Alzheimer's Association® Dementia Care Practice Recommendations

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The Alzheimer's Association is the leading voluntary health organization in Alzheimer research, care and support. Our mission is to eliminate Alzheimer's disease through the advancement of research; to provide and enhance care and support for all affected; and to reduce the risk of dementia through the promotion of brain health.

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Editorial

Alzheimer's Association Dementia Care Practice Recommendations

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Background and Introduction

Alzheimer's disease is a degenerative brain disease and the most common cause of dementia. Dementia is a syndrome—a group of symptoms—that has a number of causes. The characteristic symptoms include difficulties with memory, language, problem solving, and other cognitive skills that affect a person's ability to perform everyday activities (Alzheimer's Association, 2017).

According to the *Alzheimer's Association 2017 Alzheimer's Disease Facts and Figures*, an estimated 5.5 million Americans are living with Alzheimer's dementia. One in 10 people aged 65 years and older (10%) has Alzheimer's dementia, and almost two-thirds of Americans with Alzheimer's are women. In addition to gender differences, Alzheimer's dementia affects racial and ethnic groups disproportionately. Compared to older white adults, African Americans are about twice as likely to have Alzheimer's or other dementias, and Hispanics are approximately 1.5 times as likely (Alzheimer's Association, 2017).

Almost 60% of older adults with Alzheimer's or other dementias reside in the community, only 25% of who live alone. As their disease progresses, people with Alzheimer's or other dementias generally receive more care from family members, unpaid caregivers, and community-based and residential care providers. Forty-two percent of residents in assisted living communities have Alzheimer's or other dementias (Caffrey et al., 2012; Zimmerman, Sloane, & Reed, 2014), and 61% of nursing home residents have moderate or severe cognitive impairment (Centers for Medicare and Medicaid Services, 2016). Further, by age 80, 75% of people with Alzheimer's dementia are admitted to a nursing home, compared with only 4% of the general population (Arrighi, Neumann, Lieberburg, & Townsend, 2010).

Since its inception, the Alzheimer's Association has been a leader in outlining principles and practices of quality care for individuals living with dementia. Early on, the *Guidelines for Dignity* described goals for quality care, followed by *Key Elements of Dementia Care* and the *Dementia Care Practice Recommendations*, as more evidence became available. In this new iteration, the *Alzheimer's Association Dementia Care Practice Recommendations* outline recommendations for quality care practices based on a comprehensive review of current evidence, best practice, and expert opinion. The Dementia Care Practice Recommendations were developed to better define quality care across all care settings, and throughout the disease course. They are intended for professional care providers who work with individuals living with dementia and their families in residential and community-based care settings.

With the fundamentals of person-centered care as the foundation, the Dementia Care Practice Recommendations (see Figure 1) illustrate the goals of quality dementia care in the following areas:

- Person-centered care
- Detection and diagnosis
- Assessment and care planning
- Medical management
- Information, education, and support
- Ongoing care for behavioral and psychological symptoms of dementia, and support for activities of daily living
- Staffing
- Supportive and therapeutic environments
- Transitions and coordination of services

Figure 1. Dementia Care Practice Recommendations.

This article highlights the recommendations from all 10 articles in the Supplement Issue of *The Gerontologist* entitled, *Alzheimer's Association Dementia Care Practice Recommendations*. Each article provides more detail about the specific recommendations, as well as the evidence and expert opinion supporting them. This supplement includes two areas that generally are not included in recommendations for providers in community and residential care settings, although these topics are frequently included in recommendations for physicians and other medical care providers—detection and diagnosis and ongoing medical management. Different from existing recommendations on these two topics, the articles are written for nonphysician care providers and address what these providers can do to help with these important aspects of holistic, person-centered dementia care. Throughout all of the articles, Alzheimer's disease and dementia are used interchangeably. Care partner is used to refer to those people supporting individuals in the early stages of dementia, and caregivers is used to refer to those supporting individuals in the middle and late stages; care provider is used for paid professionals. Lastly, the closing article by Thornhill and Conant (2018) outlines the interplay of policy and practice rounds out the supplement.

The Alzheimer's Association is hopeful that these Recommendations will greatly inform and substantially influence dementia care standards, training, practice, and policy.

Practice Recommendations for Person-Centered Care (Fazio, Pace, Flinner, & Kallmyer, 2018)

1. *Know the person living with dementia*
   The individual living with dementia is more than a diagnosis. It is important to know the unique and complete person, including his/her values, beliefs, interests, abilities, likes, and dislikes—both past and present. This information should inform every interaction and experience.
2. *Recognize and accept the person's reality*
   It is important to see the world from the perspective of the individual living with dementia. Doing so recognizes behavior as a form of communication, thereby promoting effective and empathetic communication that validates feelings and connects with the individual in his/her reality.
3. *Identify and support ongoing opportunities for meaningful engagement*
   Every experience and interaction can be seen as an opportunity for engagement. Engagement should be meaningful to, and purposeful for, the individual living with dementia. It should support interests and preferences, allow for choice and success, and recognize that even when the dementia is most severe, the person can experience joy, comfort, and meaning in life.
4. *Build and nurture authentic, caring relationships*
   Persons living with dementia should be part of relationships that treat them with dignity and respect, and where their individuality is always supported. This type of caring relationship is about being present and concentrating on the interaction, rather than the task. It is about "doing with" rather than "doing for" as part of a supportive and mutually beneficial relationship.
5. *Create and maintain a supportive community for individuals, families, and staff*
   A supportive community allows for comfort and creates opportunities for success. It is a community that values each person and respects individual differences, celebrates accomplishments and occasions, and provides access to and opportunities for autonomy, engagement, and shared experiences.
6. *Evaluate care practices regularly and make appropriate changes*
   Several tools are available to assess person-centered care practices for people living with dementia. It is important to regularly evaluate practices and models, share findings, and make changes to interactions, programs, and practices as needed.

Practice Recommendations for Detection and Diagnosis (Maslow & Fortinsky, 2018)

1. *Make information about brain health and cognitive aging readily available to older adults and their families*
   Within their scope of practice and training, nonphysician care providers who work with older adults and their families in community or residential care settings should either talk with them or refer them to other experts for information about brain health, changes in cognition that commonly occur in aging, and the importance of lifestyle behaviors and other approaches

to maintain brain health. They should suggest print and online sources of additional information as appropriate.

2. *Know the signs and symptoms of cognitive impairment, that signs and symptoms do not constitute a diagnosis of dementia, and that a diagnostic evaluation is essential for diagnosis of dementia*
   All nonphysician care providers who work with older adults in community or residential care settings should be trained to recognize the signs and symptoms of cognitive impairment. They should be trained that signs and symptoms are not sufficient for a diagnosis of dementia and that a diagnostic evaluation must be conducted by a physician who can make the diagnosis.
3. *Listen for concerns about cognition, observe for signs and symptoms of cognitive impairment, and note changes in cognition that occur abruptly or slowly over time*
   Depending on their scope of practice, training, and agency procedures, if any, nonphysician care providers who work with older adults in community or residential care settings should listen for older adults' concerns about dementia and observe for signs and symptoms of cognitive impairment and changes in cognition. As appropriate and in accordance with agency procedures and respect for individuals' privacy, nonphysician care providers should communicate with coworkers about observed signs and symptoms, changes in cognition, and concerns of older adults and family members about the older adult's cognition. Depending on their scope of practice and training, they should encourage the older adult and family to talk with the individual's physician about the signs and symptoms, changes in cognition, and older adult and family concerns.
4. *Develop and maintain routine procedures for detection of cognition and referral for diagnostic evaluation*
   Administrators of organizations that provide services for older adults in community or residential care settings and self-employed care providers should develop and maintain routine procedures for assessment of cognition. They should, at a minimum, maintain an up-to-date list of local memory assessment centers and physicians, including neurologists, geriatricians, and geriatric psychiatrists, who can provide a diagnostic evaluation for older adults who do not have a primary care physician or have a primary care physician who does not provide such evaluations. Ideally, nonphysician care providers and organizations that work with older adults should partner with physicians, health plans, and health care systems to establish effective referral procedures to ensure that older adults with signs and symptoms of cognitive impairment can readily receive a diagnostic evaluation.
5. *Use a brief mental status test to detect cognitive impairment only if*:
   - such testing is within the scope of practice of the nonphysician care provider, and
   - the nonphysician care provider has been trained to use the test; and
   - required consent procedures are known and used; and
   - there is an established procedure for offering a referral for individuals who score below a preset score on the test to a physician for a diagnostic evaluation.
6. *Encourage older adults whose physician has recommended a diagnostic evaluation to follow through on the recommendation*
   Within their scope of practice, training, and agency procedures, if any, nonphysician care providers who work with older adults in community or residential care settings and are aware that an older adult's physician has recommended a diagnostic evaluation should encourage the older adult and family, if appropriate, to follow through on the recommendation. They should talk with the older adult and family about the reasons for and importance of getting a diagnostic evaluation and provide print and online sources of additional information.
7. *Support better understanding of a dementia diagnosis*
   Within their scope of practice, training, and agency procedures, if any, nonphysician care providers who work with older adults in community or residential care settings and are aware that the older adult has received a dementia diagnosis but does not understand the diagnosis (or the older adult's family does not understand the diagnosis) should encourage the older adult and family to talk with the diagnosing physician. The care provider should also offer print and online sources of additional information as appropriate.

Practice Recommendations for Person-Centered Assessment and Care Planning (Molony, Kolanowski, Van Haitsma, & Rooney, 2018)

1. *Perform regular, comprehensive person-centered assessments and timely interim assessments*
   Assessments, conducted at least every 6 months, should prioritize issues that help the person with dementia to live fully. These include assessments of the individual and care partner's relationships and subjective experience and assessment of cognition, behavior, and function, using reliable and valid tools. Assessment is ongoing and dynamic, combining nomothetic (norm-based) and idiographic (individualized) approaches.
2. *Use assessment as an opportunity for information gathering, relationship-building, education, and support*
   Assessment provides an opportunity to promote mutual understanding of dementia and the specific situation of the individual and care partners, and to enhance the quality of the therapeutic partnership. Assessment should reduce fear and stigma and result in referrals to community resources for education, information and

support. Assessment includes an intentional preassessment phase to prepare the assessor to enter the experience of the person living with dementia and their care partner(s).

3. *Approach assessment and care planning with a collaborative, team approach*
   Multidisciplinary assessment and care planning are needed to address the whole-person impact of dementia. The person living with dementia, care partners, and caregivers are integral members of the care planning team. A coordinator should be identified to integrate, document and share relevant information and to avoid redundancy and conflicting advice from multiple providers.
4. *Use documentation and communication systems to facilitate the delivery of person-centered information between all care providers*
   Comprehensive, high-quality assessment is of benefit only if it is documented and shared with care providers for use in planning and evaluating care. Information must be current, accessible, and utilized.
5. *Encourage advance planning to optimize physical, psychosocial, and fiscal wellbeing and to increase awareness of all care options, including palliative care and hospice*
   Early and ongoing discussion of what matters, including values, quality of life and goals for care, are essential for person-centered care. The person living with dementia's preferences and wishes should be honored in all phases of the disease, even when proxy decision making is required. The individual and family should be referred to health care team members to provide ongoing education and support about symptom management and palliative care.

