important component of the project, with RNs and a geriatric psychiatrist playing important clinic roles, but the project does not provide medical care. The clinical team and care coordinators teach caregivers to monitor symptoms and behavior changes and make adjustments to the home environment to avoid falls. With permission, the care plan is sent to the primary care physician.	Does not address medical management issues; if such issues arise coaches will work with caregivers to get appropriate assistance.

TABLE 3-2 (continued)

Care Components	BRI Care Consultation™	Comfort Matters™	Healthy Aging Brain Center	MIND at Home	RCI REACH
6. Information, Education, and Informed and Supported Decision Making	The CCIS has educational resources and materials that are searchable by keyword and can be sent via e-mail or mail. Care consultants facilitate informed and supported decision making by working with family members and friends to plan for future caregiving and other care needs.	The program supports the individual in decision making as much as possible and encourages family caregivers to be advocates for the resident.	The program provides educational resources on topics such as understanding dementia behaviors, disease management strategies, behavioral techniques to help manage behavioral symptoms, coping strategies for caregivers to maintain their physical and emotional health, and community resources for dementia care.	The program provides educational materials, and coaching to the person with dementia and the caregiver. Much of the education takes place by phone, although care coordinators do make some in-person visits. The program maintains a database of educational materials. The information is to help participants make informed decisions regarding needed care.	Provided to caregivers throughout the intervention through the <i>Dealing with Dementia</i> guide, videos, webinars, and handouts.
7. Acknowledgement and Emotional Support for the Person with Dementia	Care consultants involve the person living with dementia whenever possible. The process works best if the person with dementia has a caregiver involved.	Provided through positive interactions and by acknowledging a resident's experience in the present moment.	Provided by care coordinator assistants through positive interactions; program also encourages the patients to reach out to the resources within the Eskenazi Health System or within the community for emotional support.	Memory care coordinators involve the person with dementia when possible, but the interactions are primarily by phone with the caregivers.	Does not directly provide for the person with dementia; program indirectly addresses these issues by providing assistance to caregivers.
8. Assistance for the Person with Dementia with Daily Functioning and Activities	Care consultants do not assist the person directly with daily functioning and activities.	Daily activities including personal care are resident-driven based on preferences and prior routines.	Screening for ADLs is included in the home portion of the program. The clinic portion of the program is not involved in providing assistance with daily functioning and activities.	The assessment identifies people who need help with daily functioning, but the program does not directly provide help with the ADLs or the IADLs. Memory care coordinators will help to connect participants with programs that provide these services, but many have waiting lists.	If caregiver identifies daily functioning and activities of person with dementia as one of the target areas in the risk appraisal, the caregiver coach will address these issues.
9. Involvement, Emotional Support, and Assistance for Family Caregiver(s)	Caregivers are involved in all aspects of the program and work closely with the care consultant to determine areas of concern and action steps. Care consultants listen to concerns and help develop proactive response.	Ongoing communication with family members and building strong partnerships in the care of the resident with dementia is integral to the success of the program.	Caregivers are involved throughout the care process. Caregivers are encouraged to accompany the individuals during the clinic visits and home visits.	The program works with caregivers to provide them with emotional support. Contact is largely by telephone or e-mail and is part of the process of building trust and relationship with the participants. Care coordinators talk by phone with caregivers at least once a month.	Including caregivers and providing them with emotional support is the basis of the program and conducted throughout the intervention.

TABLE 3-2 (continued)

Care Components	BRI Care Consultation™	Comfort Matters™	Healthy Aging Brain Center	MIND at Home	RCI REACH
10. Prevention and Mitigation of Behavioral and Psychological Symptoms of Dementia	Care consultants do not assist the person directly with behavioral and psychological symptoms of dementia or train family caregivers on effective approaches.	Staff are trained that behavior is a form of communication for residents who may have difficulty expressing their needs verbally.	A tool called the HABC monitor is used to measure the cognitive, functional, behavioral, and psychological symptoms of dementia. Antipsychotic medications are avoided for as long as possible.	The care team assesses the problem behavior, how often it occurs, and what triggers the behavior, ruling out medical problems. Care coordinators offer coaching and modeling for problematic behaviors and provide skills training. The CMS-funded participants are also offered the TAP, a home-based occupational therapy intervention.	Caregivers learn a 9-step problem-solving process to assist them in addressing behavioral and psychological symptoms of dementia.
11. Safety for the Person with Dementia	Care consultants can respond to a variety of safety concerns including home safety, elder abuse, falls, or inability to maintain the home.	For residents who are at risk of a fall, the program uses lowered beds; hallways and public spaces are kept free of unnecessary clutter; also at night, the corridors and access to the bathroom are well-lit.	For the home portion of the program, the initial assessment includes a home safety evaluation. The clinic portion of the program is not involved in providing assistance with safety for the individual with dementia.	The home environment is a major focus of the program because falls are a major cause hospitalization and other transitions. During the home assessment, the care team identifies any fall safety issues, such as throw rugs and will discuss eliminating them with the caregivers as part of the care plan. The program also addresses wandering, driving, kitchen safety, and guns.	Initial Risk Priority Inventory includes a home safety assessment examining issues such as wandering, presence of firearms in the home, and suicide.
12. Therapeutic Environment, Including Modifications to the Physical and Social Environment of the Person with Dementia	Care consultants can access information and counsel the person with dementia or family caregiver on a variety of ways to ensure therapeutic environment.	A comforting and familiar environment is created by inviting residents to bring their furniture, pictures, and decorations from home.	For the home portion of the program, the HABC monitor is used to identify issues related to social and physical environment. The clinic portion is not involved in the physical and social environment of the person with dementia.	MIND at Home works with caregivers to make the home setting pleasant to the person with dementia, but it is not a major focus.	Caregiver coach will work with the caregiver to address environmental issues if they arise.

TABLE 3-2 (continued)

Care Components	BRI Care Consultation™	Comfort Matters™	Healthy Aging Brain Center	MIND at Home	RCI REACH
13. Care Transitions	If there is a significant change in medical condition or living situation, a care consultant can provide coaching and ongoing decision making support to ease transitions.	Staff works with medical team to ensure smooth transitions from 1 setting into another.	The program assists patient and caregivers with transitions from the hospital or emergency department to the home.	A major goal of MIND at Home is to reduce transitions to hospitals, nursing homes, and assisted living facilities. In their view, the main controllable factors related to hospitalizations are problems with home safety, including falls; inadequate medication adherence and poor prescribing on the part of physicians; and missing medical appointments. The program attempts to address these factors by working with the caregivers.	Does not explicitly address; general information is in the <i>Dealing with Dementia</i> guide.
14. Referral and Coordination of Care and Services that Match the Needs of the Person with Dementia and Family Caregiver(s) and Collaboration Among Agencies and Providers	Partners in Dementia Care, a version of the model, use a formal collaborative partnership between health care organization and community service organization.	Does not have formal referral and coordination of care protocol.	Does not have specific protocols for collaboration among agencies and providers.	Does not have formal referral and coordination of care protocol. Since MIND at Home does not directly provide services, it refers caregivers to organizations that may be able to provide them with the services they need.	There is no formal referral and coordination of care protocol; caregiver coaches can provide caregivers with information for needed resources and services.

3.1. BRI Care Consultation™

3.1.1. Description of Model

The Benjamin Rose Institute on Aging (BRIA) in Cleveland, Ohio, developed BRI Care Consultation™ to empower people with dementia and their caregivers to take an active role in their health and well-being. Care consultants assist people with dementia and family caregivers with developing and achieving personalized goals. The program has three main components: initial assessment, action plan, and ongoing maintenance and support, which includes monitoring and follow-up with reassessment, as needed. The Care Consultation Information System (CCIS) is an important component of the program and contains a variety of tools to ensure fidelity to the model including the assessment trigger and follow-up questions, action step template, progress report format, and educational resources on a variety of topics.

The intervention is delivered by BRIA-trained care consultants via telephone, regular mail, and e-mail with in-person contact rarely provided. Care consultants usually have degrees in social work or nursing but other helping professionals have also been trained in the model program. Care consultants manage a caseload of up to 150 families, with contact with a client varying from once every 3 months to a few times a week depending on the situation. The standard protocol for the model requires three contacts in the first month; a minimum of at least one contact per month for months 2, 3, 4, and 5; and a minimum of one contact per month at month 6 and then every 3 months for the duration of enrollment.

BRI Care Consultation™ has been studied for many years in various local and national research projects and is recognized as an evidence-based program by the RCI and the Administration on Aging. BRIA provides training to organizations and care consultants on the BRI Care Consultation™ philosophy, service delivery protocols, and use of the CCIS along with ongoing individual coaching, refresher training, and fidelity reviews.

Information for this case study was gathered by reviewing published articles, the BRIA website, and by conducting an in-person site visit at the institute on April 28-29, 2016, in Cleveland, Ohio. As part of the site visit, RTI staff interviewed BRI Care Consultation™ staff and nearby organizations that are licensed by BRIA to implement the model including the Cleveland VA Medical Center, Western Reserve Area Agency on Aging, Alzheimer's Association, Cleveland Chapter, and Alzheimer's Association, Greater East Ohio Chapter.

3.1.2. Dementia Care Framework Components

Detection of Possible Dementia

BRI Care Consultation™ does not have a specific protocol for detection of possible dementia.

Diagnosis

Care consultants ask about memory problems during the initial assessment and ongoing reassessment to determine whether the client wants more information or more tests to understand memory problems. If the client responds affirmatively, the care consultant will ask follow-up questions and provide referrals to health care providers trained in diagnosis.

Assessment and Ongoing Reassessment

The initial assessment is completed over the course of 4 months, enabling the care consultant to build rapport and trust during several contacts. This prolonged assessment period also allows the care consultant to address immediate concerns while doing a comprehensive assessment. Through guided conversation the care consultant assists the person with dementia or caregiver to determine specific action steps with completion dates and then coaches the person with dementia and caregiver toward meeting his or her goals. Ongoing maintenance and support involves follow-up on progress made and periodic reassessment every 6 or 12 months or more often if there is a persistent problem.

The initial assessment covers 24 domains for people with dementia (e.g., activities of daily living [ADLs], memory problems, difficult behaviors) and 11 domains for caregivers (e.g., financial concerns, relationship strain, sleep). If the client indicates a concern with the domain, the care consultant may ask follow-up questions to gather more information. This additional information will then help to inform how best to coach the clients on possible solutions. The care consultants interviewed during the site visit consistently spoke about the assessment process as “free form” and driven by conversation because there is no requirement for the domains be addressed in any particular order during the 4-month assessment period. The care consultant completes the initial assessment in the CCIS by checking off each trigger question that is relevant to the client. Trigger questions and detailed follow-up questions can be revisited at any time, and each reassessment is recorded in the CCIS to capture changes over time and the progress made.

Care Planning

The person living with dementia or his or her caregiver identifies medical and nonmedical concerns during the initial assessment, and the care consultant helps them formulate goals with action steps to address those concerns. Action steps are

individualized to the needs and preferences of the person living with dementia and caregiver. Each action step in the plan designates a person responsible for completion of a task and a completion date.

Care consultants receive extensive training and coaching from the BRI staff on writing action steps that are manageable and measurable to help the clients achieve their goals. During a follow-up call, progress for each step is noted in the action plan, and a report is mailed or e-mailed to the client. With the client’s approval, the action plan can also be sent to the primary care provider (PCP). According to care consultants, family members express an increased sense of accomplishment seeing their progress report after the call with the care consultant. If an action step is not accomplished, the care consultant will help to break down the action step into smaller, more manageable steps and coach the client through each step. The process of action planning is continuous and builds on both previously established action steps and developing new ones. Examples of action steps are in **Table 3-3**.

TABLE 3-3. Action Steps Examples	
Person Living with Dementia	<ul style="list-style-type: none"> • Attend morning exercise group at 10am and lunch at noon at Forest View Senior Center on Mondays, Wednesdays, and Fridays • Participate in early-stage support group at Park Center the third Tuesday of the month at 1:30pm
Family Caregiver	<ul style="list-style-type: none"> • Register for upcoming workshop at the Alzheimer’s Association located in Centerville on Behavioral Symptoms of Dementia • Follow-up with Dr. Hollinger by calling 555-555-5555 this week about refilling mom’s heart medication prescription • Review bank statement and balance checkbook every month
Care Consultant	<ul style="list-style-type: none"> • Mail home safety checklist to Mary (caregiver) • Follow-up with the information about transportation options with Mary (caregiver) • E-mail possible dates and times for a family meeting
Friend/Neighbor	<ul style="list-style-type: none"> • Mow lawn every Saturday and trim bushes • Make soup and deliver on Tuesday, June 21 • Walk the dog on Mondays, Wednesdays, and Fridays at noon when Betty is at the senior center

Medical Management

BRI Care Consultation™ does not directly address medical management issues; however, during the assessment and reassessment, a care consultant will ask if the client has experienced difficulties with coexisting medical conditions and will assist the client with getting medical care. Care consultants will coach the client on ways to prepare for a medical appointment and communicate concerns with the PCP.

Information, Education, and Informed and Supported Decision Making

The CCIS has a full array of educational resources and materials that are searchable by keyword and can be sent via e-mail or regular mail to the person with dementia or family caregiver. Currently, the system contains approximately 400 resources that are continually updated and maintained. These resources address a wide range of topics such as understanding dementia behaviors, communicating with your doctor, managing diabetes, and advance planning. The care consultant determines the most appropriate resources for the client and his or her situation. After sending the resources, the care consultant follows up with the client to confirm receipt and to briefly discuss the content to ensure that it is understood.

Care consultants facilitate informed and supported decision making by working with family members and friends to plan for future caregiving, building consensus regarding advance planning and care needs, providing educational resources, and listening to concerns. The average amount of contact is 15 calls over a 12-month period, but the amount of contact is tailored to the needs of the person with dementia and his or her caregiver.

Acknowledgement and Emotional Support for the Person with Dementia

Care consultants involve the person living with dementia whenever possible by engaging their participation in the assessment and assigning action steps. The process works best if the person with dementia has a caregiver involved. BRI Care Consultation™ is a “coaching model driven by consumer choice” (Bass et al., 2015). Care consultants are trained to reinforce client autonomy and self-care; however, a person with dementia may not have the ability to manage daily activities if he or she does not have a caregiver. The geriatrician and care consultant from the Cleveland VA Medical Center stated that a large number of veterans do not have caregivers or any other support.

Care consultation with a person with dementia works best with one action step at a time and frequent check-in calls to assess progress. At times, the person with dementia may not recognize the care consultant’s name or understand the reason for the call. The care consultants interviewed said it is best to assume the person does not remember them and to always explain their role and briefly remind them what was previously discussed.

Assistance for the Person with Dementia with Daily Functioning and Activities

Care consultants do not assist the person directly with daily functioning and activities; however, they can provide information on the impact of dementia on the ability to perform daily activities and refer to services to help the person get the assistance that he or she needs.

Involvement, Emotional Support, and Assistance for Family Caregiver(s)

Caregivers are involved in all aspects of the program and work closely with the care consultant to determine areas of concern and specific action steps. The care consultant also works with the caregiver to identify other family members and friends as a way to increase the network of support and decrease caregiver burden. Any interested friend or family member can be named as the person responsible for completing an action step.

During telephone contacts, the care consultant listens to the caregiver's concerns, validates the challenges of the care situation, and helps the caregiver develop a proactive response through the action plan. The care consultant encourages the use of supportive counseling or other services such as respite or ongoing case management. The care consultant can also help the caregiver to identify and mobilize support from other family members and friends through coaching and check-in calls to assess progress made.

Prevention and Mitigation of Behavioral and Psychological Symptoms of Dementia

Care consultants do not assist the person directly with behavioral and psychological symptoms of dementia or train family caregivers on effective approaches for responding to behaviors. However, care consultants provide information on behavioral and psychological symptoms of dementia and train family caregivers on effective strategies for preventing and mitigating behavioral and psychological symptoms.

Safety for the Person with Dementia

Care consultants can respond to a variety of safety concerns such as home safety, elder abuse, falls, or inability to keep up with routine home maintenance. The care consultant can provide educational materials via e-mail or regular mail and follow up to monitor for progress. If it is a situation of suspected elder abuse or self-neglect, the care consultant may involve other providers or Adult Protective Services. The Cleveland VA Medical Center care consultant spoke about some situations where she worked with the primary care physician to evaluate decision making capacity and changes in executive function when a veteran cannot follow through on any action steps.

Therapeutic Environment, Including Modifications to the Physical and Social Environment of the Person with Dementia

Depending on the individual's action steps, care consultants can access information and counsel the person with dementia or family caregiver on a variety of ways to ensure a therapeutic environment. For example, care consultants can help a person with dementia maintain daily routines that feel consistent and familiar. Another example is teaching family and friends about ways to avoid unsafe wandering by

providing safe access to the outdoors and offering opportunities for meaningful activity throughout the day to prevent boredom.

Care Transitions

If there is a significant change in the person's medical condition or living situation, a care consultant will conduct additional phone calls to provide coaching and ongoing decision making support to ease transitions across providers and care settings. Numerous studies of BRI Care Consultation™ have found that the program decreases hospital readmissions and emergency department visits (Bass et al., 2003, 2013, 2014, 2015; Clark et al., 2004).

Referral and Coordination of Care and Services that Match the Needs of the Person with Dementia and Family Caregiver(s) and Collaboration Among Agencies and Providers

The care consultants during the site visit consistently distinguished the BRI Care Consultation™ use of coaching and empowerment of the individual to take action from case management or care coordination with professionals making the arrangements for the client. Care consultants reinforce a client's autonomy and responsibility for their own self-care. Clients are monitored for completion of the action steps with follow-up calls to check on progress made. The BRI model emphasizes the importance of improving problem-solving skills and self-confidence in managing chronic health conditions. A challenge with this model is that persons with dementia will need assistance if they are not able to successfully complete action steps.

Partners in Dementia Care is a version of BRI Care Consultation™ using a formal partnership between a health care organization and a community service organization. This version of BRI Care Consultation™ is designed to facilitate better coordination between medical care and community services, improve access to care, and increase awareness of health care providers about nonmedical needs of people with dementia and family members (Bass et al., 2014). The Cleveland VA Medical Center partnered with the local Alzheimer's Association chapter to find ways to support veterans living with dementia and their caregivers because they found that traditional medical care was not sufficient. Care consultants from the Cleveland VA Medical Center and from the Alzheimer's Association worked as a team to provide support to families enrolled in the program. They sought to provide seamless support through a shared version of the CCIS and access to the U.S. Department of Veterans Affairs (VA) electronic medical record. Alzheimer's Association care consultants went through the process to become VA employees without compensation to allow access to the VA system. This partnership between the local agencies allowed for collaboration with other care consultants on shared clients and problem-solving during weekly team meetings. The care consultants were able to better assist the clients in navigating the VA health care system and access dementia education resources and support through the local Alzheimer's Association.

3.2. Comfort Matters™

3.2.1. Description of Model

Originally called Palliative Care for Advanced Dementia, Comfort Matters™ is a comfort-focused and person-directed approach to care for people with dementia developed through a partnership between the Beatitudes Campus and the Hospice of the Valley in Phoenix, Arizona. Beatitudes Campus is a continuing care retirement community established by the Church of the Beatitudes, a United Church of Christ congregation, which also provides companion care, home health, and medical services. The Comfort Matters™ approach to care extends beyond end-of-life to any stage of dementia and engages the person as an “expert in their own comfort.” Comfort Matters™ uses five key concepts (**Table 3-4**) that are the foundation of interdisciplinary team efforts to meet the medical, physical, social, spiritual, and emotional needs of people with dementia (Alonzo et al., 2015). The program teaches long-term care staff, medical providers, and families about the palliative care approach to dementia care with the goal of improving the person’s quality of life by relieving physical pain, behavioral symptoms, and stress.

TABLE 3-4. Key Concepts of Comfort Matters™

Comfort Matters™ uses five key concepts: <ol style="list-style-type: none">1. Promote personal comfort at all times.2. Incorporate the person’s life story into his or her care plan.3. Create a personalized homelike environment.4. Anticipate the person’s needs rather than respond primarily to discomfort or behaviors.5. Empower caregivers to do whatever is needed to make the person comfortable. Comfort Matters™ website http://www.comfortmatters.org/about-us/ .
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Comfort Matters™ trains all staff who have contact with people living with dementia. This includes dietary professionals, housekeeping-laundry-maintenance staff, recreational therapists, social workers, certified nursing assistants, licensed nurses, spiritual care providers, medical care providers, and administrators. In addition, an online training is in development for family caregivers called *What Families Need to Know about Comfort Care*.

Information for this case study was gathered by reviewing published articles and the Beatitudes website and by conducting an in-person site visit on May 11-12, 2016, in Phoenix, Arizona. As part of the site visit, RTI staff interviewed the Comfort Matters™ program team, Beatitudes executive leadership, direct care staff, nursing management, dining services, and spiritual life enrichment activities staff.

3.2.2. Dementia Care Framework Components

Detection of Possible Dementia

Every new resident of the assisted living facility receives a mini-mental state examination (MMSE) at admission. Residents are reevaluated every quarter and annually for any changes from admission. All staff who regularly interact with the residents are trained to look for visual clues indicating an increase in behavioral symptoms, decrease in mobility, or cognitive changes such as decline in social interaction with others or ability to recognize family members. Staff report observed changes to the nurse in charge or to the medical director who will perform a formal cognitive screen, the Montreal Cognitive Assessment, and conduct a comprehensive diagnostic evaluation.

Diagnosis

The Beatitudes campus has a geriatrician on staff who works with the interdisciplinary team and family when conducting a comprehensive diagnostic evaluation. If there is diagnostic uncertainty or atypical symptomatology, the geriatrician makes a referral to one of the diagnostic clinics affiliated with the Arizona Alzheimer's Consortium. The diagnostic clinics are based in the Phoenix area and in other parts of the state and they include Barrow Neurological Institute, Banner Alzheimer's Institute, Banner Sun Health Research Institute, T-Gen, Dignity Health, Mayo Clinic, Arizona State University, and University of Arizona.

Assessment and Ongoing Reassessment

Whenever possible, staff meet with individuals and family members interested in living on the Beatitudes campus prior to admission to discuss program offerings and living arrangement options. During this time, staff assess the person's care needs and individual preferences, and family members are encouraged to ask questions and provide relevant medical information. Staff conduct pre-admission assessments of individuals from other programs on the Beatitudes campus, hospitals in the Phoenix metropolitan area, and the community. It is not unusual for staff to have several meetings or telephone conversations with families before a person is admitted.

During the admission process, family members are invited to share personal information that will ease the person's transition to a new environment such as the person's life story, daily routine, preferences, and physical, psychological, social, and spiritual history. The initial assessment also includes a MMSE, nursing assessment, detailed medical record review, dietary screening, social work assessment, inventory of activities and interests, medication review, and medical history and physical exam. Staff are engaged in ongoing reassessment over the course of a resident's stay such as daily pain assessment, weekly medication review, and falls monitoring. Direct care staff involved in assisting with daily activities report any changes they observe in a resident that may indicate a decline in physical or cognitive health.

Care Planning

Care planning meetings are conducted within 14 days of a new admission. Interdisciplinary team members work with family members and the person with dementia, as much as possible, to identify treatment goals for the care plan. The team members involved in care planning include the charge nurse, doctor, director of nursing, Minimum Data Set coordinator, pharmacy consultant, social worker, and assistant director of nursing. Family members are invited to participate at a time that is convenient for them. Each resident's care plan is updated quarterly and whenever there is a significant change in medical condition or cognitive status.

Medical Management

The interdisciplinary team includes a licensed geriatrician who oversees medical management. The Comfort Matters™ model incorporates a theory of holistic comfort that consists of three states--relief, ease, and transcendence--and that comfort occurs in different contexts--physical, psychospiritual, social, and environmental (Kolcaba, 1994). This comfort focus permeates every aspect of the person's overall care and medical management.

Pain is often underrecognized and undertreated in long-term care residents with dementia because they cannot easily communicate comfort needs to their care providers. Staff observe for signs of pain in residents daily using the *Pain Assessment in Advanced Dementia (PAINAD)* scale (Warden et al., 2003). The scale assigns scores to five domains of behavior, and staff can observe residents under different conditions such as at rest, during a pleasant activity, and during care routines. If it appears that a resident is in pain, nursing staff will administer pain medication and then reassess using the PAINAD scale to determine if it was effective. The model also emphasizes medication reconciliation; the advanced dementia residents are on an average of four medications.

Weight loss, a common occurrence in people with advanced dementia, is managed by having residents eat their favorite foods, and food is available at all times of the day and night. Since using this weight management approach, residents have generally gained or maintained their weight without the use of dietary supplements.

Information, Education, and Informed and Supported Decision Making

Comfort Matters™ supports the individual in decision making as much as possible and encourages family caregivers to be advocates for the resident. Staff provide education and information relevant to the situation so that the resident and family members can make an informed decision. An example of their approach is demonstrated by a consultation for a 90-year-old resident with a history of breast cancer who was rejecting her routine mammogram. The director facilitated the family decision making process by asking, "If your mother could see herself now, would she want

treatment if she was diagnosed with stage IV breast cancer?” The Beatitudes campus participates in the National Healthcare Decisions Day, an annual event to educate the public about the importance of advance care planning by providing information and resources to residents to put their wishes in writing. By making decisions ahead of time, family members are relieved of the burden of trying to make difficult medical decisions by honoring the resident’s stated wishes.

Acknowledgement and Emotional Support for the Person with Dementia

Comfort Matters™ staff are encouraged to provide emotional support through positive interactions and to acknowledge a resident’s experience in the present moment. During the site visit, one of the housekeeping staff stopped what he was doing to dance with a resident. He said that he enjoys dancing with her every morning and making her smile. Another staff member said that she talks to residents about their children if they have pictures in their room or sings a favorite spiritual hymn with them. She shared that the interactions she has with residents do not take a lot of time and can really boost their spirits.

Assistance for the Person with Dementia with Daily Functioning and Activities

Comfort Matters™ policies and procedures for the assisted living and nursing home residences on the Beatitudes campus address a variety of areas including activities, bathing, bowel and bladder management, dining, and grooming. Comfort Matters™ staff do not adhere to structured routines but rather daily activities are resident-driven based on preferences and prior routines. For example, there are mealtimes but residents can also eat any time they are hungry. Residents are not required to go to bed or wake at a specific time. If there is a particular personal care activity that a resident does not like, staff are empowered to try doing it differently such as warming up the bathroom before bathing to make it more comfortable or offering coffee while the resident gets dressed in the morning. The program has a wide variety of activities based on resident interest including chair Zumba, yoga, and weekly religious services. Residents from other parts of the campus are invited to join birthday celebrations on the advanced dementia care unit, and the staff encourage interaction with residents from all parts of the Beatitudes campus through campus-wide events.

Involvement, Emotional Support, and Assistance for the Family Caregiver(s)

Comfort Matters™ underscores ongoing communication with family members and building strong partnerships in the care of the resident with dementia as integral to the success of the program. Staff educate family members, provide reassurance, and help them with difficult decisions. The program involves caregivers throughout the course of a resident’s stay and provides bereavement counseling after the death of a resident. The Comfort Matters™ staff meet with family members before the person moves to the campus to determine the appropriate level of care and support. After admission, families have the option of staying with the person to ease transition into the program, and family are always welcome to join at mealtime. During the resident’s stay, family

members are invited to participate in the regular care planning meetings and meet with the team any time there is a change in the resident's cognitive or health status. Caregivers are also invited to participate in various social events carried out on the campus.

Comfort Matters™ encourages family involvement in all aspects of the program throughout a resident's stay. Family are welcome to visit the resident at any time of day and to join at mealtime. Staff are encouraged to take the time necessary to meet with family members and to be available by phone to listen to family member concerns and to provide emotional support.

Prevention and Mitigation of Behavioral and Psychological Symptoms of Dementia

Comfort Matters™ staff are trained that behavior is a form of communication for residents who may have difficulty expressing their needs verbally. Staff know to intervene when observing signs of distress such as pacing, hitting the person next to them, rocking back and forth, or tapping repeatedly. Once staff get to know a resident, they may be able to reduce or prevent behavioral symptoms by anticipating and responding to a resident's needs. For example, a resident with advanced dementia reverted to traumatic experiences she had as a child in Iran and anytime someone approached her, she became anxious and self-protective. Direct care staff assisting her with daily activities learned to say "I will keep you safe" in Farsi, and that would calm her down.

Safety for the Person with Dementia

Residents with advanced dementia are on a third-floor unit, and a rope barrier is used to deter access to the elevator. Hallways and public spaces are kept free of unnecessary clutter that may present a fall risk. Staff eliminate crowding in the activity and dining areas by spreading out the activities in different areas or at different times. At night, the corridors and access to the bathroom are well-lit. The facility is free of physical restraints such as rails on the beds or belts on the wheelchairs. For residents who are at risk of a fall, the program uses lowered beds.

Therapeutic Environment, Including Modifications to the Physical and Social Environment of the Person with Dementia

The program creates a comforting and familiar environment by inviting residents to bring their furniture, pictures, and decorations from home, and family members are welcome to help with decorating the room. An overall slower pace, noise reduction, and quiet spaces help to create a therapeutic environment that minimizes resident agitation by balancing between a tolerable level of social engagement and overstimulation. The program promotes community activities that support a home-like atmosphere among residents, family members, and staff as a way to enhance quality of life and comfort.

Care Transitions

Prior to any new admission from the hospital, Comfort Matters™ staff go to the hospital to ensure that the patient is discharged to the appropriate level of care. Sometimes a returning resident may require a higher level of care such as assisted living or nursing home care after a hospitalization, and staff will work with the medical team to ensure a smooth transition. Comfort Matters™ staff also visit people with dementia in their homes if they are interested in coming to the Beatitudes campus to talk about the different living arrangements on campus and determine the best fit for their needs. The Success Matters team of staff members from different parts of the Beatitudes campus meet weekly to discuss residents showing signs of cognitive decline. The team discusses options for helping these residents to remain in their current living situation and assists residents and family members transition to another program on campus.

Referral and Coordination of Care and Services that Match the Needs of the Person with Dementia and Family Caregiver(s) and Collaboration Among Agencies and Providers

Comfort Matters™ does not have a specific protocol for referral and coordination of care and services that match the needs of the person with dementia and family caregivers or a specific protocol for collaboration among agencies and providers.

3.3. Healthy Aging Brain Center

3.3.1. Description of Model

Indiana University and Eskenazi Health System, a safety-net integrated health care system in Indianapolis, Indiana, developed the Healthy Aging Brain Center, a dementia and depression care program that aims to reduce dementia-related burden among individuals with dementia and their caregivers. The program operates within Eskenazi Health System and delivers services through clinic and home-based approaches. The program was initiated in 2008 as a clinic-based program, designed to serve individuals with dementia and their caregivers in the clinic. In 2015, the clinic had approximately 1,500 person enrolled in the program. In 2012, with support from a Health Care Innovation Award from Center for Medicare and Medicaid Innovation, the program expanded to serve persons with dementia or depression in their homes (LaMantia et al., 2015). In 2015, the home portion of the program had approximately 703 individuals actively enrolled in the program.

The Healthy Aging Brain Center includes individuals with dementia who are seen both in the clinic and home portion of the program and individuals who are seen only in the clinic or only at home. An interdisciplinary group of staff run the program including physicians, social workers, nurses, neuropsychiatric technicians, and care coordinator assistants. The care coordinator assistants serve individuals enrolled only in the home

portion of the program. For the clinic portion, although the majority of referrals come from primary care doctors within the Eskenazi Health System, the clinic does accept self-referral for patients outside the system. The home portion of the program serves only individuals who have a primary care physician within the Eskenazi Health System. The population enrolled in the home portion of the program is concentrated mostly in Marion County. The program has seven care coordinator assistants on staff who each serve between 14 and 21 individuals a day. The home portion of the program ends if the client transfers to another home-based program, is admitted to an institutional long-term care setting, is no longer connected to Eskenazi Health System, or the individual terminates participation.

The Healthy Aging Brain Center uses a tool called the Healthy Aging Brain Care (HABC) monitor to measure the cognitive, functional, behavioral, and psychological symptoms of the person with dementia and his or her caregiver. The HABC monitor has two versions. The self-report version is used to collect information, including quality of life, directly from the patients. The caregiver report version is used to collect information on the patient from his or her caregiver and also about caregiver burden (Monahan et al., 2012, 2014).

Information for this case study was gathered by reviewing published articles and the Healthy Aging Brain Center website and by conducting an in-person site visit on May 23-24, 2016, in Indianapolis, Indiana. As part of the site visit, RTI staff interviewed the team based in the clinic portion of the program, team based in the home portion of the program, care coordinator assistants, physicians, and executive leadership.

3.3.2. Dementia Care Framework Components

Detection of Possible Dementia

Every individual enrolled in the home portion of the program receives a MMSE during their first home visit. Individuals are reevaluated every 6 months for any changes from the initial home visits. The home portion of the program serves people with dementia, depression and mild cognitive impairment. For an individual with no initial diagnosis of memory problem, a lower score on a follow-up visit triggers additional screening and is referred to the clinic. The protocols for the clinic portion of the program include a standardized intake interview with the caregiver, which is conducted over the phone with a social worker and a nurse. The intake interview includes items related to functional and behavioral symptoms and change in social function. Following the intake interview, the first clinic visit is scheduled with the individual/caregiver dyads for a complete diagnostic evaluation. During the first clinic visit, a diagnosis is determined based on a neuropsychological assessment, neurological exams, the intake interview, and laboratory tests. A second clinic visit is scheduled with the individual and the caregiver to provide the diagnosis. This second clinic visit is called the family conference.

Being able to conduct the neuropsychological testing and neurological imaging on site and on the same day of the first clinic visit is important for the individuals with dementia and their caregivers. The biggest challenge is addressing caregivers' denial and conflicting family dynamics that are not helpful to the person with dementia. Another challenge for the clinic portion of the program is a high no show rate, which is a major source of inefficiency for the program.

Diagnosis

Diagnostic tests and full evaluation are conducted in the clinic. In addition, some form of problem identification has already been made for these patients prior to their entry into the program. For a small proportion of clinic patients who are referred from the home-based program, the diagnosis is made in the clinic. These include home-based individuals who joined the program with a diagnosis of depression and mild cognitive impairment, and are referred to the clinic for dementia. The home-based program is not involved in the diagnosis of dementia.

Assessment and Ongoing Reassessment

Individuals with dementia in the program are assessed periodically in a number of domains. For every individual enrolled in the home portion of the program, a care coordinator assistant meets with the individual, caregiver, or both to conduct an initial assessment. This assessment includes MMSE, measurement of the individual's and caregiver's reported cognitive, functional, behavioral, and psychological of the individual using the HABC monitor, Patient Health Questionnaire-9 (PHQ9) depression screening, and recording information on all medications the patient is taking. Care coordinator assistants are engaged in ongoing reassessment during home visits such as a MMSE every 6 months, recording medications on every visit, assessing ADLs and instrumental activities of daily living (IADLs), and assessing home safety.

In the clinic portion of the program, the first assessment is conducted during the intake interview over the phone with the caregiver. The first part of the interview is conducted by social workers, and the second part is conducted by nursing staff. The comprehensive interview includes questions related to the individual's ADLs; cognitive, behavioral, and psychological symptoms' social, family, and medical history; current medications; and caregiver status. During the first clinic visit, the assessment includes measurement of cognitive, functional, behavioral, and psychological status of the individual using the HABC monitor, PHQ9 depression screening, MMSE, and neuropsychological testing. The clinic staff is engaged in ongoing reassessment during clinic visits. The cognitive, functional, behavioral, and psychological status is assessed using the HABC monitor at every clinic visit. The MMSE and depression screening is done every 6 months. Neuropsychological testing is not repeated after the first clinic visit.

The HABC monitors provide important information on the individual's cognitive, functional, behavioral, and psychological symptoms of the individual. Other program

successes include bundling the diagnosis and care plan and working with the caregivers.

Care Planning

For the home portion of the program, care planning meetings are conducted following the home visits. The care coordinator assistants bring back the information they had discussed with the individual or their caregiver in their homes to discuss with care coordinators. The care coordinator can be a registered nurse (RN) or a social worker. The care planning meetings include discussions about referrals to the clinic portion of the program, referrals to the primary care doctor, and connecting the individual with community resources. Once the staff have devised the care plan, they conduct home visits to review the care plan with the individual and caregiver and deliver relevant information--nurses give information on medications, social workers provide details on community resources and insurance-related issues, and in some cases, care coordinator assistants provide other information to patients. Each individual's care plan is updated after every home visit or whenever there is a medical event. For example, if a patient is hospitalized or has an emergency room visit, an effort is made to understand the cause of the event, and a new care plan is developed to prevent future events. Nurses visit individuals in their homes following hospitalization or an emergency room visit, sometimes jointly with care coordination assistants.

For the clinic portion of the program, care planning starts with the family conference. The care plan is personalized based on the intake interview and first clinic visit. The entire team, which includes the doctor, nurse, social worker, medical assistant, and neuropsychological tester, meet to discuss the diagnosis prior to the family conference. Professional staff included in the family conference are the doctor and the nurse or social worker. The program strongly encourages at least one family member to accompany the patient for the family conference. One of the main goals of the family conference is to educate family about the patient's dementia and help caregivers understand more about the disease, including how the disease likely will progress, and to identify treatment goals. The family conference has been helpful for the caregivers to understand that the program is designed to focus on both the individual with dementia and his or her caregiver. A major difficulty is that a substantial number of participants fail to show up for their clinic appointments. Some of the other challenges for care planning include: (1) family dynamics because the program is limited in its role to advise or educate family members; (2) absence of a family member who is competent to take on the role of caregiver; and (3) handling the expectation that the program will "fix everything" and to have quick solutions to the problems.

Medical Management

The medical management for both the clinic and home-based portion of the program usually defaults to the individual's primary care physician, who is usually within the Eskenazi Health System. An exception to this protocol is when an individual comes to the clinic with an issue that needs urgent attention. In this situation, the clinic contacts

the primary care physician and makes care recommendations. Because a majority of individuals with dementia in the program use the Eskenazi Health System, their information is already in an electronic medical record. Program nurses conduct medication reconciliation for all individuals enrolled in the program. A majority of individuals have comorbidities, so it is important to make sure that they are taking their medications correctly. To keep the primary care physicians informed of their patients' visits through the clinic, the program's protocol involves transferring the dictation from the clinic visits to the primary care physician. As a part of medical management, the program also educates the caregivers about new diagnoses and the plan of care for when they see other doctors.

The biggest challenge for the program is to manage individuals with dementia who have physicians outside the Eskenazi Health System or those who move into a long-term care facility. Also seen as a challenge is that individuals and caregivers are involved with many physicians, not just their primary care physician. Another challenge for the program is communication with health care providers outside their program. Conflict also can arise with the individual and their prescriber about taking certain medications if the clinic recommends to stop some medications.

Information, Education, and Informed and Supported Decision Making

The Healthy Aging Brain Center supports the individual in decision making as much as possible and encourages family caregivers to be an advocate for the individual. The program has a wide array of educational resources on topics such as understanding dementia behaviors, disease management strategies, behavioral techniques to help manage behavioral symptoms, coping strategies for caregivers to maintain their physical and emotional health, and community resources for dementia care. In the home portion of the program, the care coordinator assistants provide education and information relevant to the particular situation so that the individual and caregivers can make informed decisions. The care coordinators and care coordinator assistants receive a 9-month training with a palliative care team on how to develop advance directives, which was part of a HHS Centers for Medicare & Medicaid Services (CMS) Innovation Grant. Being in the individual's home environment where they are comfortable makes it easier for care coordinator assistants to initiate conversations about end-of-life care.

For the clinic portion of the program, the education material relevant to the needs of the individual and the caregiver is provided as a guidebook during the family conference. The clinic staff continue to provide information and support during follow-up clinic visits and by telephone consultation. The crisis plan and preparing for end-of-life care are discussed in the follow-up clinic visits. A challenge of providing information on advance directives is serving patients and caregivers who are non-English speaking because most of the education material is in English.