Practice Recommendations for Medical Management (Austrom, Boustani, & LaMantia, 2018)

1. *Take a holistic, person-centered approach to care and embrace a positive approach to the support for persons living with dementia and their caregivers that acknowledges the importance of individuals' ongoing medical care to their well-being and quality of life*
   Nonphysician care providers must adopt a holistic approach to providing care and ongoing support to the person living with dementia and their family caregivers. They should work to reduce existing barriers to coordination of medical and nonmedical care and support. Adopting a positive approach towards care can reduce real or perceived messages of hopelessness and helplessness and replace these with positive messages and an approach that encourages persons living with dementia and their caregivers to seek support and care over the course of the disease.
2. *Seek to understand the role of medical providers in the care of persons living with dementia and the contributions that they make to care*
   Nonmedical care providers and family caregivers should work with medical providers towards developing a shared vision of care to support the person living with dementia.
3. *Know about common comorbidities of aging and dementia and encourage persons living with dementia and their families to talk with the person's physician about how to manage comorbidities at home or in residential care settings*
   Common comorbidities can negatively impact a person living with dementia, and conversely, a diagnosis of dementia can make the treatment and management of comorbid conditions quite challenging. Nonmedical care providers should encourage persons living with dementia and their families to report acute changes in health and function to the person's physician, and to let the physician know about difficulties they encounter in managing acute and chronic comorbidities at home or in a residential care facility.
4. *Encourage persons living with dementia and their families to use nonpharmacologic interventions for common behavioral and psychological symptoms of dementia first*
   Increasing evidence suggests nonpharmacological interventions are effective at managing behavioral and psychological symptoms of dementia. Community care providers should encourage persons with dementia and their families to try these interventions first before considering pharmacological treatments.
5. *Understand and support the use of pharmacological interventions when they are necessary for the person's safety, well-being, and quality of life*
   Although nonpharmacological interventions are preferred, there are times when pharmacological treatment is warranted for behavioral and psychological symptoms. It is important for community care providers to understand that pharmacological treatment can have value for the person living with dementia in certain situations and to help them and their family caregiver to accept such treatment. Community care providers should also understand the general principles for starting and more importantly, ending pharmacological treatments and encourage the person living with dementia and family caregivers to ask their medical providers for regular medication reviews and to consider the discontinuation of medications when appropriate.
6. *Work with the person living with dementia, the family, and the person's physician to create and implement a person-centered plan for possible medical and social crises*
   It is helpful for persons living with dementia and their caregivers to have a plan in place should a medical or

social crisis occur, such as an illness, hospitalization or the death of a caregiver. Having a plan in place will help the person's physician and community care providers provide care and support that reflects the preferences of the person living with dementia and reduce stress for family members and care providers who have to make decisions for the person during a crisis.

7. *Encourage persons living with dementia and their families to start end-of-life care discussions early*
   Persons living with dementia and their caregivers should understand options available for care during the later stages of Alzheimer's disease. Having discussions early with the person's physician and other care providers and communicating the preferences of the person and family across care settings can make the transitions during the progression of dementia more manageable.

Practice Recommendations for Information, Education, and Support for Individuals Living with Dementia and their Caregivers (Whitlatch & Orsulic-Jeras, 2018)

1. *Provide education and support early in the disease to prepare for the future*
   Intervening during the early stages creates opportunities to identify, meet, and, in turn, honor the changing and future care needs and preferences of individuals living with dementia and their family caregivers. Discussing the individual's care values and preferences early in the disease can aid in planning during the moderate and advanced stages, as well as at end of life. Early intervention gives individuals living with dementia a voice in how they are cared for in the future, while giving their caregivers piece of mind when making crucial care-related decisions.
2. *Encourage care partners to work together and plan together*
   In recent years, interventions have been developed that bring together individuals living with dementia and their family caregivers, rather than working with each person separately. This person-centered approach supports, preserves, and validates the individual living with dementia's care values and preferences while acknowledging the concerns, stressors, and needs of the caregiver. By discussing important care-related issues earlier on, the individual with dementia's desires and wishes for their own care will remain an important part of their caregiver's decision-making process as the care situation changes.
3. *Build culturally sensitive programs that are easily adaptable to special populations*
   It is very important to design effective evidence-based programming that is sensitive to the unique circumstances of families living with dementia, such as minority, LGBT, and socially disadvantaged populations. However, many minority or socially disadvantaged families living with dementia do not seek out or accept support from nonfamilial sources. Highlighting multicultural issues when training professionals and providing guidance for reaching out to these special populations will lead to more effective programs that embrace the unique needs of all care partners.
4. *Ensure education, information, and support programs are accessible during times of transition*
   There are many transitional points throughout the disease trajectory that have variable effects on both care partners. For example, transitioning from early to middle to late stage often introduces new symptoms and behaviors that, in turn, increase care partners' questions and concerns about what to expect in the future. Progression through the various stages of dementia also brings about other types of transitions, such as changes in living arrangements or care providers (i.e., from in-home to nursing home care). Providing education, information, and support that honor the individual with dementia's values and preferences during these transitions will be reassuring to caregivers as they make hard choices on behalf of the individual living with dementia.
5. *Use technology to reach more families in need of education, information, and support*
   Supportive interventions and programs that use technology (such as Skype, Facetime, etc.) to reach those in need of services are expectedly on the rise. As technology continues to advance and become more accessible and reliable, delivering programs using electronic devices (computer, table, smart phone) could help reach more families. These programs would be especially useful in rural communities where caregivers and individuals living with dementia are often isolated with little access to supportive services.

Practice Recommendations for Care of Behavioral and Psychological Symptoms of Dementia (BPSD) (Scales, Zimmerman, & Miller, 2018)

1. *Identify characteristics of the social and physical environment that trigger or exacerbate behavioral and psychological symptoms for the person living with dementia*
   Behavioral and psychological symptoms of dementia (BPSDs) result from changes in the brain in relation to characteristics of the social and physical environment; this interplay elicits a response that conveys a reaction, stress, or an unmet need, and affects the quality of life of the person living with dementia. The environmental triggers of BPSDs and responses to them differ for each person, meaning that assessment must be individualized and person-centered.
2. *Implement nonpharmacological practices that are person-centered, evidence-based, and feasible in the care setting*

Antipsychotic and other psychotropic medications are generally not indicated to alleviate BPSDs, and so nonpharmacological practices should be the first-line approach. Practices that have been developed in residential settings and which may also have applicability in community settings include sensory practices, psychosocial practices, and structured care protocols.

3. *Recognize that the investment required to implement nonpharmacological practices differs across care settings*
   Different practices require a different amount of investment in terms of training and implementation, specialized caregiver requirements, and equipment and capital resources. Depending on the investment required, some practices developed in residential settings may be feasible for implementation by caregivers in home-based settings.
4. *Adhere to protocols of administration to ensure that practices are used when and as needed, and sustained in ongoing care*
   Protocols of administration assure that there is a "guideline" for care providers as they strive to alleviate BPSDs. These protocols may evolve over time, responsive to the particular components of the practice that are most effective for the person living with dementia.
5. *Develop systems for evaluating effectiveness of practices and make changes as needed*
   The capacity and needs of persons living with dementia evolve over time, and so practices to alleviate BPSDs also may need to evolve over time. Therefore, it is necessary to routinely assess the effectiveness of the practice and, if necessary, adapt it or implement other evidence-based practices.

Practice Recommendations for Support of Activities of Daily Living (ADLs) (Prizer & Zimmerman, 2018)

1. *Support for ADL function must recognize the activity, the individual's functional ability to perform the activity, and the extent of cognitive impairment*
   Dementia is a progressive disease, accompanied by progressive loss in the ability to independently conduct ADLs. Needs for supportive care increase over time—such as beginning with support needed for dressing, and later toileting, and later eating—and must address both cognitive and functional decline as well as remaining abilities.
2. *Follow person-centered care practices when providing support for all ADL needs*
   Not only are dignity, respect, and choice a common theme across all ADL care, but the manner in which support is provided for functionally-specific ADLs must attend to the individualized abilities, likes, and dislikes of the person living with dementia.
3. *When providing support for dressing, attend to dignity, respect, and choice; the dressing process; and the dressing environment*
   In general, people living with dementia are more able to dress themselves independently if, for example, they are provided selective choice and simple verbal instructions, and if they dress in comfortable, safe areas.
4. *When providing support for toileting, attend to dignity and respect; the toileting process; the toileting environment; and health and biological considerations*
   In general, people living with dementia are more able to be continent if, for example, they are monitored for signs of leakage or incontinence, have regularly scheduled bathroom visits and access to a bathroom that is clearly evident as such, and avoid caffeine and fluids in the evening.
5. *When providing support for eating, attend to dignity, respect and choice; the dining process; the dining environment; health and biological considerations; adaptations and functioning; and food, beverage and appetite*
   In general, people living with dementia are more likely to eat if, for example, they are offered choice, dine with others and in a quiet, relaxing, and homelike atmosphere, maintain oral health, are provided adaptive food and utensils, and offered nutritionally and culturally appropriate foods.

Practice Recommendations for Staffing (Gilster, Boltz, & Dalessandro, 2018)

1. *Provide a thorough orientation and training program for new staff, as well as ongoing training*
   A comprehensive orientation should be provided that includes the organization's vision, mission and values, high performance expectations, and person-centered dementia training. This training is essential for new staff, and should be included in ongoing education for all staff members.
2. *Develop systems for collecting and disseminating person-centered information*
   It is important that all staff know the person living with dementia as an individual. Establish procedures for collecting person-centered information that includes choices, preferences, and life history. It is also essential that an effective process be developed to share this information with all staff.
3. *Encourage communication, teamwork, and interdepartmental/interdisciplinary collaboration*
   An organization should promote staff participation and interdepartmental/ interdisciplinary collaboration through routinely scheduled inservice programs and meetings. Training is most effective when designed to include ongoing education, communication and support. Offering inservices and conducting meetings on

all shifts is important, and will impact attendance, participation and facilitate relationships between staff.

4. *Establish an involved, caring and supportive leadership team*
   Creating a person-centered "community" is not possible without service-oriented leaders, managers and supervisors. It is also vital that the leadership team be vision-driven, open, and flexible. High performing leaders know that staff are the foundation of success, and when staff are valued, recognized, and feel served themselves, they in turn will more likely value and serve others.
5. *Promote and encourage resident, staff, and family relationships*
   Encouraging relationships among persons living with dementia, staff and families is central to person-centered care, and is fostered in part by implementing consistent staff assignment. The involvement of all parties in planning care, activities, education, and social events may cultivate successful relationships as well.
6. *Evaluate systems and progress routinely for continuous improvement*
   It is important that an organization routinely collect and evaluate information on all staff processes, including hiring, orientation, training and satisfaction. Analysis of the data should be used to evaluate the effectiveness of all systems and identify areas for improvement. In addition, leaders should share this information with staff, and act upon the results.

Practice Recommendations for Supportive and Therapeutic Environments (Calkins, 2018)

1. *Create a sense of community within the care environment*
   The care community includes the person receiving care, their family and other chosen care partners, and professional care providers. The environment should support building relationships with others as a result of sharing common attitudes, interests, and the goals of the individuals living with dementia, their caregivers, and other care providers.
2. *Enhance comfort and dignity for everyone in the care community*
   It is important that members of the care community are able to live and work in a state of physical and mental comfort free from pain or restraint. Environments are designed to maintain continuity of self and identity through familiar spaces that support orientation to place, time, and activity.
3. *Support courtesy, concern, and safety within the care community*
   Members of the care community should show politeness and respect in their attitudes and behavior toward each other. Doing so includes creating a supportive environment that does not put unnecessary restrictions on individuals and helps them feel comfortable and secure, while also ensuring their safety. The environment compensates for physical and cognitive changes by maximizing remaining abilities and supporting caregiving activities.
4. *Provide opportunities for choice for all persons in the care community*
   The culture of the care community supports a range of opportunities for all persons to make decisions concerning their personal and professional lives, as well as their health and welfare. The environment can provide opportunities for self-expression and self-determination, reinforcing the individual's continued right to make decisions for him/herself.
5. *Offer opportunities for meaningful engagement to members of the care community*
   Relationships are built on knowing the person, which itself is based on doing things together. An environment that provides multiple, easily accessible opportunities to engage in activities with others supports deeper knowing and the development or maintenance of meaningful relationships.