Acknowledgement and Emotional Support for the Person with Dementia

For the home portion of the program, it is mostly the care coordinator assistants who are involved in providing emotional support to the patient with dementia through positive interactions and showing that they care and by acknowledging the individual's experience in the present moment. Within the clinic, the social workers do supportive counselling. The Healthy Aging Brain Center encourages the patients to reach out to the resources within the Eskenazi Health System or within the community for emotional support. Success for the home portion of the program lies in having care coordinator assistants who are good listeners, empathetic, and able to validate feelings of the patients. The program has been successful in getting patients connected to resources that help them have a good quality of life.

Assistance for the Person with Dementia with Daily Functioning and Activities

The home portion of the program includes screening for ADLs. The care coordinator assistants help patients connect to community services and home resources that can provide assistance. The program has been successful in developing relationships with organizations such as Indiana Council of Aging, which has helped in getting patients connected to appropriate services. Involvement of social service organizations has helped reduce some of the stress experienced by care coordinator assistants. It is challenging for the program when they have younger patients because a majority of needed services are designed for the population over age 60. The clinic portion of the program is not involved in providing assistance with daily functioning and activities, but the clinic will refer patients to appropriate services and resources.

Involvement, Emotional Support, and Assistance for Family Caregiver(s)

The HABC is dedicated to including caregivers throughout the care process. Caregivers are encouraged to accompany the individuals during the clinic visits and home visits. The program uses multiple modes of communication to stay in constant contact with caregivers, including text, e-mail, and phone. The program encourages caregivers to participate in monthly support groups and to use services through local Alzheimer's Association chapters. The clinic portion of the program encourages caregivers to take weekly retreats, which include 8 hours of respite for the caregiver. To arrange caregiver retreats, the program staff work with local resources, such as adult day care or bringing the aide at home. It is at times challenging for the program to involve caregivers because of family dynamics. The clinic is designed on the premise that the family caregiver is the key provider, but it may require negotiation with the caregivers to find common ground to accomplish the care plan. The biggest challenge has been in addressing caregivers' denial and conflicting family dynamics that are not helpful to the patient.

Prevention and Mitigation of Behavioral and Psychological Symptoms of Dementia

For the home portion of the program the care coordinator assistants measure cognitive, functional, behavioral, and psychological status of the individual using the self-report and caregiver version of the HABC monitor. The HABC monitors are conducted at every home visit. Based on the responses from the HABC monitor, the care coordinator assistants provide necessary resources and procedures. The information from monitors is transferred to the individual's electronic medical record, which helps in monitoring the results over time. The program staff refer to nonpharmacological interventions to treat the behavioral and psychological symptoms of dementia identified using the HABC monitor. One of these nonpharmacological treatments is cognitive behavioral therapy provided by a team of psychiatrists from Eskenazi Health System who see patients once a week in the clinic portion of the program. The program avoids use of antipsychotic medications for as long as possible. If used, then it is only for a short time and when nonpharmacological therapies have not worked. One challenge has been educating family members about why the program does not advocate using medications for individuals with dementia.

Safety for the Person with Dementia

For the home portion of the program, a home safety evaluation is done on the initial assessment. The care coordinator assistants address safety conversations during the home visits and take note of the condition of the house, such as broken steps, no running water, hoarding, and other safety concerns. The care coordinator assistants refer to community resources to help the patients with safety issues. When safety is an issue, the program may suggest transition to another living arrangement such as an assisted living facility. The program has been successful in helping patients get connected to appropriate community resources. A challenge, in some cases, has been getting the individual and caregiver to listen to the care coordinator assistants' suggestions for modifications. The clinic portion of the program is not involved in providing assistance with safety for the individual with dementia.

Therapeutic Environment, Including Modifications to the Physical and Social Environment of the Person with Dementia

In the home portion of the program, the issues related to the physical and social environment are identified using the HABC monitor. The care coordinator assistants refer to community resources to help individuals with modifications. A challenge, in some cases, has been getting the patient and caregiver to listen to the care coordinator assistant's suggestions for modifications. The clinic portion of the program does not have a specific protocol related to the physical and social environment of the person with dementia.

Care Transitions

For the home portion of the program, protocols require that a nurse go to the individual's home within 72 hours of hospitalization and within a week of emergency room discharge to reconcile medications and to coordinate a post-discharge care plan. If an individual with dementia moves to a long-term care facility, the program staff can provide coaching and education to the caregiver and share information about the individual with the nursing staff of the assisted living facilities.

Referral and Coordination of Care and Services that Match the Needs of the Person with Dementia and Family Caregiver(s) and Collaboration Among Agencies and Providers

The program is dedicated to building relationship with agencies and providers serving the patient population. However, the program does not have specific protocols for referrals, coordination of care, or collaboration among agencies and providers. The program provides options to patients for home health agencies, nursing homes, adult day care, and hospice.

3.4. MIND at Home

3.4.1. Description of Model

MIND at Home is two closely related studies funded by the NIA and CMS. The CMS study is similar to the NIA research project, but includes the provision of the Tailored Activity Program (TAP), when appropriate, and is targeted largely on people dually eligible for Medicare and Medicaid. The program, operated by Johns Hopkins University in Baltimore, Maryland, provides intensive care management and care coordination to people with dementia and their caregivers, with most of the interaction taking place with the caregiver. Reducing transitions to hospitals, nursing homes, and assisted living facilities is an important goal of the project and the studies. The full intervention lasts for 18 months. In May 2016, about 400 persons participated in the program.

The intervention is primarily provided by noncredentialed memory care coordinators, but there is substantial RN involvement, and a geropsychiatrist plays a prominent medical role and is available for consultations. The manualized care coordination protocol consist of four key components: identification of needs and individualized care planning based on the Johns Hopkins Dementia Care Needs Assessment to address unmet needs and to match the priorities and preferences of the patient and family; provision of dementia education and skill-building strategies; coordination, referral, and linkage to services; and care monitoring. Care components are individually tailored to current unmet needs and updated based on emergent needs of participants and caregivers.

Following a detailed assessment by a nurse and a care coordinator, a care plan is developed with the caregiver and the person with dementia. A key component of the program is the use of a computerized resource system that is able to identify resources and recommendations for identified problems. Following the establishment of the care plan, care coordinators work with the caregiver and person with dementia to implement the plan, with most contact being by telephone, mail, and e-mail. In-person meetings can occur at any time, but are built into the protocol at 9 and 18 months.

3.4.2. Dementia Care Framework Components

Detection of Possible Dementia

The program does screening of program applicants to ensure that they meet the cognitive impairment required by the program, that they are live in the catchment area for the project, and that they are looking for the types of services that the project offers. In most cases, it is the caregiver who contacts the program, usually by telephone. Screening of the person with dementia is conducted by telephone by student research assistants using a simple cognitive screening instrument. Once the person with dementia passes the screen and other criteria are met, they will be scheduled for an in-person visit for a full assessment. As of May 13, 2016, of the 1,053 people who have been screened, about half meet the criteria and indicated an interest in participating in the program/study. The most common reason for not participating was “declined/not interested,” which partly reflected lack of interest in participating in a study.

Diagnosis

A formal diagnosis of dementia is not required to participate in the program. At the initial home visit, the physician or nurse will administer the MMSE and other cognitive assessment tests to assess whether the person has dementia. The clinical team will refer the participant to their primary care physician for a more thorough workup or to the Johns Hopkins University memory clinic if there is an unusual presentation of the disease, or if there is a question about the diagnosis. Reportedly, there is a 4-month wait for an appointment at the Johns Hopkins University memory clinic.

Assessment and Ongoing Reassessment

A comprehensive initial assessment of the person with dementia and their caregiver, usually conducted by a nurse and a memory care coordinator, is a key component of MIND at Home program. The initial assessment is completed at the home of the person with dementia and typically takes 2.0-2.5 hours, including signing various study consent forms. The assessment gathers information on sociodemographics, home safety, cognitive status (using the MMSE), the health of the person with dementia and the caregiver, legal concerns, functional status, meaningful activities in their daily routine, caregiver stress, neuropsychiatric status, planning for the dyad, any support they are currently receiving, etc. A physical exam is conducted by the nurse or other medical clinician. There are three categories of needs: unmet, partially met, and met. A

walkthrough the inside and outside of the house is conducted to determine if there are safety issues. Medications are reviewed for both the person with dementia and the caregiver. Challenges in conducting the assessment include “getting in the door and establishing rapport,” bed bugs, presence of firearms, having no place to sit, the presence of pets, allergies, and suspicions of the motives of researchers. The assessment is entered into a computerized form on a laptop. Areas that the caregiver or the assessment team believe should be addressed are checked off on the assessment form. Another full assessment is conducted at 9 months and at the conclusion of the intervention at 18 months.

Care Planning

After the initial assessment, the nurse and memory care coordinator will discuss the person with dementia and caregiver, identify areas that they believe, given the views of the dyad, that need to be addressed, and develop recommendations. In developing their recommendations, they rely heavily on a web-based care management database that contains an actions log and a library of available resources for each need. MIND at Home has extracted the relevant resources to the dementia population and included those in the database. Sources include the Maryland Aging and Disability Resource Center, the Alzheimer’s Association, and legal aid. The available resources include toolkits, tips sheets, and other reading materials addressing the identified problem areas. Common areas identified for action include legal documents, medications, and general health care management, fall risk and home safety, caregiver support, medical workup for a formal diagnosis, assessment of driving capacity, help with the ADLs, and activities to prevent social isolation, such as adult day care. If the team feels the participants need formal services, they will refer them to a provider.

After the care plan is developed, a detailed letter with the recommendations of the care team is sent to the caregiver. There is a fairly general letter template but the team can customize it so that it is personalized and has more specific recommendations. With permission of the person with dementia or their caregiver, a copy of the letter is sent to the primary care physician; the participant is encouraged to review the letter with his or her doctors. Approximately 2 weeks after the initial visit, the care coordinator will visit again to review and discuss the care plan. At that time, the care plan will be revised to meet the priorities, interests, and abilities of the person with dementia and caregiver. At this point, the participants decide on tasks to complete and timelines are established for accomplishing those activities.

Following the initial care planning meeting, follow-up frequency is based on the needs of the person with dementia and the caregiver. Minimum contact is once a month via telephone call or e-mail. If the participant cannot be reached, the care coordinator may send a resource and then follow up. For care coordination purposes, in-person visits average about every 4.5 months. This is not a formal or structured visit but rather guided by the need and circumstances of each case. The goal is to teach the participants and empower them to seek out the available resources and help from other

family members and the community. At the end of the intervention at 18 months, another comprehensive set of recommendations are provided.

Medical Management

Medical management is an important component of the project, with RNs and a geriatric psychiatrist playing important clinic roles, but the project does not provide medical care. One of the main outcomes being tracked is hospitalization rates and transfer to nursing homes. The clinical team and care coordinators teach caregivers to monitor symptoms and behavior changes and to make adjustments to the home environment to avoid falls. The care coordinators try to make sure the person with dementia is getting preventive and general medical care.

The clinical team and care coordinators focus on a variety of issues including:

- Teaching caregivers to recognize infections and urinary tract infections.
- Checking blood pressure, monitoring any swelling of the feet, and watching for pressure sores.
- Ensuring hydration (reportedly, many people with disabilities live in two-story houses with the bathroom on the second floor, leading some people to reduce their liquid intake so that they do not have to negotiate the stairs to use the bathroom).
- Reviewing medications and ensuring appropriate medication adherence.
- Reducing falls by managing the home environment.
- Ensuring that persons with dementia is seen by their primary care physician after hospital discharge.
- Identifying needs for specialty care.

Establishing a connection with the primary care physician is thought to be essential, but is difficult, in part because of time constraints on the part of the doctor. Care coordinators will contact the study physician from the field if there is an urgent issue, such as if the participant or caregiver appears to be suicidal.

The program is exploring telemedicine to increase its clinical reach. This innovation would involve using an iPad with a secure connection to enable the care coordinator in the field to connect with the program physician. Technically, it would be a consultation to the care coordinator and not a medical consultation to the caregiver or person with dementia, but it would provide “another set of eyes” on the person with dementia or his or her caregiver.

Information, Education, and Informed and Supported Decision Making

The program provides educational materials and coaching to the person with dementia and the caregiver. Much of the education takes place by phone, although care coordinators do make some in-person visits. As noted above, the program maintains a database of educational materials, which includes a wide range of resources organized by topics, which the care coordinators can use. The resources include relevant resources from the Alzheimer's Association and other organizations, books, and websites. The care coordinators work with the caregivers and do not just "dump" the material and leave it to the caregivers to learn what to do. The purpose of the information is to help the person with dementia and caregivers to make informed decisions regarding needed care.

Assistance for the Person with Dementia with Daily Functioning and Activities

The assessment identifies people who need help with daily functioning, but the program does not directly provide help with the ADLs, such as eating, bathing, and dressing, or the IADLs, such as help with housekeeping or meal preparation. Memory care coordinators will help connect participants with programs that provide these services. Although Maryland does have a Medicaid home and community-based services waiver that provides these services, the waiting list is reported to be more than a year long and is limited to people who need a nursing home level of care and who meet the financial requirements.

Acknowledgement and Emotional Support for the Person with Dementia

Memory care coordinators involve the person with dementia when possible, but the interactions are primarily by phone with the caregivers.

Involvement, Emotional Support, and Assistance for Family Caregiver(s)

The program works with caregivers to provide them with emotional support. Care coordinators often find that just giving caregivers the opportunity to talk with another person about their problems is helpful. Contact is largely by telephone or e-mail and is part of the process of building trust and relationships with the participants. Care coordinators talk by phone with caregivers at least once a month but the level of contact depends on the needs of the caregiver. If participants are working on important recommendations or addressing a complicated issue, care coordinators and caregivers will talk more often, and it sometimes helps to have another in-person visit.

Prevention and Mitigation of Behavioral and Psychological Symptoms of Dementia

The team addresses behavioral symptoms by conducting an assessment of the problem behavior, how often it occurs, and determining what triggers the behavior. They begin by first trying to rule out any medical problems that may be causing behavior change. Most behavior can be managed by caregivers who are provided appropriate

training. Care coordinators offer coaching and modeling for the problematic behaviors. Care coordinators provide skills training and use available protocols and resources depending on what the problem is. The strategy is to listen to the caregivers as most have no one to talk to and to send written materials, which the caregivers can read when they have time and then follow up with them during the next contact. In addition, for the CMS-funded participants, the TAP, a home-based occupational therapy intervention shown to reduce behavioral symptoms and caregiver burden, is offered (Gitlin et al., 2009).

Safety for the Person with Dementia

The home environment is a major focus of the program because falls are a major cause of hospitalization and transitions to assisted living and nursing homes. During the home assessment, the RNs and care coordinators note if there are safety issues, such as throw rugs or tables on wheels and inadequate lighting. If these hazards exist, the care coordinators will discuss eliminating them with the caregivers.

The program also addresses a variety of other safety issues, including wandering, driving, and kitchen safety. They often recommend medical alert systems and medical identification bracelets for both the caregiver and the person with dementia. In some cases, the presence of guns in the home is a safety issue.

Therapeutic Environment, Including Modifications to the Physical and Social Environment of the Person with Dementia

MIND at Home works with caregivers to make the home setting pleasant to the person with dementia, but as a home-based program, it is not a major focus.

Care Transitions

A major goal of MIND at Home is to reduce transitions to hospitals, nursing homes, and assisted living facilities. In their view, the main controllable factors related to hospitalizations are problems with home safety, including falls, inadequate medication adherence and poor prescribing on the part of physicians, and missing medical appointments (which occurs for a variety of reasons). The program attempts to address all of these by working with the caregivers.

When hospitalization does occur, the program strongly encourages caregivers to notify the program when the person will be coming home. Care coordinators stress to the caregivers the importance of receiving and understanding the discharge orders. Program staff try to make an in-person visit soon after the person with dementia has been discharged from the hospital.

When a transition is needed to a long-term care facility, the entire team helps with the placement process. Once the participant transitions to a long-term care facility, he or she can no longer participate in the program.

Referral and Coordination of Care and Services that Match the Needs of the Person with Dementia and Family Caregiver(s) and Collaboration Among Agencies and Providers

Since MIND at Home does not provide any direct services, it does not explicitly collaborate with other agencies and providers in supplying the care that participants with dementia and their caregivers need. The exceptions are the Jewish Family Services Agency in which the care coordinators are embedded and Johns Hopkins University Home Care where the nurses are embedded; supervisors from those agencies come to the MIND at Home clinical meetings.

MIND at Home refers caregivers to organizations that may be able to provide them with the services they need. Because the program is time-limited (18 months), they attempt to teach caregivers how to locate the services they need on their own. MIND at Home refers to the VA, the Alzheimer's Association, Action in Maturity, Senior Legal Services, Medicaid, Area Agencies on Aging, and several adult day centers. The program developed a Health Provider Directory, which includes all the doctors that participants are seeing or have seen. Similarly, it has built a directory that includes a large number of services, providers, and agencies in the Baltimore area.

3.5. RCI REACH

3.5.1. Description of Model

Rosalynn Carter Institute for Caregiving's (RCI's) Resources for Enhancing Alzheimer's Caregiver Health (REACH) focuses on the overall well-being of family caregivers of people with dementia. RCI is located in Georgia, but the Institute supports REACH programs throughout the United States. REACH began in 1995 as behavioral research based on a number of multicomponent interventions that were designed to enhance family caregiving for Alzheimer's disease and related disorders. The interventions were based on various theories consistent with basic health-stress models, which are designed to recognize or change the stressor or adapt the caregivers' response to the stressor. Results of this first study emphasized the need for further research. REACH II was studied through a randomized control trial and implemented with caregivers of people with dementia. The multicomponent intervention assesses and addresses issues identified by caregivers. Findings of the randomized control trial indicated that caregivers demonstrated improvement in caregiver burden, depression, and management of difficult behaviors, social support and self-care, which created a better environment for care for the care recipient (Easom et al., 2013). The RCI REACH program is based on REACH II.

Caregiver coaches serve as interventionists for the RCI REACH program and meet with caregivers in individualized sessions to provide them with information and techniques to manage their caregiving activities. Caregiver coaches ideally have some

formal education in addition to experience in providing social services or hands-on personal experience with dementia. An essential part of the RCI REACH intervention is the *Dealing with Dementia: A Caregiver's Guide* provided to caregivers. The *Guide* is in the format of a more than 300-page book directed at caregivers and how to work through the various stages of dementia. The *Dealing with Dementia* guide includes resources related to various caregiving topics and is used during sessions and as a reference for caregivers during and after the intervention.

RCI REACH lasts 6 months and consists of 12 individual coaching sessions with the option of three additional sessions, if needed. Of the 12 sessions, up to nine are delivered face to face and up to three are delivered by telephone. At the initial meeting with caregivers, the caregiver coaches collect demographic data and conduct a risk appraisal assessment related to caregiver depression, burden, health, social support, self-efficacy and desire to institutionalize, and any behavioral issues of the person with dementia (Easom et al., 2013). The results of the risk assessment guide the remainder of the intervention sessions with each session focused on assisting the caregiver with an issue identified in the risk assessment. For example, if the risk assessment found that a caregiver was feeling a great deal of stress, the caregiver coach would teach the caregiver stress management and coping skills.

RCI has been working with REACH since 2008 by translating the intervention initially from a clinical trial to replicating and implementing the REACH protocol in various communities. RCI's Training Center for Excellence has provided training on how to administer RCI REACH to more than 20 agencies across the United States. Technical assistance is also offered to agencies implementing RCI REACH through the Training Center for Excellence.

Information for this case study was gathered by reviewing published articles and the RCI website and by conducting phone interviews with staff involved in RCI REACH. In June 2016, RTI staff interviewed key RCI staff who administer the RCI REACH program and staff who work in the RCI REACH program through the Coastal Georgia Regional Commission Area Agency on Aging.

3.5.2. Dementia Care Framework Components

Detection of Possible Dementia

RCI REACH uses the Functional Assessment Staging of Alzheimer's Disease (FAST[®]) Scale to determine a person's stage of dementia. This is the same screening tool that is used to determine if Medicare beneficiaries with dementia are eligible for hospice care. It has been beneficial to RCI REACH to use this tool so they can coach caregivers to consider hospice if the person with dementia is eligible and the service is needed. At times, it has been challenging to use the FAST[®] tool if caregivers do not want to meet in their homes and choose to meet at a public location such as a coffee shop or library. In these instances, the caregiver coaches must solely rely on responses provided by the caregiver to the items included in the FAST[®] tool.

Diagnosis

Although RCI REACH does not directly get involved in the diagnosis of dementia, caregiver coaches encourage caregivers to obtain a formal diagnosis from their primary care physician or neurologist for their care recipient if they do not have one.

Assessment and Ongoing Reassessment

A thorough assessment of persons with dementia is not conducted through RCI REACH. However, the caregiver coach completes an assessment of caregiver risks through a Risk Priority Inventory, which assesses caregiver depression, burden, health, social support, self-efficacy, desire to institutionalize, and behavioral problems (Easom et al., 2013). It also includes a walkthrough of the home environment to assess safety in the home.

Care Planning

Because RCI REACH primarily focuses on the family caregiver, there is no formal care planning process for the person with dementia's care goals and needs. Rather, RCI REACH is designed around five main issues, which are addressed by the coach: safety, caregiver health, problem-solving, caregiver well-being, and social support. As issues arise with any of these components, individualized solutions are developed to assist the caregiver. The coach and caregiver work together to develop strategies to solve the issues, but the caregiver is encouraged to take specific actions on his or her own. This method helps build caregiver confidence.

To address everyday care needs, the caregiver coach will work to identify needed community resources. The coach also will encourage caregivers to develop a daily routine and will assist in finding appropriate activities based on the person with dementia's abilities. The schedule is informal, however, allowing the caregiver to determine when each activity occurs.

Medical Management

RCI REACH does not address medical management issues. However, if medical management is identified as a challenge for caregivers during the Risk Priority Inventory or otherwise during the course of the intervention, the caregiver coach will work with the caregiver to get necessary resources and support. There is also a section on medical management in the *Dealing with Dementia* guide that caregivers can refer to as needed.

Information, Education, and Informed and Supported Decision Making

Caregiver coaches provide information and education to caregivers on an ongoing basis throughout the intervention through the *Dealing with Dementia* guide, videos, webinars, and handouts. All caregivers receive the *Dealing with Dementia* guide, and

during the second visit, all coaches provide a standard explanation on how to use the guide. The guide includes information on many topics related to caregiving for a person with dementia, such as dementia education, care planning, and end-of-life decisions. The caregiver coach provides information on the disease process that is necessary for caregivers to make informed decisions. This includes explaining that dementia is a terminal disease because many caregivers do not fully understand that aspect of the disease process. Caregiver coaches consistently work to help caregivers understand how dementia affects a person's brain and explain that behaviors they observe are the result of the disease. Materials provided to caregivers are tailored to meet their individual needs.

Acknowledgement and Emotional Support for the Person with Dementia

RCI REACH does not directly provide acknowledgement and emotional support for the person with dementia. However, the program indirectly addresses these issues by providing assistance to caregivers, such as helping them reduce stress and manage difficult behaviors and encouraging them to find enjoyable activities for both themselves and the person with dementia. The caregiver coach can also refer the caregiver to the local Area Agency on Aging or other organization to provide support for the care recipient.

Assistance for the Person with Dementia with Daily Functioning and Activities

If the person with dementia's daily functioning and activities is one of the target areas identified by caregivers in the risk appraisal, the caregiver coach will work with the caregiver to determine strategies to address these issues. Strategies may come from the *Dealing with Dementia* guide, which includes a chapter on finding activities suitable for the care recipient. Caregiver coaches can refer caregivers to the local Aging and Disability Resource Center or other organizations for assistance. Some caregivers find it difficult to follow through with activities agreed upon with the caregiver coach. In those cases the caregiver coach will work with the caregiver to modify the activities or find coping strategies to assist the caregiver.

Involvement, Emotional Support, and Assistance for Family Caregiver(s)

Inclusion of caregivers is the foundation of RCI REACH, and the provision of emotional support for the caregiver is emphasized throughout the program. The process of the caregiver working with the coach to identify areas of concern and developing solutions empowers caregivers. As noted above, in addition to sessions being focused on caregivers, *Dealing with Dementia: A Caregiver's Guide* is provided to all RCI REACH caregiver participants. Because caregivers can be overwhelmed by their role or unable to focus on the coaching process, it can be challenging to complete the full intervention protocol and, at times, caregiver coaches have difficulties building rapport with the caregiver participants. Despite these challenges, RCI REACH has been shown to reduce caregiver depression and burden, and improve caregiver self-efficacy and self-reported health (Easom et al., 2013).

In addition, the caregiver coaches focus on encouraging and praising the actions of caregivers and providing them the support necessary to maintain emotional stability. Although it can be a challenge, the caregiver coach works with caregivers on strategies for dealing with their personal feelings. The caregiver coach also encourages caregivers to attend support groups, teaches problem-solving skills, provides necessary resources, and ensures that caregivers take care of themselves.

Prevention and Mitigation of Behavioral and Psychological Symptoms of Dementia

Caregivers are trained on a nine-step problem-solving process to assist them in addressing behavioral and psychological symptoms of dementia. If the caregiver coach believes medications may be contributing to behavioral or psychological symptoms, he or she will encourage the caregiver to consult with the care recipient's physician about the issues.

Safety for the Person with Dementia

The initial Risk Priority Inventory includes a home safety assessment. The assessment examines issues such as wandering, presence of firearms in the home, and suicide. If safety risks are identified, the caregiver coach provides caregivers with strategies to manage the safety risks. In some cases, caregiver coaches need to convince caregivers to be proactive to avoid a major crisis.

Therapeutic Environment, Including Modifications to the Physical and Social Environment of the Person with Dementia

The caregiver coach will work with the caregiver to address environmental issues if they arise. Strategies such as using labels around the home, handrails and grab bars, and locks on the doors and windows are suggested if needed. Caregiver coaches share ideas and help each other during bimonthly staff meetings.

Care Transitions

RCI REACH does not explicitly address care transitions, but information on care transitions is included in the *Dealing with Dementia* guide for caregivers to refer to.

Referral and Coordination of Care and Services that Match the Needs of the Person with Dementia and Family Caregiver(s) and Collaboration Among Agencies and Providers

RCI REACH does not have a formal referral and coordination of care protocol. However, caregiver coaches, through their experience and knowledge of the local aging network, can provide caregivers with information for needed resources and services. For example, one RCI REACH program is managed through an Area Agency on Aging. All caregivers in the program are screened by the Area Agency on Aging staff who

place them on waitlists for services or make referrals to other resources as needed. RCI REACH does not explicitly collaborate with other agencies and providers.

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4. CONCLUSION

A growing number of programs to help persons with dementia and their family caregivers are being developed, tested, and implemented in the United States. To learn more about whether and how a sample of these programs are meeting practice standards, the Examining Models of Dementia Care project team identified 14 components of dementia care and conducted site visits to assess implementation of the components by selected programs.

The dementia care components were identified through a detailed analysis of 37 existing clinical guidelines and practice recommendation documents. Some of these guidelines and practice recommendation documents were developed by and focus on dementia care practices of specific professional groups (e.g., neurologists, psychologists, occupational therapists). Other guidelines and practice recommendation documents focus on dementia care in particular settings (e.g., home care, residential care, primary care). Still other guidelines and practice recommendation documents focus on dementia care for persons in various stages of the condition, most frequently late-stage dementia.

The 14 identified components differ from most of the clinical guidelines and practice recommendation documents in that they encompass aspects of care for people in all stages of dementia and their families, in multiple care settings, from home to nursing home and medical care settings, and provided by a wide array of medical, social, and allied health care professionals, paraprofessionals, and direct care workers. The project postulated that most of the activities required to address the components could be performed by various types of trained professional, paraprofessional, and direct care workers. An exception to this assumption is medical management activities that can only be performed by a physician or other medical care provider who is authorized to perform them under state law and regulations for particular public programs and settings (e.g., prescribing medications).

Five dementia care programs were selected for site visits from more than 50 possible programs. With only five programs, it is not possible to represent the full array of existing programs to help persons with dementia and their family caregivers. Nevertheless, the five programs were chosen to represent various program settings and ways of implementing the 14 identified dementia care components.

One of the five programs was based in a medical clinic, one program was based in a residential care setting, and three programs were based in community agencies. The five programs were:

- BRI Care Consultation™ in Cleveland, Ohio;
- Comfort Matters™ in Phoenix, Arizona;

- Healthy Aging Brain Center in Indianapolis, Indiana;
- MIND at Home in Baltimore, Maryland; and
- RCI REACH, in Americus, Georgia.

In-person site visits were conducted for four of the programs and telephone interviews were conducted for one program because of the travel distances involved. The purpose of the site visits was to examine how the programs were addressing each of the care components. Structured discussion guides were prepared for each site visit. As a result of the site visit experience, project team members also learned about perspectives of program administrators and other staff at the program sites about real-world implementation of their programs.

Despite the small sample of dementia care programs examined, the site visits resulted in useful findings about whether and how the programs were addressing the 14 components. This included noting similarities and differences in how they were interacting with persons with dementia and family caregivers, and perceptions and observations of program administrators and other staff, some of which cannot be found in the published literature.

Findings from the site visits include the following:

- **None of the five programs had procedures in place to detect possible dementia in general populations.**

The five programs were all working with persons whose possible dementia had been detected by someone before they and their family caregivers entered the program. None of the programs were attempting to identify people with possible dementia in general populations, such as all patients of a particular physician or physician practice or all enrollees in a particular health plan. Individuals with dementia and family caregivers were usually referred to the programs by health care or social service professionals or other service providers who had detected signs and symptoms of possible dementia, although some were self-referred or referred by a family member who was aware of their possible dementia.

Some program administrators and staff responded to questions about the detection of possible dementia by noting brief mental status tests they use to decide whether a person with possible dementia who has been referred to the program meets its entry requirements or to determine stage of dementia. These tests result in valuable information for the program. The programs do not, however, use the tests or any other methods of detection in general populations to identify persons with possible dementia who could benefit from the programs.

- **None of the five programs directly addressed all 14 components, but most of the programs addressed most of the components. Program administrators indicated that some of the components are out of the scope of their program.**

As expected, none of the five programs addressed all the components. Nevertheless, most of the programs addressed most of the components. Some components, including assessment, care planning, and safety for the person with dementia, were addressed by all five programs, although the programs differed in the ways they addressed these and each of the other components.

During the site visits, the program administrators and staff acknowledged the importance of all the components. When asked whether they address each of the components in their program, however, they generally responded that some components were outside the scope of the program or were not a major focus. When asked explicitly about barriers they face in addressing the components, they talked most often about challenges they encounter in implementing the components already included in their programs.

These responses suggest that inclusion or exclusion of particular components is probably intentional, reflecting not only limitations due to staffing and resources but also commitment to a specific model or set of components they believe will reduce the problems in dementia care that concern them most. Some of the problems the program administrators and staff talked about trying to solve with their programs include the pervasive lack of assistance for the specific needs of people with dementia, the lack of individualized information, education, and skills training that can increase family caregivers' self-confidence and effectiveness in their caregiving role, and the lack of high-quality, comfort-focused care for persons with advanced dementia.

- **The five programs used at least three ways to address the components: direct provision of the needed assistance; referral to another agency or individual that could provide the needed assistance; and information, education, skills training, and encouragement to help family caregivers provide the needed assistance.**

Although programs that furnish various kinds of assistance are often described as either providing or referring *for* the assistance, dementia care programs frequently furnish assistance in a third way: information, education, skills training, and encouragement for the family caregiver who may then be more able to provide the needed assistance. Findings from the site visits conducted for this project indicate that this third way of addressing the components was used at least as often as either of the other two ways (direct provision and referral). One example is the way the four programs working with community-living persons with dementia addressed prevention and mitigation of behavioral and psychological symptoms of dementia. All four programs used information about particular symptoms, education about recommended approaches, skills training to practice the approaches, and encouragement for family caregivers to help the caregivers prevent or reduce the symptoms. This third way of addressing the

components, referred to as “coaching” in at least two of the programs, was also being used for many of the other components.

The program administrators and staff interviewed in the site visits talked less frequently about referral to other agencies than about the other two ways of addressing the components. Moreover, when they did talk about referral, they often emphasized that it is only an effective option if accessible sources of the needed assistance are in the person’s community. They pointed out that waiting lists are often long for assistance paid by public and philanthropic sources and that many persons with dementia and their families cannot afford to pay privately for the kinds of assistance they need.

- **All five programs conducted assessment, reassessment, and care planning activities that facilitated the provision of individualized, person-centered care.**

Although person-centeredness is a desired attribute of high-quality dementia care, only one of the 37 clinical guideline and practice recommendation documents reviewed for this project focuses explicitly on person-centeredness. During the project site visits, however, program administrators and staff stressed the importance of person-centeredness. Their comments indicate that person-centeredness begins in the programs’ assessment, ongoing reassessment, and care planning activities. Through these activities, the programs identify the unique characteristics, unmet needs, and care preferences of the person with dementia and the family caregiver and develop individualized care plans to address the identified needs.

The programs then reassess formally and informally, on an ongoing basis, to determine whether the original needs have been met and other needs have developed. Implementation of other components can be considered person-centered to the extent that it reflects information about the unique characteristics, unmet needs, and preferences of the person with dementia and the family caregiver that are obtained through the programs’ assessment, reassessment, and care planning activities. Thus, for example, person-centeredness would mean that the information, education, skills training, and encouragement provided for the family caregiver to help the caregiver prevent or reduce behavioral and psychological symptoms of dementia are specifically targeted to the symptoms identified by the caregiver during the assessment and reassessment processes.

- **There are similarities and differences in exactly how the programs interacted with persons with dementia and family caregivers.**

All five programs interacted directly with family caregivers. One program only interacted directly with the family caregiver and did not interact with the person with dementia. Three programs interacted directly with the family caregiver and

the person with dementia to a lesser degree, and one program interacted directly with the person with dementia and the family caregiver to a lesser degree.

Four programs included in-person interactions with the family caregiver, and three programs included in-person interactions with the person with dementia. All five programs included telephone interactions with the family caregiver, and one program routinely included telephone interactions with persons with dementia who are able to respond. All five programs also used e-mail and regular mail to communicate with family caregivers, and three programs included home visits.

- **Programs with physicians or other PCPs on staff were able to provide diagnostic evaluations leading to a formal diagnosis of dementia. Other programs were able to refer for diagnostic evaluations, but a formal diagnosis was not a prerequisite for participation in any of the programs.**

Program administrators and staff described how persons with possible dementia who did not have a formal diagnosis could receive or be referred for diagnostic evaluation. Three programs had physicians or other PCPs on staff who could provide diagnostic evaluation. The other two programs could refer persons with dementia who did not have a formal diagnosis to their own PCP for diagnostic evaluation.

Despite these responses about how the programs could provide or refer persons with possible dementia for diagnostic evaluation, the programs do not always require a formal diagnosis of dementia for the persons served in their programs. Rather, at least in some cases, they counsel the person with dementia and family caregiver to obtain a formal diagnosis and offer to provide a diagnostic evaluation or refer the person and family caregiver to a physician or other PCP who can provide such evaluation.

- **All five programs provided assessment and ongoing reassessment, but the assessment instruments and procedures they used vary.**

Some of the programs used highly structured assessment instruments, and others used less structured instruments. Either way, the program assessments and reassessments were intended to obtain information about a wide array of personal characteristics, needs, concerns, problems, care preferences, and the available social supports and other resources of the person with dementia and the family caregiver. Some of the programs also included mental status tests, nursing, dietary and social work assessments, medical records and medication reviews, physical exams, and home safety inspections.

Some of the programs conducted assessments and reassessments in person, some conducted assessments and reassessments on the phone, and some used both methods. Most of the programs conducted assessments and reassessments directly with the person with dementia when the person was able

to respond. In contrast, one program always conducted assessments and reassessments with the family caregivers, who were asked questions about themselves and the persons with dementia.

The assessments and reassessments used by the programs are generally intended to identify problems, strengths, and topics of high concern to the person with dementia or the family caregiver. At least two of the programs incorporate trigger questions about various topics that can be followed by additional questions if a trigger question elicits a response from the person with dementia or family caregiver that suggests concerns or problems.

Assessment was not a one-time activity for any of the programs. Some programs took more than one visit or call to complete the initial assessment. As previously noted, all programs reassessed formally and informally, on an ongoing basis, to determine whether the original needs, concerns, and problems had been resolved and whether other needs had developed.

- **Some of the programs provided medical management, and others did not.**

Comfort Matters™, MIND at Home, and the Healthy Aging Brain Center attended to some medical issues, in part because they had physicians and nurses on staff. Program administrators and staff for the other two programs referred persons with dementia and their family caregivers to their primary care physician or another medical care provider if they suspected a medical problem.

- **All five programs had assembled information on many relevant topics to educate persons with dementia and family caregivers and support informed decision making.**

All of the programs had information on many topics in print, online, on video, and in other formats. This information was used by the program staff to help persons with dementia and family caregivers understand various aspects of the person's condition, available medications, functioning, and behaviors. The programs also had information in all these formats to help family caregivers understand their own physical, functional, and other reactions to caregiving and to reduce risks to their own health. Much of this information is generally available to all people with dementia, family caregivers, and the public. The distinctive factor for all five programs is that they used their assembled information to select the information about topics and formats that are most relevant and appropriate for particular persons with dementia and family caregivers. Although some of the information was specific to the geographic area in which the program was located, there appeared to be a substantial duplication of effort across programs.

- **The four programs that were working with community-living people with dementia and their family caregivers interacted less often and less directly with persons with dementia than with family caregivers.**

The two components, acknowledgement and emotional support for the person with dementia and assistance with daily functioning and activities for the person with dementia, call attention to several kinds of program activities that imply direct interaction with persons with dementia. Assistance with daily functioning, including personal care and ADLs, clearly involves direct interaction with the person with dementia, but the four programs that were working with community-living people with dementia and their family caregivers did not provide this kind of assistance. Instead, they provided information, education, skills training, and encouragement to help the family caregiver provide the assistance or referred the family caregiver to other agencies and individuals that may provide the assistance. Acknowledgement, emotional support, and assistance with activities could, in theory, be provided in direct interactions with the person with dementia without going through the family caregiver.

By design, one program, RCI REACH, had no direct interaction with persons with dementia. Program directors and staff of the three other programs that work with community-living people with dementia and their families described different amounts of direct interaction to provide acknowledgement, emotional support, and assistance with activities for persons with dementia. They also provided little detail about this kind of direct interaction. The program administrators and staff for two of the three programs said they work directly with persons with dementia “when possible,” thus indicating one important barrier to direct interaction to provide acknowledgement, emotional support, and assistance with activities for persons with dementia.

- **At least two of the five programs have been disseminated to other sites across the country.**

Program administrators and staff were not asked directly about whether their programs have been disseminated to other sites, but comments of program administrators and staff for two programs, BRI Care Consultation™ and RCI REACH, said that their programs have been disseminated to 20 or more sites across the country. These program administrators and staff also said they were providing staff training at the other sites. The program developer for BRI Care Consultation™ said his agency is licensing the other sites that are replicating that program and providing ongoing consultation, refresher training, and fidelity monitoring for those sites. The site visit for BRI Care Consultation™ included interviews with staff at four sites that are replicating the BRI Care Consultation™ program.

4.1. Possible Next Steps

Possible next steps to increase understanding about whether and how existing dementia care programs are meeting best practice standards could include using the 14

components developed for this project to assess additional programs. Information from additional programs would add to the findings from this project and allow comparisons among more programs about how particular components can be and are being implemented.

Other possible next steps could address two issues described in the preceding bullets: (1) that none of the five dementia care programs selected for this project had procedures in place to detect possible dementia in general populations; and (2) that the four programs working with community-living persons with dementia and their family caregivers were interacting less often and less directly with persons with dementia than with family caregivers, including identifying the need for direct interactions to provide acknowledgement, emotional support, and assistance with activities for the person with dementia.

Lack of procedures to detect possible dementia in general populations is an important issue because people with possible dementia whose condition is not detected are unlikely to be enrolled in dementia care programs that are intended to help them, including the five programs included in this project. Identification of barriers to detection of possible dementia and development of new programs or additions to existing programs to address this component of dementia care would benefit these people and their family caregivers. Identification of barriers to direct interactions with persons with dementia to provide acknowledgement, emotional support, and assistance with activities and development of new programs or additions to existing programs to increase such interactions would likewise benefit people with dementia and, in turn, their family caregivers.