Practice Recommendations for Transitions in Care (Hirschman & Hodgson, 2018)

1. *Prepare and educate persons living with dementia and their family caregivers about common transitions in care*
   Preparing and educating persons living with dementia and their care partners/caregivers about transitions in care should occur before, during and after transitions. Because family caregivers are integral to the care of individuals living with dementia, it is important to understand their need for information about common transitions, including across care settings, such as home to hospital or skilled nursing facility, nursing home to emergency department; within care settings, such as from an emergency department to an intensive care unit; or from one team of clinicians or care providers to another. For example, tools are publically available from the Alzheimer's Disease Education and Referral Center (ADEAR) and the Alzheimer's Association that can be provided to persons living with dementia and their caregivers to help them prepare for the possibilities of hospitalization and transition to long-term care settings such as nursing homes or assisted living.
2. *Ensure complete and timely communication of information between, across and within settings*
   Individuals living with dementia are frequently transferred across facilities without essential clinical information. Careful attention is essential to ensure a safe "handoff." Finding timely and standardized ways to share medical records and advance care planning forms

between patients, caregivers and providers throughout transitions is needed. Linking electronic health records across care settings also offers this potential. Open communication between providers, across settings, and within organizations or clinical practices is essential (both written and verbal). Assisting persons living with dementia and their caregivers in accessing and sharing information in a person- and family-centered way can help to avoid poor outcomes often associated with transitions in care (e.g., rehospitalizations, emergency department visits, medication errors, and caregiver stress). Information must be clinically meaningful, appropriate in amount; it should be communicated by a method useful to the receiving site of care. Achieving these objectives by using standardized forms or standardized approaches to communicate hand-offs can increase the accuracy of information and minimizes risk of error.

3. *Evaluate the preferences and goals of the person living with dementia along the continuum of transitions in care*
   Revisiting preferences and goals for care, including treatment preferences, advance directives, and social and living situation, while the person living with dementia can participate is essential during transitions in care. If a person living with dementia is unable to participate, including caregivers or others who know the person well is vital. After any hospitalization or other significant change requiring a transition in care or level of care, a review and reassessment of the preferences and goals of the person living with dementia should include an assessment of safety, health needs, and caregiver's ability to manage the needs of the person living with dementia. This requires improved competencies of the entire interprofessional team in conducting goals of care conversation, and more effective processes to ensure appropriate assessments are performed before the decision to move a person with dementia to another setting of care is made.
4. *Create strong interprofessional collaborative team environments to assist persons living with dementia and their care partners/caregivers as they make transitions*
   Creation of a strong interprofessional collaborative team environment to support the person living with dementia throughout transitions in care is crucial. Each member of the team needs to have a basic set of competencies in the fundamentals of caring for individuals living with dementia at all stages and their family caregivers. All of the evidence-based interventions described here were specifically designed to address the challenges for individuals living with dementia and other complex chronic conditions as well as the needs of their family caregivers. For example, in the MIND study case, managers were trained in dementia care management over a 4-week period of time, in another study, Naylor and colleagues (2014) developed a set of web-based education modules designed specifically on how to manage the care needs of older adults living with dementia and their family caregiver as they transition from the hospital to home. Furthermore, this type of work requires continuity of the same clinicians (whenever possible) to support the person living with dementia and their family as they move between providers and across setting. Every member of the health care team must be accountable and responsive to ensure the timely and appropriate transfer of responsibility to the next level or setting of care. Optimally clinicians from the sending site of care should maintain responsibility for individuals with dementia until the caregivers at the receiving site assume clinical responsibility.
5. *Initiate/Use evidence-based models to avoid, delay, or plan transitions in care*
   The seven evidence-based models of care in this review focused on avoiding unnecessary transitions (such as hospitalization, or emergency department visits), delaying or supporting placement in residential care settings (such as nursing homes or assisted living communities). Although many evidence-based models have excluded or limited the inclusion of persons living with dementia, adaptations of these models should be considered whenever possible to improve transitions. Among the interventions that targeted hospitalizations and emergency department visits, it is important to note that these events are often tied to nondementia-related conditions. Furthermore, targeting avoidable hospitalizations or rehospitalization for persons living with dementia has the potential to interrupt poor outcomes more common with this population such as risk of delirium and falls. As evidence-based models of care are adapted and modified to meet the needs of persons living with dementia transitioning between, across and within settings of care it is critical to share the findings from these adapted transitions in care models.

About the Alzheimer's Association

The Alzheimer's Association is the leading voluntary health organization in Alzheimer's care, support, and research. Founded in 1980 by a group of family caregivers and individuals interested in research, the Association includes a home office in Chicago, a public policy office in Washington, D.C., and a presence in communities across the country.

Currently, an estimated 47 million people worldwide are living with dementia. In the United States alone, more than 5 million have Alzheimer's, and over 15 million are serving as their caregivers. The Alzheimer's Association addresses this global epidemic by providing education and support to the millions who face dementia every day, while advancing critical research toward methods of treatment, prevention and, ultimately, a cure.

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Review Article

The Fundamentals of Person-Centered Care for Individuals With Dementia

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Abstract

Background and Objectives: Person-centered care is a philosophy of care built around the needs of the individual and contingent upon knowing the unique individual through an interpersonal relationship. This review article outlines the history, components, and impact of person-centered care practices.

Research Design and Methods: Through literature review, published articles on person-centered measures and outcomes were examined.

Results: The history of person-centered care was described, core principles of care for individuals with dementia outlined, current tools to measure person-centered care approaches reviewed, and outcomes of interventions discussed.

Discussion and Implications: Evidence-based practice recommendations for person-centered care for individuals with dementia are outlined. More research is needed to further assess the outcomes of person-centered care approaches and models.

Keywords: Alzheimer's disease, Dementia care, Individualized care, Recommendations

Person-centered care is essential to good dementia care and the underlying philosophy of the 2018 Alzheimer's Association Dementia Care Practice Recommendations. Person-centered care is a philosophy of care built around the needs of the individual and contingent upon knowing the person through an interpersonal relationship. It challenges the traditional medical model of care that tends to focus on processes, schedules, and staff and organizational needs. It requires commitment from everyone within the organization, especially leadership. Whether referred to as "person-directed," "resident-focused" or something similar, the core principles are essentially the same.

This article will describe the history of person-centered care, outline the core principles of care for individuals with dementia, review current tools to measure person-centered care approaches, and discuss outcomes of interventions. Lastly, this article will outline practice recommendations for person-centered care for individuals with dementia.

Overview of Person-Centered Care for People with Dementia

Origins of Person-Centered Care

The term *person-centered care* has its origins in the work of Carl Rogers, which focused on individual personal experience as the basis and standard for living and therapeutic effect. Tom Kitwood first used the term in 1988 to distinguish a certain type of care approach from more medical and behavioral approaches to dementia. Kitwood used the term to bring together ideas and ways of working that emphasized communication and relationships. Kitwood (1998) proposed that dementia could be best understood as an interplay between neurological impairment and psychosocial factors, namely, health, individual psychology, and the environment, with particular emphasis on social context. He believed that the environment has as much effect on the brain as the brain has on a person's abilities. Fundamental

to Kitwood's theory was a rejection of the standard medical approach to dementia, which focused on rigidly treating a disease. He believed that the basic assumption in the medical sciences of dementia carried far too negative and predictable implications for the nature of caregiving.

Kitwood and Bredin (1992) shared evidence from studies of different care practices, suggesting that dementia does not universally progress in a linear fashion, and most importantly, it varies from person to person. They concluded that the person with dementia is in a state of relative well-being or ill-being, and that indicators can be observed through detailed observation. They found a need for high-quality interpersonal care that affirms personhood; one that implies recognition, respect, and trust. The approach that Kitwood and Bredin developed to fill this need was *person-centered care*. Philosophically, they looked at what persons with dementia need and determined that the answer began with love at the center surrounded by the following five offshoots: comfort, attachment, inclusion, occupation, and identity (Kitwood, 1997). Individuals need comfort or warmth to "remain in one piece" when they may feel as though they are falling apart. Individuals with dementia need to feel attachment when they so often feel as though they are in a strange place. Individuals need to be included and involved both in care and in life, and more than simply being occupied; they need to be involved in past and current interests and sources of fulfillment and satisfaction. Finally, people with dementia need to have an identity and their caregivers must help maintain this identity (Kitwood, 1997). As Kitwood (1997) stated, "To have an identity is to know who one is, in cognition and in feeling. It means having a sense of continuity with the past; and hence a 'narrative,' a story to present to others"(p43). Due to declining cognition, persons with dementia need others to "hold their story" and to respond to them as "thou, in the uniqueness of their being" (Kitwood, 1997).

Kitwood (1997) developed a conceptual approach to care that provides staff with a way of thinking about what they do according to principles that guide care and reinforce or support personhood and well-being throughout the course of dementia. Rather than simply providing care in accordance with routines organized for staff convenience, efficiency, or some other criteria, Kitwood (1997) suggested that the focus should be on the person who is the recipient of care. Kitwood's framework encourages staff to focus less on *what* is done and more on *how* it is done. Kitwood's principles assist those who provide care to critically evaluate how programs and communication strategies can be adopted and implemented to support the multidimensional person with dementia.

Selfhood and Person-Centered Care

At the core of person-centered care is the self—who we are, our values and beliefs, etc. Selfhood is much more than memory and should not be viewed only in terms of cognitive abilities. Recognizing and maintaining selfhood is key to person-centered care. Researchers have found intact manifestations of selfhood in spite of significant cognitive impairments and that it is not intact autobiographical memory that constitutes self or personal identity (Sabat & Harré, 1992; Sabat & Collins, 1999). Sabat and Harré (1992) revealed through case studies that the self of personal identity persists far into the end stage of AD. Sabat and Collins (1999) suggested that the multiple personae presented in public and in relationships can be lost, partly as a result of how others treat and view the person with AD. Thus, losses in aspects of selfhood might be traced, in part, to dysfunctional social interactions rather than solely the neuropathology of Alzheimer's disease. Based on findings suggesting a connection between self and interactions with healthy others, Sabat (2002) concluded that it is possible—through discourse, or language—to observe intact selves in individuals with AD. He also suggested that a self of social identity could be seen by the attributes or characteristic that one possesses, and a self of personal identity by pronouns used.

Building on Sabat's research, Fazio and Mitchell (2009) quantitatively evaluated the persistence of self in persons with dementia through language use and visual self-recognition. They found that although overall frequency of language usage declined across impairment levels, there were no significant differences in either *rates* or *proportions* of pronoun and attribute usage. This suggests that it is not a loss of self per se that is responsible for a lower frequency of language usage, but more likely a decreased ability to initiate conversation. In addition, when individuals were asked to identify themselves in photographs, cognitively impaired individuals—in spite of forgetting the photographic session only minutes earlier—exhibited unimpaired self-recognition, consistent with a preserved self.

Others are an essential part of maintaining the self in people with dementia. When a person is seen as diminished due a decline in cognitive functioning, they can be treated as if they were no longer a human being and in nonhuman ways (Fazio, 2008). Kitwood and Bredin (1992) state that some of the most disabling effects of brain disease are to be found not in functional impairment but in the threats to one's self and personhood. They believe personhood is dependent on other people. Recognizing that selfhood persists, learning about the complete self, and finding ways to maintaining selfhood though interactions and conversations are fundamental components of person-centered care for people with dementia.

Relationships and Person-Centered Care

Maintaining selfhood is a key part of building and nurturing relationships. Kitwood and Bredin (1992) discussed how interdependence is a necessary condition of being human. However, due to the Alzheimer's disease, a dependence on others is a necessity for persons with

dementia. The care provider becomes an absolute necessity, both physically and psychologically. This relationship is critical. Kitwood and Bredin (1992) explained that personhood can be ensured only within the context of a mutually recognizing, respecting, and trusting relationship. In his earlier work, Kitwood (1990) described 10 processes and interactions that tend to depersonalize a person with dementia, which include disempowerment, labeling, infantilism, and objectification. Words do matter, as language leads to perceptions, and ultimately approaches to care (Fazio, 1996). Labels depersonalize individuals and can lead them to be treated in ways that do not support their personhood.

Relationships with others do have a great impact on personhood. Kitwood and Bredin (1992) believe that the personhood of individuals with dementia needs to be continually replenished, their selfhood continually evoked and reassured. The other person, the caregiver, is needed to offset degeneration and fragmentation and sustain personhood. The further the dementia advances, the greater the need for "person-work." The caregiver is needed to hold the pieces together to become the memory (Fazio, 2008). Kitwood and Bredin (1992) believe that this may be understood as the true agenda of dementia care. Care partners need to be the support that maintains the self and structure the environment and interactions within it to effectively do so. Knowing the person is central to care that is based in mutual trusting and caring relationship.

Key Components of Person-Centered Dementia Care

Researchers have worked to find commonalities among models and practices of person-centered dementia care. Levy-Storms (2013) conducted a literature review and found several commonalities among models and practices including (a) supporting a sense of self and personhood through relationship-based care and services, (b) providing individualized activities and meaningful engagement, and (c) offering guidance to those who care for them. Kogan, Wilber, & Mosqueda (2016) conducted an extensive literature review for definitions of person-centered care. They identified 15 definitions, addressing 17 principles or values. They found that the six most prominent domains were (a) holistic or person-centered care, (b) respect and value, (c) choice, (d) dignity, (e) self-determination, and (f) purposeful living. In all, it was clear that there is a shift in focus away from the traditional biomedical model in favor of embracing personal choice and autonomy.

Brooker (2004), a colleague of Tom Kitwood, has outlined one of the most respected descriptions. Brooker outlined that four key components are integral to a person-centered care approach for people with dementia and can result in a shift in practice and culture. These components are: (a) valuing and respecting persons with dementia and those who care for them; (b) treating people with dementia as individuals with unique needs; (c) seeing the world from the perspective of the person with dementia, so as to understand the person's behavior and what is being communicated, and validating the subjective experience that is being perceived as the reality of the individual; and (d) creating a positive social environment in which the person with dementia can experience relative well-being through care that promotes the building of relationships.

In *Person-Centered Dementia Care: Making Services Better*, Brooker (2006) expanded upon these components and identified key indicators or practices for each of the four components. Key indicators in *valuing care providers* include having a clear vision, developing practices that value employees, creating systems to support staff development, designing supportive and inclusive physical and social environments, and ensuring quality improvement mechanisms. Key indicators of *individualized care* include developing and regularly reviewing care plans that reflect strengths and needs, allowing use of personal possessions, accommodating individual preferences and daily routines, learning about individual life stories, and offering a variety of activities. Key indicators in taking the *perspective of the person with dementia* include communicating effectively, experiencing empathy, monitoring the physical environment, assessing physical health, uncovering reasons for behaviors, and being an advocate. Lastly, key indicators for the *social environment* include treating individuals with respect, creating an atmosphere of warmth, validating feelings, providing appropriate support and assistance, and fostering a sense of community. Indicators such as these outlined by Brooker are important to consider as providers find ways to implement a person-centered philosophy within every day practices (Table 1).

Evolution of Person-Centered Care Models

Elements of person-centered care can be seen in the Federal 1987 Nursing Home Reform Act (OBRA '87). OBRA '87 states that each person receives the necessary care and services to attain or maintain the highest practicable physical, mental, and psychosocial well-being, in accordance with the comprehensive assessment and plan of care. Additionally the culture change movement, consisting of models like the Eden Alternative, Wellspring, and Greenhouse/Small House, implemented various elements of what we now call person-centered care. One of the best known of these models is The Eden Alternative, founded by Bill Thomas. Its central mission is to eliminate the three "intolerable plagues" of nursing home life—loneliness, helplessness, and boredom—by following ten Eden principles, thereby improving elders' quality of life (Thomas, 1996). One important strategy in this approach is to transform the physical institutional environment to be more homelike. Plants, animals, and intergenerational programs are included in the homelike environment to enhance the elder's social engagement. The Green House or Small House model aims to provide

Table 1. Examples of Person-Centered Care Approaches Throughout the Progression of Alzheimer's Disease or Related Dementia

Person-centered care in practice
Below you will find examples of person-centered care approaches throughout the progression of Alzheimer's disease or related dementia. Early Tom has always been a very independent man. Although he was diagnosed with Alzheimer's disease, he wants to remain as independent as possible. He goes through his day as he always did, although now his wife Joan is always there for support if needed. Joan sometimes has to assist with a task, help with finding the right word, or give a friendly reminder. She also continues to include Tom in decisions, including treatments, future care and finances. Middle Frank was a professional musician and played at all of the local and regional clubs. Since he played late night gigs, he was used to staying up late each night as well as sleeping late each morning. When Frank's care needs became too much for his wife, she looked for a memory care center that would support his lifelong schedule. In his new home, Frank stays up late in his room, oftentimes listening to old records. Staff let him wake on his own each morning and include that information in his care plan. Since there is a piano in the reception area, Frank often plays for other residents and visitors. Late Emily was an avid gardener. Her yard was perfectly kept with many varieties of plants, which she grew from seed. He loved fragrant bushes, especially lavender. One side of her yard was filled with beautiful bushes. Throughout the progression, she stayed involved in gardening. In the later stage of the Alzheimer's disease, care providers looked through seed catalogues with her, and talked about different varieties. They kept fragrant cut flowers and plants in her room, especially lavender when available. They kept a small satchel of dried lavender under her pillow, and also used a nice lavender lotion to moisturize her hands and feet.

a good quality of life for residents by transforming physical environments, radically revising staff configurations, and emphasizing companionship under normal rather than therapeutic circumstances (Li & Porock, 2014). Person-centered care is also an important component of the 2016 Centers for Medicare and Medicaid Service (CMS) Quality Strategy as noted in "Goal 2: Strengthen person and family engagement as partners in their care." The objectives of Goal 2 are to ensure all care delivery incorporates person and family preferences, improve experience of care for persons and families and promote self-management.

Tools for Measuring Person-Centered Care Practices

A variety of tools to assess person-centered care practices currently can be found in the literature. Edvardsson and Innes (2010) conducted a critical comparative review of published tools measuring the person-centeredness of care for older people and people with dementia. The tools were compared in terms of conceptual influences, perspectives studied and intended use, applicability, psychometric properties, and credibility. Twelve tools eligible for review were identified; eight tools for evaluating long-term care for older adults, three for hospital-based care, and one for home care. One tool, Dementia Care Mapping (DCM), was dementia specific. Each tool explicitly aimed to measure forms of person-centered care as perceived by care recipients, family members, or staff. Edvardsson and Innes (2010) did recommend that their validity, reliability, and applicability be further explored. A brief summary of each tool included in their extensive review is provided below. Although most of them have not been specifically designed for individuals with dementia, their focus on knowing the person, interpersonal relationships and individual autonomy makes them relevant for assessing person-centered dementia care.

Specifically for long-term care settings, DCM (Brooker & Surr, 2005, as cited by Edvardsson & Innes, 2010) is an observational tool that uses four predetermined coding frames that aim to make the observer view the world from the point of view of the person with dementia. Coding frames of DCMs are as follows: mood enhancers (6-item scale), behavior categories (23 items), personal detractions (PD, 17 items), and personal enhancers (PE, 17 items). Items are rated on a 2-point scale ranging between "detracting" and "highly detracting" for PD and "enhancing" and "highly enhancing" for PE. DCM was developed through a systematic process of item development.

Also for long-term care settings, the Person-Directed Care Measure (White et al., 2008, as cited by Edvardsson & Innes, 2010) consists of 50 items covering eight domains of person-centered care and is divided into two dimensions: person-directed care and person-directed environment. Another tool, the Person-Centered Care Assessment Tool (P-CAT) (Edvardsson et al., 2010, as cited by Edvardsson & Innes, 2010) consists of 13 items in three subscales: personalizing care, organizational support, and environmental accessibility. In addition, the Measures of Individualized Care (Chappell, Reid, & Gish, 2007, as cited by Edvardsson & Innes, 2010) consists of three tools to measure individualized care. The first tool operationalizes the domain "knowing the person" (13 items). The second tool operationalizes "resident autonomy" (15 items), and the third tool measures "communication" (18 items). Lastly, the Family Involvement in Care (Reid, Chappell, & Gish, 2007, as cited by Edvardsson & Innes, 2010) consists of two measures of family involvement in the care of a relative with dementia in a long-term care setting. The first measure (20 items) measures to what extent family members perceive they are involved in the care of their relative. The second measure (18 items) measures the importance attached to being involved in the care of the relative living in long-term care.

Designed for hospital settings, the Person-Centered Climate Questionnaire (PCQ) (Edvardsson et al., 2009, 2010, as cited by Edvardsson & Innes, 2010) consists of two tools (staff and patient versions) to measure to what extent the psychosocial environment of health care settings is perceived to be person centered. The staff tool (14 items) consists of four subscales: safety, everydayness, community, and comprehensibility. The patient tool (17 items) consists of two subscales: safety and hospitality. Another instrument, the Person-Centered Impatient Scale (Coyle & Williams, 2001, as cited by Edvardsson & Innes, 2010), measures recipient experiences of care and contains 20 items in five dimensions: personalization, empowerment, information, approachability/availability, and respectfulness. Intended for home care settings, the Client-Centered Care Questionnaire (DeWitte et al., 2006, as cited by Edvardsson & Innes, 2010) is 15-item questionnaire that was developed to measure to what extent older people receiving home care experience the care as being client centered.

A few additional tools were found that were developed after the 2010 review of Edvardsson and Innes. Zimmerman et al. (2014) developed the Person-Centered Practices in Assisted Living (PC-PAL) in collaboration with the Center for Excellence in Assisted Living (CEAL) as part of a toolkit for person-centered care in assisted living. The PC-PAL includes one questionnaire for completion by residents, and one for completion by staff. They are research quality, evidence-based questionnaires to help organizations measure their person-centered practices and inform their quality improvement efforts. The Resident PC-PAL (49 items) includes four areas that reflect person- centeredness in assisted living: (a) well-being and belonging (18 items), (b) individualized care and services (12 items), (c) social connectedness (10 items), and (d) atmosphere (9 items). The Staff PC-PAL (62 items) includes five areas that reflect person-centeredness in assisted living: (a) workplace practices (23 items), (b) social connectedness (16 items), (c) individualized care and services (8 items), (d) atmosphere (8 items), and (e) caregiver-resident relationships (7 items).

In addition, the Advancing Excellence in America's Nursing Home Campaign developed a Person-Centered Care Tracking Tool consisting of seven steps to success. The steps include (a) explore goal, (b) identify baseline, (c) examine process, (d) create improvement, (e) engage, (f) monitor and sustain, and (g) celebrate success. This tool includes spreadsheets, forms, links to resources, etc. to help gather data, make changes, and celebrate success. Lastly, Burke, Stein-Parbury, Luscombe, & Chenoweth (2016) developed the Person-Centered Environment and Care Assessment Tool (PCECAT) to assess and improve residential care standards using person-centered principles, while also meeting Australian care guidelines for older adults. The development included a review of existing assessment instruments and their alignment with person-centered principles and Australian dementia care quality standards—management systems, staffing and organizational development, health and personal care, resident lifestyle, physical environment, and safe systems. The tool successfully moved from concept to development and testing, proving to be valid and reliable. The tool is specific to Australian care standards but can be adapted for use in other countries. As shown, a variety of tools are currently available to measure person-centered care practices but more research and consistency is needed. It is important that tools continue to be developed and tested so we can consistently measure the outcomes associated with person-centered care practices.

Benefits of Person-Centered Care Approaches

Early research in person-centered care demonstrated measurable results. Epp (2003) highlighted several studies that revealed positive results from implementing person-centered care practices including improved quality of life, decreased agitation, improved sleep patterns and maintenance of self-esteem. More broadly, research in the application of person-centered practices and culture-change principles has shown how they can make life better for residents and improve working conditions for staff (Koren, 2010). Relatively simple interventions have produced measurable results—for example, keeping shower rooms warm can make bathing a more pleasurable experience for residents, reduce staff stress, and save time (Koren, 2010). Koren (2010) also stated that several management studies support the link between strategic human resource management and organizational performance, lending support for the organizational redesign called for by culture-change proponents.