APPENDIX A-1. GUIDELINE STANDARDS, BY CATEGORY

Category	Guidelines
1. Detection of possible dementia	<p>Dementia Care Practice Recommendations for Professionals Working in a Home Setting (Alzheimer's Association, 2009)</p> <ul style="list-style-type: none"> • Direct care providers need training not only to recognize the signs of early dementia but also to understand when and how to communicate changes to supervisors, discuss observations with the home care team, or consult with an external expert. • Families can also benefit from education about the warning signs. Family caregivers who witness signs of dementia should be referred to a physician or other qualified practitioner.
	<p>Geriatric Emergency Department Guidelines: Delirium and Dementia in the Geriatric Emergency Department (American College of Emergency Physicians, 2013)</p> <ul style="list-style-type: none"> • Validated screening tools will be used to identify patients presenting with dementia and delirium. • An assessment for dementia should be conducted after delirium screening.
	<p>Dementia in the Long-Term Care Setting (American Medical Directors Association, 2012)</p> <ul style="list-style-type: none"> • Review available information about the patient's recent or past physical, functional, cognitive, and behavioral status. Look for previous diagnoses in which dementia is a key symptom. • Check current medical orders for medications that can alter cognitive function (e.g., antiarrhythmics, opioids, hypnotics, psychotropics, sedatives, medications with significant anticholinergic properties). Also ask about the use of over-the-counter medications or herbal preparations that may affect cognitive function. • Search for evidence of specific impairments or symptoms (e.g., neurological or behavior symptoms) that may suggest underlying dementia. • Professional staff should observe the patient's current physical, functional, and psychosocial status.
	<p>Guidelines for the Evaluation of Dementia and Age-Related Cognitive Change (American Psychological Association, 2012)</p> <ul style="list-style-type: none"> • Psychologists conducting evaluations of dementia and age-related cognitive change: <ul style="list-style-type: none"> – Are aware of and attempt to reduce or eliminate the effects of cultural perspectives, personal and societal biases, and tests that are inappropriate for an individual on the diagnostic evaluation.
	<p>Cognitive Impairment: Recognition, Diagnosis and Management in Primary Care (British Columbia Ministry of Health, 2014)</p> <ul style="list-style-type: none"> • Do not screen asymptomatic population for cognitive impairment. • Suspect cognitive impairment when there is functional decline and work in usual activities. • Communication difficulties, cultural factors, low education and literacy impact formal cognitive screening, with poor inter-rater reliability. Use interpreter services to assist in more accurate patient screening and assessment.
	<p>Clinical Practice Guideline for Dementia. Part I: Diagnosis and Evaluation (Clinical Research Center for Dementia of South Korea, 2011)</p> <ul style="list-style-type: none"> • Medical intervention aimed at early detection and prevention of dementia should be implemented as a 5 year delay in the onset of dementia is known to cut the prevalence by half. • Periodic and continuous medical intervention alert to any changes in the cognitive function in the ADLs performance should be implemented in patients with suspected mild cognitive impairment.
	<p>Alzheimer's Association Recommendations for Operationalizing the Detection of Cognitive Impairment during the Medicare Annual Wellness Visit in a Primary Care Setting (Cordell et al., 2013)</p> <ul style="list-style-type: none"> • Detection of cognitive impairment is a stepwise, iterative process. • Informal observation alone by a physician is not sufficient without a specific cognitive evaluation. • Detection of cognitive impairment can be enhanced by specifically asking about changes in memory, language, and the ability to complete routine tasks. • Although no single tool is recognized as the "gold standard" for detection of cognitive impairment, and initial structured assessment should provide either a baseline for cognitive surveillance or a trigger for further evaluation. • Clinical staff can offer valuable observations of cognitive and functional changes in patients who are seen over time. • Informants (family member, caregiver, etc.) can provide valuable information about the presence of a change in cognition.

Category	Guidelines
1. (continued)	<p>Recognition and Management of Dementia (Fletcher, 2012)</p> <ul style="list-style-type: none"> No formal recommendations for cognitive screening are indicated in asymptomatic individuals. Clinicians are advised to be alert for cognitive and functional decline in older adults to detect dementia and dementia-like presentation in early stages.
	<p>Report and Recommendations (Gerontological Society of America Workgroup on Cognitive Impairment Detection and Earlier Diagnosis, 2015)</p> <ul style="list-style-type: none"> PCPs should routinely ask Medicare beneficiaries about any changes in memory or cognition; they should use their clinical judgment and observational skills to determine whether such changes have occurred. PCPs should use the Medicare Annual Wellness Visit as an opportunity to initiate and continue a discussion with beneficiaries and families about memory-related signs and symptoms. The workgroup did not endorse the use of any specific risk factors for dementia (e.g., attainment of any specific age that would automatically trigger a conversation about cognition). When falls and gait disorders occur in primary care patients, PCPs could use these events to trigger for a conversation about cognition. PCPs should routinely use an evidence-based assessment tool to detect cognitive impairment in 3 groups of Medicare beneficiaries: (1) those who report concerns about their memory or cognition; (2) those whose family members, friends, or other caregivers report concerns about the beneficiary's memory or cognition; and (3) those with observable clinical signs and symptoms of cognitive impairment. PCPs should document in the person's medical record the results of the assessment process and the assessment tool used. PCPs could use 1 of the 12 assessment tools identified by an NIA working group and an Alzheimer's Association working group.
	<p>Dementia: A NICE-SCIE Guideline on Supporting People with Dementia and Their Carers in Health and Social Care (National Institute for Health and Clinical Excellence, 2007)</p> <ul style="list-style-type: none"> Memory assessment services (which may be provided by a memory assessment clinic or by community mental health teams) should be the single point of referral for all people with a possible diagnosis of dementia. Primary health care staff should consider referring people who show signs of mild cognitive impairment for assessment by memory assessment services to aid early identification of dementia, because more than 50% of people with mild cognitive impairment later developed dementia. A basic dementia screen should be performed at the time of presentation, usually within primary care.
	<p>Dementia. Diagnosis and Treatment (Regional Health Council, 2011)</p> <ul style="list-style-type: none"> The general practitioner knows the cognitive behavioral profile of his/her patients and can identify the clinical signs of cognitive decay at their onset, taking also into account the observations of relatives. The general practitioner should assess the presence of symptoms of depression in case of cognitive behavioral alterations. Delirium can be suspected in subjects presenting a clinical/behavioral profile similar to the one described by diagnostic criteria.
	<p>Caregiving Strategies for Older Adults with Delirium, Dementia and Depression 2010 Supplement (Registered Nurses' Association of Ontario, 2010)</p> <ul style="list-style-type: none"> Nurses should maintain a high index of suspicion for the prevention, early recognition, and urgent treatment of delirium to support positive outcomes. Nurses should initiate standardized screening methods to identify risk factors for delirium on initial and ongoing assessments. Nurses should maintain a high index of suspicion for the early symptoms of dementia to initiate appropriate assessments and facilitate individualized care. Nurses should maintain a high index of suspicion for early recognition/early treatment of depression to facilitate support and individualized care.
	<p>Third Canadian Consensus Conference on Diagnosis and Treatment of Dementia (2007)</p> <ul style="list-style-type: none"> Physicians should be aware that most dementias may be preceded by a recognizable phase of mild cognitive decline. Physicians should closely monitor individuals who have mild cognitive impairment or cognitive impairment without dementia because of the known increased risk of both dementia and death. In cases where there is suspicion of cognitive impairment or concern about the patient's cognitive status, and the MMSE score is in the "normal" range, other cognitive assessment instruments could be administered to help demonstrate objective cognitive loss.

Category	Guidelines
2. Diagnosis	<p>Dementia in the Long-Term Care Setting (American Medical Directors Association, 2012)</p> <ul style="list-style-type: none"> • Assess the patient's cognition, mood, and behavior using a validated tool, such as the MDS 3.0 instrument. • Decide if further workup is useful and appropriate. • Evaluate if the patient meets the criteria for a diagnosis of dementia. • Consider consultation with appropriate specialists for neuropsychiatric evaluation and testing if basic workup and testing do not enable adequate assessment of the patient's conditions, identification of the causes of the patient's symptoms, or proper management. Formal neuropsychological testing may also be helpful when the results of screening tests are inconsistent with clinical observations of the degree and type of cognitive impairment. Neuropsychological testing also has the benefit of being able to identify the patient's cognitive assets and weaknesses. <p>Guidelines for the Evaluation of Dementia and Age-Related Cognitive Change (American Psychological Association, 2012)</p> <ul style="list-style-type: none"> • Psychologists conducting evaluations of dementia and age-related cognitive change: <ul style="list-style-type: none"> – Know the prevailing diagnostic nomenclature and specific diagnostic criteria. – Are familiar with the broad range of psychological and medical conditions that can affect an individual's cognitive status and are able to differentiate between psychiatrically related cognitive impairment and mood changes that sometimes signal the onset of dementia. – Are aware of the challenge of informed consent in dementia evaluations and know feasible, ethical options for obtaining informed consent. – Are aware of complex issues that arise during dementia evaluation, e.g., multiple medical comorbidities, medication side effects, genetic and heritability issues, abuse or neglect, issues regarding legal competence or guardianship, conflicting or unclear assessment results, and families divided by the potential diagnosis; they consult with a wide array of other professionals to understand these issues, and refer persons with possible dementia to these other professionals to support availability and integration of the full range of information to inform decisions about diagnosis, level of severity, and treatment plan. – Are aware of and attempt to reduce or eliminate the effects of cultural perspectives, personal and societal biases, and tests that are inappropriate for an individual on the diagnostic evaluation. – Attempt to obtain all medical records and other relevant information to support the diagnostic evaluation, recognizing that persons with dementia may not be able to provide accurate information. – Conduct a clinical interview with the person with possible dementia as part of the evaluation and obtain corroboration from knowledgeable informants. – Use standardized psychological and neuropsychological tests that measure multiple cognitive domains as part of the evaluation. – Recognize that technology-assisted assessments are advancing but still lack necessary norms and data on psychometric properties. – Recognize the need to estimate premorbid abilities to determine whether the decline from a previously higher level of cognitive function (which is required for a diagnosis of dementia) has occurred. – Recognize that there are multiple sources of variability and error in psychometric performance of tests and diagnostic decision making and are appropriately qualifying their judgments and conclusions. <p>Cognitive Impairment: Recognition, Diagnosis and Management in Primary Care (British Columbia Ministry of Health, 2014)</p> <ul style="list-style-type: none"> • Conduct a complete medical history including a comprehensive review of medications (including over-the-counter and alternative medications). • Encourage patient to allow collateral information to be obtained from family and caregivers to assist with diagnosis. • Rule out/treat remediable contributory causes of cognitive impairment such as delirium and depression, hyponatremia, thyroid disorders, alcohol dependence, adverse drug effects and polypharmacy and comorbid diseases. • When contributory causes have been ruled out or treated and cognitive impairment persists, suspect mild cognitive impairment or dementia. • When available, consider referral to secondary services for the following: diagnostic uncertainty or atypical features; rapid decline in cognition; under 65 years of age; management issues that are difficult to resolve; risk of harm to self or others.

Category	Guidelines
2. (continued)	<p>Redesigning Systems of Care for Older Adults with Alzheimer's Disease (Callahan et al., 2014)</p> <ul style="list-style-type: none"> • Make a formal diagnosis using a standardized instrument and with input from a family member. • Consider referral to a specialty memory care practice. • Evaluate the patient for treatable causes of cognitive impairment or excess disability. <p>Discuss the diagnosis, progression, treatment choices, and goals of Alzheimer's disease care with the patient and family in a manner consistent with their values, preferences, culture, educational level, and patient's abilities.</p> <p>Clinical Practice Guideline for Dementia. Part I: Diagnosis and Evaluation (Clinical Research Center for Dementia of South Korea, 2011)</p> <ul style="list-style-type: none"> • Diagnosis of dementia should be made through a comprehensive assessment that includes but is not limited to the following: history taking, physical and neurological examinations; evaluation of cognitive function and mental state using a standardized neuropsychological examination; assessment of ADLs; brain imaging; and laboratory tests. • History taking in patients with dementia should obtain sufficient information that includes the following: the time of onset, the pattern of progression, cognitive impairment, and behavioral changes; behavioral and psychological symptoms of dementia from a mental state examination; interviews of reliable informants. • Cognitive assessment should involve a brief cognitive test in a more detailed neuropsychological battery. • ADL impairment is an essential part of the diagnostic criteria for dementia and should be included in the diagnostic evaluation. • Laboratory tests of dementia should be aimed at assessing medical states that could affect cognitive functioning or become the primary cause of dementia. • Structural and functional brain imaging should be performed for the diagnosis of dementia. <p>Alzheimer's Association Recommendations for Operationalizing the Detection of Cognitive Impairment during the Medicare Annual Wellness Visit in a Primary Care Setting (Cordell et al., 2013)</p> <ul style="list-style-type: none"> • Components of a full dementia evaluation can vary depending on the presentation including tests to rule in or out the various causes of cognitive impairment and establish its severity. • Diagnostic evaluations include a complete medical history; assessment of multiple cognitive domains, including episodic memory, executive function, attention, language, and visual-spatial skills; neurologic exam; ADL and IADL functioning; assessment for depression; and review for medications that may adversely affect cognition. • Standard laboratory tests include TSH, complete blood count, serum B-12, folate, complete metabolic panel, and, if the patient is at risk, testing for sexually transmitted diseases. • Structural brain imaging, including MRI or CT, is a supplemental aid in the differential diagnosis of dementia, especially if neurologic physical exam findings are noted. • An MRI or CT can be especially informative in the following cases: dementia that is of recent onset and is rapidly progressing; younger onset dementia; history of head trauma; or neurologic symptoms suggesting focal disease. • Informants (family member, caregiver, etc.) can provide valuable information about the presence of a change in cognition. <p>Clinical Practice Guideline on the Comprehensive Care of People with Alzheimer's Disease and Other Dementias (De Sanidad, 2014)</p> <ul style="list-style-type: none"> • Obtaining data from an independent and reliable informant is recommended. • The execution of a general physical and neurological examination of patients with dementia is recommended to detect comorbidity and associated neurological signs that may help towards the differential diagnosis of some subtypes of dementia. • Neuropsychological testing: patients with cognitive complaints must be assessed by means of global cognition screen tests, neuropsychological test batteries, short cognitive instruments focused on specific aspects of cognition or standardized structured questionnaires to quantify the degree of cognitive impairment. The dementia diagnosis must include a formal objective cognitive assessment with validated instruments. The choice of a specific instrument must be made depending on the time available, on the clinical experience and on the availability of regulatory data in the language and in the medium where they will be applied. • Cerebrospinal fluid analysis must always be performed whenever dementia secondary to an infection or encephalitic process is suspected. • MRI is recommended to detect vascular changes with greater sensitivity than CT. • Genetic analyses: In patients with prion diseases, a genetic study would be indicated in all cases, regardless of family history or age. A genetic study is also recommended if Huntington's disease is suspected, to confirm the diagnosis. <p>Recognition and Management of Dementia (Fletcher, 2012)</p> <ul style="list-style-type: none"> • When the diagnosis remains unclear, the patient may be referred for more extensive screening and neuropsychological testing, which might provide more direction and support for the patient and caregivers. • Laboratory tests are valuable in differentiating irreversible from reversible forms of dementia.

Category	Guidelines
2. (continued)	<p>Report and Recommendations (Gerontological Society of America Workgroup on Cognitive Impairment Detection and Earlier Diagnosis, 2015)</p> <ul style="list-style-type: none"> • PCPs should evaluate with a full diagnostic assessment if cognitive impairment is detected. • PCPs should rule out reversible, physiological causes of cognitive impairment as described in published clinical practice guidelines. • Qualified PCPs should conduct a full diagnostic evaluation as described in published clinical practice guidelines. • PCPs who are unfamiliar with a full dementia diagnostic evaluation should refer the patient to a clinical specialist or specialty team. <p>EFNS Guidelines for the Diagnosis and Management of Alzheimer’s Disease (Hort et al. & European Federation of Neurological Sciences Scientist Panel on Dementia, 2010)</p> <ul style="list-style-type: none"> • A neurological and physical examination should be performed on all patients with dementia. • ADLs impairment because of cognitive decline is an essential part of the diagnostic criteria for dementia and should be assessed in the diagnostic evaluation. • Cognitive assessment should be performed in all patients. Quantitative neuropsychological testing should be made in patients with questionable or very early Alzheimer’s disease. The assessment of cognitive functions should include a general cognitive measure and more detailed testing of the main cognitive domains, and in particular an assessment of delayed recall. In patients with moderate memory impairment cued recall could be more appropriate than free recall. • CT and MRI may be used to exclude treatable causes of dementia. • EEG is recommended in differential diagnosis of atypical clinical presentations of Alzheimer’s disease. • Routine cerebrospinal fluid analysis is recommended in differential diagnosis for atypical clinical presentations of Alzheimer’s disease. • Screening for known pathogenic mutations can be undertaken in patients with appropriate phenotype or a family history of an autosomal dominant dementia. Routine genotyping is not recommended. <p>Fourth Canadian Consensus Conference on the Diagnosis and Treatment of Dementia: Recommendations for Family Physicians (Moore et al., 2014)</p> <ul style="list-style-type: none"> • All patients with early-onset dementia (before age 65) should be referred to a memory clinic, preferably one with access to genetic counseling and testing. • After exclusion of delirium, persons with rapidly progressive dementia should be referred to physicians who are experienced with the condition and are able to provide an organized and comprehensive diagnostic process. <p>Dementia: A NICE-SCIE Guideline on Supporting People with Dementia and Their Carers in Health and Social Care (National Institute for Health and Clinical Excellence, 2007)</p> <ul style="list-style-type: none"> • A diagnosis of dementia should be made only after a comprehensive assessment, which should include: history taking, cognitive and mental state examination, physical examination and other appropriate investigations, a review of medications to identify and minimize use of drugs, including over-the-counter products that may adversely affect cognitive functioning. • The experience of the diagnosis of dementia is challenging both for people with dementia and family members and for health care professionals, so health care professionals should make time available to discuss the diagnosis and its implications with the person with dementia and also with family members. Health care professionals should be aware that people with dementia and family members may need ongoing support to cope with the difficulties presented by the diagnosis. • Following a diagnosis of dementia, health and social care professionals should, unless a person with dementia clearly indicates to the contrary, provide them and their family with written information about: the signs and symptoms of dementia, the course and prognosis of the condition, treatments, local care and support services, support groups, sources of financial and legal advice and advocacy, medical legal issues, including driving, local information sources, including libraries and voluntary organizations. Any advice and information given should be recorded in the notes.

Category	Guidelines
2. (continued)	<p>American Psychiatric Association Practice Guideline for the Treatment of Patients with Alzheimer's Disease and Other Dementias (Rabins et al., 2007)</p> <ul style="list-style-type: none"> • Perform a diagnostic evaluation and refer the patient for any needed general medical care. Patients with dementia should undergo a thorough diagnostic evaluation aimed at identifying the specific etiology of the dementia syndrome, because knowledge of the etiology may guide specific treatment decisions. In addition, evaluation should determine if any treatable psychiatric or general medical conditions might be causing or exacerbating the dementia. • The evaluation of a patient with dementia frequently involves coordination with a number of medical professionals, including the patient's primary care physician. It should include a clear history of the onset and progression of symptoms; a review of patient's medical problems and medications; assessment of functional abilities; a complete physical examination and a focused neurological examination; and a psychiatric examination, including a cognitive assessment that should include at least a brief assessment of the cognitive domains of attention, memory, language, and visual-spatial skills, ideally used with age and education-adjusted norms. An assessment for past or current psychiatric illnesses that might mimic or exacerbate dementia is also critical, as are laboratory studies. Many elements of the history will need to be obtained from the caregiver or the documented medical record and from the patient. Often, it may be necessary to conduct a portion of the interview with the caregiver without the patient present, to allow for full disclosure of sensitive information. • Risks of driving should be discussed with all patients with dementia and their families, and these discussions should be carefully documented. Discussions should include an exploration of the patient's current driving patterns, transportation needs, and potential alternatives. For patients with dementia who continue to drive, the issue should be raised repeatedly and reassessed over time.
	<p>Dementia. Diagnosis and Treatment (Regional Health Council, 2011)</p> <ul style="list-style-type: none"> • The general practitioner raises the diagnostic hypothesis of dementia through previous knowledge, a general examination, an assessment of possible iatrogenic causes, and a structured interview, carried out within a multiprofessional team. • General practitioners should assess all pathological conditions that could cause cognitive disorders. • General practitioners should assess for risk factors because of social isolation. • General practitioners should prescribe blood tests and a brain imaging exam to patients with suspected dementia.
	<p>Occupational Therapy Practice Guidelines for Adults with Alzheimer's Disease and Related Disorders (Schaber, 2010)</p> <ul style="list-style-type: none"> • Some specialty memory disorder clinics that use a team approach have a standing referral for clients that includes an occupational therapy evaluation is an integral part of a comprehensive assessment for dementia.
	<p>EFNS-ENS Guidelines on the Diagnosis and Management of Disorders Associated with Dementia (Sorbi et al., 2012)</p> <ul style="list-style-type: none"> • Clinical diagnosis should include medical history, laboratory, neurological, and physical examination. Clinical history should be supplemented by an informant. Cognitive assessment is central to diagnosis and management of dementia and should be performed in all patients. • Diagnosis should include assessment of cognitive functions, screening tests, and assessment of specific cognitive domains. • Assessment of behavioral and psychological symptoms of dementia is essential for both diagnosis and management and should be performed in each patient. • ADL and IADL impairment because of cognitive decline is an essential part of the diagnostic criteria for dementia and should be assessed in the diagnostic evaluation. • Assessment of comorbidity is important in demented patients, both at the time of diagnosis and throughout the course of the illness and should always be considered as a possible cause of behavioral and psychological symptoms of dementia. • Structural imaging should be used in the evaluation of every patient affected by dementia. • Routine cerebrospinal fluid analysis may help to rule out or rule in certain infectious causes.

Category	Guidelines
2. (continued)	<p>Third Canadian Consensus Conference on Diagnosis and Treatment of Dementia (2007)</p> <ul style="list-style-type: none"> • The diagnosis of dementia remains clinical. • Neuropsychological assessment alone cannot be used for diagnosis or differential diagnosis of dementia, but in-depth neuropsychological testing can be recommended to aid in the confirmation of the diagnosis. • Primary care physicians should communicate appropriate information concerning dementia, including realistic treatment expectations, to patients and their families. • The process of diagnostic disclosure for a person with cognitive impairment or dementia must begin as soon as the possibility of cognitive impairment is suspected. • Both the diagnosis of dementia and the disclosure of the diagnosis must be considered processes that provide opportunities for education and discussion. • The potential for adverse psychological consequences of diagnostic disclosure must be assessed and addressed through education of the patient and the family/caregivers. • Although each case should be considered individually, in general the diagnosis of dementia should be disclosed to the patient and family in a manner that is consistent with the expressed wishes of the patient. This process should include a discussion of prognosis, diagnostic uncertainty, advance planning, driving issues, treatment options, support groups, and future plans. • Follow-up plans must be made and discussed at the time of diagnostic disclosure.
3. Assessment and Ongoing Reassessment	<p>Dementia Care Practice Recommendations for End-of-Life Care (Alzheimer's Association, 2007)</p> <ul style="list-style-type: none"> • Direct care workers observe the resident's comfort level at the end-of-life and report symptoms to their supervisors such as: <ul style="list-style-type: none"> – Changing behaviors, such as becoming more withdrawn or agitated. – Change in mental status, such as increased confusion or lack of responsiveness. – Verbal communication, such as yelling or calling out. – Motor restlessness. – Facial grimacing or teeth grinding. – Gestures that may communicate distress. – Rigidity of body posture and position or posturing of extremities. – Labored breathing pattern. – Changes in swallowing ability. – Loss of appetite and thirst. – Excessive thirst. – Disturbed or restless sleep. – Scratching or picking at skin or other body parts. – Changes in skin condition, such as bruising, open or discolored areas. – Excessive sweating. – Dry mouth or problem with oral cleanliness. – Excessive oral secretions or drooling. – Accumulation of secretions in the eyes, nose, lungs, genitalia. – Bowel patterns and incontinence. – Change in general cleanliness, such as dirty nails, body odor, etc. – Change in grooming habits, such as unkempt hair, unbrushed teeth, etc. • Direct care workers observe residents behavioral and psychological symptoms and report the symptoms to their supervisors such as: <ul style="list-style-type: none"> – Changes in attention span. – Changes in level of arousal (distractible, inattentive, fluctuating arousal, variably alert). – Psychomotor agitation. – Changes in mood/affect. – Hallucinations. – Withdrawal from others. – Groaning or calling out. – Facial grimacing. – Striking out or other physical gestures of discomfort or distress.

Category	Guidelines
3. (continued)	<p>Dementia Care Practice Recommendations for Assisted Living and Nursing Homes (Alzheimer's Association, 2009)</p> <ul style="list-style-type: none"> • A holistic assessment includes understanding a resident's: <ul style="list-style-type: none"> – Cognitive health. – Physical health. – Physical functioning. – Behavioral status. – Sensory capabilities. – Decision making capacity. – Communication abilities. – Personal background. – Cultural preferences. – Spiritual needs and preferences. • Assessments should acknowledge that the resident's functioning might vary across different staff shifts. • Thorough assessment includes obtaining verbal information directly from residents and from family when possible. • Regular formal assessment, as required by federal or state regulation, is key to appropriate management of resident's care. Equally important is ongoing monitoring and assessment of residents, particularly upon return from the hospital or upon a significant change in their condition. • Provide good screening and preventive systems for nutritional care. • Treat pain as the "fifth vital sign" by routinely assessing and treating it in a formal systematic way, as one would treat blood pressure, pulse, respiration and temperature. • Ensure that causes of wandering are assessed and addressed, with particular attention to unmet needs.
	<p>Dementia Care Practice Recommendations for Professionals Working in a Home Setting (Alzheimer's Association, 2009)</p> <ul style="list-style-type: none"> • Assess family members to identify needs for education, support and services and reassess as the person's dementia progresses or the caregiver's health and emotional well-being is impacted. • A person showing behavioral symptoms needs a thorough medical evaluation especially when symptoms come on suddenly. • Assessment of behavioral symptoms can also include nonmedical causes such as a change in the person's care, admission to the hospital, a change in care provider, the presence of houseguests, or a request to bathe or change clothes at a different time of day. Assessment should also address personal comfort, pain, hunger, thirst, constipation, full bladder/bowel and fatigue. Loss, boredom and isolation can also cause behavioral symptoms. • Direct care providers need to be able to recognize behavioral symptoms of dementia and communicate the symptoms to supervisors or other members of the home care team. • Improve pain assessment and treatment by routinely assessing pain as the fifth vital sign. • Monitor the person for changes in eating and drinking habits and help him or her avoid significant weight loss or gain. Any significant changes should be communicated to the physician. • Assess the causes of wandering and address any unmet needs that may be inducing the behavior. • Identify problems that have led to restraint use in the past and address them using other methods. • Evaluate surroundings for any particular dangers and intervene to ensure safety at all times. • Assess the person's ability to manage daily activities and be alert to any changes in condition. • Monitor for caregiver strain or stress.
	<p>Dementia in the Long-Term Care Setting (American Medical Directors Association, 2012)</p> <ul style="list-style-type: none"> • Soon after admission or a significant condition change, assess the patient's capabilities in various domains. • Assess the patient's cognition, mood and behavior using a validated tool, such as items in the MDS 3.0 instrument.
	<p>Guidelines for the Evaluation of Dementia and Age-Related Cognitive Change (American Psychological Association, 2012)</p> <ul style="list-style-type: none"> • Psychologists recognize the value of longitudinal follow-up for monitoring change in cognitive status.
	<p>Best Practice Guideline for Accommodating and Managing Behavioural and Psychological Symptoms of Dementia in Residential Care (British Columbia Ministry of Health, 2012)</p> <ul style="list-style-type: none"> • Conduct an assessment to evaluate the person's behavioral symptoms and define specific goals. • Assess for possible causes and triggers that may contribute to behavioral and psychological symptoms of dementia. It is important to have a baseline reference point, including information from others on admission, to enable comparisons of newly expressed behaviors over time. • Assess for possible medical causes for the behaviors through a comprehensive assessment and review of medical and psychiatric history and to distinguish dementia from depression or delirium.

Category	Guidelines
3. (continued)	<p>Guideline for Alzheimer's Disease Management (California Workgroup on Guidelines for Alzheimer's Disease Management, 2008)</p> <ul style="list-style-type: none"> • Conduct and document an assessment and monitor changes in: <ul style="list-style-type: none"> – Daily functioning, including feeding, bathing, dressing, mobility, toileting, continence, and ability to manage finances and medications. – Cognitive status using a reliable and valid instrument. – Comorbid medical conditions which may present with sudden worsening in cognition, function, or as change in behavior. – Behavioral symptoms, psychotic symptoms, and depression. – Medications, both prescription and nonprescription (at every visit). – Living arrangement, safety, care needs, and abuse or neglect. – Need for palliative or end-of-life care planning. • Reassessment should occur at least every 6 months, and sudden changes in behavior or increase in the rate of decline should trigger an urgent visit to the PCP. • Identify the primary caregiver and assess the adequacy of family and other support systems, paying particular attention to the caregivers on mental and physical health. • Assess the patient's decision making capacity and determine whether a surrogate has been identified. • Identify the patient's and family's culture, values, primary language, literacy level, and decision making process. • Use a structured approach to the assessment of patient capacity, being aware of the relevant criteria for particular kinds of decisions.
	<p>Redesigning Systems of Care for Older Adults with Alzheimer's Disease (Callahan et al., 2014)</p> <ul style="list-style-type: none"> • Regularly reassess the psychoactive side effects of prescription and nonprescription medications and alcohol and other substance abuse.
	<p>Clinical Practice Guideline for Dementia. Part I: Diagnosis and Evaluation (Clinical Research Center for Dementia of South Korea, 2011)</p> <ul style="list-style-type: none"> • Assessment of behavioral and psychological symptoms of dementia is essential for both diagnosis and management, and should be performed in all patients. • ADLs should be assessed in all patients for diagnosis of dementia. Assessment of ADLs should include both the physical and instrumental fields.
	<p>Advanced Dementia Expert Panel Summary and Key Recommendations (Coleman & Mitchell, 2015)</p> <ul style="list-style-type: none"> • Incentivize documentation and tracking of level of functional and cognitive status to identify people with advanced dementia. • Use quality metrics to measure effective symptom assessment.

Category	Guidelines
3. (continued)	<p>Alzheimer's Association Recommendations for Operationalizing the Detection of Cognitive Impairment during the Medicare Annual Wellness Visit in a Primary Care Setting (Cordell et al., 2013)</p> <ul style="list-style-type: none"> • The Annual Wellness Visit requires the completion of a Health Risk Assessment by the patient either before or during the visit. The Health Risk Assessment should be reviewed for any reported signs and symptoms indicative of possible dementia. • The Annual Wellness Visit will likely occur in a primary care setting. Tools for initial cognitive assessments should be brief (less than 5 minutes), appropriately validated, easily administered by nonphysician clinical staff, and available free of charge for use in a clinical setting. • If further evaluation is indicated based on the results of the Annual Wellness Visit, a more detailed evaluation of cognition should be scheduled for a follow-up visit in primary care or through referral to a specialist. • By assessing and documenting cognitive status on an annual basis during the Annual Wellness Visit, clinicians can more easily determine gradual cognitive decline over time in an individual patient--a key criterion for diagnosing dementia because of Alzheimer's disease and other progressive conditions affecting cognition. • Annual unstructured and structured cognitive assessments could be used to monitor significant changes in cognition and potentially lead to a new diagnosis of dementia for those with mild cognitive impairment or new care recommendations for those with dementia. • The first step in detection of cognitive impairment during the Annual Wellness Visit involves a conversation between the clinician and the patient and, if present, any family member or other person who can provide collateral information. This introduces the purpose and content of the visit, which includes: a review of the Health Risk Assessment; observations by clinicians (medical and associated staff); acknowledgment of any self-reported or informant-reported concerns; and conversational queries about cognition directed toward the patient and others present. • A noted deficit in ADLs (e.g., eating and dressing) or IADLs (e.g., shopping and cooking) that cannot be attributed to physical limitations should prompt concern, as there is a strong correlation between decline in function and decline in cognitive status across the full spectrum of dementia. • Recognizing that there is no single optimal tool to detect cognitive impairment for all patient populations and settings, clinicians may select other brief tools to use in their clinical practice. Any patient who does not have an informant present should be assessed with the structured tool. <p>Dementia Care: The Quality Chasm (Dementia Initiative, 2013)</p> <ul style="list-style-type: none"> • The reasons for behavioral expressions are complex and vary by individual. Determine the root cause of the behavior and then address the cause, such as pain, hunger, thirst, boredom, illness, loneliness, or an underlying medical condition that the person with dementia is challenged to communicate. <p>Clinical Practice Guideline on the Comprehensive Care of People with Alzheimer's Disease and Other Dementias (De Sanidad, 2014)</p> <ul style="list-style-type: none"> • The assessment of the impact of cognitive impairment on the ADLs is recommended given their affectation, which forms the dementia diagnostic criterion and determines the subsequent management of these patients. • An assessment of the psychological and behavioral symptoms is recommended because of their importance for the diagnosis. • The systematic assessment of the presence of BPSD is recommended as a fundamental component of the clinical picture, as it appears very frequently, it is difficult to manage, it has an impact on the quality of life and is a frequent reason for urgent care, family claudication and institutionalization. • The use of specifically designed instruments is recommended to evaluate BPSD in dementia independently from cognitive and functional alterations. • Starting treatment with nonpharmacological strategic measures to manage BPSD is recommended. • A meticulous assessment is recommended if behavioral and psychological symptoms of dementia appear, to rule out concomitant pathology and achieve optimal environmental surroundings. • Sensory stimulation, behavioral therapy, structured activities and social contact should be used to reduce the incidence of behavioral and psychological symptoms of dementia, although there is no scientific evidence to support this. • It is advisable to inform and train caregivers of dementia patients on strategies to address and manage the behavioral and psychological symptoms of dementia so that it is possible to adopt and promote an appropriate attitude towards patients and prevent strain and claudication of the caregivers.

Category	Guidelines
3. (continued)	<p>Recognition and Management of Dementia (Fletcher, 2012)</p> <ul style="list-style-type: none"> • Assessment domains include cognitive, functional, behavioral, physical, caregiver, and environment. • Tests that assess functional limitations are useful in monitoring the progression of functional decline. • Assess and monitor for behavioral changes; in particular, the presence of agitation, aggression, anxiety, disinhibitions, delusions, and hallucinations. • Evaluate for depression because it commonly coexists in individuals with dementia. • A comprehensive physical examination with a focus on the neurological and cardiovascular system is indicated in individuals with dementia to identify the potential cause or existence of a reversible form of cognitive impairment. • A thorough evaluation of all prescribed, over-the-counter, Homeopathic, herbal, and nutrition products taken is done to determine the potential impact on cognitive status. <p>Follow-up appointments are regularly scheduled; frequency depends on the patient's physical, mental, and emotional status and caregiver needs.</p> <p>Practice Guidelines for Assessing Pain in Older Persons with Dementia Residing in Long-Term Care Facilities (Hadjistavropoulos, Fitzgerald, & Marchildon, 2010)</p> <ul style="list-style-type: none"> • Determine if MMSE scores are available or can be obtained. This would facilitate determination of patient ability to provide valid self-report. • Baseline scores should be collected for each individual (ideally on a regular basis which would allow for the examination of unusual changes from the person's typical pattern of scores). • Patient history and physical examination results should be taken into consideration. • If assessments are to be repeated over time, assessment conditions should be kept constant (e.g., use the same assessment tool, use the same assessor where possible and conduct pain assessment during similar situations). • Pain assessment results should be used to evaluate the efficacy of pain management interventions. • Use of synonyms when asking about the pain experience (e.g., hurt, aching) will facilitate the self-report of some patients who have limitations in ability to communicate verbally. • Self-report scales should be modified to account for any sensory deficits that occur with aging (e.g., poor vision, hearing difficulties). • Use self-report tools that have been found to be the most valid among seniors (e.g., the Colored Analog Scale, Numeric Rating Scales, Behavioral Rating Scales, 21 Point Box Scale). • Use of horizontal visual analog scales should be avoided, as some investigators have found unusually high numbers of unscorable responses among seniors. • Observational tools that have been shown to be reliable and valid for use in this population include PACSLAC and DOLOPLUS-2. The PACSLAC is the only tool that covers all 6 behavioral pain assessment domains that have been recommended by the American Geriatrics Society. Nonetheless, clinicians should always exercise caution when using these measures because they are relatively new and research is continuing. • When assessing pain in acute care settings tools that primarily focus on evaluation of change over time should be avoided. • Observational assessments during movement-based tasks would be more likely to lead to the identification of underlying pain problems than assessments during rest. • Some pain assessment tools do not have specific cutoff scores because of recognition of tremendous individual differences among people with severe dementia. Instead, it is recommended that pain be assessed on a regular basis (establishing baseline scores for each patient) with the clinician observing score changes over time. • Examination of pain assessment scores before and after the administration of analgesics is likely to facilitate pain assessment. • Some of the symptoms of delirium (which are seen frequently in long-term care) overlap with certain behavioral manifestations of uncontrolled pain (e.g., behavioral disturbance). Clinicians assessing patients with delirium should be aware of this. On the positive side, delirium tends to be a transient state, and pain assessment, which can be repeated or conducted when the patient is not delirious, is more likely to lead to valid results. It is important to note also that pain can cause delirium, and clinicians should be astute to avoid missing pain problems among patients with delirium. • Observational pain assessment tools are screening instruments only and cannot be taken to represent definitive indicators of pain. Sometimes they may suggest the presence of pain when pain is not present, and at other times they may fail to identify pain. • In addition to improved scores on various assessment tools, evidence of more effective pain management can be observed in areas such as greater participation in activities, improved sleep, reduced behavioral disturbance, improved ability to ambulate, and improved social interactions.

Category	Guidelines
3. (continued)	<p>Pain Assessment in the Patient Unable to Self-Report: Position Statement with Clinical Practice Recommendations (Herr et al., 2011)</p> <ul style="list-style-type: none"> • Attempts should be made to obtain self-report of pain from all patients. When self-report is absent or limited, explain why self-report cannot be used and further investigation and observation are needed. • Iatrogenic pain associated with procedures should be treated before initiation of the procedure. • A change in behavior requires careful evaluation of pain or other sources of distress, including physiologic compromise (e.g., respiratory distress, cardiac failure, hypertension). Generally, one may assume that pain is present, and if there is reason to suspect pain, an analgesic trial can be diagnostic and therapeutic. Other problems that may be causing discomfort should be ruled out (e.g., infection, constipation) or treated. • In the absence of self-report, observation of behavior is a valid approach to pain assessment. • Establish a procedure for pain assessment: <ul style="list-style-type: none"> – Identify pathologic conditions or procedures that may cause pain. Consider common chronic pain etiologies. Musculoskeletal and neurologic disorders are the most common causes of pain in older adults. – List patient behaviors that may indicate pain. A behavioral assessment tool may be used. Observe facial expressions, verbalizations/vocalizations, body movements, changes in interactions, changes in activity patterns or routines, and mental status. Behavioral observation should occur during activity whenever possible. – Identify behaviors that caregivers and others knowledgeable about the patient think may indicate pain. In the long-term care setting, the certified nursing assistant is a key health care provider shown to be effective in recognizing presence of pain. The family is helpful if they visit regularly. – Attempt an analgesic trial. Estimate the intensity of pain based on information obtained from prior assessment steps and select appropriate analgesic. Opioid dosing in older adults warrants initial dose reduction to 25% to 50% of adult dose. <p>EFNS Guidelines for the Diagnosis and Management of Alzheimer’s Disease (Hort et al. & European Federation of Neurological Sciences Scientist Panel on Dementia, 2010)</p> <ul style="list-style-type: none"> • Assessment of behavioral and psychological symptoms of dementia should be performed in each patient. Information should be gathered from an informant using an appropriate rating scale. <p>Using Dementia as the Organizing Principle when Caring for Patients with Dementia and Comorbidities (Lazaroff et al., 2013)</p> <ul style="list-style-type: none"> • Assessment by an occupational therapist or another member of the health care team can help determine what the patient is capable of doing independently with the help of aids and with which activities the patient needs assistance. • An environmental assessment can identify modifications that can be made to a home to reduce a person’s risk of falling and wandering off. <p>Fourth Canadian Consensus Conference on the Diagnosis and Treatment of Dementia: Recommendations for Family Physicians (Moore et al., 2014)</p> <ul style="list-style-type: none"> • Nonpharmacologic interventions for agitation and aggression in dementia include recognition and management of potentiating factors (medical, psychiatric, medications, environment). <p>Dementia: A NICE-SCIE Guideline on Supporting People with Dementia and Their Carers in Health and Social Care (National Institute for Health and Clinical Excellence, 2007)</p> <ul style="list-style-type: none"> • All people with suspected or known dementia using inpatient services are assessed by a liaison service that specializes in the treatment of dementia. Care for such people in acute care should be planned jointly by the hospital staff, liaison teams, relevant social care professionals and the person with suspected or known dementia and his or her carers. • At the time of diagnosis of dementia, and at regular intervals subsequently, assessment should be made for medical comorbidities and key psychiatric features associated with dementia, including depression and psychosis, to ensure optimal management of coexisting conditions. • Care for people with dementia should include assessment and monitoring for depression or anxiety. A range of tailored interventions, such as reminiscence therapy, multisensory stimulation, animal assisted therapy and exercise, should be available for people with dementia who have depression or anxiety.