Effects of Person-Centered Care Interventions on Individuals

Li and Porock (2014) provided a comprehensive review article that synthesized current evidence of the effects of multiple person-centered care models on resident outcomes. Systematic searches were conducted using various databases, using multiple keywords. Searches were limited to articles written in English and published from January 1990 to April 2013. In addition, a manual search of the reference lists of selected relevant articles was conducted.

Twenty-four studies from three countries were reviewed and compared in terms of person-centered interventions, measurement, and resident outcomes. Fifteen culture change studies for residents who were cognitively intact or with minor cognitive impairment and nine studies for residents

with dementia were reviewed. Across the studies, culture change models had some beneficial effects on residents' psychological wellbeing. Person-centered dementia care had significant effects on decreasing behavioral symptoms and psychotropic medication use in residents with dementia in long-term care. The outcomes of these culture change and person-centered care studies outlined by Li and Porock (2014) are summarized in the paragraphs that follow.

Culture Change Studies

Most of the 15 culture change studies focused on residents with intact cognition or with mild dementia and aimed to test a single component of a culture change model. Nine of the studies were guided by the Eden Alternative, two by Green House/Small House model, one by Wellspring, one by "resident-centered care," one by "Social Care Model," and one was conducted by Pioneer Network to test PCC principles. Across studies, there were challenges with weak designs, threats to internal and external validity, simplistic methods, and small biased sample sizes (Li & Porock, 2014). Residents' cognition, quality of life (QoL), psychological wellbeing, physical wellbeing, and other care-related resident outcomes were measured in these studies. The effectiveness of culture change in terms of QoL, depression, loneliness, helplessness, boredom, and activities of daily living (ADL) was the major focus of all studies. Other outcomes examined included restraint use, pressure ulcers, infections, medication use, falls, and nutrition problems (Li & Porock, 2014).

Three of the five studies that examined the impacts of culture change models on residents' QoL found beneficial effects, including dignity, security, individuality, and autonomy (Li & Porock, 2014). Other studies illustrated impact on depression as shown by a significant decrease in the Global Depression Scale in both cognitively intact and cognitively impaired residents over time, and by lower levels of helplessness, boredom, and loneliness (Li & Porock, 2014). Activities of daily living were examined in four Eden studies and two Green House studies, showing a lower percentage of residents who were dependent in eating and lower incidence of decline in late-loss ADLs than residents in comparison groups (Li & Porock, 2014). In addition, physical restraint use was reported in five studies, with less physical restraint use was found in three studies (Li & Porock, 2014).

Person-Centered Dementia Care Studies

Li and Porock (2014) reported that eight of nine person-centered dementia care studies were grounded by Kitwood's concepts. Seven of the nine person-centered dementia care studies developed individualized interventions based on understanding residents' needs, histories, and wishes. Dementia care mapping was used to develop the person-centered dementia care interventions in two studies. Studies applied a variety of validated instruments to measure residents' cognitive impairment, QoL, behavioral symptoms, affects, and other physical wellbeing (Li & Porock, 2014).

Behavioral disturbance was observed in eight studies. The five studies that used aggression or agitation as primary outcomes showed that interventions significantly decreased the challenging behaviors expressed by residents with dementia (Li & Porock, 2014). However, three studies that did not primarily target such behaviors nevertheless did achieve significant findings. Integrating results of these studies shows that person-centered interventions seem to be effective in decreasing agitated behaviors in residents with dementia (Li & Porock, 2014). Emotional disturbance, such as depression and affect, was measured in five studies. Overall, these studies showed that person-centered dementia care interventions helped to produce more positive affections but did not reduce depression symptoms (Li & Porock, 2014). Psychotropic drug use was evaluated in three studies, and a reduction of neuroleptic or antipsychotic use by the intervention groups was found in two of the three studies (Li & Porock, 2014). Lastly, four validated QoL measurements for people with dementia were used in two studies. However, the effect of person-centered dementia care on QoL in residents with dementia cannot be determined due to inconsistent findings (Li & Porock, 2014).

In short, of all the culture change studies, the Eden Alternative seemed to have some beneficial effects on residents' psychological wellbeing, including depression, loneliness, helplessness, and boredom (Li & Porock, 2014). Studies also showed positive outcomes for effectiveness of culture change models in terms of QoL, ADL function, restraint use, and other outcomes, however more research is needed. In relation to person-centered dementia care studies, interventions had significant effects on decreasing behavioral symptoms, producing positive affect, and reducing psychotropic medication use in residents living with dementia in long-term care (Li & Porock, 2014). However, the effects of person-centered intervention on residents' living with dementia QoL, depression, sleep, and other physiological outcomes cannot be determined based on the inconsistent results of the reviewed studies (Li & Porock, 2014).

Effects of Person-Centered Care Approaches on Staff

Barbosa, Sousa, Nolan, & Figueiredo (2015) conducted a review to assess the impact of person-centered care approaches on stress, burnout, and job satisfaction of staff caring for people with dementia in residential care communities. The review was limited to experimental and quasiexperimental studies, published in English and involving direct care workers. Seven studies were included and addressed different person-centered care approaches, including DCM; stimulation-oriented approaches, such as recreational therapy (storytelling) or multisensory stimulation (Snoezelen); emotion-oriented; and behavioral-oriented approaches. Of the seven studies, five assessed burnout, four measured staff's stress, and three measured job satisfaction.

van Weert and colleagues, as cited by Barbosa et al. (2015), investigated the effectiveness of integrated Snoezelen on work-related outcomes of staff in nursing homes. Fritsch and colleagues, as cited by Barbosa et al. (2015), evaluated the impact of a group storytelling approach on people with dementia and care assistants. Finnema and colleagues, as cited by Barbosa et al. (2015), examined the effect of integrated emotion-oriented care (validation in combination with other interventions such as reminiscence and sensory stimulation) on both nursing home residents living with dementia and staff. Schrijnemaekers and colleagues, as cited by Barbosa et al. (2015), studied the effect of emotion-oriented care on staff through a pre–post randomized controlled trial (RCT). Wells and colleagues, as cited by Barbosa et al. (2015), implemented a behavioral approach consisting of training staff through five educational sessions to use an abilities-focused morning care routine with residents. Jeon and colleagues, as cited by Barbosa et al. (2015), implemented DCM through an RCT conducted in 15 care communities assessed the efficacy of DCM and person-centered care on staff stress and burnout.

Barbosa and colleagues (2015) stated that methodological weaknesses and heterogeneity among studies make it difficult to draw firm conclusions. However, five of seven studies reported benefits on dementia care workers, suggesting a tendency toward the effectiveness of person-centered care on staff. Each of the two RCTs that assessed emotion-oriented approaches were successful in reducing direct care workers' stress, burnout, and job dissatisfaction (Barbosa et al., 2015). However, emotion-oriented approaches were comprised of multiple components (e.g., validation and reminiscence), making it difficult to understand which one was the most effective (Barbosa et al., 2015). An additional RCT found that DCM positively affected direct care workers' stress and burnout, and a nonrandomized controlled study based on multisensory stimulation showed immediate significant positive impacts on the three outcomes of interest (Barbosa et al., 2015). Finally, one of two behavioral-oriented approaches, which adopted a nonrandomized design, showed a reduced burnout in direct care workers (Barbosa et al., 2015). The remaining two studies reported no effects on staff's psychological outcomes (Barbosa et al., 2015). As a group, these studies provide some of the strongest evidence available as the staff-related benefits of person-centered care models. Additionally, reduction in stress, burnout and job dissatisfaction may also lead to reduced staff turnover—a significant challenge within long-term care.

Effects of Person-Centered Care Approaches on Residents and Staff

Brownie and Nancarrow (2013) performed a systematic literature review, resulting in nine articles (seven studies) that met the inclusion criteria. There was one randomized, controlled trial, while others were quasiexperimental pre–post-test designs. The studies included in the review incorporated a range of different outcome measures to evaluate the impact of person-centered interventions on residents and staff. Brownie and Nancarrow (2013) found that person-centered culture change interventions were not homogeneous or single-element interventions. Instead, they incorporated several features including: environmental enhancement; opportunities for social stimulation and fulfilling relationships; continuity of resident care by assigning residents to the same care staff; changes in management and leadership approaches, with the introduction of democratized approaches to decision making that involve residents and staff; changes to staffing models focused on staff empowerment; and individualized humanistic philosophy of care (Brownie & Nancarrow, 2013). Brownie and Nancarrow (2013) found that the Eden Alternative was the only intervention identified in this review that articulated a framework (incorporating all features) for a person-centered approach to caring for older residents, and improving staff working conditions. In contrast, other types of person-centered interventions were community-specific that focused on one or two features.

Three Eden Alternative studies met the inclusion criteria for this review. Two studies reported improvements in residents' psychological well-being as measured by the prevalence of feelings of boredom, loneliness, helplessness, and depression in Eden Alternative communities (Brownie & Nancarrow, 2013). These studies found statistically significant reductions in these feelings (except loneliness) for residents in Eden Alternative communities when using validated psychological assessment tools (Brownie & Nancarrow, 2013). Coleman and colleagues, as cited by Brownie and Nancarrow (2013), found that environmental enhancement was actually associated with adverse outcomes for residents in an Eden Alternative community, compared with residents in a traditional (control) nursing home. They found that residents in the Eden Alternative community had a higher rate of falls (31% within a 30-day period) compared with controls (17%). In this study, the residents in the Eden Alternative community were on average younger than those in the control community (82.6 years of age vs 88 years of age), with fewer impediments in relation to functional status (Brownie & Nancarrow, 2013).

One Green House model study met the inclusion criteria for this review. This 2-year study compared residents in four 10-bed Green House homes with two comparison sites (Brownie & Nancarrow, 2013). The aim of the study was to determine the effects of the Green House model on residents' quality of life (via interviews) and quality of care (via MDS data). After controlling for baseline characteristics, there was a statistically significant improvement in Green House residents' perception of their quality of life, compared with the control groups (Brownie & Nancarrow, 2013).

Three community-specific person-centered care studies met the inclusion criteria for this review. Two of these

community-specific approaches evaluated the impact of person-centered interventions on organizational and workplace characteristics in addition to residents' well-being (Brownie & Nancarrow, 2013). According to Brownie and Nancarrow (2013), one study confirmed that person-centered care positively impacted nurses' job satisfaction and work conditions, as well as improving their capacity to meet the individual needs of residents with dignity and respect. Furthermore, these person-centered approaches improved the continuity of residents' care because they were more likely to be assigned to the same nursing staff and also led to increased social interaction between residents (Brownie & Nancarrow, 2013).

Lastly, Brownie and Nancarrow (2013) described a large Australian study that randomly assigned 289 residents across 15 care communities to receive person-centered care, dementia care mapping, or usual care. The communities were selected because they used a task-focused, rather than a person-centered, approach to care and were similar in terms of management structures, staffing, standards, and size. Agitation was significantly lower with both person-centered and dementia care mapping than usual care. However, the incidence of falls was higher in person-centered care than in usual care (Brownie & Nancarrow, 2013).

Brownie and Nancarrow (2013) concluded that forming accurate conclusions about the impact of person-centered interventions on residents and staff is hampered by the heterogeneity of the interventions and significant methodological differences between studies. However, person-centered interventions are associated with positive influences on staff outcomes (satisfaction and capacity to provide individualized care); improvement in the psychological status of residents (lower rates of boredom and feelings of helplessness); and reduced levels of agitation in residents living with dementia. However, it did appear that some person-centered interventions might be associated with an increased risk of falls in aged-care residents (Brownie & Nancarrow, 2013). While more research into the cause of increased risk for falls is needed, it may be possible that residents are more at risk for falls when they are ambulatory and active as opposed to being sedentary and prone to sitting or laying down for much of the day.