Category	Guidelines
3. (continued)	<p>PQRS 2105 Measure List, Measure Numbers 25, and 149-157 (Physician Quality Reporting System, 2014)</p> <ul style="list-style-type: none"> • Staging of Dementia: Percentage of patients, regardless of age, with a diagnosis of dementia whose severity of dementia was classified as mild, moderate or severe at least once within a 12-month period. • Cognitive Assessment: Percentage of patients, regardless of age, with a diagnosis of dementia for whom an assessment of cognition is performed and the results reviewed at least once within a 12-month period. • Functional Status Assessment: Percentage of patients, regardless of age, with a diagnosis of dementia for whom an assessment of functional status is performed and the results reviewed at least once within a 12-month period. • Neuropsychiatric Symptom Assessment: Percentage of patients, regardless of age, with a diagnosis of dementia and for whom an assessment of neuropsychiatric symptoms is performed and results reviewed at least once in a 12-month period. • Screening for Depressive Symptoms: Percentage of patients, regardless of age, with a diagnosis of dementia who were screened for depressive symptoms within a 12-month period.
	<p>American Psychiatric Association Practice Guideline for the Treatment of Patients with Alzheimer's Disease and Other Dementias (Rabins et al., 2007)</p> <ul style="list-style-type: none"> • The treatment of patients with dementia should be based on a thorough psychiatric, neurological, and general medical evaluation of the nature and cause of the cognitive deficits and associated noncognitive symptoms, in the context of a solid alliance with the patient and family. • It is particularly critical to identify and treat general medical conditions, most notably delirium, that may be responsible for or contribute to the dementia or associated neuropsychiatric symptoms. • Ongoing assessment includes periodic monitoring of the development and evolution of cognitive and noncognitive psychiatric symptoms and their response to intervention. • Recommended assessments include evaluation of suicidality, dangerousness to self and others, and the potential for aggression, and evaluation of living conditions, safety of the environment, adequacy of supervision, and evidence of neglect or abuse. • To offer prompt treatment, enhance safety, and provide timely advice to the patient and family, it is generally necessary to see patients, usually together with their caregivers, in routine follow-up at least every 3-6 months. Patients who require active treatment of psychiatric complications should be seen regularly to adjust doses and monitor for changes in target symptoms and side effects. • Monitor and enhance the safety of the patient and others: the psychiatrist should assess suicidality, assess the potential for aggression and agitation, make recommendations regarding adequate supervision, for example, medication administration, make recommendations regarding the prevention of falls and choking, address nutritional and hygiene issues, and be vigilant regarding neglect or abuse. Patients who live alone require careful attention. Events that indicate that the patient can no longer live alone include several falls, repeated hospitalization, dehydration, malnutrition, repeated errors and taking prescribed medication, dilapidated living conditions, or other signs of self-neglect. Other important safety issues in the management of patients with dementia include interventions to decrease the hazards of wandering and recommendations concerning activities such as cooking, driving, hunting, and the operation of hazardous equipment.
	<p>Dementia. Diagnosis and Treatment (Regional Health Council, 2011)</p> <ul style="list-style-type: none"> • General practitioners should assess the presence of comorbidities.
	<p>Caregiving Strategies for Older Adults with Delirium, Dementia and Depression 2010 Supplement (Registered Nurses' Association of Ontario, 2010)</p> <ul style="list-style-type: none"> • Nurses should use the diagnostic criteria from the DSM-IV-R to assess for delirium, and document mental status observations of hypoactive and hyperactive delirium. • Nurses must monitor, evaluate, and modify the multicomponent intervention strategies on an ongoing basis to address the fluctuating course associated with delirium. • Nurses should contribute to comprehensive standardized assessments to rule out or support the identification and monitoring of dementia based on their ongoing observations and expressed concerns from the client, family, and interdisciplinary team. • Nurses caring for clients with dementia should be knowledgeable about pain assessment and management in this population to promote physical and emotional well-being. • Nurses should use the diagnostic criteria from the DSM-IV-R to assess for depression. • Nurses should use standardized assessment tools to identify the predisposing and precipitating risk factors associated with depression. • In care settings where Resident Assessment Instrument and MDS instruments are mandated assessment tools, nurses should use the MDS data to assist with assessment for delirium, dementia and depression.

Category	Guidelines
3. (continued)	<p>Occupational Therapy Practice Guidelines for Adults with Alzheimer's Disease and Related Disorders (Schaber, 2010)</p> <ul style="list-style-type: none"> • Occupational Therapy evaluation questions should be directed toward the client, allowing the client to take an active and central role in the interview process. Information is gathered through an occupational profile, analysis of occupational performance, and standardized and nonstandardized assessments. • If cognition is the primary concern limiting participation, a brief cognitive assessment using a screening tool such as the Large Allen Cognitive Lacing Screen is administered to determine whether a full cognitive functional assessment is warranted. • An individual with cognitive deficits may exhibit a decline or impairment in performance of functional activities caused by comorbidities that affect motor and praxis, sensory-perceptual, emotional regulation, cognitive, communication, and social skills. One difficulty in assessment with comorbidities is delineating the source of the performance deficit. With clinical expertise, all factors that limit occupational performance are considered, along with thinking, memory, or executive function abilities. • The purpose of an occupational therapy evaluation is to design an intervention plan to create opportunities for participation, maintain occupational performance or modify activity demands, or prevent deterioration in performance capability. The area of occupation targeted depends on the cognitive ability of the client and stage of the disease. For instance, the focus of intervention in the early stages work or employment, if applicable, and IADL participation, whereas the focus in the middle and later stages of the disease is ADL performance. Leisure, social participation, and rest/sleep are considered through the early to the later stages of the disease. • Occupational therapy evaluation with people with Alzheimer's disease entails an exploration of the activity demands relative to the client's capabilities. • The purpose of the evaluation is to determine what potential the client brings to the intervention process and to identify the barriers to optimal performance on the basis of physiological functions of body systems or personal values and beliefs.
	<p>EFNS-ENS Guidelines on the Diagnosis and Management of Disorders Associated with Dementia (Sorbi et al., 2012)</p> <ul style="list-style-type: none"> • Cognitive assessment is central to diagnosis and management of dementia and should be performed in all patients. • Assessment of behavioral and psychological symptoms of dementia is essential for both diagnosis and management and should be performed in each patient. • Assessment of comorbidity is important in demented patients, both at the time of diagnosis and throughout the course of the illness and should always be considered as a possible cause of behavioral and psychological symptoms of dementia. • Advice either to allow driving, but to review after an interval, to cease driving, or to refer for retesting should be given.
	<p>Third Canadian Consensus Conference on Diagnosis and Treatment of Dementia (2007)</p> <ul style="list-style-type: none"> • Determination of how medications are being consumed and identification of any problems/concerns with medication management, including poor adherence, should be conducted for all patients with mild or moderate dementia. The effectiveness of any alterations in medication management has to be assessed. • Assess cognitive status, functional abilities, and behavior and neuropsychiatric symptoms, and reassess regularly. • Obtain information from caregivers about the person's cognition, behavior, and social and daily functioning. • Patients with sleep problems should be assessed for medical illnesses (including pain), psychiatric illnesses (including depression), potentially contributing medications, poor sleep habits (including naps), and environmental factors that may be adversely affecting sleep. • Patients with severe dementia should be assessed at least every 4 months. Assessment should include cognition, function, behavior, medical status, nutrition, safety, and caregiver health. • Clinicians should counsel persons with a progressive dementia and their families that giving up driving will be an inevitable consequence. Strategies to ease this transition should occur early in the clinical course of the condition. The driving ability of persons in earlier stages of dementia should be tested on an individual basis. For persons deemed safe to drive, reassessment of their ability to drive should occur at least every 6-12 months.

Category	Guidelines
4. Care Planning	<p>Dementia Care Practice Recommendations for End-of-Life Care (Alzheimer's Association, 2007)</p> <ul style="list-style-type: none"> • Care plans need to be flexible enough to adapt to daily changes in a resident's needs and wishes. • Regularly scheduled care planning meetings that involve the resident, proxy decision makers, family and the broader care team facilitate communication about end-of-life care and help ensure that care is person-centered and adapted to the resident's changing condition. • As the resident's condition declines with the progression of dementia, care goals may change from curing coexisting conditions or preserving function to palliative care. It is important to reevaluate and, if necessary, revise the care goals and decisions and regularly schedule care planning meetings based on the resident's current status, desires regarding care and family input.
	<p>Dementia Care Practice Recommendations for Assisted Living and Nursing Homes (Alzheimer's Association, 2009)</p> <ul style="list-style-type: none"> • Effective care planning includes a resident and family, when appropriate, and all staff (including direct care staff) who regularly interact with the resident throughout the process. • An effective care plan builds on the residents abilities and incorporate strategies such as task breakdown, fitness programs and physical or occupational therapy to help residents complete their daily routines and maintain their functional abilities as long as possible. • When all staff involved in a resident's care are familiar with the care plan, they will be better equipped to provide appropriate care to the resident. • Care plans will remain current and most useful if they are regularly updated in conjunction with periodic assessments. • Care plans need to be flexible enough to adapt to daily changes in a resident's needs and wishes.
	<p>Dementia Care Practice Recommendations for Professionals Working in a Home Setting (Alzheimer's Association, 2009)</p> <ul style="list-style-type: none"> • To ensure that home care is person-centered and aligned with an individual's choices, there must be good communication among the individual living with the disease and his or her health care proxy decision maker, family caregivers and entire care team. • During care planning, discuss the person's choices about end-of-life care and any related doctor's orders. Based on these choices, the person and family need to know what the agency will do at the end of life. • Effective care plans use information from the assessment to design a set of services that will meet a person's needs and maximize his or her independence. • The care plan stays useful over time if it is regularly updated and modified as a person's needs, abilities and wishes change. • When providers and family members understand the care plan and determine roles and responsibilities, they will be better able to provide care. • Care plans should identify family caregivers and address family caregiver needs.
	<p>Dementia in the Long-Term Care Setting (American Medical Directors Association, 2012)</p> <ul style="list-style-type: none"> • Prognostication is important in the long-term care setting for appropriate care planning and timely use of available resources. Prognostication is not a guarantee of future events but rather an estimate of what can be reasonably expected. Prognostication of dementia is challenging; evidence supports using age, decline and functional status and oral intake, and increasing dependence in ADLs as the most important features in determining prognosis in end-stage dementia. • Prepare an individualized interdisciplinary care plan that defines treatment goals that are appropriate for the individual patient, taking into account the wishes of the patient or family; incorporates definite, measurable objectives derived from those treatment goals; and, allows for modification as the patient's needs change.
	<p>Best Practice Guideline for Accommodating and Managing Behavioural and Psychological Symptoms of Dementia in Residential Care (British Columbia Ministry of Health, 2012)</p> <ul style="list-style-type: none"> • Select psychological and meaningful social interventions based on individualized goals of care. • Continue to assess whether the goals of treatment are being met using a reliable tool such as the Pocket Guide Tool on the Assessment and Treatment of Behavioral Symptoms of Older Adults Living in Long-Term Care Facilities. • A care plan that focuses on nonpharmacological interventions is considered best practice is the first line management of most behavioral and psychological symptoms of dementia. • Interdisciplinary care plans should be developed by the health care provider in collaboration with the resident and family or substitute decision maker with goals and outcomes carefully documented, evaluated and adjusted as required.
	<p>Palliative Care for Advanced Dementia (Bryant, Alonzo & Long, 2010)</p> <ul style="list-style-type: none"> • Be knowledgeable about a person's physical, psychological, social and spiritual history. Assure that the life story is incorporated into the care plan.

Category	Guidelines
4. (continued)	<p>Guideline for Alzheimer’s Disease Management (California Workgroup on Guidelines for Alzheimer’s Disease Management, 2008)</p> <ul style="list-style-type: none"> • Develop and implement an ongoing treatment plan with defined goals. Discuss with patient and family: <ul style="list-style-type: none"> – Use of cholinesterase inhibitors, NMDA antagonist, and other medications, if clinically indicated, to treat cognitive decline.
	<p>Redesigning Systems of Care for Older Adults with Alzheimer’s Disease (Callahan et al., 2014)</p> <ul style="list-style-type: none"> • Discuss goals of care. • Track the patient’s outcomes and adjust goals of care as appropriate.
	<p>Recognition and Management of Dementia (Fletcher, 2012)</p> <ul style="list-style-type: none"> • Determine the continued efficacy of pharmacological/nonpharmacological approaches to the care plan and modify as appropriate.
	<p>Report and Recommendations (Gerontological Society of America Workgroup on Cognitive Impairment Detection and Earlier Diagnosis, 2015)</p> <ul style="list-style-type: none"> • PCPs should initiate a care plan to document how ongoing medical management of comorbidities will be done, how progression of dementia-related neuropsychiatric symptoms will be monitored, and how referrals will be made to community resources.
	<p>EFNS Guidelines for the Diagnosis and Management of Alzheimer’s Disease (Hort et al. & European Federation of Neurological Sciences Scientist Panel on Dementia, 2010)</p> <ul style="list-style-type: none"> • Assessment of comorbidity is important in Alzheimer’s disease patients, both at the time of diagnosis and throughout the course of illness and should always be considered as a possible cause of behavioral and psychological symptoms of dementia. In patients with Alzheimer’s disease, treatment with cholinesterase inhibitors should be considered at the time of diagnosis, taking into account expected therapeutic benefits and potential safety issues. • Regular patient follow-up, which should include scales like the MMSE, to monitor response to treatment and disease progression, should be an integral part of management. • Currently, there is insufficient evidence to support the use of other agents, including anti-inflammatory drugs, or statins in the treatment or prevention of Alzheimer’s disease. • Antipsychotics should only be used for moderate or severe behavioral and psychological symptoms of dementia causing significant distress which have either not responded to other treatments (like nonpharmacological measures or cholinesterase inhibitors) or when other treatments are not appropriate.
	<p>Using Dementia as the Organizing Principle when Caring for Patients with Dementia and Comorbidities (Lazaroff et al., 2013)</p> <ul style="list-style-type: none"> • Goals of care should include reducing the suffering that accompanies the disease, reducing the negative impact on both the patient’s health and quality of life and that of his or her family, and optimizing the management of any comorbid conditions. • Address quality of life by maximizing a person’s functional independence, ensuring that he or she has adequate support, effectively managing any behavioral issues that may arise, emphasizing safety, and encouraging socialization and community engagement to the extent that the person is comfortable with it and enjoys it. • Address risks such as poor adherence to medication regimens, lack of recognition of adverse drug reactions, falls, delirium and preventable hospitalizations. • Ongoing monitoring and modification of care goals and treatments will be necessary. • The care plan for the patient should not place unreasonable expectations on the patient or caregiver; instead, treatment should be adapted to what can be reasonably accomplished.

Category	Guidelines
4. (continued)	<p>Dementia: A NICE-SCIE Guideline on Supporting People with Dementia and Their Carers in Health and Social Care (National Institute for Health and Clinical Excellence, 2007)</p> <ul style="list-style-type: none"> • Nondiscrimination: people with dementia should not be excluded from any services because of their diagnosis, age or coexisting learning disabilities. • Acute and General Hospital trusts should plan and provide services that address the specific personal and social care needs and the mental and physical health of people with dementia who use acute hospital facilities for any reason. • Care plans should address ADLs that maximize independent activity, enhance function, adapt and develop skills, and minimize the need for support. When writing care plans, the varying needs of people with different types of dementia should be addressed. Care plans should always include: <ul style="list-style-type: none"> – Consistent and stable staffing. – Retaining a familiar environment. – Minimizing relocations. – Flexibility to accommodate fluctuating abilities. – Assessment and care planning advice regarding ADLs and ADL skill training from an occupational therapist. • Assessment and care planning advice about independent toileting skills; if incontinence occurs all possible causes should be assessed and relevant treatments tried before concluding that it is permanent. • Environmental modifications to aid independent functioning, including assistive technology, with advice from an occupational therapist or clinical psychologist. • Physical exercise with assessment and advice from a physiotherapist when needed. • Support for people to go at their own pace and participate in activities they enjoy.
	<p>Dementia Care: The Quality Chasm (Dementia Initiative, 2013)</p> <ul style="list-style-type: none"> • Meaningful and engaging things to do throughout the day are essential to support health and well-being. These rhythms of daily life not only provide purpose and structure to the day, but the meaningful activities help to support life roles and functions that are important to preserving value, self-esteem, and confidence, and to identify and create a sense of belonging. • Focus on the strengths of the person living with dementia rather than on what abilities and capabilities have been diminished or lost. • Learn the preferences of the person with dementia for bathing, dressing, grooming, and other ADLs to make these activities comforting and pleasant.
	<p>American Psychiatric Association Practice Guideline for the Treatment of Patients with Alzheimer's Disease and Other Dementias (Rabins et al., 2007)</p> <ul style="list-style-type: none"> • Specific clinical features influencing the treatment plan include demographic and social factors such as age, gender, ethnic and cultural background, and other demographic and psychosocial factors such as the availability of a spouse, adult child, or other loved one with physical and emotional ability to supervise and care for the patient, communicate with treating physicians, and otherwise coordinate care. In addition, a social network of friends, neighbors, and community may play a key role in supporting the patient and primary caregivers. Spiritual supports and religious beliefs have been shown to have positive benefits for caregivers' well-being. Resource availability varies widely by geographic region and socioeconomic status. • The development of a treatment plan for a patient with dementia focuses not only on the identification of specific symptoms and associated general medical problems but also depends on features of the environment in which the patient is cared for, as certain issues are specific to particular care settings such as home care, day care, long-term care and inpatient general medical or surgical services.
	<p>Occupational Therapy Practice Guidelines for Adults with Alzheimer's Disease and Related Disorders (Schaber, 2010)</p> <ul style="list-style-type: none"> • The goal of occupational therapy interventions is to maximize the quality of life. With all interventions, the challenge is balancing client safety and performance with maximum independence. • The intervention plan, developed by an occupational therapist and corroborated with the client (family), reflects client and caregiver needs, occupational therapy evaluation, knowledge of theory, and evidence guiding best practice. • Throughout the intervention implementation, the client and family responses monitored and recorded, and the intervention is modified on the basis of progress toward the goals. The implementation review is a review of the plan and includes a periodic measure of progress toward the targeted outcomes.
	<p>Third Canadian Consensus Conference on Diagnosis and Treatment of Dementia (2007)</p> <ul style="list-style-type: none"> • Even when the patient is safely self-managing their medications, there should be planning for the involvement of a third party in medication management for all patients with a progressive dementia, as this will eventually become necessary in nearly all patients.

Category	Guidelines
5. Medical Management	<p>Dementia Care Practice Recommendations for Assisted Living and Nursing Homes (Alzheimer's Association, 2009)</p> <ul style="list-style-type: none"> • Ease the distress associated with pain and help residents enjoy an improved quality of life. • Tailor pain management techniques to each resident's needs, circumstances, conditions and risks.
	<p>Dementia Care Practice Recommendations for Professionals Working in a Home Setting (Alzheimer's Association, 2009)</p> <ul style="list-style-type: none"> • Enhance a person's quality of life by controlling or minimizing pain and improving his or her function and ability to socialize. • Tailor pain relief methods to each person's needs and risks and adjust treatment as the person's condition changes. • If a person uses medications, physicians in consultation with members of the home care team need to consider how they will be given: <ul style="list-style-type: none"> – Can the person with dementia take the medications on his or her own? – If not, who will help with medications? – Can the practitioner who prescribes the medicine adjust the schedule for taking it so family or home care team members are available to help? – Who will be responsible for overseeing changes in medications? – Is mail order or pharmacy delivery of medications preferable? – What kind of insurance coverage does the person have to help pay for medications? • A person with dementia should have an up to date medication list (including over-the-counter medications) that is available in his or her medical record and accessible to all health care providers. This will allow providers to identify potential medication related causes of new symptoms, identify and eliminate inappropriate duplication of therapies, correct dangerous interactions, and streamline the regimen to improve adherence. • A person with dementia should have an annual medication regimen review. • When a person with dementia is prescribed a new medication, the prescribed medication should have a clearly defined indication. • A person with dementia and the family caregiver should receive appropriate education about the use of any new medication to improve adherence and clinical outcomes and to alert the person or caregiver to potential adverse effects. <ul style="list-style-type: none"> – When a person is prescribed an ongoing medication for a chronic medical condition, response to therapy should be documented.
	<p>Geriatric Emergency Department Guidelines: Delirium and Dementia in the Geriatric Emergency Department (American College of Emergency Physicians, 2013)</p> <ul style="list-style-type: none"> • A therapeutic environment should be provided whenever possible. Preventative measures should include: <ul style="list-style-type: none"> – Eliminate or minimize identified risk factors. – Avoid high risk medications. – Prevent/promptly and appropriately treat infections. – Prevent/promptly treat dehydration and electrolyte disturbances. – Provide adequate pain control. – Maximize oxygen delivery. – Use sensory aids as appropriate. – Foster orientation. – Regulate bowel/bladder function. – Provide adequate nutrition. – Increase supervised mobility. – Increase awareness and vision whenever possible. – Minimize use of restraints. – Provide appropriate sensory stimulation such as quiet room, adequate light, noise reduction. – Foster familiarity such as encourage family/friends to stay at bedside, bring familiar objects from home, minimize relocations. – Communicate clearly. – Reassure and educate family. – Minimize invasive interventions.
	<p>Dementia in the Long-Term Care Setting (American Medical Directors Association, 2012)</p> <ul style="list-style-type: none"> • Consider medical interventions if appropriate. • Monitor the patient's condition and adjust management as appropriate. • Monitor the facility's management of dementia.

Category	Guidelines
5. (continued)	<p>Best Practice Guideline for Accommodating and Managing Behavioural and Psychological Symptoms of Dementia in Residential Care (British Columbia Ministry of Health, 2012)</p> <ul style="list-style-type: none"> • Recommendations are that antipsychotic medications be used when alternative therapies are ineffective on their own; there is an identifiable risk of harm to the resident and others; and the symptoms are severe enough to cause suffering and distress to the individual. • Careful consideration of the benefits and risks of treatment should be assessed as research has demonstrated that these medications can produce serious potential adverse effects resulting in a significantly decreased quality of life for the individual including increased confusion, extrapyramidal symptoms, anticholinergic effects including delirium, increased risk of falling, increased risk of cerebrovascular events, and increased risk of death. • Regularly review the need (or not) for ongoing antipsychotic therapy for behavioral psychological symptoms of dementia and trial withdrawal.
	<p>Cognitive Impairment: Recognition, Diagnosis and Management in Primary Care (British Columbia Ministry of Health, 2014)</p> <ul style="list-style-type: none"> • Drug treatment has limited value; first consider nonpharmacological management of the behavioral and psychological symptoms of dementia. • Make early and regular use of adjunct services. • Always start with nonpharmacological interventions. • Physicians are encouraged to deliver timely, individualized care to the patient and their caregiver and to support patient independence at a level that is appropriate for their cognitive and physical capabilities. • Consider general care and supplementary supports for patients in the following areas: memory, behavioral symptoms, nutrition, shopping, household safety, medication management, hygiene, socialization, financial and legal issues, driving, self-neglect/neglect/abuse, mental health and specialty services, caregiver support. • Polypharmacy and multimorbidity can both be causes and effects of cognitive impairment.
	<p>Guideline for Alzheimer's Disease Management (California Workgroup on Guidelines for Alzheimer's Disease Management, 2008)</p> <ul style="list-style-type: none"> • Provide appropriate treatment for comorbid medical conditions. • Provide appropriate end-of-life care, including palliative care as needed.
	<p>Redesigning Systems of Care for Older Adults with Alzheimer's Disease (Callahan et al., 2014)</p> <ul style="list-style-type: none"> • Consider cognition enhancing drugs • Detect and treat vascular risk factors. • Manage the patient's comorbid conditions in the context of dementia.
	<p>Clinical Practice Guideline for Dementia. Part I: Diagnosis and Evaluation (Clinical Research Center for Dementia of South Korea, 2011)</p> <ul style="list-style-type: none"> • Early detection of the risk factors of dementia and subsequent medical intervention is important for prevention of dementia. A thorough control of the vascular risk factors is particularly critical for prevention and management of not only cardiovascular or cerebrovascular disease but dementia. • Behavioral and psychological symptoms often have somatic comorbidity or complications. A possible causative comorbidity or complication should be included in evaluation.
	<p>Advanced Dementia Expert Panel Summary and Key Recommendations (Coleman & Mitchell, 2015)</p> <ul style="list-style-type: none"> • Ensure access to high-quality palliative care for persons with dementia and their families across all care settings. • Provide specialized medical care, including relief from the symptoms, pain, and stress. • Use quality metrics to measure effective symptom management.
	<p>Clinical Practice Guideline on the Comprehensive Care of People with Alzheimer's Disease and Other Dementias (De Sanidad, 2014)</p> <ul style="list-style-type: none"> • Following the indications of the technical data sheet of the drug, it is recommended to assess adverse effects and contraindications of the ACE inhibitors and Memantine. • Individual assessment of the suspension of specific pharmacological treatment is recommended, as the guideline developers have no studies that assess this item, and in the only study where the treatment with donepezil was interrupted, neither cognition nor function returned to the level achieved before the interruption. • Bearing in mind that patients with vascular dementia usually suffer a high cardiovascular risk, treatment with ACE inhibitors should be assessed individually, paying special attention to how the treatment is managed. • It is advisable to follow the indications given in the product technical data sheet. • Start with low doses and slowly reach the minimum effective doses. Preferential use of oral route. Review the dose and the actual treatment need at regular intervals, generally every 3 months.
	<p>Recognition and Management of Dementia (Fletcher, 2012)</p> <ul style="list-style-type: none"> • Identify and treat any underlying or contributing conditions. • Monitor the effectiveness and potential side effects of medications given to improve cognitive function or delay cognitive decline. • Avoid pharmacological restraints.

Category	Guidelines
5. (continued)	<p>EFNS Guidelines for the Diagnosis and Management of Alzheimer's Disease (Hort et al. & European Federation of Neurological Sciences Scientist Panel on Dementia, 2010)</p> <ul style="list-style-type: none"> • Assessment of comorbidity is important in Alzheimer's disease patients, both at the time of diagnosis and throughout the course of illness and should always be considered as a possible cause of behavioral and psychological symptoms of dementia. In patients with Alzheimer's disease, treatment with cholinesterase inhibitors should be considered at the time of diagnosis, taking into account expected therapeutic benefits and potential safety issues. • Regular patient follow-up, which should include scales like the MMSE, to monitor response to treatment and disease progression, should be an integral part of management. • Currently, there is insufficient evidence to support the use of other agents, including anti-inflammatory drugs, or statins in the treatment or prevention of Alzheimer's disease. • Antipsychotics should only be used for moderate or severe behavioral and psychological symptoms of dementia causing significant distress which have either not responded to other treatments (like nonpharmacological measures or cholinesterase inhibitors) or when other treatments are not appropriate.
	<p>Using Dementia as the Organizing Principle when Caring for Patients with Dementia and Comorbidities (Lazaroff et al., 2013)</p> <ul style="list-style-type: none"> • Dementia has a profound effect on a patient's ability to participate in his or her own care that must be accounted for in the clinician's treatment plan. Thinking of the patient as "a person with dementia who has multiple comorbidities" is more effective than thinking of the patient as "a person with diabetes, osteoporosis and hypertension who also has dementia." Therefore, the presence of dementia often is the most important thing to know about a patient when making decisions about his or her health care. • See patient regularly, perhaps every 3 to 6 months. This allows the clinician to: monitor the progression of cognitive and functional impairment and adapt the goals and treatment plan; look for adverse effects of medications and poor adherence to the medication regimen, signs of acute intercurrent problems and the exacerbation of chronic disease; and check on how the caregiver is coping. • Dementia alters the benefits/burden equation for treating comorbid illness in several ways. First, it reduces life expectancy, making some prevention activities a lower priority. As dementia progresses, standard treatment options carry an increased risk of adverse outcomes. • Any sudden increase in confusion should prompt an evaluation to identify an underlying acute cause. Medications, infection, constipation, urine retention, pain, myocardial ischemia, dehydration, sleep deprivation and dental disease can be common causes of delirium or acute mental status changes in patients with Alzheimer's disease. • Good prescribing practice for the patient with dementia requires paying special attention to both the patient's adherence to drug regimens and susceptibility to adverse effects of certain drugs.
	<p>Palliative Care of Patients with Advanced Dementia (Mitchell, 2015)</p> <ul style="list-style-type: none"> • Provision of palliative care and advanced dementia should be guided by a preference for comfort-focused care, not estimated prognosis. • Conservative measures that may improve oral intake include altering the texture of food and offering finger foods, smaller portions, favorite foods, and nutritional supplements. When feeding problems persist despite conservative measures, we suggest continued oral feeding by hand rather than tube feeding for nutritional support. • Clinicians should ensure that minimal criteria to suspect an infection are present before initiating testing and treatment, and antimicrobial use should be aligned with patient and family goals of care. • Chronic daily medications can be discontinued when they no longer have clear benefits for patients with advanced dementia.
	<p>Fourth Canadian Consensus Conference on the Diagnosis and Treatment of Dementia: Recommendations for Family Physicians (Moore et al., 2014)</p> <ul style="list-style-type: none"> • Since many persons have dementia caused by more than 1 condition, medical management for a person with dementia should be based on those diagnoses that are believed to be the predominant contributing causes for that person. • Physicians should consider the use of medications developed specifically for Alzheimer's disease in persons with dementia caused by other diseases that cause dementia. • Because of known side effects and drug costs of continuing therapy, discontinuation of medications developed specifically for Alzheimer's disease should be considered and balanced against possible worsening of cognitive function and greater functional impairment. • Physicians should be sensitive to the special issues associated with early-onset dementia, particularly in regard to loss of employment, insurance, disability benefits, pensions, and access to support services appropriate for that group.
	<p>HEDIS Summary Table of Measures, Product Lines, and Changes (National Committee for Quality Assurance, 2015)</p> <ul style="list-style-type: none"> • Potentially harmful drug/disease interactions: Percentage of Medicare members 65 years of age and older who have a diagnosis of dementia and a prescription for tricyclic antidepressants or anticholinergic agents.

Category	Guidelines
5. (continued)	<p>Dementia: A NICE-SCIE Guideline on Supporting People with Dementia and Their Carers in Health and Social Care (National Institute for Health and Clinical Excellence, 2007)</p> <ul style="list-style-type: none"> • People with dementia who develop noncognitive symptoms or behavior that challenges should be offered a pharmacological intervention in the first instance only if they are severely distressed but there is an immediate risk of harm to the person or others. The assessment and care planning approach, which includes behavioral management, should be followed as soon as possible. If distress or agitation are less severe, the interventions described should be followed before pharmacological intervention is considered. • People with Alzheimer's disease, vascular dementia or mix dementias with mild to moderate noncognitive symptoms should not be prescribed antipsychotic drugs because of the possible risk of cerebrovascular adverse events and death. • People with dementia who also have major depressive disorder should be offered antidepressant medication. Treatment should be started by staff with specialist training, who should follow the clinical guideline for depression management in primary and secondary care after a careful risk-benefit assessment. • Health and social care professionals working with people with dementia and their carers should adopt a palliative care approach. They should consider physical, psychological, social and spiritual needs to maximize the quality of life of the person with dementia and their family. <p>American Psychiatric Association Practice Guideline for the Treatment of Patients with Alzheimer's Disease and Other Dementias (Rabins et al., 2007)</p> <ul style="list-style-type: none"> • A careful evaluation for general medical, psychiatric, environmental, or psychosocial problems that may underlie a behavioral disturbance should be undertaken. If possible and safe, such underlying causes should be treated first. If this does not resolve the symptoms and if they do not cause significant danger or distress to the patient or others, such symptoms are best treated with environmental measures, including reassurance and redirection. • Depressed mood may respond to improvements in the patient's living situation or to stimulation-oriented treatments. Although evidence for antidepressant efficacy in patients with dementia and depression is mixed, clinical consensus supports a trial of an antidepressant to treat clinically significant, persistent depressed mood. • Manage co-occurring conditions such as general medical conditions, delirium, and other dementias. • When using pharmacotherapy in patients with dementia, low starting doses, small increases in dose, and long intervals between dosing governments may be needed, in addition to ensuring that a system is in place that can enhance proper medication adherence. <p>Guideline Watch: Practice Guideline for the Treatment of Patients with Alzheimer's Disease and Other Dementias (Rabins et al., 2014)</p> <ul style="list-style-type: none"> • The available evidence remains modest for the efficacy of cholinesterase inhibitors for mild to severe Alzheimer's disease and of Memantine for moderate to severe Alzheimer's disease. • Additional evidence has clarified that the adverse effects of cholinesterase inhibitors when these agents are used on a long-term basis. Such effects include anorexia, weight loss, falls, hip fractures, syncope, bradycardia, and increased use of cardiac pacemakers. • No new evidence supports the use of other pharmacological agents to prevent or treat cognitive symptoms. • New evidence indicates that antipsychotics provide weak benefits for the treatment of psychosis and agitation in patients with dementia. Adverse effects of antipsychotics reported in new studies include sedation, metabolic effects, and cognitive impairment. • New evidence indicates that for many patients with Alzheimer's disease, antipsychotics can be tapered and discontinued without significant signs of withdrawal or return of behavioral symptoms. • New studies indicate that cholinesterase inhibitors and Memantine have no clinically significant effects on disruptive behaviors. <p>Dementia. Diagnosis and Treatment (Regional Health Council, 2011)</p> <ul style="list-style-type: none"> • Starting a therapy with acetylcholinesterase inhibitors, whose effectiveness on treating symptoms is proven, should be considered at the moment of diagnosis of mild and moderate Alzheimer's disease. • The use of antidepressant drugs, preferably SSRI, can be useful in the treatment of patients with dementia and depression. Trazodone can be useful in case of agitation. • Antipsychotic drugs have partial efficacy in the treatment of psychosis and aggressiveness associated with dementia. Their use should be limited to at risk or extremely suffering patients or caregivers, and should be limited if possible in time, because of the potentially severe adverse effects of these drugs. Associations of antipsychotic drugs should be avoided.

Category	Guidelines
5. (continued)	<p>Caregiving Strategies for Older Adults with Delirium, Dementia and Depression 2010 Supplement (Registered Nurses' Association of Ontario, 2010)</p> <ul style="list-style-type: none"> • Nurses need to maintain awareness of the effect of pharmacological interventions, carefully review the older adult's medication profiles, and report medications that may contribute to potential delirium. • Nurses caring for clients with dementia should be knowledgeable about pharmacological interventions, and contribute to the decisions and education regarding the risks and benefits of medication for targeted symptoms, monitor for efficacy and side effects, document response, and advocate for reevaluation and withdrawal of psychotropics after a time period of behavioral stability.
	<p>Guidelines for the Management of Cognitive and Behavioral Problems in Dementia (Sadowski & Galvin, 2012)</p> <ul style="list-style-type: none"> • Family physicians should use pharmacologic and nonpharmacologic approaches to manage cognitive and behavioral problems in dementia. • Use medications to preserve cognitive and functional ability, minimize behavioral disturbances and slow disease progression. • Assist with evaluation and treatment of visual and hearing deficits. • There continues to be mixed evidence for the efficacy of antidepressants to treat depression in patients with dementia. • New evidence shows inconsistent effects of psychostimulants in treating severe apathy in patients with dementia.
	<p>Third Canadian Consensus Conference on Diagnosis and Treatment of Dementia (2007)</p> <ul style="list-style-type: none"> • Most patients with dementia can be assessed and managed adequately by their primary care physicians. Reasons for referral to a geriatrician, geriatric psychiatrist, neurologist, or other health care professional (e.g., neuropsychologist, nurse, nurse practitioner, occupational therapist, physical therapist, psychologist, social worker, other) with the appropriate knowledge and expertise in dementia care include: <ul style="list-style-type: none"> – Continuing uncertainty about the diagnosis. – Request by the patient or family for another opinion. – Presence of significant depression, especially if there is no response to treatment. – Treatment problems or failure with Alzheimer's-specific medications. – Need for additional help in patient management (e.g., behavioral problems or functional impairments) or caregiver support. – Patients with mild to moderate dementia, when hospitalized should be identified as being at increased risk for delirium. To reduce that risk, they should be offered multicomponent interventions including orienting communication, therapeutic activities, sleep enhancement strategies, exercise and mobilization, provision of vision and hearing aids, or fluids to avoid dehydration. – Comorbidities of patients with mild to moderate dementia should be appropriately managed. The management of comorbid conditions may have to be modified in a person with dementia. In general, there should be less reliance on patient self-care and a concomitant increase in the role played by caregivers. – Determination of how medications are being consumed and identification of any problems/concerns with medication management, including poor adherence, should be conducted for all patients with mild or moderate dementia. If problems are detected, in particular with adherence, use of compliance aids or the assumption of medication management by another party will be necessary. – The use of medications with anticholinergic effects should be minimized in persons with dementia. – Alzheimer's-specific medications are viable treatment options for most patients with Alzheimer's disease. Selection of which medication to use should be based on stage of disease or condition, adverse effect profile, ease of use, familiarity, and beliefs. If adverse effects occur, the medication should be discontinued, the dose reduced, or the manner of administration changed. Combinations of Alzheimer's-specific medications can be beneficial. – Alzheimer's-specific medications should be discontinued if the patient or proxy decision maker decides to stop, the patient refuses to take the medications or is nonadherent, there is no response, there are intolerable side effects, or comorbidities of the patient make continued use unacceptable risk or futile. – For patients with advanced dementia, medical management includes treatment of intercurrent medical conditions (e.g., infections, Parkinsonian symptoms, seizures, pressure ulcers), ameliorating pain, improving nutritional status and optimizing sensory function.