Shifts in Organizational Culture

As noted, person-centered care exists within the larger movement of culture change, a broad-based effort to transform nursing homes from interpersonal health care institutions into true person-centered homes offering long-term care services (Koren, 2010). After much work in the early 1980s among various organizations and advocates, the Pioneer Network took the lead in fostering the culture-change movement within nursing homes. Koren (2010) stated that culture change movement's overarching goals are to individualize care for residents, making communities more homelike and less "institutional." "It promotes person-centered care through reorientation of the community's culture—its values, attitudes, and norms—along with its supporting core systems (such as breaking down departmental hierarchies, creating flexible job descriptions, and giving front-line workers more control over work environments)" (p2). In addition, it strives to honor residents' individual rights, offering them quality of life and quality of care in equal measure. Culture change also recognizes the importance of all staff members' contributions to the pursuit of excellence (Koren, 2010).

The culture-change movement espouses a set of principles, instead of offering a prescriptive set of practices or dictating conformance to a model. Early in the culture-change movement, there was a lack of agreement as to precisely how all of these changes would manifest themselves in a nursing home transformed by culture change. A gathering of stakeholders came together to develop a consensus that the "ideal" community would feature the following components: resident direction, homelike atmosphere, close relationships, staff empowerment, collaborative decision making, and quality-improvement processes (Koren, 2010).

Over the years, various models have been evaluated and research has demonstrated results. However, there is still much work to be done to identify outcomes and support the overall business model. Koren (2010) stated that several aspects of the nursing home field, including its workforce, regulation, and reimbursement, limit the initiation of culture-change practices. Culture change requires dedicated leadership over a period of years, a stable workforce, the buy-in of nursing, and funds for environmental improvements (Koren, 2010).

Koren (2010) concluded that "With a policy environment conducive to innovation, and supportive of both initial and sustained adoption of new models, it is possible that—before the baby-boom generation needs long-term care—nursing homes will have become a better value proposition" (p3). The culture-change movement has shown that provision of high-quality nursing home care, individualized to meet each resident's needs in a setting that maximizes self-determination and well-being, can be a vision made real—with person-centered care as the central focus.

In Closing: Making Recommendations for Quality Care

What this literature review establishes is that there is nothing clear-cut about demonstrating scientific evidence for complicated, individualized, psychosocial interventions such as person-centered care. Overall, the research has limitations including sample sizes, varied interventions within person-centered care models and finally, a paucity of funding and incentives for psychosocial research. Most certainly, more research is needed to continue to understand how to effectively measure person-centered care, what elements are required to make a difference and how does all of this translate into everyday care delivery practices.

However, when examining person centered care through the combined aspects of available evidence (mostly in residential communities), current best practices, expert opinion and common decency, it becomes clear that providing care based on knowing the person within the context of an interpersonal relationship in a way that supports individualized choice and dignity is difficult to argue against. While the evidence in support of person-centered care models and interventions may not be wholly conclusive, there is sufficient evidence to support the following recommendations.

Practice Recommendations for Person-Centered Care

1. Know the person living with dementia.

   The individual living with dementia is more than a diagnosis. It is important to know the unique and complete person, including his/her values, beliefs, interests, abilities, likes and dislikes—both past and present. This information should inform every interaction and experience.

2. Recognize and accept the person's reality.

   It is important to see the world from the perspective of the individual living with dementia. Doing so recognizes behavior as a form of communication, thereby promoting effective and empathetic communication that validates feelings and connects with the individual in his/her reality.

3. Identify and support ongoing opportunities for meaningful engagement.

   Every experience and interaction can be seen as an opportunity for engagement. Engagement should be meaningful to, and purposeful for, the individual living with dementia. It should support interests and preferences, allow for choice and success, and recognize that even when the dementia is most severe, the person can experience joy, comfort, and meaning in life.

4. Build and nurture authentic, caring relationships.

   Persons living with dementia should be part of relationships that treat them with dignity and respect, and where their individuality is always supported. This type of caring relationship is about being present and concentrating on the interaction, rather than the task. It is about "doing with" rather than "doing for," as part of a supportive and mutually beneficial relationship.

5. Create and maintain a supportive community for individuals, families, and staff.

   A supportive community allows for comfort and creates opportunities for success. It is a community that values each person and respects individual differences, celebrates accomplishments and occasions, and provides access to and opportunities for autonomy, engagement, and shared experiences.

6. Evaluate care practices regularly and make appropriate changes.

   Several tools are available to assess person-centered care practices for people living with dementia. It is important to regularly evaluate practices and models, share findings, and make changes to interactions, programs, and practices as needed.

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Conflict of Interest

None reported.

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Review Article

Nonphysician Care Providers Can Help to Increase Detection of Cognitive Impairment and Encourage Diagnostic Evaluation for Dementia in Community and Residential Care Settings

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Abstract

In the United States, at least half of older adults living with dementia do not have a diagnosis. Their cognitive impairment may not have been detected, and some older adults whose physician recommends that they obtain a diagnostic evaluation do not follow through on the recommendation. Initiatives to increase detection of cognitive impairment and diagnosis of dementia have focused primarily on physician practices and public information programs to raise awareness about the importance of detection and diagnosis. Nonphysician care providers who work with older adults in community and residential care settings, such as aging network agencies, public health agencies, senior housing, assisted living, and nursing homes, interact frequently with older adults who have cognitive impairment but have not had a diagnostic evaluation. These care providers may be aware of signs of cognitive impairment and older adults' concerns about their cognition that have not been expressed to their physician. Within their scope of practice and training, nonphysician care providers can help to increase detection of cognitive impairment and encourage older adults with cognitive impairment to obtain a diagnostic evaluation to determine the cause of the condition. This article provides seven practice recommendations intended to increase involvement of nonphysician care providers in detecting cognitive impairment and encouraging older adults to obtain a diagnostic evaluation. The Kickstart-Assess-Evaluate-Refer (KAER) framework for physician practice in detection and diagnosis of dementia is used to identify ways to coordinate physician and nonphysician efforts and thereby increase the proportion of older adults living with dementia who have a diagnosis.

Keywords: Dementia, Early Detection, Diagnosis, Cognitive Impairment, Community-based care providers

Introduction

In the United States, less than half of older adults living with dementia say, or their proxy respondents say, that a physician has diagnosed the condition (Amjad, Roth, Samus, Yasar, & Wolff, 2016). A much smaller proportion of older adults living with dementia has a diagnosis of the condition documented in their medical record (Boise, Neal, & Kaye, 2004; Boustani, Callahan, Unverzagt, Austrom, & Perkins, 2005; Chodosh et al., 2007; McCarten et al., 2012). Cognitive impairment in older adults is frequently not detected in primary care and other physician practice settings (Borson, Scanlan, Watanabe, Tu, & Lessig, 2006; Chodosh et al., 2004). When cognitive impairment is not detected in such settings, the older adult is very unlikely to

receive a diagnostic evaluation that could identify its cause and diagnose dementia if it is present. Often, even when a physician is aware of an older adult's cognitive impairment and recommends that the older adult have a diagnostic evaluation, the individual does not follow through on the recommendation (Boustani et al., 2005; Fowler, Frame, Perkins, Gao, & Watson, 2015; Harris, Ortiz, Adler, Yu, & Maines, 2011; McCarten et al., 2012). Moreover, most persons living with dementia who have been given a dementia diagnosis are not aware of or do not understand the diagnosis (Bradford, Upchurch, Bass, Judge, & Snow, 2011; Centers for Disease Control and Prevention, 2017). Likewise, their family members are sometimes unaware of or do not understand the diagnosis.

People who have dementia but have not been diagnosed and their families are unlikely to receive the valuable dementia services and supports described in other articles in this journal issue. These services and supports include: assessment to identify their specific care and service needs and care planning to meet those needs (Molony, Kolanowski, Van Haitsma, & Rooney, 2018); information about dementia and support for dementia care (Whitlatch & Orsulic-Jeras, 2018); help with dementia-related limitations in personal care and other daily activities (Prizer & Zimmerman, 2018); assistance to avoid or reduce behavioral symptoms (Scales, Zimmerman, & Miller, 2018); modifications to their physical environment to improve safety and increase quality of life (Calkins, 2018); ongoing medical management that takes account of their dementia (Austrom, Boustani, & LaMantia, 2018); and assistance with care transitions that similarly takes account of their dementia (Hirschman & Hodgson, 2018).

To date, most initiatives of international, national, and state organizations to increase detection of cognitive impairment and diagnosis of dementia have focused on the role of physicians (see, e.g., Alzheimer's Association, 2015; Alzheimer's Association and Centers for Disease Control and Prevention, 2013; Georgia Alzheimer's Disease and Related Dementias State Plan Task Force, 2014; Michigan Dementia Coalition, 2009; Prince, Bryce, & Ferri, 2011; Prince, Comas-Herrera, Knapp, Guerchet, & Karagiannidou, 2016; U.S. National Institute on Aging, no date; U.S. Department of Health and Human Services, 2013; U.S. Department of Veterans Affairs, 2016; World Health Organization, 2016). These organizations have also supported public information initiatives to increase general awareness of dementia and the importance of detection and diagnosis. The same organizations have supported initiatives to encourage individuals with concerns about their memory and families that have concerns about an older adult's cognition to express those concerns to the person's physician.

Less attention has been given to the role of nonphysician care providers who work with older adults and their families in community and residential care settings. These care providers include individuals who work in area agencies on aging, aging and disability resource centers, information and referral agencies, senior centers, senior housing, personal care homes, assisted-living facilities, nursing homes, home health agencies, homemaker and personal care agencies, care management agencies, adult day centers, pharmacies, and public health and community nursing agencies. They also include self-employed geriatric care consultants, family counsellors, and home care aides.

Although no prevalence data are available, it is likely that many nonphysician care providers interact frequently with older adults who have signs and symptoms of cognitive impairment but have not had a diagnostic evaluation. Some of these care providers may notice signs and symptoms of cognitive impairment before the signs and symptoms are detected by an older adult's physician. Likewise, some nonphysician care providers may be aware of concerns of older adults and their families about the older adult's cognition that older adults and families have not expressed to physicians. Some nonphysician care providers may also be aware that older adults whose physician has recommended a diagnostic evaluation have not followed through on that recommendation. In addition, nonphysician care providers may be aware that older adults who have received a dementia diagnosis, and sometimes their families, are not aware of or do not understand the diagnosis. Despite the greater amount of attention that has been given to the roles of physicians and public information initiatives in increasing detection of cognitive impairment and diagnosis of dementia, nonphysician care providers can also help with these objectives by encouraging older adults to talk with their physician about cognitive concerns, and encouraging them to follow through on physician recommendations to obtain a diagnostic evaluation, thereby increasing diagnosis of dementia.

This article begins with an overview of the 4-step Kickstart-Assess-Evaluate-Refer (KAER) framework for detection and assessment of cognitive impairment, diagnosis of dementia, and referral of persons living with dementia and their families to potentially beneficial community resources. The KAER framework was developed for primary care physicians by the Gerontological Society of America (GSA) Workgroup on Cognitive Impairment Detection and Earlier Diagnosis (Gerontological Society of America, 2015). In this article, the KAER framework is used as a point of departure to help organize and discuss ways in which nonphysician care providers can help to increase detection of cognitive impairment, encourage older adults to obtain a diagnostic evaluation, and support awareness and understanding of the diagnosis. The article then summarizes recommendations from published dementia care guidelines that pertain to the roles that nonphysician care providers can play in the detection of cognitive impairment and diagnosis of dementia, discusses precedents found in the roles nonphysician care providers now play in detecting other health-related conditions, such as fall risk and depression in older adults, and provides examples of research and

demonstration projects that have involved nonphysician care providers in detection of cognitive impairment. The article presents seven practice recommendations intended to increase and support the involvement of nonphysician care providers in detecting cognitive impairment and encouraging diagnostic evaluation within their authorized scope of practice and training and relevant agency policies and procedures, if any.

In the United States, legal authority to diagnose dementia resides with physicians. This article does not suggest that nonphysician care providers should diagnose dementia. Rather it points out valuable contributions they can make in helping to detect cognitive impairment and encouraging older adults with cognitive impairment to obtain a diagnostic evaluation. Involving nonphysician care providers in these activities is person-centered because it acknowledges the frequent contacts and trusting relationships many older individuals have with one or more nonphysician care providers. Because of these relationships, older individuals may turn first to such providers with questions and concerns about their cognition and rely strongly on the information and advice these care providers offer. By acknowledging and building on these relationships, efforts to involve nonphysician care providers in detecting cognitive impairment and supporting older adults in obtaining a diagnosis reflect a more person-centered approach than efforts that focus only on physicians and public information initiatives.

The KAER Framework for Detection of Cognitive Impairment and Diagnosis of Dementia

The 4-step KAER framework is intended to guide primary care physicians through the process of detecting and assessing cognitive impairment, diagnosing dementia, and referring persons with diagnosed dementia to dementia-capable community resources. Depending on state regulations, physician assistants and advance practice nurses may have legal authority to diagnose dementia, and these primary care providers are considered equivalent to primary care physicians in the context of the KAER framework.

The KAER framework acknowledges the fear and stigma that surround memory loss and cognitive decline, and recognizes the importance of care partners within family and friend networks throughout the process of cognitive impairment detection, diagnosis of dementia, and post-diagnosis referrals. Including family and other care partners along with the physician and persons with cognitive impairment or dementia reflects the health care triad model in dementia care (Fortinsky, 2001). Adding nonphysician care providers, as discussed in this article, expands the triad model by engaging a fourth group of stakeholders to achieve more systematic detection of cognitive impairment and earlier diagnosis of dementia.

The KAER framework can be viewed within the context of the many transitions in the dementia journey that are experienced by individuals living with dementia and their care partners. A person's transition from dementia-related symptom recognition to diagnosis is often delayed due to the reluctance of individuals and families to seek help because they fear that a diagnosis will lead to disrupted relationships and diminished quality of life. A recent review of national dementia strategies in seven countries, including the United States, found that this transition is widely recognized as difficult and requiring support to overcome fear and stigma associated with dementia (Fortinsky and Downs, 2014).

Figure 1 illustrates the KAER framework in a 4-step person-centered and family-centered flow diagram. The intended starting point for the 4-step process is a visit with an individual's physician. However, broadening the scope of care providers with whom older people and their families interact, this article recognizes that increased detection of cognitive impairment could be undertaken in other settings where nonphysician care providers may offer information, assistance, or supervision, such as individuals' homes, residential care facilities, and senior centers.

STEP 1—Kickstart the Cognition Conversation

A critical first step in detecting cognitive impairment and promoting earlier diagnosis of dementia is to "kickstart"—that is, to initiate and continue—a conversation with individuals and their families about brain health and memory-related signs and symptoms that might develop in older adulthood. There are many reasons why physicians might be reluctant to kickstart this conversation. Similarly, individuals and families may be reluctant to raise concerns about cognition with their physician due to fear and stigma often associated with dementia. Nevertheless, a frank yet sensitive discussion about the importance of brain health and early investigation of cognition-related complaints or concerns is a highly appropriate first step that might open the way for individuals and family members to reveal potential concerns.

Additional steps that physicians might take to initiate or continue cognition conversations include:

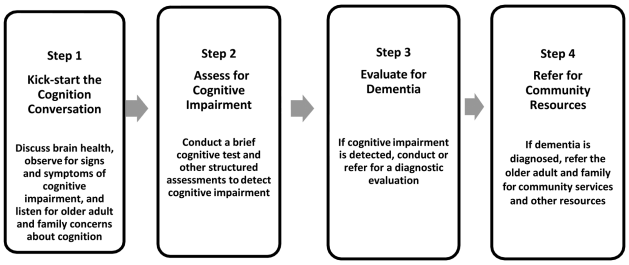

Figure 1. KAER framework to promote increased cognitive impairment detection and earlier diagnosis of dementia.

- Ask older adult patients whether they have concerns about their memory or cognition or have noticed changes in their memory or cognition since a previous office visit.
- Listen for and acknowledge concerns about memory and cognition that are expressed by older adult patients.
- Listen for family concerns about the older adult's memory and cognition.
- Observe for signs and symptoms of cognitive impairment.
- Add a question about memory or cognition on the health risk assessment or other questionnaire that older adults are asked to complete either before the physician visit or in the office before meeting with the physician. Possible questions could include, "Are you worried about your memory?" or "Have you experienced confusion or memory loss that is happening more often or is getting worse?"
- Use information about health conditions and functional difficulties from existing patient records, for example, falls or difficulty managing medications, both of which are common in older adults with cognitive impairment (Amjad et al., 2016; Verghese et al., 2008) as an entrée to engage patients in a conversation about the importance of monitoring cognitive health.

STEP 2—Assess if Symptomatic

This step focuses on the routine use of a brief, evidence-based assessment instrument to detect cognitive impairment. The KAER framework emphasizes the use of such assessment instruments to detect cognitive impairment in individuals with observable evidence of, or who expressed concern about, memory or associated cognitive symptoms. These individuals come to a physician's attention in one of three ways: (a) they report concerns about their memory or other cognitive abilities; (b) family members, friends, or others report concerns about older adults' memory or other cognitive abilities; and (c) physicians or primary care office staff notice observable clinical signs and symptoms of cognitive impairment based on changes compared to previous encounters. The GSA Workgroup on Cognitive Impairment Detection and Earlier Diagnosis also recognized that, although universal screening is highly controversial, some clinicians and other dementia care experts support routine use of a brief, evidence-based assessment instrument to detect cognitive impairment in older adults, including those who do not have observable evidence or have not expressed concerns about memory or other cognitive symptoms. (Borson and Chodosh, 2014; Borson et al., 2006; Dementia Friendly America, 2016).

Numerous evidence-based cognitive impairment assessment instruments have been reviewed by expert panels against properties that would encourage their widespread use: (a) can be administered in 5 minutes or less, (b) widely available free of charge, (c) designed to assess age-related cognitive impairment, (d) assess at least memory and one other cognitive domain, (e) validated in primary care or community-based samples in the United States, (f) easily administered by medical staff members who are not physicians, and (g) relatively free from educational, language, and/or cultural bias. Table 1 shows candidate assessment instruments recommended by an Alzheimer's Association workgroup (Cordell et al., 2013) and a National Institute on Aging (NIA) workgroup under contract with the U.S. Centers for Medicare and Medicaid Services (Ling, 2012). Although there is no perfect cognitive impairment assessment instrument, the table offers a limited number of assessment instruments that are widely available, free of charge, and fulfill clinically relevant and scientifically rigorous criteria.

The GSA Workgroup did not consider whether nonphysician care providers should use these or other assessment instruments to detect cognitive impairment outside a medical care setting. Whether the assessment instruments are adopted by physicians or nonphysician care providers, however, they should be used only after proper training is completed, and within the scope of practice of the user, regardless of professional background or care setting.

STEP 3—Evaluate With Full Diagnostic Workup if Cognitive Impairment is Detected

If, as a result of using an evidence-based assessment instrument to detect cognitive impairment per Step 2, individuals are found to have cognitive impairment, then qualified physicians should, at a minimum, rule out

Table 1. Selected Cognitive Impairment Assessment Instruments

	NIA Workgroup	Alzheimer's Association Workgroup
Ascertain dementia (AD8)	X	X
Brief Alzheimer's screen	X	
GPCOG for use with the patient		X
GPCOG for use with an informant		X
Memory impairment screen		X
Mental Status Questionnaire	X	
Mini-Cog	X	X
Short Blessed Test	X	
Short IQCODE for use with an informant		X
Short Portable Mental Status Questionnaire	X	
Short Test of Mental Status	X	
Six-Item Screener	X	

Source: Gerontological Society of America (GSA) Workgroup on Cognitive Impairment Detection and Earlier Diagnosis (Gerontological Society of America, 2015).

reversible, physiological causes of cognitive impairment per published clinical practice guidelines (e.g., thyroid or vitamin deficiency) by ordering appropriate laboratory tests. Qualified physicians also should conduct a full diagnostic evaluation per published clinical practice guidelines. Physicians who are unfamiliar with a full dementia diagnostic evaluation should refer patients to an available clinical specialist or team (e.g., geriatrician, neurologist, geriatric psychiatrist, neuropsychologist, nurse practitioner with geropsychiatric expertise) for a full diagnostic evaluation per published clinical practice guidelines. Numerous such guidelines are available to help PCPs and specialists diagnose dementia (see, e.g., American Academy of Neurology, 2013; American Geriatrics Society, 2011; American Psychological Association, 2012; Galvin & Sadowsky, 2012; Geldmacher & Kerwin, 2013).

It is critical to convey to individuals who have been found to have cognitive impairment in either KAER Step 1 or Step 2, and their families that there is an important distinction between detecting cognitive impairment and diagnosing dementia. As noted earlier, many studies have shown that only modest proportions of primary care patients who are found to have cognitive impairment and whose physician recommends a diagnostic evaluation actually follow through on the recommendation (Boustani et al., 2005; Fowler et al., 2015; Harris et al., 2011; McCarten et al., 2012). Adopting the health care triad perspective (Fortinsky, 2001), it is highly likely that reasons for the low rate of diagnostic evaluation include factors related to individuals with cognitive impairment, family members, and PCPs. Other factors that may account for low diagnostic evaluation rates among those found to have cognitive impairment include the lack of available specialists to conduct full diagnostic evaluations, as well as long waiting times for appointments with specialists, even in areas where they are available (GSA Workgroup, 2015).

STEP 4—Refer to Community Resources

The fourth step in the KAER framework recommends that physicians should refer all individuals with diagnosed dementia and their families to dementia-capable community resources to learn more about the condition and how to prepare for the future with a dementia diagnosis. Diagnosing physicians should also initiate a care plan for patients with diagnosed dementia, documenting 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.

In this context, it is important note that many of the nonphysician care providers discussed in this article are also the providers of dementia-capable services to whom physicians should refer older individuals with diagnosed dementia and their families. Indeed, if recommendations from this article are adopted, organizational relationships between physicians and the health systems they work in, on the one hand, and nonphysician care providers on the other hand, will strengthen and develop two-way referral and communication pathways. From a person-centered perspective, action on Step 4 of the KAER framework is required if the full value of earlier steps in the framework is to be realized and translated into positive health-related outcomes for individuals living with dementia and their family caregivers.

Published Dementia Care Guidelines that Support Involvement of Nonphysician Care Providers in Detection of Cognitive Impairment and Referral for Diagnostic Evaluation

Many international, national, and state organizations, professional associations, and advocacy organizations have published dementia care guidelines that emphasize the importance of increasing detection of cognitive impairment and diagnosis of dementia. Most of the guidelines focus on the role of physicians and public information initiatives in achieving these objectives, but a few published dementia care guidelines also support a role for nonphysician care providers in detection of cognitive impairment.

A recent analysis of dementia care guideline documents that were published in the United States and other countries identified 13 documents that include guidelines and practice recommendations for detection of cognitive impairment (Wiener et al., 2016.) One of these guideline documents, the Alzheimer's Association's 2009 *Dementia Care Practice Recommendations for Professionals Working in a Home Setting*, includes a practice recommendation for involvement of nonphysician care providers in detection of signs and symptoms of cognitive impairment:

> "Studies have shown that the signs of early dementia are subtle…. Direct care providers need training not only to recognize the signs 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" (Alzheimer's Association 2009).

As of early 2017, 28 Alzheimer's State Plans included provisions to support early detection and diagnosis. Although most of the state plan provisions were directed to physicians, a few focus on the role of nonphysician care providers in detection of cognitive impairment (Alzheimer's Association, 2017). For example, the 2014 Georgia Alzheimer's Disease and Related Dementias State Plan includes the following action step:

> Develop a strategic plan that supports faith- and community-based organizations in their efforts to provide early detection, education, and resources for individuals and families experiencing symptoms of memory loss and dementia. Make training programs available for all

> faith- and community-based organizations. (Georgia Alzheimer's Disease and Related Dementias State Plan Task Force, 2014).