Category	Guidelines
6. Information, Education, and Informed and Supported Decision Making	<p>Dementia Care Practice Recommendations for End-of-Life Care (Alzheimer's Association, 2007)</p> <ul style="list-style-type: none"> • Ensure open and ongoing communication among the resident, proxy decision maker, family and care team so that all parties have a clear and common understanding of what constitutes optimal end-of-life care for the individual resident. • During the initial assessment and care planning process, it is important to discuss the resident's preferences regarding end-of-life decisions and any related doctor's orders such as "comfort care only," "do not resuscitate," "do not hospitalize," or "do not intubate." These orders are designed to prevent reviving, hospitalizing or inserting a tube to help the resident breathe when he or she is dying. • It is important that residents and families consider the following care decisions and the relationship of each of them to the resident's care goals during planning for the end-of-life: <ul style="list-style-type: none"> – Cardiopulmonary resuscitation. – Invasive medical procedures and tests (e.g., surgery, blood tests, dialysis). – Hospitalization. – Use of intensive care units and ventilators. – Artificial nutrition/hydration. – Use of antibiotics. – Use of preventive health screenings, medications and dietary restrictions.
	<p>Dementia Care Practice Recommendations for Assisted Living and Nursing Homes (Alzheimer's Association, 2009)</p> <ul style="list-style-type: none"> • Obtaining the most current advance directive information and information about a resident's preferences regarding palliative care and funeral arrangements helps ensure that the resident's wishes will be honored.
	<p>Dementia Care Practice Recommendations for Professionals Working in a Home Setting (Alzheimer's Association, 2009)</p> <ul style="list-style-type: none"> • To be effective, providers must understand the communication challenges presented by those living with dementia. • Providers must also consider what, how and when information should be delivered to family and other team members. • The ability of a person with dementia to understand care choices and make decisions about care varies with the progression of the disease and the type of decision required. • Ensure open and ongoing communication, among the person, health care decision maker, family and home care team, so that everyone knows the person's choices about end-of-life care and provides the best care. • Support families when an individual is dying and after death by addressing their need for education about dementia and the dying process. Reassure them about the experiences the person with dementia has while dying.
	<p>Dementia in the Long-Term Care Setting (American Medical Directors Association, 2012)</p> <ul style="list-style-type: none"> • Address ethical issues. Facilities should develop policies and procedures or guidelines for managing issues such as attempted sexual activity between 2 cognitively impaired patients or between a cognitively impaired and cognitively intact patient. The facility should have a systematic, consistent process for managing ethical issues and documenting patient wishes. The practitioner should help to define the potential benefits and burdens of treatments for the patient with dementia, clarify the patient's prognosis, and supported decision making by families or surrogates. The practitioner should review the relevance and appropriateness to the patient's overall care various treatment recommendations made by other disciplines or consultants. • Good evidence exists that artificial nutrition does not materially prolong life or improve quality of life in patients with advanced dementia. Substantial functional decline and recurrent or progressive medical illnesses may indicate that a patient who is not eating is unlikely to obtain any significant or long-term benefit from artificial nutrition and hydration.
	<p>Guidelines for the Evaluation of Dementia and Age-Related Cognitive Change (American Psychological Association, 2012)</p> <ul style="list-style-type: none"> • Psychologists recognize the value of constructive feedback, support, education, and maintenance of a therapeutic alliance with the person with possible dementia during the diagnostic evaluation process; providing feedback to the person and the family/caregiver allows the psychologist to assist with differences of opinion, respond to individual questions, and facilitate the interactions between the person and others in his/her support network. • As part of the evaluation process, psychologists appropriately recommend interventions available to persons with cognitive impairment and their caregivers (e.g., cognitive training, external aids, such as medication dispensers, approaches for managing behavioral symptoms that are consistent with the likely causes of such behaviors in a particular person); and approaches to provide optimal levels of stimulation. • Psychologists should discuss therapeutic goals with the person with dementia.

Category	Guidelines
6. (continued)	<p>Best Practice Guideline for Accommodating and Managing Behavioural and Psychological Symptoms of Dementia in Residential Care (British Columbia Ministry of Health, 2012)</p> <ul style="list-style-type: none"> • Prior to the initiation of any psychotropic medication for treating behavioral and psychological symptoms of dementia, physicians, nurses and other clinicians should carefully evaluate the risks versus benefits for each resident and obtain informed consent from the resident or their substitute decision maker prior to commencing treatment. • With the exception of emergency situations, British Columbia's health care consent law requires that the capable resident or their substitute decision maker when the adult is incapable must provide consent prior to the prescribing and administration of any health care treatment including pharmacological interventions for behavioral and psychological symptoms of dementia.
	<p>Cognitive Impairment: Recognition, Diagnosis and Management in Primary Care (British Columbia Ministry of Health, 2014)</p> <ul style="list-style-type: none"> • Dementia symptoms may be unfamiliar or viewed as part of the aging process, and there may be stigma to mental health issues, resulting in diagnosis delay-provide culturally sensitive patient information on dementia to patients and families. • Introduce advance care planning early.
	<p>Guideline for Alzheimer's Disease Management (California Workgroup on Guidelines for Alzheimer's Disease Management, 2008)</p> <ul style="list-style-type: none"> • Discuss the diagnosis, progression, treatment choices, and goals of Alzheimer's disease care with the patient and family in a manner consistent with their values, preferences, culture, educational level, and patient's abilities. • Pay particular attention to the special needs of early-stage patients, involving them in care planning, heeding their opinions and wishes, and referring them to community resources, including the Alzheimer's Association. • Discuss the patient's need to make care choices at all stages of the disease through the use of advance directives and identification of surrogates for medical and legal decision making. • Discuss the intensity of care and other end-of-life care decisions with the Alzheimer's disease patient and involved family members while respecting their cultural preferences. • Include discussion of the importance of basic legal and financial planning as part of the treatment plan as soon as possible after the diagnosis of Alzheimer's disease.
	<p>Redesigning Systems of Care for Older Adults with Alzheimer's Disease (Callahan et al., 2014)</p> <ul style="list-style-type: none"> • Educate the patient and family caregiver about the diagnosis and care options.
	<p>Advanced Dementia Expert Panel Summary and Key Recommendations (Coleman & Mitchell, 2015)</p> <ul style="list-style-type: none"> • Provide care for persons with advanced dementia that is concordant with their values and preferences.
	<p>Alzheimer's Association Recommendations for Operationalizing the Detection of Cognitive Impairment during the Medicare Annual Wellness Visit in a Primary Care Setting (Cordell et al., 2013)</p> <ul style="list-style-type: none"> • Counseling before and after cognitive assessment is an essential component of any cognitive evaluation.
	<p>Clinical Practice Guideline on the Comprehensive Care of People with Alzheimer's Disease and Other Dementias (De Sanidad, 2014)</p> <ul style="list-style-type: none"> • People with mild cognitive impairment and mild dementia should be advised to protect themselves through self-guardianship, or giving special power or writing the advance directive document. • Any person with dementia who still has sufficient capacity to act should appoint a guardian, foreseeing the possibility of being declared incapable, and adopt any provision referring to their personal care or the administration of their assets, identifying any person who should not be appointed, under any circumstances. • People with dementia who have lost their self-management capacity should have a legal representative or guardian to protect them, and substitute them. • People with dementia with reduced decision capacity should name a representative who shall care for their conservatorship, accompanying them, advising them and helping them make decisions. • People with dementia with reduced decision making capacity should name an administrator for their estate to administer their assets if these were considerable. • A judicial defender of the person with dementia must be named to cope with urgent situations if a tutor has not been named or when important differences arise between guardian and the ward.
	<p>Recognition and Management of Dementia (Fletcher, 2012)</p> <ul style="list-style-type: none"> • Provide education for caregivers. • Explain trajectory of progressive dementia, treatment options and advance directives. • Encourage and support advance care planning.

Category	Guidelines
6. (continued)	<p>EFNS Guidelines for the Diagnosis and Management of Alzheimer's Disease (Hort et al. & European Federation of Neurological Sciences Scientist Panel on Dementia, 2010)</p> <ul style="list-style-type: none"> • Diagnosis of Alzheimer's disease should be disclosed to the patient (and caregivers as appropriate). Disclosure of diagnosis should be individually tailored. It should be accompanied by information and counseling, and useful contacts such as the Alzheimer's patient organizations. Patients and caregivers should be provided with education and support. • Driving, medical legal issues, and the need for other support services should be considered. • If possible, physicians may encourage patients to draw up advance directives containing future treatment and care preferences. • Realistic expectations for treatment effects of cholinesterase inhibitors and Memantine and potential side effects should be discussed with the patient and caregivers. • Low dose of atypical agents should be used only after assessment of risk-benefit and full discussion with patient (when capacity allows) and caregiver.
	<p>Palliative Care of Patients with Advanced Dementia (Mitchell, 2015)</p> <ul style="list-style-type: none"> • Clinicians should be prepared to promote compassionate, evidence-based counseling and shared decision making to avoid burdensome care that is of limited clinical benefit and not aligned with preferences. • Patients with dementia and their families should be informed about what to expect at the end stage of the disease. Formal advance directives and an appointment of a health care proxy should be ascertained prior to the end stage of dementia.
	<p>Dementia: A NICE-SCIE Guideline on Supporting People with Dementia and Their Carers in Health and Social Care (National Institute for Health and Clinical Excellence, 2007)</p> <ul style="list-style-type: none"> • Health and social care managers should ensure that all staff working with older people in the health, social care and voluntary sectors have access to dementia care training/skill development that is consistent with their roles and responsibilities. • The experience of the diagnosis of dementia is challenging both for people with dementia and family members and for health care professionals, so health care professionals should make time available to discuss the diagnosis and its implications with the person with dementia and also with family members. Health care professionals should be aware that people with dementia and family members may need ongoing support to cope with the difficulties presented by the diagnosis. • Following a diagnosis of dementia, health and social care professionals should, unless a person with dementia clearly indicates to the contrary, provide them and their family with written information about: the signs and symptoms of dementia, the course and prognosis of the condition, treatments, local care and support services, support groups, sources of financial and legal advice and advocacy, medical legal issues, including driving, local information sources, including libraries and voluntary organizations. Any advice and information given should be recorded in the notes. • Health and social care professionals should always seek valid consent from people with dementia. This should entail informing the person of options, and checking that he or she understands, that there is no coercion and that he or she continues to consent over time. If the person lacks the capacity to make a decision, the provisions of the Mental Capacity Act 2005 must be followed. • Diagnostic disclosure: People who are assessed for the possibility of dementia should be asked if they wish to know the diagnosis and with whom this should be shared.
	<p>PQRS 2105 Measure List, Measure Numbers 25, and 149-157 (Physician Quality Reporting System, 2014)</p> <ul style="list-style-type: none"> • Caregiver Education and Support: Percentage of patients, regardless of age, with a diagnosis of dementia whose caregiver(s) were provided with education on dementia disease management and health behavior changes and referred to additional sources for support within a 12-month period. • Care Plan: Percentage of patients aged 65 years and older who have an advance care plan or surrogate decision maker documented in the medical record or documentation in the medical record that an advance care plan was discussed but the patient did not wish or was not able to name a surrogate decision maker or provide an advance care plan; includes persons with Chronic Kidney Disease, Heart Failure, HIV/AIDS, Parkinson's Disease, Chronic Obstructive Pulmonary Disorder, and Dementia.

Category	Guidelines
6. (continued)	<p>American Psychiatric Association Practice Guideline for the Treatment of Patients with Alzheimer's Disease and Other Dementias (Rabins et al., 2007)</p> <ul style="list-style-type: none"> • Patients and families should be advised about potential benefits and risks of antipsychotic agents particularly the risk of mortality. Second-generation antipsychotics currently have a black box warning for increased risk of mortality in elderly patients; recent data suggest that first-generation typical agents carry at least a similar risk. • Risks of driving should be discussed with all patients with dementia and their families, and these discussions should be carefully documented. Discussions should include an exploration of the patient's current driving patterns, transportation needs, and potential alternatives. For patients with dementia who continue to drive, the issue should be raised repeatedly and reassessed over time. <p>Dementia. Diagnosis and Treatment (Regional Health Council, 2011)</p> <ul style="list-style-type: none"> • Expected benefits of treatment should be discussed with patients and caregivers. <p>Caregiving Strategies for Older Adults with Delirium, Dementia and Depression 2010 Supplement (Registered Nurses' Association of Ontario, 2010)</p> <ul style="list-style-type: none"> • Nurses should determine whom the client has appointed as powers of attorney for personal care, and property and whenever possible include the power of attorney along with the client in decision making, consent, and care planning. • If there is no power of attorney for personal care, nurses should encourage and facilitate the process for older adults to appoint power of attorney for personal care and to have discussions about end-of-life treatment and wishes while mentally capable. <p>Dementias including Alzheimer's Disease (Healthy People 2020, 2014)</p> <ul style="list-style-type: none"> • Awareness of diagnosis: Increase the proportion of persons with Alzheimer's disease and other dementias, or their caregiver, who are aware of the diagnosis. <p>Third Canadian Consensus Conference on Diagnosis and Treatment of Dementia (2007)</p> <ul style="list-style-type: none"> • Primary care physicians should communicate appropriate information concerning dementia, including realistic treatment expectations, to patients and their families. • The process of diagnostic disclosure for a person with cognitive impairment or dementia must begin as soon as the possibility of cognitive impairment is suspected. • Both the diagnosis of dementia and the disclosure of the diagnosis must be considered processes that provide opportunities for education and discussion. • The potential for adverse psychological consequences of diagnostic disclosure must be assessed and addressed through education of the patient and the family/caregivers. • Although each case should be considered individually, in general the diagnosis of dementia should be disclosed to the patient and family in a manner that is consistent with the expressed wishes of the patient. This process should include a discussion of prognosis, diagnostic uncertainty, advance planning, driving issues, treatment options, support groups, and future plans. • Follow-up plans must be made and discussed at the time of diagnostic disclosure. • Primary care physicians should be aware of the laws in their jurisdiction about informed consent, assessment of capacity, identification of a surrogate decision maker, and the responsibilities of physicians in these matters. • While patients with dementia retain capacity, they should be encouraged to update their will and enact both an advance directive and an enduring power of attorney. • A diagnosis of dementia does not preclude competence to provide informed consent, whether it be for treatment decisions or participation in research. The potential that competency for treatment and research decision making will change over time must be recognized. Such change may require movement from obtaining the patient's ongoing consent to obtaining ongoing assessment. Assent is almost invariably required, and the decision to discontinue treatment, whether it be therapy or research, must always be an option. • To the best of their ability, clinicians must ensure that the decisions made by proxies are based on the prior attitudes and values of the patient. Proxies have a responsibility to represent the patient, and all parties must recognize the challenges of doing so.
7. Acknowledgement and Emotional Support for the Person with Dementia	<p>Dementia Care Practice Recommendations for Professionals Working in a Home Setting (Alzheimer's Association, 2009)</p> <ul style="list-style-type: none"> • It is obligatory to protect a person with dementia from seriously harmful consequences, and it is equally obligatory to respect his or her competent decisions. Neither law nor ethics allow interference with the competent person's choices. • In general, respect for the autonomy, freedom and choice of a person with Alzheimer's disease or related dementia, to the extent possible, is ethically important and the appropriate alternative to unnecessary coercion. • People with dementia should be allowed to exercise their remaining capacities for choice, consistent with their cultural expectations. Denying this free exercise challenges their independence and dignity.

Category	Guidelines
7. (continued)	<p>Clinical Practice Guideline on the Comprehensive Care of People with Alzheimer's Disease and Other Dementias (De Sanidad, 2014)</p> <ul style="list-style-type: none"> • The fundamental rights of the person to dignity, participation, autonomy and self-determination must be preserved. <p>Recognition and Management of Dementia (Fletcher, 2012)</p> <ul style="list-style-type: none"> • Provide social engagement. • Emphasize residual strengths. <p>Practice Guidelines for Assessing Pain in Older Persons with Dementia Residing in Long-Term Care Facilities (Hadjistavropoulos, Fitzgerald, & Marchildon, 2010)</p> <ul style="list-style-type: none"> • Always attempt self-report regardless of level of cognitive functioning. <p>Pain Assessment in the Patient Unable to Self-Report: Position Statement with Clinical Practice Recommendations (Herr et al., 2011)</p> <ul style="list-style-type: none"> • Attempt first to elicit a self-report from patient and, if unable, document why self-report cannot be used. Self-report of pain is often possible in mild to moderate cognitive impairment, but ability to self-report decreases as dementia progresses. <p>Dementia Care: The Quality Chasm (Dementia Initiative, 2013)</p> <ul style="list-style-type: none"> • Services should be provided based on individual preferences, culture, values, lifestyle choices and needs to support his/her unique rhythms of daily living. • Every person has his/her own meaning of life, authenticity (personality, spirit, and character) history, interests, personal preferences, and needs to continue to experience life at all stages of dementia. The person is not their dementia illness; rather the condition is only 1 aspect of their current status. Personalized practices recognize and support the whole person. • Interact with the person with dementia in ways that honor and support his or her individual personhood. <p>American Psychiatric Association Practice Guideline for the Treatment of Patients with Alzheimer's Disease and Other Dementias (Rabins et al., 2007)</p> <ul style="list-style-type: none"> • Among the emotion oriented treatments, supportive psychotherapy can be employed to address issues of loss in the early stages of dementia. <p>Guideline Watch: Practice Guideline for the Treatment of Patients with Alzheimer's Disease and Other Dementias (Rabins et al., 2014)</p> <ul style="list-style-type: none"> • Support programs for caregivers and patients with dementia significantly decreased the odds of institutionalization and improved caregiver well-being. <p>Caregiving Strategies for Older Adults with Delirium, Dementia and Depression 2010 Supplement (Registered Nurses' Association of Ontario, 2010)</p> <ul style="list-style-type: none"> • Nurses need to establish and maintain a therapeutic supportive relationship with older adults based on the individual's social and psychological aspects. <p>Guidelines for the Management of Cognitive and Behavioral Problems in Dementia (Sadowski & Galvin, 2012)</p> <ul style="list-style-type: none"> • Increase social interaction.
8. Assistance for the Person with Dementia with Daily Functioning and Activities	<p>Dementia Care Practice Recommendations for End-of-Life Care (Alzheimer's Association, 2007)</p> <ul style="list-style-type: none"> • Use a person-centered, culturally sensitive approach to providing care that meets a resident's changing needs and respects his or her preferences regarding end-of-life care. • Minimize the resident's physical, emotional and spiritual distress, while maximizing comfort and well-being in a manner consistent with an individual's preferences regarding end-of-life care. <p>Dementia Care Practice Recommendations for Assisted Living and Nursing Homes (Alzheimer's Association, 2009)</p> <ul style="list-style-type: none"> • Staffing patterns should ensure that residents with dementia have sufficient assistance to complete their health and personal care routines and to participate in the daily life of the residence. • Direct care staff need education, support and supervision that empowers them to tailor their care to the needs of residents. • Staff who understand the prognosis and symptoms of dementia and how this differs from normal aging and reversible forms of dementia are better prepared to care for people with dementia. • Assure proper nutrition and hydration, given resident preferences and life circumstances. • Promote mealtimes as pleasant and enjoyable activities where staff have an opportunity to observe and interact with residents. • Offer many opportunities each day for providing a context with personal meaning, a sense of community, choices and fun. • Design interactions to do with--not to or for--the resident. • Respect resident preferences even if the residents prefer solitude.

Category	Guidelines
8. (continued)	<p>Dementia Care Practice Recommendations for Professionals Working in a Home Setting (Alzheimer's Association, 2009)</p> <ul style="list-style-type: none"> • Consistent staff assignment and having the same direct care providers at the same time of day creates a more predictable daily routine and can improve the quality of the relationships among direct care providers, people with dementia and their families. • Provide care that is sensitive to the person's abilities, and maximizes independence and participation in personal care. • Provide care that takes into account cultural sensitivities around such issues as communication, care delivery and care choices. • Anticipate changes and plan ahead to provide care that is based on knowledge of the individual's choices, needs and abilities. • Help the person eat and drink what he or she likes, and provide food that meets dietary needs to promote health and safety. • Help to make mealtimes pleasant and enjoyable, involve family when the person and family are amenable. • Provide care that meets the person's changing needs, respects his or her choices about end-of-life care, and adapts to changes in care goals as a person's condition worsens. • Minimize the person's physical, emotional and spiritual distress while maximizing comfort and well-being. • Help the person with dementia have and sustain meaningful social relationships. • Develop trust with the person by showing a sincere interest in the social relationships and activities he or she enjoys. • Design meaningful activities that match a person's interests, choices and abilities and that providers or family do with--not to or for--the person so that he or she can have the best quality of life possible. • Encourage daily exercise to increase or maintain physical strength.
	<p>Geriatric Emergency Department Guidelines: Delirium and Dementia in the Geriatric Emergency Department (American College of Emergency Physicians, 2013)</p> <ul style="list-style-type: none"> • A therapeutic environment should be provided whenever possible. Preventative measures should include: <ul style="list-style-type: none"> – Use sensory aids as appropriate. – Foster orientation. – Regulate bowel/bladder function. – Provide adequate nutrition. – Increase supervised mobility. – Increase awareness and vision whenever possible. – Communicate clearly.
	<p>Dementia in the Long-Term Care Setting (American Medical Directors Association, 2012)</p> <ul style="list-style-type: none"> • Manage functional deficits. A restorative nursing program may help to optimize the function of a patient who has impaired cognition and behavior. Practitioners should help to identify patients who are likely to benefit from such interventions and authorize appropriate evaluations and management.
	<p>Palliative Care for Advanced Dementia (Bryant, Alonzo & Long, 2010)</p> <ul style="list-style-type: none"> • Anticipate the person's needs instead of waiting for the behavior to occur. Address basic needs at all times. • Know how to make the person comfortable and communicate this to other team members caring for this individual. • Empower staff to do whatever makes the person with advanced dementia most comfortable.
	<p>Redesigning Systems of Care for Older Adults with Alzheimer's Disease (Callahan et al., 2014)</p> <ul style="list-style-type: none"> • Facilitate regular cognitive, physical, and social activity.
	<p>Advanced Dementia Expert Panel Summary and Key Recommendations (Coleman & Mitchell, 2015)</p> <ul style="list-style-type: none"> • Use quality metrics to ensure avoidance of burdensome, nonbeneficial treatments (e.g., tube feeding).

Category	Guidelines
8. (continued)	<p>Dementia Care: The Quality Chasm (Dementia Initiative, 2013)</p> <ul style="list-style-type: none"> • Focus on the strengths of the person living with dementia rather than on what abilities and capabilities have been diminished or lost. • Care partners should learn the preferences of the person with dementia for bathing, dressing, grooming and other daily activities and provide care based on those preferences. • Having the same staff members consistently provide care and support for a person with dementia helps to build relationships and knowledge about how to best provide the care and support. • Movement should be encouraged throughout the stages of dementia. It can be used to maintain and enhance motor functions, increase balance, mobility, strength and stamina, and manage stiffness and atrophy. • For individuals living with dementia, relationships and belonging are especially important and add familiarity, comfort, meaning, and context to daily living. • Having meaningful things to do adds purpose and enjoyment in daily life and fosters emotional health and a sense of connection with others. Since people have different needs for solitude and socialization, what is purposeful and meaningful for each individual is unique to them. • Meaningful and engaging things to do throughout the day are essential to support health and well-being. These rhythms of daily life not only provide purpose and structure to the day, but the meaningful activities help to support life roles and functions that are important to preserving value, self-esteem, and confidence, and to identify and create a sense of belonging. • Many people need to feel a connection to something beyond their own person. This can be through spiritual/religious practices. Spirituality is more diverse than religion as it is not restricted to any specific religious beliefs, institutions, or practices. For many people, religious or spiritual memories and rituals bring a sense of great comfort. <p>Clinical Practice Guideline on the Comprehensive Care of People with Alzheimer's Disease and Other Dementias (De Sanidad, 2014)</p> <ul style="list-style-type: none"> • Cognitive intervention programs, especially those based on reality counseling therapies and cognitive training, must be adapted to the cognitive skills and the emotional tolerance of each patient, to avoid adverse emotional consequences. <p>Recognition and Management of Dementia (Fletcher, 2012)</p> <ul style="list-style-type: none"> • Provide graded assistance as needed with ADLs and IADLs. • Ensure adequate rest, sleep, fluid, nutrition, elimination, pain control, and comfort measures. • Maximize functional capacity; maintain mobility and encourage independence as long as possible; provide scheduled toileting and prompted voiding to reduce urinary incontinence; encourage an exercise routine that expends energy and promotes fatigue at bedtime, and establish bedtime routine and rituals. • Provide appropriate end-of-life care in terminal phase; provide comfort measures including adequate pain management; weigh the benefits/risks of the use of aggressive treatment (e.g., tube feeding, antibiotic therapy). <p>EFNS Guidelines for the Diagnosis and Management of Alzheimer's Disease (Hort et al. & European Federation of Neurological Sciences Scientist Panel on Dementia, 2010)</p> <ul style="list-style-type: none"> • Cognitive stimulation or rehabilitation may be considered in patients with mild to moderate Alzheimer's disease. Occupational therapy can improve a patient's functioning and reduce the need for informal care. <p>Caregiving Strategies for Older Adults with Delirium, Dementia and Depression 2010 Supplement (Registered Nurses' Association of Ontario, 2010)</p> <ul style="list-style-type: none"> • Nurses should know their clients, recognize their retained abilities, understand the impact of the environment, and relate effectively when tailoring and implementing their caregiving strategies. • In consultation/collaboration with the interdisciplinary team: nurses should determine if a client is capable of personal care, treatment, and property decisions. If the client is incapable, nurses should approach substitute decision makers regarding care issues. <p>Guidelines for the Management of Cognitive and Behavioral Problems in Dementia (Sadowski & Galvin, 2012)</p> <ul style="list-style-type: none"> • Establish regular sleep habits.

Category	Guidelines
8. (continued)	<p>Occupational Therapy Practice Guidelines for Adults with Alzheimer's Disease and Related Disorders (Schaber, 2010)</p> <ul style="list-style-type: none"> • Performance skills: the Occupational Therapy practitioner needs to be aware of individual skills on a case-by-case basis. • Performance patterns are the habits, routines, rituals, and roles in daily activity. Habits become strengths that the person can draw from when he or she is no longer able to remember how to perform. Because habits are automatic, people may engage in an occupation beyond their cognitive ability to do so. A person in the middle and later stages of dementia can function optimally when he or she is able to draw from early learning and long-term memory and replicate skills that are well rehearsed. New learning is challenging with dementia. The person who is unable to learn a new routine may be able to carry out former routines successfully. People with cognitive impairment report that consistency in task demands and stability in their daily environment contributes to decreased stress and anxiety. Part of the evaluation process is to consider the person's former habits, routines, and rituals that were familiar and support occupational performance. The goal for family caregivers is to support habitual behavior and adapt routines for optimal functional performance. <p>Third Canadian Consensus Conference on Diagnosis and Treatment of Dementia (2007)</p> <ul style="list-style-type: none"> • Provide individualized exercise activities to maintain physical functioning. • Nonpharmacological approaches to manage sleep disturbances can be effective, but a combination of these approaches is likely to be required. When clinically necessary, pharmacological interventions can be used at the lowest effective dose for the shortest possible time. • The care and management of patients with dementia from specific cultural groups should take into account the risk of isolation, the importance of culturally appropriate services, and issues that arise in providing caregiver support. • The goals for management for persons with advanced dementia are to improve quality of life for the patient and caregivers, maintain optimal function and provide maximum comfort. • Patients with mild to moderate dementia, when hospitalized should be identified as being at increased risk for delirium. To reduce that risk, they should be offered multicomponent interventions including orienting communication, therapeutic activities, sleep enhancement strategies, exercise and mobilization, provision of vision and hearing aids, or fluids to avoid dehydration.
9. Involvement, Emotional Support, and Assistance for	<p>Dementia Care Practice Recommendations for End-of-Life Care (Alzheimer's Association, 2007)</p> <ul style="list-style-type: none"> • Family members are an important part of the care team and often derive satisfaction in knowing that they can still help with the care and comfort of their loved ones. To facilitate this, staff may provide suggestions for activities that the family members can engage in with the resident. • Soliciting input from the proxy decision maker or family regarding care options and development of a care plan helps them know that they are contributing to the well-being of the resident. <p>Dementia Care Practice Recommendations for Professionals Working in a Home Setting (Alzheimer's Association, 2009)</p> <ul style="list-style-type: none"> • Family members may play a vital role in helping a person with dementia remain at home. • Assess family caregivers to determine what type of support is needed. Responses to the following will help providers shape care for family caregivers: caregiver's health status, caregivers communication needs, kind of help the family caregiver is providing including how often and how long, tasks the family caregiver would like to continue/discontinue and tasks the caregiver is unsafe or unqualified to handle, support the family caregiver would like to have, caregivers emotional status and additional responsibilities the caregiver has such as childcare and employment. • Every family needs easy access to a home care team that responds to its needs and questions. Responsive communication can include team meetings that involve family. It can also include assigning a primary nurse or social worker to the person with dementia, and keeping regular contact through home visits, phone calls, or e-mail, text messages or other electronic technologies. • Whenever possible, a family member should be designated as the primary contact for all members of the home care team. However it is important to recognize that different family members can have different responsibilities. <p>Cognitive Impairment: Recognition, Diagnosis and Management in Primary Care (British Columbia Ministry of Health, 2014)</p> <ul style="list-style-type: none"> • Always involve the caregiver and plan on several visits to establish and inform patient/caregiver of diagnosis. <p>Redesigning Systems of Care for Older Adults with Alzheimer's Disease (Callahan et al., 2014)</p> <ul style="list-style-type: none"> • Accept the caregiver-care recipient dyad as the target of care.

Category	Guidelines
9. (continued)	<p>Guideline for Alzheimer's Disease Management (California Workgroup on Guidelines for Alzheimer's Disease Management, 2008) Identify the primary caregiver and assess the adequacy of family and other support systems, paying particular attention to the caregivers on mental and physical health.</p>
	<p>Clinical Practice Guideline on the Comprehensive Care of People with Alzheimer's Disease and Other Dementias (De Sanidad, 2014)</p> <ul style="list-style-type: none"> • The use of specific adapted and validated instruments is recommended to assess other aspects that may be affected by the caregiver burden. • It is recommended for those caregivers who express a significant degree of stress or depression to be referred to their primary care physician or mental health specialist for their assessment and treatment.
	<p>Recognition and Management of Dementia (Fletcher, 2012)</p> <ul style="list-style-type: none"> • The caregiver of the patient with dementia often has as many needs as the patient with dementia; therefore, a detailed assessment of the caregiver and the caregiving environment is essential. • Elicit the caregiver perspective of patient function and the level of support provided. • Evaluate the impact that the patient's cognitive impairment and problem behaviors have on the caregiver (mastery, satisfaction, and burden). • Evaluate the caregiver's experience and patient-caregiver relationship. • Respect family systems/dynamics and avoid making judgments; encourage open dialogue.
	<p>Practice Guidelines for Assessing Pain in Older Persons with Dementia Residing in Long-Term Care Facilities (Hadjistavropoulos, Fitzgerald, & Marchildon, 2010)</p> <ul style="list-style-type: none"> • Knowledgeable informants (e.g., caregivers) should be asked about typical pain behaviors of the individual.
	<p>Pain Assessment in the Patient Unable to Self-Report: Position Statement with Clinical Practice Recommendations (Herr et al., 2011)</p> <ul style="list-style-type: none"> • Credible information can be obtained from a family member or another person who knows the patient well (e.g., spouse, parent, child, caregiver). Consistent caregivers should be encouraged to actively participate in the assessment of pain. Familiarity with the patient and knowledge of the usual and past behaviors can assist in identifying subtle less obvious changes in behavior that may be indicators of pain presence.
	<p>EFNS Guidelines for the Diagnosis and Management of Alzheimer's Disease (Hort et al. & European Federation of Neurological Sciences Scientist Panel on Dementia, 2010)</p> <ul style="list-style-type: none"> • Clinical history should be supplemented by an informant. • Several informant-based questionnaires are available and should be used where possible.
	<p>Using Dementia as the Organizing Principle when Caring for Patients with Dementia and Comorbidities (Lazaroff et al., 2013)</p> <ul style="list-style-type: none"> • Because dementia gradually degrades a person's ability to participate in his or her own medical care, good care requires the assistance of the care partner (in the early stages) or caregiver (later on as disability increases) who will bring the patient to appointments, participate in the visit, oversee or supervise medication adherence, and serve as a source of information about the patient's progress. • Identifying and developing a working relationship with the care partner or caregiver is essential to caring for a person with dementia. • Physicians and other PCP should stress the importance of the caregiver and insist that he or she attend all office visits. They also should offer them ongoing support and look for clues that might suggest that the support the patient is receiving at home may be inadequate or that the caregiver is overburdened.
	<p>Dementia: A NICE-SCIE Guideline on Supporting People with Dementia and Their Carers in Health and Social Care (National Institute for Health and Clinical Excellence, 2007)</p> <ul style="list-style-type: none"> • Health and social care managers should ensure that the rights of carers to receive an assessment of needs, as set out in the Carers and Disabled Children Act 2000 and the Carers Equal Opportunities Act 2004, are upheld. • Those carrying out carers assessment should seek to identify any psychological distress and the psychosocial impact on the carer. This should be an ongoing process and should include any period after the person with dementia has entered residential care. • Care plans for carers of people with dementia should involve a range of tailored interventions. These may consist of multiple components including: individual or group psychoeducation; peer support groups with other carers, tailored to the needs of individuals depending on the stage of dementia of the person being cared for and other characteristics; support and information by telephone and through the Internet; training courses about dementia, services and benefits, and communication and problem-solving in the care of people with dementia; involvement of other family members and the primary care or in family meetings. • Consideration should be given to involving people with dementia in psychoeducation, support, and other meetings for carers.

Category	Guidelines
9. (continued)	<p>American Psychiatric Association Practice Guideline for the Treatment of Patients with Alzheimer's Disease and Other Dementias (Rabins et al., 2007)</p> <ul style="list-style-type: none"> • Decisions regarding the need for temporary or permanent placement in a long-term care facility often depend on the degree to which the patient's needs can be met in the community, either by relatives or other caregivers, either in an assisted living facility or at home. The decision to remain at home should be reassessed regularly, with consideration of the patient's clinical status and the continued ability of the patient's caregivers to care for the patient, manage the burden of care, and use available support services. • As with any psychiatric care, a solid therapeutic alliance is critical to the treatment of a patient with dementia. The care of a patient with dementia requires an alliance with the patient, and with the family and other caregivers. Family members and other caregivers are critical sources of information, as the patient is frequently unable to give a reliable history, particularly as the disease progresses. Because family members are often responsible for implementing and monitoring treatment plans, their own attitudes and behaviors can have a profound effect on the patient, and they often need the treating physician's compassion and concern. For these reasons, treatment is directed to the patient-caregiver system. • Caregivers should be referred to available books that provide advice and guidance about maximizing the safety of the environment for patients with dementia. • Provide education and support to patients and families: <ul style="list-style-type: none"> – Educate the patient and family about the illness and available treatments. – Refer the family to appropriate sources of care and support. – Watch for signs of caregiver distress. – Support families during decisions about institutionalization. – Advise the family to address financial and legal issues. • At each stage of the illness, the psychiatrist should be vigilant for cognitive and noncognitive symptoms likely to be present and should help the patient and family anticipate future symptoms. The family may also benefit from reminders to plan for the care likely to be necessary at later stages.
	<p>Dementia. Diagnosis and Treatment (Regional Health Council, 2011)</p> <ul style="list-style-type: none"> • Times and ways for the training and support of caregivers should be planned.
	<p>Caregiving Strategies for Older Adults with Delirium, Dementia and Depression 2010 Supplement (Registered Nurses' Association of Ontario, 2010)</p> <ul style="list-style-type: none"> • Nurses should create partnerships with family members or significant others in the care of clients. This is true for clients who live in either the community or in health care facilities.
	<p>Guidelines for the Management of Cognitive and Behavioral Problems in Dementia (Sadowski & Galvin, 2012)</p> <ul style="list-style-type: none"> • Assess the role and needs of the caregiver.
	<p>Occupational Therapy Practice Guidelines for Adults with Alzheimer's Disease and Related Disorders (Schaber, 2010)</p> <ul style="list-style-type: none"> • Family centered care model: affects all steps of the evaluation and intervention planning process by including family caregivers in obtaining information for the occupational history, setting goals, and exploring strengths and limitations.
	<p>EFNS-ENS Guidelines on the Diagnosis and Management of Disorders Associated with Dementia (Sorbi et al., 2012)</p> <ul style="list-style-type: none"> • Counseling and case/care management amongst caring family members have positive effects on burden and satisfaction for caregivers of people with dementia.
	<p>Third Canadian Consensus Conference on Diagnosis and Treatment of Dementia (2007)</p> <ul style="list-style-type: none"> • The clinician should acknowledge the important role played by the caregiver, work with caregivers and families on an ongoing basis, and schedule regular appointments for patients and caregivers together and alone. • The clinician should inquire about caregiver information and support needs, caregiver health (both physical and psychiatric), and the effect of the patient's problem behaviors on the caregiver.
	<p>Dementia Care Practice Recommendations for End-of-Life Care (Alzheimer's Association, 2007)</p> <ul style="list-style-type: none"> • Provide support to families, other residents and staff when an individual is dying and after death has occurred to help them achieve meaningful closure. • Families of dying residents benefit from ready access to the broader care team and team members who are approachable and responsive to family needs and questions.
	<p>Geriatric Emergency Department Guidelines: Delirium and Dementia in the Geriatric Emergency Department (American College of Emergency Physicians, 2013)</p> <ul style="list-style-type: none"> • A therapeutic environment should be provided whenever possible. Preventative measures should include: <ul style="list-style-type: none"> – Reassure and educate the family.

Category	Guidelines
9. (continued)	<p>Dementia Care: The Quality Chasm (Dementia Initiative, 2013)</p> <ul style="list-style-type: none"> • Changes in the person with dementia can be confusing and upsetting to their family and friends and may be disruptive to these relationships. Help family and friends acknowledge the changes and offer them tools for engaging with the person as he or she is today. This approach will enhance well-being for both the person with dementia and the family and friends on whom they increasingly rely. <p>Recognition and Management of Dementia (Fletcher, 2012)</p> <ul style="list-style-type: none"> • Provide caregiver support. • Teach caregivers the skills of caregiving. <p>Dementia: A NICE-SCIE Guideline on Supporting People with Dementia and Their Carers in Health and Social Care (National Institute for Health and Clinical Excellence, 2007)</p> <ul style="list-style-type: none"> • Carers of people with dementia who experience psychological distress and negative psychological impact should be offered psychological therapy, including cognitive behavioral therapy, conducted by a specialist practitioner. • Health and social care professionals should ensure that support, such as transport or short break services, is provided for carers to enable them to participate in the interventions. • Health and social care managers should ensure that carers of people with dementia have access to a comprehensive range of respite/short break services. <p>Guideline Watch: Practice Guideline for the Treatment of Patients with Alzheimer's Disease and Other Dementias (Rabins et al., 2014)</p> <ul style="list-style-type: none"> • Support programs for caregivers and patients with dementia significantly decreased to the odds of institutionalization and improved caregiver well-being. <p>Third Canadian Consensus Conference on Diagnosis and Treatment of Dementia (2007)</p> <ul style="list-style-type: none"> • The clinician should offer treatment for physical and psychiatric problems of the caregiver, including psychotherapy or medications as indicated, and refer the caregiver to appropriate specialists. • The care and management of patients with dementia from specific cultural groups should take into account the risk of isolation, the importance of culturally appropriate services, and issues that arise in providing caregiver support. • The clinician should assist in recruiting other family members and formal community services to share the caregiving role and refer the caregiver to specialized programs that offer caregiver education, support, and training.
10. Prevention and Mitigation of Behavioral and Psychological Symptoms of Dementia	<p>Dementia Care Practice Recommendations for Assisted Living and Nursing Homes (Alzheimer's Association, 2009)</p> <ul style="list-style-type: none"> • The behavior and emotional state of people with dementia often are forms of communication because residents may lack the ability to communicate verbally and other ways. • Staff need initial and ongoing training to identify potential triggers for resident's behavioral and emotional symptoms, such as agitation and depression. • When staff recognize these triggers, they can use environmental and behavioral strategies to modify the triggers' impact. • If nonpharmacological treatment options fail after they have been applied consistently, then introducing new medications may be appropriate when residents have severe symptoms or have the potential to harm themselves or others. • Minimize injuries by avoiding physical restraints. • Identify the underlying problems or needs that prompt the use of restraints, and address them using restraint-free methods. • Provide staff with techniques they can use to prevent, reduce and eliminate use of restraints. <p>Dementia Care Practice Recommendations for Professionals Working in a Home Setting (Alzheimer's Association, 2009)</p> <ul style="list-style-type: none"> • All behaviors, including reactions to daily care, are a form of communication. The direct care provider is responsible for interpreting and responding to behaviors. • Use gentle caregiving techniques including: warnings before touching a person or beginning care, apologies for causing distress and keeping the person covered and warm. • Listen to and validate the person's concerns, address those concerns, and provide reassurance. • Educate direct care providers and family members about methods they can use to prevent, reduce and eliminate restraints. <p>Geriatric Emergency Department Guidelines: Delirium and Dementia in the Geriatric Emergency Department (American College of Emergency Physicians, 2013)</p> <ul style="list-style-type: none"> • Limit the use of chemical and physical restraints to only those situations in which they are absolutely necessary. <p>Dementia in the Long-Term Care Setting (American Medical Directors Association, 2012)</p> <ul style="list-style-type: none"> • Identify triggers for disruptive behaviors. Do not assume that a behavior is triggered by environmental or other nonmedical factors until alternate causes have been considered. This is especially important when patients are newly admitted, have recently been hospitalized, or have a significant change of condition.

Category	Guidelines
10. (continued)	<p>Best Practice Guideline for Accommodating and Managing Behavioural and Psychological Symptoms of Dementia in Residential Care (British Columbia Ministry of Health, 2012)</p> <ul style="list-style-type: none"> • Consider the person's physical, intellectual, emotional, capabilities, and environmental and social factors to understand his/her behaviors. • Individualize interventions based on assessment. Use nonpharmacological interventions before turning to pharmacological interventions, and if medications are medically indicated, continue using nonpharmacological, person-centered approaches. • Successful management of behavioral and psychological symptoms of dementia require physicians, nurses, other clinicians and all health care providers to understand the resident's needs behind the dementia-related behaviors, rather than attempt to control or extinguish them. • Make adjustments in the understanding of what can influence or trigger behaviors, and implement approaches to care that are person-centered and tailored to the individual with an emphasis on the patient's remaining abilities and strengths. • Consider the multifactorial nature of behavioral and psychological symptoms of dementia and that not all behaviors are strictly responsive to stimuli but rather some may be related to neurochemical changes in the brain, which can contribute to behavioral presentations along with environmental press. • It is important for the interdisciplinary team to identify the triggers of the behavior to initiate preventative measures and appropriate interventions. • By using the ABC model to understand behaviors in terms of antecedents, behavior and the consequences, it is possible to affect change in some behaviors by manipulating triggers in the physical or social environment, or altering responses to the behavior that perpetuate, rather than using a pharmacological intervention. • There is some evidence that individualized treatments and approaches that combined pharmacological and nonpharmacological interventions can lead to a significant reduction in agitation. • All interventions should be based on an approach that assesses the person's behaviors comprehensively, implements person-centered strategies to mitigate antecedents and consequences, evaluates and documents outcomes, prevents recurrence and focuses on quality improvement.
	<p>Guideline for Alzheimer's Disease Management (California Workgroup on Guidelines for Alzheimer's Disease Management, 2008)</p> <ul style="list-style-type: none"> • Treat behavioral symptoms and mood disorders using nonpharmacologic approaches, such as environmental modification, task simplification, appropriate activities etc. • If nonpharmacological approaches prove unsuccessful, then use medications, targeted to specific behaviors, if clinically indicated. Note that side effects may be serious and significant.
	<p>Redesigning Systems of Care for Older Adults with Alzheimer's Disease (Callahan et al., 2014)</p> <ul style="list-style-type: none"> • Regularly assess the patient for problem behaviors and train the caregiver in identifying and managing those behaviors.
	<p>Dementia Care: The Quality Chasm (Dementia Initiative, 2013)</p> <ul style="list-style-type: none"> • Behaviors are often expressions of unmet needs, such as pain, hunger, thirst, boredom, loneliness, or an underlying medical condition that the person with dementia is challenged to communicate to a care partner or to address him or herself. <ul style="list-style-type: none"> – The alternative to treating behavioral symptoms with medications is to determine the root cause of the behavior and then address the cause with the appropriate person-centered strategies. A personalized approach yields far better results from a humanistic context, carries less medical risk for the person with dementia, and promotes well-being. – Many people with dementia have a lifetime of experiences being creating and making creative things such as paintings, sculpture, music, photograph, etc. For persons living with dementia with considerable communication challenges, the symbolic and emotional language of the arts provides a way to express themselves without frustration, have meaning, and connect with others. Providing opportunities for them to express creative and artistic interests can help increase their feelings of self-identify, worth, purpose, and self-confidence. – Music that is perceived as familiar and pleasant by the listener has been found to override confusing stimuli by providing a comforting auditory environment that can decrease distress, evoke positive feelings, and create a sense of meaningful connection with others. Music can be used to introduce a sense of familiarity into a new environment or to maximize familiarity in an existing environment. – Beneficial touch can take many forms, including massage, therapeutic touch, and Reiki. Caring touch transmits connection and compassion.
	<p>Clinical Practice Guideline on the Comprehensive Care of People with Alzheimer's Disease and Other Dementias (De Sanidad, 2014)</p> <ul style="list-style-type: none"> • It must be taken into account that mental health services carry out an essential role in the care of people with dementia, as they contribute to the diagnosis, the treatment and hospital care if severe behavioral and psychological symptoms of dementia appear. They provide coordinated, comprehensive and multidisciplinary care.

Category	Guidelines
10. (continued)	<p>Recognition and Management of Dementia (Fletcher, 2012)</p> <ul style="list-style-type: none"> • Address behavioral issues: <ul style="list-style-type: none"> – Identify environmental triggers; medical conditions, caregiver-patient conflict that may be causing the behavior. – Define the target symptom (i.e., agitation, aggression, wandering and pharmacological (psychotropics) and nonpharmacological (manage affect, limit stimuli, respect space, distract, redirect) approaches. – Provide reassurance. • Refer to appropriate mental health care professionals as necessary. • Avoid use of physical restraints. <p>EFNS Guidelines for the Diagnosis and Management of Alzheimer’s Disease (Hort et al. & European Federation of Neurological Sciences Scientist Panel on Dementia, 2010)</p> <ul style="list-style-type: none"> • Management of behavioral and psychological symptoms of dementia should begin with a careful search for triggers and causative factors (i.e., physical illness). Where possible, initial treatment should be nonpharmacological. <p>Fourth Canadian Consensus Conference on the Diagnosis and Treatment of Dementia: Recommendations for Family Physicians (Moore et al., 2014)</p> <ul style="list-style-type: none"> • Nonpharmacologic interventions for agitation and aggression in dementia include recognition and management of potentiating factors (medical, psychiatric, medications, environment). • Nonpharmacologic treatment should be considered before drug therapy in people with dementia who have agitation or aggression, because the potential benefit of all antipsychotic medications must be weighed against their substantial risk (stroke and mortality). • Antipsychotic medications should be considered for severe agitation, aggression, and psychosis with dementia where there is risk of harm to the patient or others. <ul style="list-style-type: none"> – A trial of antidepressant medications should be considered if the patient has an inadequate response to nonpharmacologic interventions or has a major depressive disorder.

Category	Guidelines
10. (continued)	<p>Dementia: A NICE-SCIE Guideline on Supporting People with Dementia and Their Carers in Health and Social Care (National Institute for Health and Clinical Excellence, 2007)</p> <ul style="list-style-type: none"> • People with dementia who develop noncognitive symptoms that cause them significant distress or who develop behavioral challenges should be offered an assessment at an early opportunity to establish the likely factors that may generate, aggravate or improve such behavior. The assessment should be comprehensive and include: the person's health, depression, possible undetected pain or discomfort, side effects of medication, individual biography, including religious beliefs and spiritual and cultural identity, psychosocial factors, physical environmental factors, and behavioral and functional analysis conducted by professionals with specific skills, in conjunction with carers and care workers. • Individually tailored care plans that help carers and staff address the behavioral challenges should be developed, recorded in the notes and reviewed regularly. The frequency of the review should be agreed upon by the carers and staff involved and written in the notes. • People with mild to moderate dementia of all types should be given the opportunity to participate in a structured group cognitive stimulation program. This should be commissioned and provided by a range of health and social care staff with appropriate training and supervision, and offered irrespective of any drug prescribed for the treatment of cognitive symptoms of dementia. • For people with all types and severity's of dementia who have comorbid agitation, consideration should be given to providing access to interventions tailored to the person's preferences, skills and abilities. Because people may respond better to 1 treatment than another, the response to each modality should be monitored and the care plan adapted accordingly. • Health and social care staff who care for people with dementia should identify, monitor and address environmental, physical health and psychosocial factors that may increase the likelihood of behavioral challenges, especially violence and aggression, and the risk of harm to self or others. These factors include: overcrowding, lack of privacy, lack of activities, inadequate staff attention, poor communication between the person with dementia and staff, conflicts between staff and carers, and weak clinical leadership. • Health and social care staff should be trained to anticipate behavioral challenges and how to manage violence, aggression and extreme agitation, including de-escalation techniques and methods of physical restraint. • Violent behavior should be managed without the prescription of high doses or combinations of drugs, especially if the person with dementia is elderly or frail. The lowest effective dose should be used. • Drugs for behavioral control should be used with caution, particularly if the person with dementia has been restrained, because of the following risks: loss of consciousness instead of sedation; oversedation with loss of alertness; damage to the relationship between the person with dementia, their carers and the health and social care team; specific issues related to age and physical and mental health. • People with dementia who have received involuntary sedation and their carers should be offered the opportunity to discuss their experiences and be provided with a clear explanation of the decision to use urgent sedation. This should be documented in their notes. • A range of tailored interventions, such as reminiscence therapy, multisensory stimulation, animal assisted therapy and exercise, should be available for people with dementia who have depression or anxiety.
	<p>What Information Can I Get About Quality Measures? (Nursing Home Compare, 2015)</p> <ul style="list-style-type: none"> • Percentage of short-stay residents who are newly administered antipsychotic medications. • Percent of long-stay residents who got an antipsychotic medication.
	<p>PQRS 2105 Measure List, Measure Numbers 25, and 149-157 (Physician Quality Reporting System, 2014)</p> <ul style="list-style-type: none"> • Management of Neuropsychiatric Symptoms: Percentage of patients, regardless of age, with a diagnosis of dementia who have 1 or more neuropsychiatric symptoms who received or were recommended to receive an intervention for neuropsychiatric symptoms within a 12-month period.

Category	Guidelines
10. (continued)	<p>American Psychiatric Association Practice Guideline for the Treatment of Patients with Alzheimer's Disease and Other Dementias (Rabins et al., 2007)</p> <ul style="list-style-type: none"> • In addition to the general psychosocial interventions subsumed under psychiatric management, a number of specific interventions are appropriate for some patients. Few of these treatments have been subjected to double-blind randomized evaluation, but some research, along with clinical practice, supports their effectiveness. <ul style="list-style-type: none"> – Behavior oriented treatments are used to identify the antecedents and consequences of problem behaviors and attempt to reduce the frequency of behaviors by directing changes in the environment that alter those antecedents and consequences. Behavioral approaches have not been subjected to large randomized clinical trials but are supported by small trials and case studies and are in widespread clinical use. – Stimulation-oriented treatments, such as recreational activity, art therapy, music therapy, and pet therapy, along with other formal and informal means of maximizing pleasurable activities for patients, have modest support from clinical trials for improving behavior, mood, and to a lesser extent, function. Common sense supports their use as part of the humane care of patients. – Reminiscence therapy has some modest research support for improvement of mood and behavior; validation therapy and sensory integration have less research support; none of these modalities has been subjected to rigorous testing. – Cognition-oriented treatments, such as reality orientation, cognitive retraining, and skills training focused on specific cognitive deficits, are unlikely to have a persistent benefit and have been associated with frustration in some patients. • Sleep disturbances are common in patients with dementia. Interventions include maintaining daytime activities and giving careful attention to sleep hygiene. Pharmacological intervention could be considered when other approaches of failed. • Care should be organized to meet the needs of patients in residential care/nursing home care, including those with behavioral problems. Employing staff with knowledge and experience concerning dementia and the management of difficult behavior is important. • A multimodal approach is often use in treatment, combining for instance, behavioral and psychopharmacological interventions is appropriate and available. The site of treatment for an individual with dementia is determined by the need to provide safe and effective treatment in the least restrictive setting.
	<p>Dementia. Diagnosis and Treatment (Regional Health Council, 2011)</p> <ul style="list-style-type: none"> • The first line of treatment for psychological and behavioral disorders is nonpharmacological, because of the potentially severe adverse effects caused by pharmacological treatments.
	<p>Caregiving Strategies for Older Adults with Delirium, Dementia and Depression 2010 Supplement (Registered Nurses' Association of Ontario, 2010)</p> <ul style="list-style-type: none"> • Nurses have a role in the prevention, identification and implementation of delirium care approaches to minimize disruptive behaviors of the person and provide a safe environment. Further, it is recommended that restraints should only be used as a last resort to prevent harm to self and others. • Nurses caring for clients with dementia should be knowledgeable about nonpharmacological interventions for managing behavior to promote physical and psychological well-being.
	<p>Guidelines for the Management of Cognitive and Behavioral Problems in Dementia (Sadowski & Galvin, 2012)</p> <ul style="list-style-type: none"> • Nonpharmacologic interventions should be used to manage behavioral symptoms. • Avoid situations that agitate or frighten the person with dementia. • Redirect and refocus the person with dementia. • Eliminate sources of conflict and frustration.
	<p>EFNS-ENS Guidelines on the Diagnosis and Management of Disorders Associated with Dementia (Sorbi et al., 2012)</p> <ul style="list-style-type: none"> • Antipsychotic medications, conventional and atypical agents, may be utilized in clinical practice for aggression, psychosis, and agitation and SSRIs for mood and behavioral disorders, however, there is little evidence to guide practice.

Category	Guidelines
10. (continued)	<p>Third Canadian Consensus Conference on Diagnosis and Treatment of Dementia (2007)</p> <ul style="list-style-type: none"> • The management of behavioral and psychological symptoms of dementia should include careful documentation of the behaviors, a search for potential triggers, recording of the consequences of the behaviors, an evaluation to rule out treatable or contributory causes, and consideration of the safety of the patient, the caregiver, and others in their environment. • Nonpharmacological treatments should be used first. Some patients with behavioral and psychological symptoms may benefit from the following: music, Snoezelen, bright light therapy, reminiscence therapy, validation therapy, aroma therapy, and massage and touch therapy. • Pharmacological treatments should be initiated only after consideration, and usually a trial, of nonpharmacological interventions. The medications should be started at a low dose and then titrated carefully based on the patient's response and the presence of adverse effects. • If the patient's behaviors are causing significant caregiver distress, the clinician should refer the caregiver and the patient to specialized dementia services that can offer treatment to the patient and assist the caregiver in modifying his or her interactions with the patient. • Community-based programs that may be effective for behavioral and psychological symptoms include adult day care; support groups that focus on management of such symptoms; in-home systematic, comprehensive support by a health care provider with advanced training in dementia care over an extended period; and in-home psychoeducational interventions that teach caregivers how to manage behavioral problems. • Depression should be diagnosed promptly when patients with dementia exhibit behavioral symptoms, weight and sleep changes, sadness, crying, suicidal statements, or excessive guilt. • Depression should be treated nonpharmacologically first. If there is an inadequate response, antidepressants should be considered.
11. Safety for the Person with Dementia	<p>Dementia Care Practice Recommendations for Assisted Living and Nursing Homes (Alzheimer's Association, 2009)</p> <ul style="list-style-type: none"> • Prevent unsafe wandering and exit seeking. • Promote safety and preserve mobility by reducing risk of falls and fall-related injuries.

Category	Guidelines
11. (continued)	<p>Dementia Care Practice Recommendations for Professionals Working in a Home Setting (Alzheimer's Association, 2009)</p> <ul style="list-style-type: none"> • Encourage safety and maintain a person's ability to move within a living space by decreasing the risk of falls and related injuries. • Minimize fall-related injuries by avoiding physical restraints, such as a chair that a person cannot leave. • Be prepared to respond if an unsafe wandering event occurs. • Additional Special Topics: <ul style="list-style-type: none"> – Considerations for Those Who Live Alone: <ul style="list-style-type: none"> ▪ Always introduce yourself and mention the name of a family member or friend to help the person understand why you are there. ▪ Allow sufficient time to build trust. ▪ If the person is suspicious, a call from the agency (to confirm that the provider is there to help) or from a family member (to verify that it is all right to let the provider in) may be enough to gain entrance. ▪ If the person will not open the door, sometimes leaving and attempting to visit again later the same day (or another day) is an effective approach. ▪ Build rapport by learning about the person's interests, history, favorite memories, family and friends. ▪ Monitor food and fluid intake. ▪ Check for fire and other safety risks as part of every visit, including food left cooking on the stove, evidence of small fires, burns on the person or on furniture, and frayed or loose wires. ▪ Provide support to help the person with dementia maintain as much independence as possible. ▪ Anticipate and avoid crisis situations. – Elder Abuse and Neglect: <ul style="list-style-type: none"> ▪ Situations of abuse and neglect are some of the more difficult and complicated situations involving people with dementia. Persons with dementia may have difficulty speaking up about or noticing abusive or neglectful situations. It is important to use communication techniques to de-escalate the situation and to intervene appropriately, including making a report of the elder abuse or neglect. ▪ Sometimes persons with dementia neglect to their own care, which can lead to illness or injury. Self-neglect can include behaviors or consequences such as hoarding, failure to take medications or get medical treatment when sick, poor hygiene and housekeeping, not wearing the right clothes for the weather, dehydration and malnutrition, eviction notices, failing to pay bills and utility shutoffs. – Emergency Preparedness: <ul style="list-style-type: none"> ▪ When people with dementia, who may already be scared or confused, are involved in an emergency situation, the response may be magnified or inappropriate. Strong communication skills may be the most important tool to keep the person safe from harm. ▪ Encourage family members to make an emergency kit. ▪ During an emergency, remember to remain calm. People with dementia are especially vulnerable to chaos and emotional trauma; they will react to the provider's emotional response. ▪ Remember that the individual has limited ability to understand directions and may forget them. ▪ Emergency situations may cause agitation, frustration, and feelings of being overwhelmed. ▪ Emergency situations often include a change in environment, and this can lead to wandering. Individuals should be enrolled in Medic Alert[®] + Alzheimer's Association Safe Return[®]. ▪ Make sure people other than the primary caregiver have copies of the person with dementia's medical history, medications, physician information and family contacts.
	<p>Guideline for Alzheimer's Disease Management (California Workgroup on Guidelines for Alzheimer's Disease Management, 2008)</p> <ul style="list-style-type: none"> • Monitor for evidence and report all suspicions of abuse, as required by law.
	<p>Clinical Practice Guideline on the Comprehensive Care of People with Alzheimer's Disease and Other Dementias (De Sanidad, 2014)</p> <ul style="list-style-type: none"> • People suffering abuse must be informed, respecting their rights to confidentiality, to support for their basic needs, preservation of their social relationships. • If there is a probable suspicion of abuse, the health personnel must activate the judicial resources that permit the defense of the victim of abuse. If there are physical injuries, a judicial report of injuries will be drafted. If there are no injuries or other acute contingencies, the public prosecutor will be informed.
	<p>Recognition and Management of Dementia (Fletcher, 2012)</p> <ul style="list-style-type: none"> • Ensure a safe environment. • Eliminate any environmental hazards and modify the environment to enhance safety.

Category	Guidelines
11. (continued)	<p>PQRS 2105 Measure List, Measure Numbers 25, and 149-157 (Physician Quality Reporting System, 2014)</p> <ul style="list-style-type: none"> • Counseling Regarding Safety Concerns: Percentage of patients, regardless of age, with a diagnosis of dementia or their caregiver(s) who were counseled or referred for counseling regarding safety concerns within a 12-month period. • Counseling Regarding Risks of Driving: Percentage of patients, regardless of age, with a diagnosis of dementia or their caregiver(s) who were counseled regarding the risks of driving and the alternatives to driving at least once within a 12-month period. <p>Caregiving Strategies for Older Adults with Delirium, Dementia and Depression 2010 Supplement (Registered Nurses' Association of Ontario, 2010)</p> <ul style="list-style-type: none"> • Nurses must initiate prompt attention for clients exhibiting suicidal ideation or intent to harm others. <p>EFNS-ENS Guidelines on the Diagnosis and Management of Disorders Associated with Dementia (Sorbi et al., 2012)</p> <ul style="list-style-type: none"> • Assessment of driving ability should be made after diagnosis with particular attention paid to visual-spatial, visual perceptual, and executive abilities. <p>Third Canadian Consensus Conference on Diagnosis and Treatment of Dementia (2007)</p> <ul style="list-style-type: none"> • Clinicians should counsel persons with a progressive dementia and their families that giving up driving will be an inevitable consequence. Strategies to ease this transition should occur early in the clinical course of the condition. The driving ability of persons in earlier stages of dementia should be tested on an individual basis. For persons deemed safe to drive, reassessment of their ability to drive should occur at least every 6-12 months.
12. Therapeutic Environment, Including Modifications to the Physical and Social Environment of the Person with Dementia	<p>Dementia Care Practice Recommendations for Assisted Living and Nursing Homes (Alzheimer's Association, 2009)</p> <ul style="list-style-type: none"> ▪ The physical environment can encourage and support independence while promoting safety. ▪ The optimal environment feels comfortable and familiar, as a home would, rather than a hospital. The environment should be less about physical structures and more about the feeling inspired by the quality of the place. ▪ Providing easy, safe and secure access to the outdoors while maintaining control over unauthorized exiting enhances the environment. ▪ Encourage, support, and maintain a resident's mobility and choice, enabling him or her to move about safely and independently. <p>Dementia Care Practice Recommendations for Professionals Working in a Home Setting (Alzheimer's Association, 2009)</p> <ul style="list-style-type: none"> ▪ A comfortable home environment can involve adjusting room temperature, providing supportive seating, eliminating glare, reducing noise levels and offering enjoyable activities, such as listening to music or reading. <p>Geriatric Emergency Department Guidelines: Delirium and Dementia in the Geriatric Emergency Department (American College of Emergency Physicians, 2013)</p> <ul style="list-style-type: none"> ▪ A therapeutic environment should be provided whenever possible. Preventative measures should include: <ul style="list-style-type: none"> – Provide appropriate sensory stimulation such as quiet room, adequate light, noise reduction. – Foster familiarity such as encourage family/friends to stay at bedside, bring familiar objects from home, minimize relocations. – Communicate clearly. <p>Dementia in the Long-Term Care Setting (American Medical Directors Association, 2012)</p> <ul style="list-style-type: none"> ▪ Optimize the patient's function and quality of life utilizing specialized environment, trained caregiver staff, and activity programs and special care units. <p>Palliative Care for Advanced Dementia (Bryant, Alonzo & Long, 2010)</p> <ul style="list-style-type: none"> ▪ Create a homelike environment and support tactile, acoustic, olfactory, visual and thermal stimulations.

Category	Guidelines
12. (continued)	<p>Dementia Care: The Quality Chasm (Dementia Initiative, 2013)</p> <ul style="list-style-type: none"> ▪ Person-centered environments are multifaceted and need to incorporate the physical and social-emotional dimensions. The attention to and interaction of effective design, indoor and outdoor space, colors, light, sound, furniture, and furnishings blend to create a warm, comfortable, orienting, safe place to be. ▪ Support relationships in the work environment by ensuring that staff have time to spend with residents/clients to form, nurture, and maintain relationships. ▪ The physical and social environment in all care settings can have a significant impact on the overall well-being and quality of life for people who have dementia. The goal of positive environments is to enable them to achieve maximum functioning, comfort, functionality, safety, and well-being. They can experience a reduced stress threshold to environmental and sensory stimulation. For instance, noise and light levels and other forms of sensory stimulation can cause unintended negative outcomes. There should be an effective physical and social environment. ▪ Everyday social interactions, including brief positive interactions with casual acquaintances and caregivers, foster a sense of well-being. Laughing, singing or simply being with others can exert a calming or energizing influence. Knowing that one is part of a social community larger than oneself can provide a reassuring context. Social interactions may also be too stimulating at times, and being alone may be what is needed for a person to recoup his or her sense of self. ▪ Exposure to light has been shown to increase total nocturnal sleep time, decrease daytime napping, reduce behavioral outburst and increase stability of rest-activity rhythms. Persons with dementia can have particular visual deficits such as difficulty distinguishing color, reduced depth perception, and reduced sensitivity to contrast because of diminished cognitive ability to decode information. Being exposed to sufficient light can boost mood. Avoid bright sunlight, slanted sunlight through windows or poorly position lighting, which can cause glare, especially if it reflects off highly polished floors and table tops, and glossy walls. ▪ Being outdoors and experiencing nature can provide pleasurable things to do (e.g., gardening, watching birds, walking). Besides the physical exercise benefit, for some, the outdoors can help them feel a spiritual connection. Exposure to natural sunlight also helps to regulate a body's circadian rhythm and sleep/wake cycles. ▪ Environmental noise and sound can create stress for persons with dementia. Background noise from phones, machines, traffic, television and radio can cause auditory overstimulation resulting in agitation. Noise can disturb rest, relaxation and sleep. It is important to be mindful of the effect of environmental noise on the person with dementia. <p>Recognition and Management of Dementia (Fletcher, 2012)</p> <ul style="list-style-type: none"> ▪ Ensure a therapeutic environment: <ul style="list-style-type: none"> – Utilize patient identifiers (name tags); medical alert systems and bracelets, locks, and wander guard. – Provide environmental cues or sensory aids that facilitate cognition. – Ensure a therapeutic environment: provide an environment that is modestly stimulating, avoiding overstimulation that can cause agitation and increase confusion and understimulation that can cause sensory deprivation and withdrawal. – Maintain consistency in caregivers and approaches. <p>Practice Guidelines for Assessing Pain in Older Persons with Dementia Residing in Long-Term Care Facilities (Hadjistavropoulos, Fitzgerald, & Marchildon, 2010)</p> <ul style="list-style-type: none"> ▪ Other aspects of the pain experience should also be evaluated including environmental factors, psychological functioning and social environment. <p>Guideline Watch: Practice Guideline for the Treatment of Patients with Alzheimer's Disease and Other Dementias (Rabins et al., 2014)</p> <ul style="list-style-type: none"> ▪ Available research does not conclusively show which psychosocial interventions work best for which service setting, specific behavior, disease stage, or caregiver and patient profile. ▪ Additional evidence suggests the value of psychosocial interventions to improve or maintain cognition, function, adaptive behavior, and quality of life but does not demonstrate whether any specific psychosocial intervention is more effective than another. <p>Caregiving Strategies for Older Adults with Delirium, Dementia and Depression 2010 Supplement (Registered Nurses' Association of Ontario, 2010)</p> <ul style="list-style-type: none"> ▪ Nurses need to identify, reduce, or eliminate environmental factors that may contribute to delirium. <p>Guidelines for the Management of Cognitive and Behavioral Problems in Dementia (Sadowski & Galvin, 2012)</p> <ul style="list-style-type: none"> ▪ Ensure a calm and predictable environment. ▪ Remove environmental stressors. ▪ Ensure a safe environment.

Category	Guidelines
12. (continued)	<p>Occupational Therapy Practice Guidelines for Adults with Alzheimer’s Disease and Related Disorders (Schaber, 2010)</p> <ul style="list-style-type: none"> ▪ Physical environment: natural and built nonhuman environment is a key area of evaluation for Occupational Therapy that has the potential to affect interventions and management of the care of a person with Alzheimer’s disease. Environments include the primary living space in places that the person frequents in day-to-day activities. Aging in place means that the environment can be adapted to provide the precautionary supports for safety and independence. ▪ Social environment: includes people in the client’s life who are able to provide supports in daily living activities. Evaluating the social supports is accomplished through interview of the client and family members. It is important to know who the primary caregiver and decision maker and what responsibilities that person is willing to accept. The social environment includes both paid (formal) and unpaid (informal) supports. Beyond family members, friends or neighbors also may be willing to provide assistance with weekly or daily tasks. ▪ Cultural context: occupational therapy evaluations include information gathered through interview about cultural influences on customs, beliefs, activity patterns, behavior standards, and expectations to design a culturally sensitive intervention. Caregiving is considered a cultural activity, with caregiving outcomes and experiences differing for ethnic groups. ▪ Personal context: the personal context includes age, gender, educational level, socioeconomic level, marital status, and family composition and should be part of the information obtained in the occupational profile. Alzheimer’s disease is an age-related disease in that the greater majority of people in the early to middle stages of the disease or in their later years. Younger onset poses a particular challenge because decisions regarding workforce involvement are emotional and affect self-worth. ▪ Temporal context: the temporal context refers to the “experience of time shaped by engagement in occupations.” Information about circadian rhythms (a measure of core body temperature and motor activity) as part of the initial interview and an occupational therapy evaluation because of the prevalence of “sundowners syndrome” in people with Alzheimer’s disease. Altered sleep-wake cycles occur in the middle stages of the disease. Altered sleep-wake cycles occur when daytime becomes confused with nighttime. ▪ Virtual (technology for home monitoring) context: defined as a simulated environment that uses communication technologies in the absence of human presence, can keep the person safe within his or her own home or in a residential facility. An interview can focus on information about behavioral issues related to wandering were exiting safe areas or potentially hazardous activities that require monitoring.
13. Care Transitions	<p>Dementia Care Practice Recommendations for End-of-Life Care (Alzheimer’s Association, 2007)</p> <ul style="list-style-type: none"> • When residents choose hospice care, effective staff training, care coordination and communication between the nursing home or assisted living residents and the hospice service help ensure the provision of high-quality end-of-life care. <p>Dementia Care Practice Recommendations for Professionals Working in a Home Setting (Alzheimer’s Association, 2009)</p> <ul style="list-style-type: none"> • Assess the need for a transition and care by considering safety, health, and care needs. • When a person is discharged from the hospital or nursing home, the person with dementia (whenever possible) and the family caregiver need an opportunity to participate in the planning and know the reason for the discharge. • At the time of discharge, the person with dementia and family caregiver need a clear understanding of the discharge plan and care instructions. • In addition, the process of medication reconciliation should be performed to ensure that all medications are current and necessary and to minimize the potential for drug interaction problems. <p>Advanced Dementia Expert Panel Summary and Key Recommendations (Coleman & Mitchell, 2015)</p> <ul style="list-style-type: none"> • Harmonize documentation and tracking of level of functional and cognitive status across care settings. • Use quality metrics to measure burdensome, nonbeneficial transitions. <p>Dementias including Alzheimer’s Disease (Healthy People 2020, 2014)</p> <ul style="list-style-type: none"> • Preventable Hospitalization: Reduce the proportion of preventable hospitalizations in persons with diagnosed Alzheimer’s disease and other dementias. <p>Palliative Care of Patients with Advanced Dementia (Mitchell, 2015)</p> <ul style="list-style-type: none"> • Hospital transfers should be avoided unless clearly needed to achieve the desired goals of care.

Category	Guidelines
14. Referral and Coordination of Care and Services that Match the Needs of the Person with Dementia and Family Caregiver(s) and Collaboration among Agencies and Providers	<p>Dementia Care Practice Recommendations for Professionals Working in a Home Setting (Alzheimer's Association, 2009)</p> <ul style="list-style-type: none"> • Understand the needs of family and other care team members, and schedule and provide access to respite care services when they need to leave the home.
	<p>Cognitive Impairment: Recognition, Diagnosis and Management in Primary Care (British Columbia Ministry of Health, 2014)</p> <ul style="list-style-type: none"> • Community supports may not provide culturally appropriate care, resulting in lack of adoption of the services and increase in caregiver stress.
	<p>Guideline for Alzheimer's Disease Management (California Workgroup on Guidelines for Alzheimer's Disease Management, 2008)</p> <ul style="list-style-type: none"> • Referral to early-stage groups or adult day services for appropriate structured activities, such as physical exercise and recreation. • Referral to social service agencies or support organizations, including the Alzheimer's Association's Medic Alert + Safe Return[®] program for patients who may wander. • Connect patient and caregiver to support organizations for linguistically and culturally appropriate educational materials and referrals to community resources, support groups, legal counseling, respite care, consultation on care needs and options, and financial resources.
	<p>Redesigning Systems of Care for Older Adults with Alzheimer's Disease (Callahan et al., 2014)</p> <ul style="list-style-type: none"> • Refer the patient to relevant community support services.
	<p>Recognition and Management of Dementia (Fletcher, 2012)</p> <ul style="list-style-type: none"> • Provide access to experienced professionals. • Integrate community resources into the plan of care to meet the needs for patient and caregiver information. • Identify and facilitate both formal (e.g., Alzheimer's associations, respite care, specialized long-term care) and informal (e.g., churches, neighbors, extended family/friends) support systems. • Community resources for education and support are accessed and utilized by the patient or caregivers.
	<p>Report and Recommendations (Gerontological Society of America Workgroup on Cognitive Impairment Detection and Earlier Diagnosis, 2015)</p> <ul style="list-style-type: none"> • Refer to community resources and clinical trials, depending on the diagnosis. • Community resources should include the local Area Agency on Aging, the local chapter of the Alzheimer's Association, state Aging and Disability Resource Centers, and, as appropriate, organizations representing different causes of dementia, such as Parkinson's disease and frontotemporal dementia.
	<p>Palliative Care of Patients with Advanced Dementia (Mitchell, 2015)</p> <ul style="list-style-type: none"> • When available, referral to hospice or specialized palliative care services should be considered in the care plan of patients with advanced dementia.
	<p>Fourth Canadian Consensus Conference on the Diagnosis and Treatment of Dementia: Recommendations for Family Physicians (Moore et al., 2014)</p> <ul style="list-style-type: none"> • Physicians should be sensitive to the special issues associated with early-onset dementia, particularly in regard to loss of employment, insurance, disability benefits, pensions, and access to support services appropriate for that group.
	<p>Dementia: A NICE-SCIE Guideline on Supporting People with Dementia and Their Carers in Health and Social Care (National Institute for Health and Clinical Excellence, 2007)</p> <ul style="list-style-type: none"> • Respite/short break care of any sort should be characterized by meaningful and therapeutic activity tailored to the person with dementia and provided in an environment that meets their needs. Providing this in the person's own home should be considered whenever possible.
	<p>American Psychiatric Association Practice Guideline for the Treatment of Patients with Alzheimer's Disease and Other Dementias (Rabins et al., 2007)</p> <ul style="list-style-type: none"> • A referral to the local chapter of the Alzheimer's Association or to a social worker or another individual knowledgeable about local resources, treatment centers, and Medicaid laws can be important in helping families find local treatment options that fit their needs and budget.
	<p>Guidelines for the Management of Cognitive and Behavioral Problems in Dementia (Sadowski & Galvin, 2012)</p> <ul style="list-style-type: none"> • Refer people with dementias and family caregivers to social service agencies and support resources, such as the Alzheimer's Association.
	<p>EFNS-ENS Guidelines on the Diagnosis and Management of Disorders Associated with Dementia (Sorbi et al., 2012)</p> <ul style="list-style-type: none"> • A dementia diagnosis mandates an inquiry to the community for available public health care support programs.
<p>Third Canadian Consensus Conference on Diagnosis and Treatment of Dementia (2007)</p> <ul style="list-style-type: none"> • All patients with dementia and their families who consent should be referred to the local chapter of the Alzheimer Society. • Primary care physicians should be aware of the resources available for the care of those with dementia in their community and make appropriate referrals to them. 	

Category	Guidelines
14. (continued)	<p>Dementia Care Practice Recommendations for Professionals Working in a Home Setting (Alzheimer's Association, 2009)</p> <ul style="list-style-type: none"> • When more than 1 agency serves a person, coordination of care, interagency coordination agreements and communication are important.
	<p>Advanced Dementia Expert Panel Summary and Key Recommendations (Coleman & Mitchell, 2015)</p> <ul style="list-style-type: none"> • Specialized medical care for persons with advanced dementia requires a team of doctors, nurses and other specialists who work with a person's other doctors to provide an extra layer of support.
	<p>Clinical Practice Guideline on the Comprehensive Care of People with Alzheimer's Disease and Other Dementias (De Sanidad, 2014)</p> <ul style="list-style-type: none"> • To optimize the comprehensive treatment of dementia, it is recommended that there be referral, admission and discharge criteria for each health care resource.
	<p>Dementia: A NICE-SCIE Guideline on Supporting People with Dementia and Their Carers in Health and Social Care (National Institute for Health and Clinical Excellence, 2007)</p> <ul style="list-style-type: none"> • Health and social care managers should coordinate and integrate working across all agencies involved in the treatment and care of people with dementia and their carers, including jointly agreeing written policies and procedures. Joint planning should include local service users and carers to highlight and address problems specific to each locality. • Care managers and care coordinators should ensure the coordinated delivery of health and social care services for people with dementia. This should involve: <ul style="list-style-type: none"> – A combined care plan agreed by health and social services that takes into account the changing needs of the person with dementia and his or her carers. – Assignment of named health or social care staff to operate the care plan. – Endorsement of the care plan by the person with dementia or carers. – Formal reviews of the care plan, at a frequency agreed between professionals involved in the person with dementia or carers and recorded in the notes. • Health and social care managers should coordinate and integrate working across all agencies involved in the treatment and care of people with dementia and their carers, including jointly agreeing to written policies and procedures. Joint planning should include local service users and carers to highlight and address problems specific to each locality. • Health and social care professionals should ensure that people with dementia and their carers are given up to date information on local arrangements including interagency working for health and social care, including the independent and voluntary sectors, and how to access such services.
	<p>American Psychiatric Association Practice Guideline for the Treatment of Patients with Alzheimer's Disease and Other Dementias (Rabins et al., 2007)</p> <ul style="list-style-type: none"> • The appropriate level of care may change over time and patience often moved from 1 level of care to another during the course of dementia. If available, consultation with a social worker or geriatric case manager may be beneficial to assess the current support system and facilitate referrals to additional services.
	<p>Caregiving Strategies for Older Adults with Delirium, Dementia and Depression 2010 Supplement (Registered Nurses' Association of Ontario, 2010)</p> <ul style="list-style-type: none"> • Nurses need to facilitate creative client/family/community partnerships to ensure quality care that is individualized for the older client with depression. • Nurses should initiate prompt consultation to specialized services.
	<p>Guidelines for the Management of Cognitive and Behavioral Problems in Dementia (Sadowski & Galvin, 2012)</p> <ul style="list-style-type: none"> • Physicians play a key role in coordination the support network of nurse practitioners, physician assistance, social workers and medical assistants.
	<p>Occupational Therapy Practice Guidelines for Adults with Alzheimer's Disease and Related Disorders (Schaber, 2010)</p> <ul style="list-style-type: none"> • Referral to occupational therapy is appropriate: <ul style="list-style-type: none"> – In the early stages of dementia if cognitive limitations are barriers to participation in daily living skills, social activities, leisure interests, or work in volunteer activities. – In the middle stages of dementia to determine service needs such as home health assistance, memory care or day service programs or caregiver respite support. – In later stages of the disease to resolve barriers to performance and self-care or to manage challenging behavior such as agitation, aggression, disruptive vocalizations, wandering, etc.
	<p>Third Canadian Consensus Conference on Diagnosis and Treatment of Dementia (2007)</p> <ul style="list-style-type: none"> • Primary care physicians should be aware of the resources available for the care of those with dementia in their community and make appropriate referrals to them.

APPENDIX A-2. COMPONENTS OF DEMENTIA CARE, BY GUIDELINE

Guidelines	Components													
	Detection of Possible Dementia	Diagnosis	Assessment & Ongoing Reassessment	Care Planning	Medical Management	Information, Education, & Informed & Supported Decision Making	Acknowledgement & Emotional Support for the Person with Dementia	Assistance for the Person with Dementia with Daily Functioning & Activities	Involvement, Emotional Support, & Assistance for Family Caregiver(s)	Prevention & Mitigation of Behavioral & Psychological Symptoms of Dementia	Safety for the Person with Dementia	Therapeutic Environment, Including Modifications to the Physical & Social Environment of the Person with Dementia	Care Transitions	Referral & Coordination of Care & Services that Match the Needs of the Person with Dementia & Family Caregiver(s) & Collaboration Among Agencies & Providers
Dementia Care Practice Recommendations for End-of-Life Care (Alzheimer's Association, 2007)			√	√		√		√	√				√	
Dementia Care Practice Recommendations for Assisted Living and Nursing Homes (Alzheimer's Association, 2009)			√	√	√	√		√		√	√	√		
Dementia Care Practice Recommendations for Professionals Working in a Home Setting (Alzheimer's Association, 2009)	√		√	√	√	√	√	√	√	√	√	√	√	√
Geriatric Emergency Department Guidelines: Delirium and Dementia in the Geriatric Emergency Department (American College of Emergency Physicians, 2013)	√				√			√	√	√		√		
Dementia in the Long-Term Care Setting (American Medical Directors Association, 2012)	√	√	√	√	√	√		√		√		√		
Guidelines for the Evaluation of Dementia and Age-Related Cognitive Change (American Psychological Association, 2012)	√	√	√			√								
Best Practice Guideline for Accommodating and Managing Behavioural and Psychological Symptoms of Dementia in Residential Care (British Columbia Ministry of Health, 2012)			√	√	√	√				√				

Guidelines	Components													
	Detection of Possible Dementia	Diagnosis	Assessment & Ongoing Reassessment	Care Planning	Medical Management	Information, Education, & Informed & Supported Decision Making	Acknowledgement & Emotional Support for the Person with Dementia	Assistance for the Person with Dementia with Daily Functioning & Activities	Involvement, Emotional Support, & Assistance for Family Caregiver(s)	Prevention & Mitigation of Behavioral & Psychological Symptoms of Dementia	Safety for the Person with Dementia	Therapeutic Environment, Including Modifications to the Physical & Social Environment of the Person with Dementia	Care Transitions	Referral & Coordination of Care & Services that Match the Needs of the Person with Dementia & Family Caregiver(s) & Collaboration Among Agencies & Providers
Cognitive Impairment: Recognition, Diagnosis and Management in Primary Care (British Columbia Ministry of Health, 2014)	√	√			√	√			√					√
Palliative Care for Advanced Dementia (Bryant, Alonzo & Long, 2010)				√				√				√		
Guideline for Alzheimer's Disease Management (California Workgroup on Guidelines for Alzheimer's Disease Management, 2008)	√	√	√	√	√	√	√	√	√	√	√	√	√	√
Redesigning Systems of Care for Older Adults with Alzheimer's Disease (Callahan et al., 2014)		√	√	√	√	√		√	√	√				√
Clinical Practice Guideline for Dementia. Part I: Diagnosis and Evaluation (Clinical Research Center for Dementia of South Korea, 2011)	√	√	√		√									
Advanced Dementia Expert Panel Summary and Key Recommendations (Coleman & Mitchell, 2015)	√		√		√	√		√					√	√
Alzheimer's Association Recommendations for Operationalizing the Detection of Cognitive Impairment during the Medicare Annual Wellness Visit in a Primary Care Setting (Cordell et al., 2013)	√	√	√			√								
Dementia Care: The Quality Chasm (Dementia Initiative, 2013)			√	√			√	√	√	√	√	√		
Clinical Practice Guideline on the Comprehensive Care of People with Alzheimer's Disease and Other Dementias (De Sanidad, 2014)		√	√		√		√	√	√	√				√
Recognition and Management of Dementia (Fletcher, 2012)	√	√	√	√	√	√	√	√	√	√	√	√		√

Guidelines	Components													
	Detection of Possible Dementia	Diagnosis	Assessment & Ongoing Reassessment	Care Planning	Medical Management	Information, Education, & Informed & Supported Decision Making	Acknowledgement & Emotional Support for the Person with Dementia	Assistance for the Person with Dementia with Daily Functioning & Activities	Involvement, Emotional Support, & Assistance for Family Caregiver(s)	Prevention & Mitigation of Behavioral & Psychological Symptoms of Dementia	Safety for the Person with Dementia	Therapeutic Environment, Including Modifications to the Physical & Social Environment of the Person with Dementia	Care Transitions	Referral & Coordination of Care & Services that Match the Needs of the Person with Dementia & Family Caregiver(s) & Collaboration Among Agencies & Providers
Report and Recommendations (Gerontological Society of America Workgroup on Cognitive Impairment Detection and Earlier Diagnosis, 2015)	√	√		√										√
Practice Guidelines for Assessing Pain in Older Persons with Dementia Residing in Long-Term Care Facilities (Hadjistavropoulos, Fitzgerald, & Marchildon, 2010)			√				√		√			√		
Dementias including Alzheimer's Disease (Healthy People 2020, 2014)													√	
Pain Assessment in the Patient Unable to Self-Report: Position Statement with Clinical Practice Recommendations (Herr et al., 2011)			√				√		√					
EFNS Guidelines for the Diagnosis and Management of Alzheimer's Disease (Hort et al. & European Federation of Neurological Sciences Scientist Panel on Dementia, 2010)		√	√	√	√	√		√	√	√				
Using Dementia as the Organizing Principle when Caring for Patients with Dementia and Comorbidities (Lazaroff et al., 2013)			√	√	√				√					
Palliative Care of Patients with Advanced Dementia (Mitchell, 2015)					√	√							√	
Fourth Canadian Consensus Conference on the Diagnosis and Treatment of Dementia: Recommendations for Family Physicians (Moore et al., 2014)		√	√		√					√				√
HEDIS Summary Table of Measures, Product Lines, and Changes (National Committee for Quality Assurance, 2015)					√									

Guidelines	Components													
	Detection of Possible Dementia	Diagnosis	Assessment & Ongoing Reassessment	Care Planning	Medical Management	Information, Education, & Informed & Supported Decision Making	Acknowledgement & Emotional Support for the Person with Dementia	Assistance for the Person with Dementia with Daily Functioning & Activities	Involvement, Emotional Support, & Assistance for Family Caregiver(s)	Prevention & Mitigation of Behavioral & Psychological Symptoms of Dementia	Safety for the Person with Dementia	Therapeutic Environment, Including Modifications to the Physical & Social Environment of the Person with Dementia	Care Transitions	Referral & Coordination of Care & Services that Match the Needs of the Person with Dementia & Family Caregiver(s) & Collaboration Among Agencies & Providers
Dementia: A NICE-SCIE Guideline on Supporting People with Dementia and Their Carers in Health and Social Care (National Institute for Health and Clinical Excellence, 2007)	√	√	√	√	√	√			√	√				√
What Information Can I Get About Quality Measures? (Nursing Home Compare, 2015)										√				
PQRS 2105 Measure List, Measure Numbers 25, and 149-157 (Physician Quality Reporting System, 2014)			√			√				√	√			
American Psychiatric Association Practice Guideline for the Treatment of Patients with Alzheimer's Disease and Other Dementias (Rabins et al., 2007)		√	√	√	√	√	√		√	√				√
Guideline Watch: Practice Guideline for the Treatment of Patients with Alzheimer's Disease and Other Dementias (Rabins et al., 2014)					√		√		√			√		
Dementia. Diagnosis and Treatment (Regional Health Council, 2011)	√	√	√		√	√			√	√				
Caregiving Strategies for Older Adults with Delirium, Dementia and Depression 2010 Supplement (Registered Nurses' Association of Ontario, 2010)	√		√		√	√	√	√	√	√	√	√		√
Guidelines for the Management of Cognitive and Behavioral Problems in Dementia (Sadowski & Galvin, 2012)					√		√	√	√	√		√		√
Occupational Therapy Practice Guidelines for Adults with Alzheimer's Disease and Related Disorders (Schaber, 2010)		√	√	√				√	√			√		√
EFNS-ENS Guidelines on the Diagnosis and Management of Disorders Associated with Dementia (Sorbi et al., 2012)		√	√						√	√	√			√

Guidelines	Components													
	Detection of Possible Dementia	Diagnosis	Assessment & Ongoing Reassessment	Care Planning	Medical Management	Information, Education, & Informed & Supported Decision Making	Acknowledgement & Emotional Support for the Person with Dementia	Assistance for the Person with Dementia with Daily Functioning & Activities	Involvement, Emotional Support, & Assistance for Family Caregiver(s)	Prevention & Mitigation of Behavioral & Psychological Symptoms of Dementia	Safety for the Person with Dementia	Therapeutic Environment, Including Modifications to the Physical & Social Environment of the Person with Dementia	Care Transitions	Referral & Coordination of Care & Services that Match the Needs of the Person with Dementia & Family Caregiver(s) & Collaboration Among Agencies & Providers
Third Canadian Consensus Conference on Diagnosis and Treatment of Dementia (2007)	√	√	√	√	√	√		√	√	√	√			√
TOTAL	14	17	27	17	24	20	10	16	22	21	10	12	5	16

APPENDIX B. SELECTED DEMENTIA MODELS

Model	Citation	Description of Intervention	Setting & Method of Care
ACCESS	Vickrey, B.G., Mittman, B.S., Connor, K.I., Pearson, M.L., Della Penna, R.D., Ganiats, T.G., DeMonte, R.W., Chodosh, J., Cui, X., Vassar, S., Duan, N., & Lee, M. (2006). The effect of a disease management intervention on quality and outcomes of dementia care: A randomized, controlled trial. <i>Annals of Internal Medicine</i> , 145(10), 713-726.	ACCESS was designed to enable 6 health care and social service organizations in San Diego to provide coordinated medical care and community support. Key components of the model include a steering committee to determine care goals and care coordination protocols; care managers; targeted provider education; and a web-based communication and decision support system. The steering committee developed 23 quality dementia care guidelines.	Primary care clinics
Acquiring New Skills (ANSWERS)	Judge, K.S., Yarry, S.J., Looman, W.J., & Bass, D.M. (2013). Improved strain and psychosocial outcomes for caregivers of individuals with dementia: Findings from Project ANSWERS. <i>Gerontologist</i> , 53(2), 280-292.	The <i>Acquiring New Skills (ANSWERS)</i> protocol was designed to focus both on the person with dementia and his or her caregiver, with an aim to reduce strain and psychosocial outcomes for dyads. The program included 6, 90-minute counseling sessions conducted by an intervention specialist. The sessions were designed to cover topics such as education on dementia and caregiving strategies, strategies to improve communication between the dyads, training to better manage behavioral and memory-related issues, and education on the importance of physical and mental activity for the dyads. Following the first introductory session, the dyads were given an opportunity to complete a strength-based inventory. The outputs from the inventory were used as a reference guide for the following sessions.	90-minute sessions Setting unclear
Advanced Caregiver Training (ACT)	Gitlin, L.N., Winter, L., Dennis, M.P., Hodgson, N., & Hauck, W.W. (2010). Targeting and managing behavioral symptoms in individuals with dementia: A randomized trial of a nonpharmacological intervention. <i>Journal of the American Geriatrics Society</i> , 58(8), 1465-1474.	The <i>Advanced Caregiver Training (ACT)</i> is designed to improve caregivers' ability to recognize problem behaviors and to manage them effectively. The intervention tracks the problem behaviors linked to 3 main triggers: patient based, caregiver based, and environment based. Target outcomes include frequency of targeted problem behaviors and caregiver's upset behavior and confidence level of managing caregiving tasks. The program is conducted in 2 phases. The main phase of the program runs over 16 weeks and includes up to 9 occupational therapy sessions and 2 nursing sessions. Using standardized checklists, the occupational therapists work with the caregiver to review the problem areas and discuss strategies to improve patient caregiver communication, coping strategies, and environmental modifications. The nursing sessions include education on common medical conditions that may be associated with behavioral problems. The maintenance phase includes 3 contacts with an occupational therapist aimed to reinforce the strategies discussed in the main phase.	Home-based, in-person, telephone

Model	Citation	Description of Intervention	Setting & Method of Care
Advanced Illness Care Team (AICT)	Chapman, D.G., & Toseland, R.W. (2007). Effectiveness of advanced illness care teams for nursing home residents with dementia. <i>Social Work</i> , 52(4), 321-329.	This study evaluated the effectiveness of <i>Advanced Illness Care Teams (AICTs)</i> for nursing home residents with advanced dementia. AICTs included members from various disciplines including medicine, nursing, social work, psychology, physical and occupational therapy, and nutrition. The AICTs used a holistic approach that focused on 4 domains: (1) medical; (2) meaningful activities; (3) psychological; and (4) behavioral. The authors recruited 118 residents in 2 nursing homes for this study and randomly assigned them to AICTs or to usual care. This is 1 of a few studies to examine the effectiveness of team care on the health and well-being of nursing home residents with advanced dementia.	Nursing home
Alzheimer's and Dementia Care (ADC) Program	Tan, Z., Jennings, L., & Reuben, D. (2014). Coordinated care management for dementia in a large academic health system. <i>Health Affairs</i> , 33(4), 619-625.	The <i>Alzheimer's and Dementia Care (ADC) Program</i> seeks to improve dementia care through support and training for caregivers, improved care transitions, and linkages to community-based resources. A key component of this model is the dementia care manager, a geriatric nurse practitioner who provides in-depth assessment, coordination of care with the medical treatment team, and referral to community resources. The electronic medical record system is designed to alert the dementia care manager when a patient is treated in a UCLA health facility. Patients and caregivers are asked to contact the dementia care manager with changes in their status such as symptoms, caregiver stress, or hospice enrollment. Formalized partnerships with other community organizations enable referral for additional supportive services.	Community-based resources
Anger and Depression	Coon, D.W., Thompson, L., Steffen, A., Sorocco, K., & Gallagher-Thompson, D. (2003). Anger and depression management: Psychoeducational skill training interventions for women caregivers of a relative with dementia. <i>Gerontologist</i> , 43(5), 678-689.	This study includes discussion on 2 psychoeducational skill training interventions: anger management and depression management. The study examines the impact of these interventions on caregivers' outcomes, such as anger-hostility, depression, use of coping strategies, and perceived self-efficacy for caregiving. Both interventions include 2-hour workshops over 8 consecutive weeks. In addition, 2 skill reinforcement sessions were conducted at the end of each month.	Small group meetings in a community setting
Assisted Living Care Transitions	Bellantonio, S., Kenny, A.M., Fortinsky, R.H., Kleppinger, A., Robison, J., Gruman, C., Kuldorff, M., & Trella, P.M. (2008). Efficacy of a geriatrics team intervention for residents in dementia-specific assisted living facilities: Effect on unanticipated transitions. <i>Journal of the American Geriatrics Society</i> , 56, 523-528.	The intervention is designed to minimize transitions out of assisted living for residents with dementia. Four multidisciplinary assessments conducted by a geriatrician, geriatrics advanced practice nurse, physical therapist, dietitian, and social worker during the first 9 months that an older adult with dementia was living in an assisted living facility in Connecticut. The categories for assessment included medical, cognitive, functional, and nutritional status and issues related psychosocial adjustment and long-term planning. The assessment was conducted at 7, 30, 120, and 320 days. The team met bimonthly to discuss assessments and provide recommendations to the primary care physician, facility director, and families. Team also provided in-person or phone consultation with facility staff through the study.	Assisted living facilities

Model	Citation	Description of Intervention	Setting & Method of Care
Behavior Treatment	Teri, L., Logsdon, R.G., Uomoto, J., & McCurry, S.M. (1997). Behavioral treatment of depression in dementia patients: A controlled clinical trial. <i>Journals of Gerontology Series B: Psychological Sciences & Social Sciences</i> , 52(4), P159-P166.	This study evaluates 2 nonpharmacological treatments aimed at treatment of depression in patients with dementia. The first program aims to reduce depression among patients by increasing pleasant events and positive interactions. The second seeks to reduce depression by training caregivers problem-solving strategies. Both interventions include 9 60-minute weekly sessions by therapists over 9 weeks. In the first session, the therapists meet with the patient and caregiver to cover the program and to discuss the importance of pleasant events in reducing depression. The next 4 sessions focus on identifying pleasant events and their implementation strategies. The following sessions examine the factors that may interfere with pleasant activities. The final session summarizes patients' pleasant event and their implementation plans.	Home-based
BRI Care Counseling	Bass, D.M., Clark, P.A., Looman, W.J., McCarthy, C.A., & Eckert, S. (2003). The Cleveland Alzheimer's managed care demonstration: Outcomes after 12 months of implementation. <i>Gerontologist</i> , 43(1), 73-85. Clark, P.A., Bass, D.M., Looman, W.J., McCarthy, C.A., & Eckert, S. (2004). Outcomes for patients with dementia from the Cleveland Alzheimer's Managed Care Demonstration. <i>Aging & Mental Health</i> , 8(1), 40-51.	<i>BRI Care Counseling</i> was delivered as a partnership between a managed care health system and an Alzheimer's Association chapter. Care consultation was delivered as a phone intervention where Association staff (2 master's trained social workers and 1 other staff person) worked with persons with dementia and their caregivers to identify personal strengths and available resources within the family, health plan, and community and then develop an individualized care plan.	Home-based, telephone counseling
Brief Occupational Therapy	Dooley, N., & Hinojosa, J. (2004). Improving quality of life for persons with Alzheimer's disease and their family caregivers: Brief occupational therapy intervention. <i>American Journal of Occupational Therapy</i> , 58(5), 561-569.	This study examined the extent to which adherence to occupational therapy recommendations would increase the quality of life of persons with Alzheimer's disease living in the community and decrease the burden felt by family members caring for them. Caregiving strategies that were recommended to participant pairs in the treatment group fell into 3 categories: environmental modifications, caregiver approaches, and community-based assistance. All participants received a combination of all 3 types of recommendations. The population targeted was people diagnosed with possible or probable Alzheimer's disease in mild to moderate stages of impairment.	Home-based
Caregiver's Friend: Dealing with Dementia	Beauchamp, N., Irvine, A.B., Seeley, J., & Johnson, B. (2005). Worksite-based internet multimedia program for family caregivers of persons with dementia. <i>Gerontologist</i> , 45(6), 793-801.	<i>Caregiver's Friend: Dealing With Dementia</i> is a web-based multimedia intervention that provides text material and videos modeling positive caregiving strategies. The goal was to evaluate the efficacy of the Internet based multimedia support program to employed family caregivers of persons with dementia. The intervention included multiple components of knowledge, cognitive, and behavioral skills and affective learning, which are presented in 3 modules: Being a Caregiver, Coping with Emotions, and Common Difficulties.	Internet based

Model	Citation	Description of Intervention	Setting & Method of Care
Caregiver Skill Building (CSB)	Farran, C., Gilley, D., McCann, J., Bienias, J., Lindeman, D., & Evans, D. (2007). Efficacy of behavioral interventions for dementia caregivers. <i>Western Journal of Nursing Research</i> , 29(8) 944-960.	The goal of <i>Caregiver Skill Building (CSB)</i> is to help caregivers address behaviors that are most distressing by understanding the causes of the behaviors, determining the care receiver's abilities and needs, and working through possible responses. The main topics addressed include prevention of behavioral symptoms during personal care, particularly verbal and physical aggression; management of restless behaviors; and management of hallucinations, delusions, and paranoid or suspicious behaviors. A social worker or nurse meets with a group of family caregivers weekly for 5 weeks, and then conducts weekly telephone sessions with each participant over the following 7 weeks to enable greater focus on the specific concerns and needs of each caregiver. The sessions start with simpler and less distressing behavioral symptoms and move on to those that are more upsetting and complex to address, such as agitation and aggression. Group booster sessions take place at 6 and 12 months, and ongoing telephone contacts are provided as needed.	Group meeting, telephone sessions
Care of Persons with Dementia in their Environments (COPE)	Gitlin, L.N., Winter, L., Dennis, M.P., Hodgson, N., & Hauck, W.W. (2010). A biobehavioral home-based intervention and the well-being of patients with dementia and their caregivers: The COPE randomized trial. <i>Journal of the American Medical Association</i> , 304(9), 983-991.	The <i>Care of Persons with Dementia in their Environments (COPE)</i> program sought to support patient capabilities by reducing environmental stressors and enhancing caregiver skills. In this multicomponent intervention, all COPE dyads received exposure to each treatment element: assessments (patient deficits and capabilities, medical testing, home environment, caregiver communication, and caregiver-identified concerns); caregiver education (patient capabilities, potential effects of medications, pain, constipation, dehydration); and caregiver training to address caregiver-identified concerns and help them reduce stress. Training in problem-solving, communication, engaging patients in activities, and simplifying tasks was tailored to address caregiver-identified concerns and patient capabilities.	Home-based
Clinical Decision Support System (CDSS)	Boustani, M.A., Campbell, N.L., Khan, B.A., Abernathy, G., Zawahiri, M., Campbell, T., Tricker, J., Hui, S.L., Buckley, J.D., Perkins, A.J., Faber, M.O., & Callahan, C.M. (2012). Enhancing care for hospitalized older adults with cognitive impairment: A randomized controlled trial. <i>Journal of General Internal Medicine</i> , 27(5), 561-567.	<i>Clinical Decisions Support System (CDSS)</i> and a screening program were used in a randomized controlled clinical trial to evaluate the efficacy of the integrated systems to enhance hospital care for elders with cognitive impairment. The intervention used CDSS to alert physicians of patients with cognitive impairment and recommend referral for a geriatric consult, discontinuation of Foley catheterization, physical restraints, and anticholinergic drugs.	Hospital
Cognitive Behavioral Therapy	Akkerman, R.L., and Ostwald, S.K. (2004). Reducing anxiety in Alzheimer's disease family caregivers: The effectiveness of nine-week cognitive behavioral intervention. <i>American Journal of Alzheimer's Disease and Other Dementias</i> , 19(2), 117-123.	This study evaluates the effectiveness of a 9-week cognitive behavioral group therapy intervention for anxious community-dwelling family caregivers of persons diagnosed with Alzheimer's disease. Caregivers were randomly assigned to receive the cognitive behavioral therapy intervention or to the waitlist control group. The small group cognitive behavioral therapy intervention included didactic skills training. Caregivers in the cognitive behavioral therapy intervention group were asked to practice skills to reduce anxiety related to physical, cognitive, and behavioral components of caregiving.	Small group meetings

Model	Citation	Description of Intervention	Setting & Method of Care
Collaborative Care	Galvin, J.E., Valois, L., & Zweig, Y. (2014). Collaborative transdisciplinary team approach for dementia care. <i>Neurodegenerative Disease Management</i> , 4(6), 455-469.	The <i>Collaborative Care</i> model seeks to improve dementia care by focusing on patient-centered care achieved by collaboration among different team members involved in patient care and inclusion of patients and caregiver in the decision making process. This article provides an example of collaborative care focuses on the role of nurse practitioners as substitutes for physicians where possible. An information packet about the program and a survey questionnaire is sent to the patients/caregiver dyads before their first visit. On the day of the visit, a 30-minute neuropsychological evaluation is conducted. As a parallel activity, the caregiver meets with a team of providers to discuss the case history of the patient. Following the first activity, the patient meets with the providers while the caregiver has a psychosocial interview needs assessment, both which take about 20 minutes. The final event is combined for the dyads where the entire team comes together to discuss assessment results, care plan, and schedule follow-ups. The final activity takes about 20 minutes.	Collaborative care dementia practice
Complementary Alternative Medicine (CAM) Therapy	Korn, L., Logsdon, R.G., Polissar, N.L., Gomez-Beloz, A., Waters, T., & Rysler, R. (2009). A randomized trial of a CAM therapy for stress reduction in American Indian and Alaskan Native family caregivers. <i>Gerontologist</i> , 49(3), 368-377.	This study includes analysis of 2 <i>complementary alternative medicine (CAM) therapies</i> : polarity therapy and enhanced respite control condition. The study compares the impact of these 2 CAM therapies on psychological and physical well-being of American Indian and Alaska Native family caregivers. The intervention group received physical therapy and the control group received enhanced respite control condition. Both groups received 8 sessions. The polarity therapy program included 50-minute sessions over 8 weeks. The interventionists followed a therapist manual and physiology and point charts developed for this project. The enhanced respite control condition provided paid care for the care recipient, allowing caregivers to participate in an activity of their choice. The enhanced respite control condition activity of the caregiver choice ranged from 60 to 120 minutes. For each session, both groups received paid care for 3 hours.	PT--Center for Traditional Medicine in Olympia, Washington, tribal health clinics ERCC--home/activity site
Coping with Caregiving	Gallagher-Thompson, D., Coon, D., Solano, N., Ambler, C., Rabinowitz, Y., & Thompson, L. (2003). Change in indices of distress among Latino and Anglo female caregivers of elderly relatives with dementia: Site-specific results from the REACH national collaborative study. <i>Gerontologist</i> , 43(4), 580-591.	<i>Coping with Caregiving</i> is a psychoeducational intervention that teaches caregivers relaxation skills, assertive communication to improve interactions with providers and others in their social networks, daily pleasant event scheduling to bolster mood and activity, ways for caregivers to appraise their loved one's behavior more realistically and intervene more appropriately, and strategies to change how caregivers think about their caregiving situations. Its goal is to help caregivers cope by reducing sources of negative feelings and bolstering sources of positive mood. Training is provided to family caregivers in a group setting. Weekly 2-hour sessions take place over 10 weeks, followed by monthly booster sessions for 8 months. Interventionists are generally psychologists, social workers, or other mental health professionals. Key components of workshops include stress management, behavior problem management, communication skills, mood management strategies, and basic education about dementia and caregiving.	Group meetings in community settings

Model	Citation	Description of Intervention	Setting & Method of Care
Creative Caregiving Training Modules	<p>National Center for Creative Aging (NCCA). Available at http://www.creativeaging.org.</p> <p>NCCA Creative Caregiving Initiative. Available at http://www.creativeaging.org/progr_ams-people/ncca-creative-caregiving-initiative.</p>	<p>The web-based <i>NCCA Creative Caregiving Guide</i>[®] and 7 <i>Creative Caregiving Training Modules</i> (available soon) were developed for family and professional caregivers of adults with dementia. The short, self-administered modules are designed to equip busy caregivers with research-based caregiving exercises using creative arts activities that help the caregiver and the person with dementia flourish in the art of daily caregiving, enhancing positive emotion, engagement and relationship, meaning, and mastery. Expected outcomes include enhanced quality of life and decreased depression and anxiety for persons with dementia and caregivers, but the program evaluation is not yet completed. Caregivers (family or professional) will be able to view the training modules online at their convenience as frequently as desired, but the modules are not downloadable. Each module features a master teaching artist demonstrating specific techniques with a person with dementia and a family caregiver. The modules incorporate self-care for the caregiver (such as conscious breathing), call-and-response and movement, a creative caregiving practice, and encourage the dyad to "savor the moment." The caregiver may watch the video first alone, or may include the person with dementia. At their own pace and comfort level, caregivers may begin using the techniques with the person with dementia. Most of the modules either focus on music (Sing Like a Bird, Love Duets, Mirror Dance) or include music in the activities (Tree Poems, Starry Night) demonstrated by the master teaching artist.</p>	Web-based
Dementia Care Consultation	<p>Fortinsky, R.H., Kulldorff, M., Kleppinger, A., & Kenyon-Pesce, L. (2009). Dementia care consultation for family caregivers: Collaborative model linking an Alzheimer's association chapter with primary care physicians. <i>Aging and Mental Health</i>, 13(2), 162-170.</p>	<p>The primary purpose of this study was to test the efficacy of a dementia care consultation intervention for family caregivers of persons with dementia living in the community. The intervention consisted of care consultants providing individualized counseling and support to family caregivers and persons with dementia over 12 months. Consultants sent copies of care plans developed with the family caregiver to the referring primary care physicians.</p>	Primary Care, Alzheimer's Association
Dementia Care Network	<p>Alzheimer's Association of Los Angeles, Riverside, and San Bernardino Counties Chapter, Inc., <i>Dementia Care Network Replication Manual</i>, (2004).</p>	<p>The <i>Dementia Care Network</i> is an interorganizational, community-based collaborative model to provide dementia care services to underserved ethnic communities. Nonprofit human services providers, community representatives, and government entities work together to achieve provide these services. The Dementia Care Network has been used in Latino, African American, Chinese, Japanese, and Vietnamese communities in California. A lead agency subcontracts with agencies in the targeted community to provide direct service. The Dementia Care Network uses a Care Advocate as the main contact for family home visits, care planning, purchase of services, and service coordination and monitoring, but range of services will vary depending on what is available in the community that is implementing a Dementia Care Network.</p>	Nonprofit human services providers, community settings

Model	Citation	Description of Intervention	Setting & Method of Care
Dementia Friendly Hospitals	Galvin, J.E., Kuntemeier, B., Al-Hammadi, N., Germino, J., Murphy-White, M., & McGillick, J. (2010). "Dementia-friendly hospitals: Care not crisis" an educational program designed to improve the care of the hospitalized patient with dementia. <i>Alzheimer Disease and Associated Disorders</i> , 24(4), 372.	The <i>Dementia Friendly Hospitals</i> program provided nurses and other direct care staff (social workers, pastoral care, discharge planners, physical therapists) working in hospital settings with information and resources to allow them to better care for patients with dementia from admission to discharge planning. The curriculum consisted of 5 learning modules (Introduction, Medical Overview, Approaches to Communication and Behavior, Dementia Friendly Care, and Connecting the Caregiver). The program lasted 7 hours with each module delivered by a different specialist in the relevant area.	Hospitals
Dialectical Behavior Therapy (DBT) Skills Training	Drossel, C., Fisher, J., & Mercer, V. (2011). A DBT skills training group for family caregivers of persons with dementia. <i>Behavior Therapy</i> , 42(1), 109-119.	<i>Dialectical Behavior Therapy (DBT) Skills Training</i> uses a type of cognitive behavioral psychotherapy to help caregivers develop mindfulness, improve dementia communication skills, increase pleasant events and self-care, and develop distress tolerance skills. The main goals of this program were to reduce the risk for elder abuse and to improve quality of life for both the caregiver and the person with dementia. The program is targeted to the caregiver and lasts 9 weeks, including regular individual psychotherapy sessions using the DBT Skills Training approach and a series of 9 weekly 2.5-hour group sessions. The first session provides an introduction to the approach and to the group; after that there are 2 sessions dedicated to each module: (1) mindfulness; (2) interpersonal effectiveness; (3) emotional regulation; and (4) distress tolerance. Two graduate student therapists lead each group. Three weeks after the end of the training, optional booster sessions begin and last for an additional 9 weeks.	Community setting
Early-Stage Memory Loss (ESML) Support Groups	Logsdon, R.G., Pike, K.C., McCurry, S.M., Hunter, P., Maher, J., Snyder, L., & Teri, L. (2010). Early-stage memory loss support groups: Outcomes from a randomized controlled clinical trial. <i>Journals of Gerontology Series B: Psychological Sciences and Social Sciences</i> , 65(6), 691-697.	This randomized controlled trial compared a time-limited ESML group program conducted by a local Alzheimer's Association chapter to a waitlist control condition. The ESML intervention is a structured support group program that follows a written manual that has been revised and updated regularly by Alzheimer's Association staff to ensure continued accuracy and regional applicability. ESML sessions averaged 90 minutes in duration and met weekly for 9 weeks. Each session included both individuals with early-stage dementia and a family care partner, who met together for part of the session and separately for part of the session. All groups were provided free of charge to participants. Groups were held in convenient community locations (adult day centers, senior centers, etc.) to minimize transportation burden on participants. Each ESML group had 3-4 volunteer facilitators. At least 2 facilitators in each group were master's degree level professionals experienced in working with individuals with dementia, who had already conducted 1 or more early-stage support groups prior to participating in this investigation. To ensure treatment fidelity, facilitators participated in a daylong training workshop each year to familiarize them with research procedures and refresh their knowledge of the intervention.	Community locations (adult day centers, senior centers, etc.)

Model	Citation	Description of Intervention	Setting & Method of Care
ECHO-AGE	Catic, A.G., Mattison, M.L.P, Bakaev, I., Morgan, M., Monti, S.M. & Lipsitz, L. (2014) ECHO-AGE: An innovative model of geriatric care for long-term care residents with dementia and behavioral issues. <i>Journal of the American Medical Directors Association</i> , 15. 938-942.	<i>ECHO-AGE</i> is a remote case-based video consultation program that connects experts in the area of managing behavior of people with dementia to nursing home care providers. The intervention tested involved long-term care facilities presenting challenging cases related to the behavior of residents with dementia or delirium to specialists via video-conferencing. Specialists included a geriatrician, geriatrics hospitalist, geriatrics psychiatrist, behavioral neurologist, and community resource specialist. Specialists typically recommended behavioral plans or medication adjustments. Patients' families were invited to participate in the video-conferencing sessions.	Long-term care facilities
Family Intervention: Telephone Tracking-Caregiver (FITT-C)	Tremont, G., Davis, J.D., Papandonatos, G.D., Ott, B.R., Fortinsky, R.H., Gozalo, P., Yue, M.S., Bryant, K., Grover, C. & Bishop, D.S. (2015). Psychosocial telephone intervention for dementia caregivers: A randomized, controlled trial. <i>Alzheimer's and Dementia</i> , 11(5), 541-548.	This was a randomized controlled trial with an objective to examine the effects of an entirely telephone-based intervention on caregiver well-being, including depressive symptoms, burden, and reactions to care recipient behavior problems in distressed dementia caregivers. Secondary aims were to examine effects of the intervention on measures of self-efficacy, family functioning, and health-related quality of life.	Academic medical center
Healthy Aging Brain Care (HABC)	<p>Boustani, M.A., Sachs, G.A., Alder, C.A., Munger, S., Schubert, C.C., Guerriero Austrom, M., Hake, A.M., Unverzagt, F.W., Farlow, M., Matthews, B.R., Perkins, A.J., Beck, R.A., & Callahan, C.M. (2011). Implementing innovative models of dementia care: The Healthy Aging Brain Center. <i>Aging and Mental Health</i>, 15(1), 13-22.</p> <p>LaMantia, M.A., Alder, C.A., Callahan, C.M., Gao, S., French, D.D., Austrom, M.G., Boustany, K., Livin, L., Bynagari, B., & Boustani, M.A. (2015). The Aging Brain Care Medical Home: Preliminary Data. <i>Journal of the American Geriatrics Society</i>, 63, 1209-1215.</p> <p>Monahan, P.O., Boustani, M.A., Alder, C., Galvin, J.E., Perkins, A.J., Healey, P., Chehresa, A., Shepard, P., Bubp, C., Frame, A., & Callahan, C. (2012). Practical clinical tool to monitor dementia symptoms: the HABC-Monitor. <i>Clinical Interventions in Aging</i>, 7, 143-157.</p> <p>Health Care Innovation Awards. Available at https://innovation.cms.gov/files/x/hcia-project-profiles-second-batch-only.pdf.</p>	<i>Healthy Aging Brain Care (HABC)</i> is a type of collaborative care model designed to reduce dementia-related burden among dementia patients and their caregivers. HABC was developed at Wishard Health Services. The first phase of the program, which is the initial assessment phase, includes 3 steps: (1) pre-visit is used for initial assessment of patient/caregiver dyads; (2) first visit is used for complete diagnostic evaluation; (3) second visit involves the initiation of the care plans, which is personalized based on the first 2 steps. The follow-up phase of the program includes: (1) telephone follow-up by the care coordinator within 2-3 weeks of initial visit; and (2) in-person follow-up to evaluate patient's individualized care plan. The frequency of in-person follow-up may vary based on patient's need.	Primary care clinic, telephone, e-mail

Model	Citation	Description of Intervention	Setting & Method of Care
Individualized Music	Park, H., & Pringle Specht, J.K. (2009). Effect of individualized music on agitation in individuals with dementia who live at home. <i>Journal of Gerontological Nursing</i> , 35(8), 47-55.	<i>Individualized Music</i> was a pilot program designed to reduce agitation in persons with dementia by selecting music based on their personal preferences and integrating the music into their daily lives. The music is intended to trigger positive memories to reduce anxiety and agitation. Key elements of the training are guidance for family caregivers in selecting culturally appropriate music for the person with dementia and in choosing the best timing for playing the music to reduce agitation. Additional benefits may include positive affect, meaningful interaction with others, expression of satisfaction, and reduction of anxiety, but these have not been tested in the home setting. A nurse trainer visits the family twice, 1 week apart, to train the family caregiver in use of individualized music, selection, and preparation of the person with dementia's choices of music on a CD using the author's Assessment of Personal Music Preference. The nurse also assesses the person with dementia's daily patterns of agitation. For 2 weeks the family caregiver plays 30 minutes of individualized music for the person with dementia a minimum of 30 minutes prior to peak agitation times. The family caregiver measured agitation levels 30 minutes before, during, and after playing music. Following a 2-week break without music, the researcher then repeated the cycle for a total of 8 weeks of intervention. The nurse visited the family once a week during music-playing weeks to answer caregiver questions.	Home-based
Interventions to Reduce Acute Care Transfers (INTERACT) at Brookdale Senior Living	Health Care Innovation Awards: Second (Final) Batch. Available at https://innovation.cms.gov/files/x/hcia-project-profiles-second-batch-only.pdf .	The University of North Texas Health Science Center, in partnership with Brookdale Senior Living, is expanding and testing the Brookside Senior Living Transitions of Care Program, which is based on an evidenced-based assessment tool called <i>Interventions to Reduce Acute Care Transfers (INTERACT)</i> for residents living in independent living, assisted living, and dementia-specific facilities in Texas and Florida. In addition, community-dwelling older adults who receive Brookside Senior Living home health services will be included in the Transitions of Care Program. Over the course of the award, the program will expand to other states where Brookside Senior Living communities are located. The program will employ clinical nurse leaders to act as program managers. Clinical nurse leaders will train care transition nurses and other staff on the use of INTERACT and health information technology resources to help them identify, assess, and manage residents' clinical conditions to reduce preventable hospital admissions and readmissions. The goal of the program is to prevent the progress of disease, thereby reducing complications, improving care, and reducing the rate of avoidable hospital admissions for older adults.	Dementia-specific facilities, other facilities, home-based

Model	Citation	Description of Intervention	Setting & Method of Care
Living Rlte	Health Care Innovation Awards: Project Profiles, University of Rhode Island. Available at http://innovation.cms.gov/initiatives/participant/Health-Care-Innovation-Awards/University-Of-Rhode-Island.html .	The University of Rhode Island's <i>Living Rlte</i> innovations project is delivering coordinated care through 2 Living Rlte Centers. The Centers provide comprehensive chronic care management to coordinate services between multiple community providers, improve health, and decrease unnecessary hospitalizations and emergency room visits. There is an interdisciplinary team that includes physicians, nurse practitioners, RNs, pharmacists, occupational therapists, physical therapists, and dietitians. Clients are trained in how to best manage their chronic diseases. Centers provide career development, benefits planning and job placement for certain clients.	Community-based
MIND at Home	Samus, Q.M., Johnston, D., Black, B.S., Hess, E., Lyman, C., Vavilikolanu, A., Pollutra, J., Leoutsakos, J.-M., Gitlin, L.N., Rabins, P.V., & Lyketsos, C.G., (2014) A multidimensional home-based care coordination intervention for elders with memory disorders: The Maximizing Independence at Home (MIND) Pilot Randomized Trial. <i>American Journal of Geriatric Psychiatry</i> , 22(4): 398-414.	<i>MIND at Home</i> is a home-based care coordination intervention with the goal of delaying transitions from the home and reducing unmet care needs in persons with dementia or persons with mild cognitive impairment who live in the community. A nonclinical community worker provided the care coordination with assistance from an RN and geriatric psychiatrist. Care coordination included identification of needs and care planning to address unmet needs based on results of Johns Hopkins Dementia Care Needs Assessment and to match preferences of the patient and family, dementia education and skill-building, coordination, referral and linkage to services within the community, and care monitoring.	Home-based
Mindfulness	Whitebird, R.R., Kreitzer, M., Crain, A.L., Lewis, B.A., Hanson, L.R., & Enstad, C.J. (2013). Mindfulness-based stress reduction for family caregivers: A randomized controlled trial. <i>Gerontologist</i> , 53(4), 676-686.	The purpose of this study was to compare a mindfulness-based stress reduction intervention to a community caregiver education and support intervention for family caregivers of people with dementia. Mindfulness-based stress reduction participants (family caregivers of persons with dementia) received instruction about concepts of mindfulness and practiced meditation and gentle yoga each week. Mindfulness-based stress reduction was compared to community caregiver education and support where caregiver participants received education on issues affecting family caregivers and social and emotional support.	Research center--in-person group sessions
Namaste Care Program	Simard, J. & Volicer, L. (2010). Effects of Namaste care on residents who do not benefit from usual activities. <i>American Journal of Alzheimer's Disease and Other Dementias</i> , 25(1), 46-50.	The <i>Namaste Care Program</i> is for nursing home residents who cannot participate in regular nursing home activities because of advanced dementia or earlier stages of dementia with agitation. Activities are conducted in a room free from environmental distractions and staffed by specially trained nursing assistants. Nursing assistants receive training on advanced dementia and the Namaste Care Program components. The program is offered 7 days a week for 5 hours a day. Once residents are in the program room, nursing assistants provide ADL care as meaningful activities, such as soaking hands in warm lavender-scented water prior to clipping nails. Other activities included watching nature DVDs and providing comfort through realistic-looking stuffed animals.	Nursing home
New York University Caregiver Intervention (NYUCI)	Mittleman, M.S., & Bartels, S.J. (2014). Translating research into practice: Case-study of a community-based dementia caregiver intervention. <i>Health Affairs</i> , 33(4), 587-595.	The goals of <i>New York University Caregiver Intervention (NYUCI)</i> are to improve caregivers' ability to handle difficulties of caregiving and to avoid or delay the need for institutional care for the person with dementia. Intervention includes individual and family counseling, caregiver support group, and telephone-based counseling for caregiver. The counselor also provides information and referrals to services.	Individual and small group meetings, telephone

Model	Citation	Description of Intervention	Setting & Method of Care
Nighttime Insomnia Treatment and Education for Alzheimer's Disease (NITE-AD)	McCurry, S., Gibbons, L., Logsdon, R., Vitiello, M., & Teri, L. (2005). Nighttime insomnia treatment and education for Alzheimer's disease: A randomized, controlled trial. <i>Journal of the American Geriatric Society</i> , 53, 793-802.	<i>Nighttime Insomnia Treatment and Education for Alzheimer's disease (NITE-AD)</i> is a 2-month intervention program on sleep in people with dementia living at home with family caregivers. The intervention was introduced in 6 1-hour sessions in their home over 2 months which were led by a geropsychologist. The targeted population was people with dementia living at home with family caregivers. Patients showed significant posttest differences with control subjects, including reductions in number of nighttime awakenings, total time awake at night, depression, and an increase in mean weekly exercise days. A treatment manual is available for both the active treatment and contact control conditions described in the article.	Home-based
Palliative Care for Advanced Dementia	Kuhn, D.R. & Forrest, J.M. (2012). Palliative care for advanced dementia: A pilot project in 2 nursing homes. <i>American Journal of Alzheimer's Disease and Other Dementias</i> , 27(1), 33-40. Long, C.O. (2009). Palliative care for advanced dementia: Approaches that work. <i>Journal of Gerontological Nursing</i> , 35(11), 19-24. Alonzo, T., Mitchell, K., & Knupp, C. (2015). Comfort care for people with dementia: The Beatitudes campus model. In M.L. Malone et al. (eds.), <i>Geriatrics Models of Care: Bringing "Best Practice" to an Aging America</i> (pp. 299-302). Switzerland: Springer International Publishing.	<i>Palliative Care for Advanced Dementia</i> includes a core training program where staff learn key concepts of dementia care, have 1:1 direct care experience peer training at a facility using the program, engage in self-study, and receive targeted training on comfort-focused behavior management, assessing and addressing pain, stimulating the senses for persons with dementia, end-of-life/hospice care, and medical provider education and support. The program takes place in a long-term care facility unit where residents in the moderate to advanced stages of dementia live. The program uses many practices to promote comfort. Care plans are written from the perspective of the person with dementia, no physical restraints are used, and there is a 24-hour restaurant with customization for dietary needs. The program also has a continuous activity program with individualized sensory-calming and sensory-stimulating activities to help avoid sundowning. Direct caregivers received training in comfort-management. Staffing ratios of 1:8 for certified nursing assistants and 1:22 for licensed nursing staff.	Long-term care facility
Palliative Excellence in Alzheimer Care Efforts (PEACE)	Shega, J.W., Levin, A., Hougham, G.W., Cox-Hayley, D., Luchins, D., Hanrahan, P., Stocking, C., & Sachs, G. A. (2003). Palliative excellence in Alzheimer care efforts (PEACE): A program description. <i>Journal of Palliative Medicine</i> , 6(2), 315-320.	The <i>Palliative Excellence in Alzheimer Care Efforts (PEACE)</i> program aims to improve end-of-life care of persons with dementia and to integrate palliative care into the primary care of patients with dementia throughout the course of the illness. The PEACE program is a disease management model for dementia that incorporates advance planning, patient-centered care, family support, and a palliative care focus from the diagnosis of dementia through its terminal stages. Patients and caregivers are interviewed every 6 months for 2 years, and a post-death interview is conducted with caregivers. These interviews assess care domains important for the optimal care of persons with dementia and their caregivers. A nurse coordinator reviews interviews and provides feedback to physicians, facilitating enhanced individual care and continuous quality improvement for the practice.	Hospice

Model	Citation	Description of Intervention	Setting & Method of Care
Partners in Dementia Care	<p>Bass, D.M., Judge, K.S., Maslow, K., Wilson, N.L., Morgan, R.O., McCarthy, C. A., Looman, W.J., Snow, A.L., & Kunik, M.E. (2015). Impact of the care coordination program "Partners in Dementia Care" on veterans' hospital admissions and emergency department visits. <i>Alzheimer's and Dementia: Translational Research and Clinical Interventions</i>, 1(1), 13-22.</p> <p>Bass, D.M., Judge, K.S., Lynn Snow, A., Wilson, N.L., Morgan, R., Looman, W.J., McCarthy, C.A., Maslow, K., Moye, J.A., Randazzo, R., Garcia-Maldonado, M., Elbein, R., Odenheimer, G., & Kunik, M.E. (2013). Caregiver outcomes of partners in dementia care: Effect of a care coordination program for veterans with dementia and their family members and friends. <i>Journal of the American Geriatrics Society</i>, 61(8), 1377-1386.</p> <p>Bass, D.M., Judge, K.S., Snow, A.L., Wilson, N.L., Morgan, R.O., Maslow, K., & Elbein, R. (2014). A controlled trial of Partners in Dementia Care: Veteran outcomes after six and twelve months. <i>Alzheimer's Research and Therapy</i>, 6(1), 9.</p>	The <i>Partners in Dementia Care</i> model provides education, resources, and support via telephone. The model also coordinates health care and community services between VA Medical Centers and Alzheimer's Association chapters with a goal of reducing hospital admissions and emergency department visits by veterans with dementia. Care coordinators from the VA and the Alzheimer's Association work with persons with dementia and their caregivers to identify priority concerns and to develop specific, manageable action steps. Care notes are shared via cross-organization electronic records.	Telephone, e-mail, mail
Progressively Lowered Stress Threshold (PLST)	<p>Gerdner, L., Hall, G., & Buckwalter, K. (1996). Caregiver training for people with Alzheimer's based on a stress threshold model. <i>Image: Journal of Nursing Scholarship</i>, 28(3), 241-246.</p> <p>Hall G.R., & Buckwalter, K.C. (1987). Progressively lowered stress threshold: A conceptual model for care of adults with Alzheimer's disease. <i>Archives of Psychiatric Nursing</i>, 1, 399-406.</p> <p>Smith, M, Gerdner, L.A., Hall, G.R., & Buckwalter, K.C. (2004). History, development, and future of the progressively lowered stress threshold: A conceptual model for dementia care. <i>Journal of the American Geriatrics Society</i>, 52, 1755-1760.</p>	The <i>Progressively Lowered Stress Threshold (PLST)</i> model addresses the anxiety and agitation caused by environmental stressors, such as unnecessary noise and internal stressors such as pain. The PLST intervention aims to reduce stress by modifying the environment which promotes adaptive behavior and in turn a decrease in anxiety, wandering, and agitation. PLST sessions take place in a nursing facility, adult day care, acute care hospitals, or the home of the person with dementia and include both the person with dementia and the caregiver as active participants. The nurse interventionist provides education about the disease process, assists with strategies that promote adaptive behavior, simplifies daily tasks, assists with problem-solving strategies over the course of the illness as abilities change, locates resources and provides support, and assumes a case management role.	Nursing facility, adult day care, acute care hospitals, home-based
Project CARE	Gonyea, J.G., O'Connor, M.K., & Boyle, P.A. (2006). Project CARE: A randomized controlled trial of behavioral intervention group for Alzheimer's disease caregivers. <i>Gerontologist</i> , 46(6), 827-832.	<i>Project CARE</i> is a behavioral intervention that included 5 weekly sessions to teach caregivers techniques for managing neuropsychiatric symptoms of dementia in their home. Each session was run by a therapist and had a different focus, including teaching the ABC model of behavior change.	Group setting

Model	Citation	Description of Intervention	Setting & Method of Care
Reducing Disability in Alzheimer's Disease (RDAD)	<p>Menne, H.L., Bass, D.M., Johnson, J.D., Primetica, B., Kearney, K.R., Bollin, S., Molea, M.J., & Teri, L. (2014). Statewide implementation of "reducing disability in Alzheimer's disease": Impact on family caregiver outcomes. <i>Journal of Gerontological Social Work</i>, 57(6-7), 626-639.</p> <p>Teri, L., Gibbons, L.E., McCurry, S.M., Logsdon, R.G., Buchner, D.M., Barlow, W.E., Kukull, W.A., LaCroix, A.Z., McCormick, W., & Larson, E.B. (2003). Exercise plus behavioral management in patients with Alzheimer disease. <i>Journal of the American Medical Association</i>, 290(15).</p> <p>Teri, L., McKenzie, G., Logsdon, R., McCurry, S., Bollin, S., Mead, J., & Menne, H. (2012). Translation of two evidence-based programs for training families to improve care of persons with dementia. <i>Gerontologist</i>, 52(4), 452-459. doi: 10.1093/geront/gnr132.</p>	<p><i>Reducing Disability in Alzheimer's Disease (RDAD)</i> is designed to increase exercise and physical activity in persons with dementia and to instruct caregivers in approaches to reducing behavioral and psychological symptoms using the ABC model of behavioral change. Outcomes of interest include physical functioning, depression, and behavioral symptoms in the person with dementia. RDAD sessions take place in the home of the person with dementia and include both the person with dementia and the caregiver as active participants. The interventionist, who may be a physical therapist, social worker, or other aging services professional trained in the intervention, guides the person with dementia through a series of exercises while the caregiver observes. The caregiver is also provided with dementia education and instructed in behavior management through problem-solving. Topics covered include disease symptoms and progression, home safety and environmental modifications, and legal and financial issues. Training takes place over 12 1-hour sessions, which occur more frequently initially (2 sessions/week for the first 3 weeks, then once/week for 4 weeks, then biweekly for 4 weeks).</p>	Home-based
Resources for Enhancing Alzheimer's Caregiver Health (REACH) ESP Home Environmental Skill-Building- (Now known as Skills2Care™)	<p>Gitlin, L.N., Winter, L., Corcoran, M., Dennis, M.P., Schinfeld, S., & Hauck, W.W. (2003). Effects of the home environmental skill-building program on the caregiver-care recipient dyad: 6-month outcomes from the Philadelphia REACH initiative. <i>Gerontologist</i>, 43(4), 532-546.</p> <p>Gitlin, L.N., Jacobs, M., & Earland, T. (2010). Translation of a dementia caregiver intervention for delivery in home care as a reimbursable Medicare service: Outcomes and lessons learned. <i>Gerontologist</i>, 50(6), 847-854.</p>	<p><i>REACH ESP</i> is a translation of the REACH project. This program is designed for patients living in their homes and is aimed at reducing family caregiver burden by educating caregivers about the disease, easing the impact of the home environment on the person with dementia's behavior, and helping develop skills to better respond to environment related issues. REACH ESP was implemented in 2 phases: The active phase was delivered through 5 90-minute home visits, and 1 30-minute telephone contact, over 6 months. The components of the home visits included assessment of areas that are difficult for the caregiver to manage, caregiver education, assessment of problem areas in the person with dementia's environment, and supporting caregivers in the process of making environmental modifications.</p>	Home-based

Model	Citation	Description of Intervention	Setting & Method of Care
Resources for Enhancing Alzheimer's Caregiver Health (REACH II)	<p>Belle, S.H., Burgio, L., Burns, R., Coon, D., Czaja, S.J., Gallagher-Thompson, D., Gitlin, L. N., Klinger, J., Koepke, K.M., Lee, C.C., Martindale-Adams, J., Nichols, L., Schulz, R., Stahl, S., Stevens, A., Winter, L., & Zhang, S. (2006). Enhancing the quality of life of dementia caregivers from different ethnic or racial groups: A randomized control trial. <i>Annals of Internal Medicine</i>, 145(10), 727-38.</p> <p>Nichols, L.O., Chang, C., Lummus, A., Burns, R., Martindale-Adams, J., Graney, M.J., Coon, D.W., & Czaja, S. (2008). The cost-effectiveness of a behavior intervention with caregivers of patients with Alzheimer's disease. <i>Journal of the American Geriatrics Society</i>, 56(3), 413-420.</p> <p>Easom, L.R., Alston, G., & Coleman, R. (2013) A rural community translation of a dementia caregiving intervention. <i>Online Journal of Rural Nursing and Health Care</i>, 13(1), 66-91.</p>	The overall objectives of <i>REACH II</i> are to identify and reduce risk factors among family caregivers, enhance quality of care for the person with dementia, and enhance the well-being of the caregiver. The REACH II intervention focuses on 5 areas linked to caregiver stress: safety, self-care, social support, emotional well-being; and problem behaviors. A risk appraisal is used to determine which areas need the greatest focus. Caregiver training and counseling are provided over a 6-month period in 9 1.5-hour sessions in the person's home, 3 half-hour telephone calls, and 5 telephone support group sessions.	Home-based
Resources for Enhancing Alzheimer's Caregiver Health (REACH VA)	Nichols, L.O., Martindale-Adams, J., Burns, R., Zuber, J., & Graney, M.J. (2016). REACH VA: Moving from translation to system implementation. <i>Gerontologist</i> , 56(1), 135-144.	<i>REACH VA</i> is a translation of the REACH II program through the VA system. The core goals of the program are the same as that of REACH II, but some details of implementation have been modified to meet the needs of the VA service providers. REACH VA has been implemented using 2 different approaches: the first was delivered through 12 individual sessions, primarily in the home, and 5 telephone support group sessions over 6 months, as in REACH II.	Home-based
Resourcefulness Training	Gonzalez, E., Polansky, M., Lippa, C., Gitlin, L., & Zauszniewski, J. (2014). Enhancing resourcefulness to improve outcomes in family caregivers and persons with Alzheimer's Disease: A pilot randomized trial. <i>International Journal of Alzheimer's Disease</i> , 1-10.	<i>Resourcefulness training</i> aims to reduce caregiver strain and depression, increase preparedness, and reduce problem behaviors using a cognitive-behavioral approach. The program uses dementia education to help caregivers understand disease-related changes, reframe thinking about caregiving issues, and use problem-solving and coping skills. Resourcefulness training sessions include 5-7 caregivers and meet weekly for 2 hours, led by a RN. Participants are guided through a process of finding facts about the situation, setting a realistic goal, developing optimism about the ability to manage the problem, using creativity to brainstorm solutions, considering which to implement, and evaluating the effectiveness of the solution.	Weekly sessions

Model	Citation	Description of Intervention	Setting & Method of Care
Savvy Caregiver	<p>Samia, L., Aboueissa, A., Halloran, J., & Hepburn, K. (2014). The Maine Savvy Caregiver project: Translating an evidence-based dementia family caregiver program within the RE-AIM framework. <i>Journal of Gerontological Social Work</i>, 57(6-7), 640-661.</p> <p>Kally, Z., Cote, S., Gonzalez, J., Villarruel, M., Cherry, D., & Howland, S. et al. (2014). The Savvy Caregiver program: Impact of an evidence-based intervention on the well-being of ethnically diverse caregivers. <i>Journal of Gerontological Social Work</i>, 57(6-7), 681-693.</p>	<p><i>Savvy Caregiver</i> is a psychoeducational program designed to train family and professional caregivers in the basic knowledge, skills, and attitudes needed to handle the challenges of caring for a family member with Alzheimer's disease and to be an effective caregiver. Targeted outcomes include caregiver knowledge, confidence, self-efficacy, and depression and development of meaningful activities for the person with dementia. Savvy Caregiver is a 12-hour training program that is delivered in a group setting, typically in 2-hour sessions over a 6-week period. Interventionists may come from a variety of professional backgrounds; train-the-trainer materials and resources are available. Session content covers dementia, the cognitive changes that are occurring and how they affect behaviors, establishing realistic caregiving goals, gauging the care recipient's abilities, designing appropriate activities for the person with dementia, and using a problem-solving approach to manage behavioral symptoms.</p>	Group meeting
Savvy Caregiver 2	<p>Samia, L., Merchant, C., O'Sullivan, A., & Fallon, K. (2014). <i>The Maine Savvy Caregiver Project-Enhanced for Caregivers of Persons with Alzheimer's Disease and Related Dementias: Translation Report</i>. Office of Aging and Disability Services, Maine Department of Health and Human Services.</p>	<p><i>Savvy Caregiver 2</i> was developed to provide advanced training to family caregivers who completed the original Savvy Caregiver program. Savvy Caregiver 2 is a 4-week program that focuses on the challenges that are likely to be faced over time as dementia progresses and addresses ADLs, advanced behavior guidance (with increased emphasis on the effect the environment can have on the person with dementia), caregiver self-care, future planning to prepare for the challenges ahead, problem-solving, and care team enhancement. Interventionists come from a variety of professional backgrounds, but because the curriculum for Savvy 2 is less structured and covers more complex situations, the developers indicate that interventionists need to have strong problem-solving skills and the ability to think on their feet.</p>	Caregiver workshop
Seamless Dementia Service Delivery for Rural Aged	<p>Specht, J., Bossen, A., Hall, G.R., Zimmerman, B., & Russell, J. (2009). The effects of a dementia nurse care manager on improving caregiver outcomes. <i>American Journal of Alzheimer's Disease and Other Dementias</i>, 24 (3) 193-207.</p>	<p>In this program, a nurse care manager with specialized training in dementia management and assessment worked with persons with dementia and their caregivers to identify, assess, and address challenges and changing needs using a number of methods. Nurse developed service plans to promote communication and collaboration among community service providers, caregivers, and other informal supports with the ultimate goal of providing seamless service delivery. Included in-home and telephone meetings/support.</p>	In-home and telephone meetings/support

Model	Citation	Description of Intervention	Setting & Method of Care
STAR-Caregivers (STAR-C)	<p>Teri, L., McCurry, S., Logsdon, R., & Gibbons, L. (2005). Training community consultants to help family members improve dementia care: A randomized controlled trial. <i>Gerontologist</i>, 45(6), 802-811.</p> <p>Teri, L., McKenzie, G., Logsdon, R., McCurry, S., Bollin, S., Mead, J., & Menne, H. (2012). Translation of two evidence-based programs for training families to improve care of persons with dementia. <i>Gerontologist</i>, 52(4), 452-459. doi: 10.1093/geront/gnr132.</p>	<p><i>STAR-C</i> is a behavioral intervention designed to decrease depression and anxiety in individuals with Alzheimer's disease and their family caregivers. Treatment components include general education about Alzheimer's disease, practice using a systematic approach to identifying and reducing behavior problems in dementia (the ABC model of behavior change), communication skills training, information about the relationship between mood and pleasant events, and caregiver support. The intervention is delivered over a 6-month period by community clinicians with a master's degree in counseling, psychology, social work, or a related field. The interventionist meets with a family caregiver in the home once a week for 8 weeks. Between meetings, caregivers record behavioral symptoms and the strategies he or she used to address them. After the in-home meetings, the consultant follows up with the caregiver through 4 monthly telephone calls. These calls are intended to help the caregiver develop strategies to address new behavioral symptom, and they help to reinforce previous learnings.</p>	Home-based
Stress Busting Program	<p>Lewis, S.L., Miner-Williams, D., & Novian, A. (2009). A stress-busting program for family caregivers. <i>Rehabilitation Nursing</i>, 34:4, 151-159.</p>	<p>The <i>Stress-Busting Program</i> provides caregivers with education, stress management, problem-solving, and support, including strategies on how to care for themselves while caring for a loved one with dementia. The goal is to improve caregiver health, mental health, and social support and to decrease anger, anxiety, burden, stress and depression. The program consists of 90-minute sessions that occur once a week for 9 weeks. The program is conducted in a small group setting with 2 group facilitators. Participants are provided many resources, including a handbook covering class material, a meditation CD, and a relaxation strategies DVD. Session topics include unique caregiver stressors; physical and emotional effects of stress; creating a relaxing environment; grief, loss and depression; coping skills; managing behavioral and psychological symptoms of dementia; positive thinking and cognitive restructuring; healthy living; and creating a plan.</p>	Small group meetings

Model	Citation	Description of Intervention	Setting & Method of Care
Tailored Activity Program (TAP)	Gitlin, L.N., Winter, L., Burke, J., Chernett, N., Dennis, M., & Hauck, W. (2008). Tailored activities to manage neuropsychiatric behaviors in persons with dementia and reduce caregiver burden: A randomized pilot study. <i>American Journal of Geriatric Psychiatry</i> , 16(3), 229-239.	The <i>Tailored Activity Program (TAP)</i> seeks to reduce behavioral disturbances and depression in the person with dementia by using occupational therapy techniques to identify patients' existing abilities and previous interests and to devise activities that build on them. The Program includes 6 90-minute home visits and 2 brief telephone contacts by occupational therapists over 4 months. Contacts are spaced to provide caregivers opportunities to practice using activities independently. During the first 2 sessions, interventionists meet with caregivers to discern daily routines and previous/current activity interests. They assess the person with dementia and the home environment and observe communication between the caregiver and person with dementia. In subsequent sessions, interventionists identify 3 activities and developed 2-3 page written plans for each, including an activity (completing a puzzle form board) and goal (engaging in the activity for 20 minutes each morning after breakfast) and specific implementation techniques. Activities are introduced through role play or direct demonstration with the person with dementia. Caregivers are also instructed in stress reducing techniques such as deep breathing to help establish a calm emotional tone. Caregivers practice using the activity between visits, and once an activity is mastered, another is introduced.	Home-based
Tailored Caregiver Assessment and Referral (TCARE)	Kwak, J., Montgomery, R.J.V., Kosloski, K, & Lang, J. (2011). The impact of TCARE on service recommendation, use, and caregiver well-being. <i>Gerontologist</i> , 51(5), 704-7013.	<i>Tailored Caregiver Assessment and Referral (TCARE)</i> is a care management process to help practitioners efficiently triage resources and services available within a community to address caregivers needs. This care management process includes 2 meetings with caregivers and a process for designing a care plan that meets the needs and preferences of the caregiver. An algorithm is used to identify an intervention goal, strategies to reach the goal, and a generic list of services consistent with the strategies.	Meetings with caregivers
Telehealth Education Program (TEP)	Wray, L.O., Shulan, M.D., Toseland, R.W., Freeman, K.E., Wasquez, B.E., & Gao, J. (2010). The effect of telephone support groups on costs of care for veterans with dementia. <i>Gerontologist</i> , 50, 623-631.	The <i>Telehealth Education Program (TEP)</i> is designed to provide education and support for spousal or partner caregivers of veterans with moderate to severe dementia. Each caregiver receives 1-hour sessions of the TEP weekly for 10 weeks. Sessions involved education about dementia and symptoms, caregiving skills and resources to address symptoms, coping strategies, and group support.	Small group via phone
Transitional Care Model (TCM)	Naylor, M.D., Hirschman, K.B., Hanlon, A.L., Bowles, K.H., Bradway, C., McCauley, K.M., & Pauly, M.V. (2014). Comparison of evidence-based interventions on outcomes of hospitalized, cognitively impaired older adults, <i>Journal of Comparative Effectiveness Research</i> , 3(3), 245-257. Naylor, M.D., Stephens, C., Bowles, K.H., & Bixby, M.B. (2005). Cognitively impaired older adults: From hospital to home. <i>American Journal of Nursing</i> , 105, 52-61.	The <i>Transitional Care Model (TCM)</i> is intended to improve transitions from hospital to home, reduce associated functional decline, readmissions, and nursing home placement, and decrease mortality for people with cognitive impairment and dementia at any stage. Beginning in the hospital and continuing with visits in the person's home and ongoing in person and telephone contacts for about 2 months, the person and the family caregiver receive information, support, counseling, and help with coordinating care from the person's medical providers, managing medications, problem-solving, and arranging needed community services.	Hospital and home, in-person and telephone

Model	Citation	Description of Intervention	Setting & Method of Care
University of California-San Francisco (UCSF) and University of Nebraska Medical Center (UNMC) Dementia Care Ecosystem	Health Care Innovation Awards Round Two: Project Profiles, Regents of the University of California San Francisco. Available at https://innovation.cms.gov/initiatives/Participant/Health-Care-Innovation-Awards-Round-Two/Regents-Of-The-University-Of-California-San-Francisco.html .	The <i>Dementia Care Ecosystem</i> is a clinical program that builds on the UCSF Memory and Aging Center's dementia care, while incorporating the UNMC expertise in functional monitoring and rural dementia care. This model emphasizes continuous and personalized care. The target population is Medicare beneficiaries and persons dually eligible for Medicare and Medicaid. By supporting family caregivers, keeping patients healthy, and helping them prepare for advancing illness, the model aims to improve satisfaction with care, prevent emergency-related health care costs, and keep patients in their home longer. The primary point of contact for patients and families will be a Care Team Navigator with 24/7 availability. An innovative "dashboard" with both Care Team Navigator and patient portals will focus on efficient and personalized communication among the Care Team Navigator, care team, and the patient and family. There are 4 modules to the Dementia Care Ecosystem: Caregiver, Decision Making, Medication, and Functional Monitoring.	Intervention run through 4 modules

APPENDIX C. SAMPLE DEMENTIA CARE PROGRAM SITE VISIT DISCUSSION GUIDE

Introduction (Read this for all interviews):

Thank you for making time to meet with us today. My name is xxx, and I am joined by xxx. We work at RTI International, a large nonprofit research institute. We'd like to discuss some questions related to your xxx program.

This site visit is part of a project funded through ASPE at U.S. Department of Health and Human Services. The project will help inform recommendations to improve services for people with Alzheimer's disease and their caregivers. Our goal is to better understand how dementia care programs operate. We also want to get your thoughts on parts of the program that you and your team find easiest and most challenging to implement.

We would like your candid views about xxx program. We want to assure you that your participation is voluntary, that you will not be identified by name in the report, and the discussion notes will be kept confidential. To ensure that our notes are accurate and complete, we would also like to record our conversation. Is it OK with you if we record the conversation?

Do you have any questions before we begin?

Let's begin by talking about the dementia care program operating at this site.

1. Please provide an overview of the xxx program.
2. What is the referral source of program participants?
3. How many people are served (per day/per month/per year)?
4. What services are provided? For how long?
5. Who provides the services?
6. What are the major sources of financing?
7. Does the program have unique features in serving people with Alzheimer's disease and their caregivers?

Next we want to discuss in detail how various parts of the program operate.

A. SCREENING/DETECTION OF POSSIBLE DEMENTIA: EXAMINE FOR COGNITIVE IMPAIRMENT WHEN THERE IS A DECLINE FROM PREVIOUS FUNCTION IN DAILY ACTIVITIES, OCCUPATIONAL ABILITY, OR SOCIAL ENGAGEMENT.

1. Our understanding is that your program doesn't explicitly conduct screening/detection of possible dementia. Is this correct?

2. If yes, we want to understand what your program does when a participant presents with a need for screening/detection of possible dementia.

If no, discuss questions 3 through 7.

3. How does the program address screening/detection for possible dementia?
4. Does your program have protocols for screening/detection of possible dementia? Please describe.
5. Who is involved in conducting screening?
6. What parts of conducting screening have been the most successful?
7. What parts of conducting screenings have been the most challenging for your program to achieve?

B. DIAGNOSIS: OBTAIN A COMPREHENSIVE EVALUATION AND DIAGNOSIS FROM A QUALIFIED PROVIDER WHEN COGNITIVE IMPAIRMENT IS SUSPECTED.

1. Our understanding is that your program doesn't explicitly provide a comprehensive evaluation and diagnosis from a qualified provider. Is this correct?
2. If yes, we want to understand what your program does when a participant does not have a formal diagnosis.

If no, discuss questions 3 through 7.

3. If an individual is identified as having a suspected cognitive impairment, does your program provide a comprehensive evaluation and diagnosis from a qualified provider or does your program refer the individual to a qualified provider?
4. Does the program have a standard protocol for doing so? Please describe.
5. Who is involved in diagnosing dementia?
6. What parts of ensuring professional diagnoses have been the most successful?
7. What parts of ensuring professional diagnoses have been the most challenging for your program to achieve?

C. ASSESSMENT AND ONGOING REASSESSMENT: ASSESS COGNITIVE STATUS, FUNCTIONAL ABILITIES, BEHAVIORAL AND PSYCHOLOGICAL SYMPTOMS OF DEMENTIA, COMFORT, MEDICAL STATUS, MEDICATIONS, LIVING ENVIRONMENT, AND SAFETY, INCLUDING DRIVING AND VULNERABILITY TO FRAUD AND ABUSE. REASSESS REGULARLY AND WHEN THERE IS A SIGNIFICANT CHANGE IN CONDITION, CARE PROVIDER OR ROUTINE.

1. Does your program formally assess cognitive status, functional abilities, behavioral and psychological symptoms of dementia, medical status, living environment, or safety?

What areas does the program formally assess? Are there other areas that are assessed but not formally? If so, describe that process.

2. Does the program have protocols to do so? Please describe.
3. Who is involved in assessment and ongoing reassessment?
4. What parts of conducting the assessment have been the most successful?
5. What parts of conducting the assessment have the most challenging for your program to achieve?

D. CARE PLANNING: DESIGN A CARE PLAN THAT MEETS CARE GOALS, SATISFIES THE PERSON'S NEEDS, AND MAXIMIZES INDEPENDENCE AND SAFETY.

1. Please tell us about your program's process of developing care plans.
2. Does the program have formal protocols for doing so? Please describe.
3. Who is involved in care planning?
4. What parts of designing care plans have been the most successful?
5. What parts of designing care plans have been the most challenging for your program to achieve?

E. MEDICAL MANAGEMENT: DELIVER TIMELY, INDIVIDUALIZED MEDICAL CARE TO THE PERSON WITH DEMENTIA INCLUDING MEDICATION MANAGEMENT AND MANAGEMENT OF COMORBID MEDICAL CONDITIONS IN THE CONTEXT OF THE PERSON'S DEMENTIA. REFER TO PROVIDERS OF OTHER MEDICAL, HEALTH-RELATED, RESIDENTIAL AND COMMUNITY CARE SERVICES, AS NEEDED.

1. Our understanding is that your program doesn't explicitly provide medical care and medical management to the person with dementia. Is this correct?
2. We want to understand what your program does when a participant presents with issues related to medical management.

If no, discuss questions 3 through 6.

3. Does your program provide medical care and medical management to the person with dementia? Please discuss some of the keys aspects of medical management at your site.
 - Does the program have standard protocols on medical care for people with dementia and their caregivers?
 - How are referrals to other providers handled?
 - If the program does not provide medical care directly, how are medical issues addressed?
4. Who is involved in medical management?

5. What aspects of medical management have been the most successful?
6. What aspects of medical management have been the most challenging for your program to achieve?

F. INFORMATION, EDUCATION, AND INFORMED AND SUPPORTED DECISION MAKING: PROVIDE INFORMATION AND EDUCATION ABOUT DEMENTIA TO SUPPORT INFORMED DECISION MAKING INCLUDING TREATMENT OPTIONS, ADVANCE CARE PLANNING AND END-OF-LIFE DECISIONS.

1. Does your program provide consumer information and education about dementia to people with Alzheimer's disease and their caregivers?
2. Are there standard protocols to do so?
3. Who is involved in providing information and education?
4. Which parts of providing information and education have been the most successful?
5. Which parts of providing information and education have been the most challenging for your program to achieve?

G. INCLUSION OF CAREGIVERS: INVOLVE CAREGIVER IN EVALUATION, DECISION MAKING, AND CARE PLANNING AND ENCOURAGE REGULAR CONTACT WITH PROVIDERS.

1. Please describe how your program involves caregivers in evaluation, decision making, and care planning.
2. Are there standard protocols for doing so?
3. Who is involved in making the arrangements to include caregivers?
4. What aspects of including caregivers have been the most successful?
5. What aspects of including caregivers have been the most challenging for your program to achieve?

H. ACKNOWLEDGEMENT AND EMOTIONAL SUPPORT FOR THE PERSON WITH DEMENTIA: ACKNOWLEDGE AND SUPPORT THE PERSON WITH DEMENTIA.

1. Does your program have processes in place to acknowledge and support the person with dementia?
2. Are there standard protocols to do so? Please describe.
3. Who is involved in the process of acknowledgement and support for the person with dementia?
4. What aspects of acknowledgement and support have been the most successful?

5. What aspects of acknowledgement and support have been the most challenging for your program to achieve?

I. ASSISTANCE FOR THE PERSON WITH DEMENTIA WITH DAILY FUNCTIONING AND ACTIVITIES: ENSURE THAT PERSONS WITH DEMENTIA HAVE SUFFICIENT ASSISTANCE TO PERFORM ESSENTIAL HEALTH-RELATED AND PERSONAL CARE ACTIVITIES AND TO PARTICIPATE IN ACTIVITIES THAT REFLECT THEIR PREFERENCES AND REMAINING STRENGTHS, HELP TO MAINTAIN COGNITIVE, PHYSICAL, AND SOCIAL FUNCTIONING FOR AS LONG AS POSSIBLE, AND SUPPORT QUALITY OF LIFE.

1. Does your program counsel families on providing assistance with health-related and personal care activities and help the person participate in activities to the person with dementia?
2. Are there protocols for doing so? Please describe.
3. Who is involved in counseling families on providing assistance providing assistance?
4. What parts of counseling families on providing assistance have been the most successful?
5. What parts of counseling families on providing assistance have been the most challenging for your program to achieve?

J. EMOTIONAL SUPPORT AND ASSISTANCE FOR THE FAMILY CAREGIVER(S): PROVIDE CULTURALLY SENSITIVE EMOTIONAL SUPPORT AND ASSISTANCE FOR THE FAMILY CAREGIVER(S).

1. Does your program provide emotional support and assistance for the family caregiver(s)? Does the program have protocols for doing so? Please describe.
2. Who is involved in providing support and assistance?
3. What parts of providing support and assistance have been the most successful?
4. What parts of providing support and assistance have been the most challenging for your program to achieve?

K. MANAGEMENT OF BEHAVIORAL AND PSYCHOLOGICAL SYMPTOMS OF DEMENTIA: IDENTIFY THE CAUSES OF OR TRIGGERS FOR BEHAVIORAL AND PSYCHOLOGICAL SYMPTOMS AND USE NONPHARMACOLOGICAL APPROACHES FIRST TO ADDRESS THOSE CAUSES. AVOID USE OF ANTIPSYCHOTICS AND OTHER MEDICATIONS UNLESS THE SYMPTOMS ARE SEVERE, CREATE SAFETY RISKS FOR THE PERSON OR OTHERS, AND HAVE NOT RESPONDED TO OTHER APPROACHES. AVOID PHYSICAL RESTRAINTS EXCEPT IN EMERGENCIES.

1. How does the program address behavioral and psychological symptoms of dementia, such as aggressive behavior and wandering? Does your program have protocols in place for counseling family caregivers about managing these symptoms of dementia? Please describe.

2. Does the program counsel families on the use of prescription drugs to manage behavioral symptoms? Does the program counsel families on the use antipsychotic medications? If so, under what circumstances? What guidance is provided to families for using these medications?
3. Does the program counsel families on the use of physical restraints? If so, what kind of guidance is provided?
4. Who is involved in counseling families about the management of behavioral and psychological symptoms?
5. What aspects of counseling families about management of behavioral and psychological symptoms been the most successful?
6. What aspects of counseling families about management of behavioral and psychological symptoms been the most challenging for your program to achieve?

L. SAFETY FOR THE PERSON WITH DEMENTIA: ENSURE A SAFE ENVIRONMENT FOR THE PERSON WITH DEMENTIA.

1. How does the program counsel families about ensuring a safe environment for the person with dementia and their caregivers at home? Does your program have protocols for counseling families on safety for the person with dementia? Please describe.
2. Who is involved in counseling families about ensuring a safe environment?
3. What aspects of counseling families about ensuring safety have been the most successful?
4. What aspects of counseling families about ensuring safety have been the most challenging for your program to achieve?

M. THERAPEUTIC ENVIRONMENT, INCLUDING MODIFICATIONS TO THE PHYSICAL AND SOCIAL ENVIRONMENT OF THE PERSON WITH DEMENTIA: CREATE A COMFORTABLE ENVIRONMENT, INCLUDING PHYSICAL AND SOCIAL ASPECTS THAT FEEL FAMILIAR AND PREDICTABLE TO THE PERSON WITH DEMENTIA AND SUPPORT FUNCTIONING, A SUSTAINED SENSE OF SELF, MOBILITY, INDEPENDENCE, QUALITY OF LIFE, AND SAFETY.

1. What steps does your program take to counsel families about creating a therapeutic and comfortable environment for the person with dementia at home, including both social and physical aspects? Please describe.
2. Who is involved in counseling families about creating a therapeutic environment?
3. What parts of counseling families about creating a therapeutic environment have been the most successful?
4. What parts of counseling families about creating a therapeutic environment have been the most challenging for your program to achieve?

N. CARE TRANSITIONS: ENSURE APPROPRIATE AND EFFECTIVE TRANSITIONS ACROSS PROVIDERS AND CARE SETTINGS.

1. Does your program have protocols to ensure appropriate and effective transitions across providers and care settings?
2. If not, can you describe what your program does when a participant presents a need for support for care transitions?

If yes, discuss questions 3 through 6.

3. From time to time persons with dementia have to transition to other providers and care settings. What does the program do to ease those transitions? Does your program have protocols to ensure appropriate and effective transitions across providers and care settings? Please describe.
4. Who is involved in organizing care transitions?
5. What parts of ensuring appropriate and effective care transition have been the most successful?
6. What parts of ensuring appropriate and effective care transition have been the most challenging for your program to achieve?

O. COLLABORATION AMONG AGENCIES AND PROVIDERS: WHEN MORE THAN 1 AGENCY OR PROVIDER IS CARING FOR A PERSON WITH DEMENTIA, COLLABORATE AMONG THE VARIOUS AGENCIES AND PROVIDERS TO PLAN AND DELIVER COORDINATED CARE.

1. Does the program work with other agencies and providers to plan and coordinate the care for individuals with dementia and their caregivers?
2. Does your program have protocols for collaboration among the various agencies and providers? Please describe.
3. Who is involved in organizing collaboration among agencies and providers?
4. What parts of collaboration among agencies have been the most successful?
5. What parts of collaboration among agencies have been the most challenging for your program to achieve?

P. REFERRAL AND COORDINATION OF CARE AND SERVICES THAT MATCH THE NEEDS OF THE PERSON WITH DEMENTIA AND FAMILY CAREGIVER (S): FACILITATE CONNECTIONS OF PERSONS WITH DEMENTIA AND THEIR FAMILY CAREGIVERS TO INDIVIDUALIZED, CULTURALLY AND

LINGUISTICALLY APPROPRIATE CARE AND SERVICES, INCLUDING MEDICAL, OTHER HEALTH-RELATED, RESIDENTIAL, AND HOME AND COMMUNITY-BASED SERVICES.

1. When a person with dementia and their caregiver needs services not provided by your program, how is referral to other providers handled?
2. Does your program have protocols in place to facilitate referral and coordination of care and services that match the needs of the person with dementia and family caregivers? Please describe.
3. How does the program take cultural and linguistic needs into account in their referrals?
4. Who is involved in facilitating referrals and coordination of care?
5. What parts of facilitating referrals and coordination of care have been the most successful?
6. What parts of facilitating referrals and coordination of care have been the most challenging for your program to achieve?

Finally, are there any other important parts of dementia care program that we have not discussed?

Do you have any other ideas about what is important for dementia care programs to do?

To obtain a printed copy of this report, send the full report title and your mailing information to:

U.S. Department of Health and Human Services
Office of Disability, Aging and Long-Term Care Policy
Room 424E, H.H. Humphrey Building
200 Independence Avenue, S.W.
Washington, D.C. 20201
FAX: 202-401-7733

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