The Georgia State Plan goes on to emphasize that only physicians can make a diagnosis, that detection of cognitive impairment is only the first step, and that "If a reason for possible concern is detected, individuals are strongly encouraged to see a physician who specializes in the diagnosis of Alzheimer's and related dementias." (Georgia Alzheimer's Disease and Related Dementias State Plan Task Force, 2014).

In 2016, the Alzheimer's Association National Plan Care and Support Milestone Workgroup recommended allocation of "funds to educate primary care physicians, other health care providers *and community workers* about the importance of timely detection of cognitive impairment, applying the appropriate diagnosis, and disclosing cognitive status to the patient and their key family and friend caregivers" (Borson et al., 2016).

In 2013, the National Task Group on Intellectual Disabilities and Dementia published Practices Consensus Recommendations for the Evaluation and Management of Dementia in Adults with Intellectual Disabilities (Jokinen et al., 2013). One of the Task Group recommendations states, as follows that:

> It is recommended that caregivers employ an early detection screening tool which can help to document the presence of certain behaviors or dysfunctions, as well as noted changes which may signal MCI or dementia, and where the data can be useful for starting that 'critical conversation' with a physician or other clinician (Jokinen et al., 2013).

The task group also developed the NTG Early Detection Screen for Dementia for use in early detection screening of adults with intellectual disability who are suspected of or may be showing signs of mild cognitive impairment or dementia. The Early Detection Screen is intended for use by "anyone who is familiar with the adult (that is, has known him or her for over six months), such as a family member, agency support worker, or a behavioral or health specialist using information derived by observation or from the adult's personal record" (National Task Group NTG-EDSD, 2013).

Finally, a 2014 document prepared for the U.S. Administration for Community Living (ACL), *Dementia-capable States and Communities: The Basics*, includes identification of people with dementia and referral to a physician for a diagnosis as one of seven components of a dementia-capable system (Tilly, Wiener, & Gould, 2014). The document comments that:

> "Providing appropriate care to people with dementia and their caregivers will not happen unless service providers can identify people with the condition. Individuals or their caregivers may contact service providers to discuss memory problems, trouble managing finances or medical care or behavior changes. Service provider staff can learn to recognize whether a person may be describing signs of cognitive problems and refer the individual for an accurate diagnosis" (Tilly et al., 2014, p. 5).

Precedents in the Roles Nonphysicians Now Play in Detection of Other Geriatric Conditions

In considering the role of nonphysician care providers in detection of cognitive impairment, it is important to acknowledge the accepted role of such care providers in detecting other health-related issues for older adults. Ample evidence has been published demonstrating willingness and usefulness of engaging nonphysician care providers in detection of other syndromes and health problems in older adults. For example, there is an extensive literature and numerous toolkits are now available to detect fall risk and implement fall prevention strategies for use by nonphysician providers and community-based organizations serving older adults at home (Baker et al., 2005; Brown et al., 2005; Fortinsky et al., 2008; National Center for Injury Prevention and Control, 2015; Stevens & Phelan, 2013). Nurses, and care managers working for publicly funded home and community-based service programs in lieu of nursing home admission, as well as home health nurses, have been successfully trained to detect depressive symptom severe enough to warrant treatment (Bruce et al., 2011; Ciechanowski et al., 2004; Delaney et al., 2013; Quijano et al., 2007). These initiatives set important precedents for actively engaging the nonphysician workforce providing health and social services to community-dwelling older adults in the detection of health problems that threaten independent living. It is very timely to consider how best to engage these nonphysician providers in the detection of cognitive impairment in older adults with whom they come into contact on a daily or otherwise frequent basis.

Research and Demonstration Projects that Involve Nonphysician Care Providers in Detecting Cognitive Impairment

Some of the dementia care guidelines noted earlier led to research and demonstration projects that involved nonphysician care providers in detecting cognitive impairment. Building on recommendations from the 2014 document, *Dementia-capable States and Communities: The Basics* (Tilly et al., 2014) and earlier discussions among ACL staff, its National Alzheimer's and Dementia Resource Center (NADRC), and states that had received ACL grants to improve dementia care and services, several states have developed and provided training for nonphysician state agency staff to help them identify individuals with possible cognitive impairment so they can make appropriate

referrals for care and services. The Minnesota Board on Aging, for example, created and delivered web-based video training designed to help nonphysician staff of the State's Aging and Disability Resource Centers (ADRCs) identify people with possible dementia and their care partners over the phone, including how to recognize concerns about memory loss and cognitive issues (Minnesota Board on Aging, 2013). Other examples of ACL-funded projects that include training for nonphysicians to detect cognitive impairment include the following:

- A Washington State project to improve the "dementia capability" of the state's ADRCs: the project included staff training for nonphysician ADRC staff to help them identify individuals with cognitive impairment, refer the individuals to a physician for a diagnostic evaluation, and connect the individuals to appropriate community services (National Alzheimer's and Dementia Resource Center, 2014b).
- A Nevada State project to create a dementia-capable system with Single Entry Point/No Wrong Door access to appropriate community services: the project included development of an assessment process that nonphysician staff in the State's Single Entry Point/No Wrong Door program can use to identify people with cognitive impairment and training for staff to use the process (National Alzheimer's and Dementia Resource Center 2014b).
- A Florida agency consortium project to train "community scouts," including nonphysician care providers and others who work with the public to identify persons with cognitive impairment who are living alone and refer them for diagnosis and community services (National Alzheimer's and Dementia Resource Center, 2014a).

Reports on these ACL-funded projects have not yet been published, but the training procedures they developed may be useful for other states and agencies that want to train nonphysician care providers to detect cognitive impairment in older adults.

The 10/66 Dementia Research Network supported research projects in Brazil and India that used community health workers to identify older adults with cognitive impairment consistent with possible dementia. The community health workers received several hours of training before visiting older adults in their homes. Diagnostic evaluations conducted later by physicians found that half to two-thirds of the older adults identified by the community health workers as having cognitive impairment in fact had dementia. Most of those who were not diagnosed with dementia were found to have major psychiatric disorders that accounted for their cognitive impairment (Jacob, Senthil Kumar, Gayathri, Abraham & Prince, 2007; Ramos-Cerqueira, 2005; Shaji, Arun Kishore, Lal, & Prince, 2002)

Lastly, Zimmerman and colleagues (2007) evaluated the ability of direct care workers in 14 residential care facilities in North Carolina to identify cognitive impairment consistent with dementia in residents who did not have a dementia diagnosis. The direct care workers were trained to use a 9-item form that asks the worker to evaluate the resident's memory, awareness of surroundings, understanding and decision-making, and dressing performance. To answer the questions, direct care workers could use their own knowledge of the resident, notations in the resident's medical record, and interviews with other staff and the resident's family. The residents also received a diagnostic evaluation from a neurologist. Comparison of the conclusions of the direct care workers and the neurologists indicated that the direct care workers identified only about half of the residents who later received a dementia diagnosis, but they correctly identified most of the residents who did not have dementia. The researchers conclude that additional training for the direct care workers could be useful.

Involving Nonphysician Care Providers in Encouraging Older Adults with Cognitive Impairment to Obtain a Diagnostic Evaluation and Helping Older Adults with a Dementia Diagnosis to be Aware of and Understand the Diagnosis

In addition to helping with detection of cognitive impairment, nonphysician care providers can also encourage older adults with cognitive impairment and their families to obtain a diagnostic evaluation for the older adult and support awareness and understanding of the diagnosis. This article addresses a wide array of nonphysician care providers, including, as noted earlier, individuals who work in ADRCs, area agencies on aging, information and referral agencies, senior centers, senior housing, personal care homes, assisted-living facilities, nursing homes, home health agencies, homemaker and personal care agencies, care management agencies, adult day centers, pharmacies, and public health and community nursing agencies. Self-employed geriatric care consultants, family counsellors, and home care aides are also included. The amount and kinds of help such care providers can offer to encourage older adults with cognitive impairment to obtain a diagnostic evaluation and to support awareness and understanding of the diagnosis clearly varies, depending on their authorized scope of practice and training and relevant policies and procedures of their agency or care setting.

Despite years of public information campaigns urging older adults to talk to their physician about concerns they may have about their memory and cognition, available data indicate that many older adults do not tell a physician about such concerns. Results from the 2011 Behavioral Risk Factors Surveillance System (BRFSS) survey show, for example, that 13% of adults age 65 and older reported that they experienced "confusion or memory loss that is happening more often or is getting worse," but less than 20% of those older adults reported that they discussed these

problems with a physician or other health care professional (Adams, 2016). Likewise, as noted at the beginning of this article, available data show that older adults whose physicians recommend a diagnostic evaluation often do not follow through on that recommendation. Results from four studies indicate that almost half (48%) to almost three-quarters (72%) of older adults did not follow through on physician recommendations to obtain a diagnostic evaluation (Boustani et al., 2005; Harris et al., 2011; Fowler et al. 2015; McCarten et al., 2012). These data point to several important ways in which nonphysician care providers can support the transition from early awareness of cognitive impairment to diagnosis of dementia, if any. When a nonphysician care provider becomes aware of an older adult's concerns about memory and cognition or concerns of family members about the older adult's cognition, the nonphysician care provider can urge the older adult and/or family to express these concerns to the older adult's physician. Similarly, when a nonphysician care provider becomes aware that an older adult has not followed through on a physician recommendation for a diagnostic evaluation, the nonphysician care provider can encourage the person and the person's family to obtain such an evaluation. These efforts do not ensure that older adults living with dementia have a diagnosis of the condition, but they do increase the likelihood of that outcome.

Other data show that the majority of older adults who have a dementia diagnosis and many of their families are not aware of or do not understand the diagnosis. One of the Healthy People 2020 program goals is to decrease the proportions of persons who have a dementia diagnosis and their families that are not aware of the diagnosis. Baseline data from responses of older adults and their families to a national survey and Medicare claims data for the period from 2007 to 2009, show that 65% of persons who had a dementia diagnosis or their families were not aware of the diagnosis (Centers for Disease Control and Prevention, 2017). These data do not distinguish awareness by the older person versus awareness by the family, but another study of older veterans with a dementia diagnosis and their family caregiver found that three-quarters of the older veterans were not aware of their dementia diagnosis. In contrast, almost all the family caregivers were aware of the diagnosis (Bradford et al., 2011). Clearly, to the extent that nonphysician care providers are informed about dementia diagnoses, they can encourage the older adult and family to talk with the diagnosing physician. The care provider can also offer print and online sources of additional information as appropriate.

Conclusion and Practice Recommendations

The preceding discussion suggests there is much room for improvement in detection of cognitive impairment and diagnosis of dementia. Some of the needed improvement, especially with respect to conducting diagnostic evaluations, requires changes in physician practices. However, the discussion also indicates opportunities for improvement that could build on the frequent interactions and trusting relationships among many older adults, their families, and nonphysician care providers. As discussed earlier, care providers could help to increase detection of cognitive impairment, encourage older adults and their families to express concerns about the older adult's cognition to the older adult's physician, and encourage them to follow through on physician recommendations to obtain a diagnostic evaluation, all of which could support increased diagnosis of dementia.

The KAER framework can be used to help nonphysician care providers understand physician practices in detection of cognitive impairment and diagnosis of dementia. In July 2017, the Gerontological Society of America (GSA) released a toolkit with assessment instruments and other materials physicians can use to implement the KAER steps, including key messages for talking with older adults and families about cognition, cognitive impairment, and dementia; videos for older adults and families; and online materials physicians may want to call to the attention of their older adult patients and patients' families. Many of these materials may also be useful for nonphysician care providers. The toolkit is available free on the GSA website at https://www.geron.org/programs-services/alliances-and-multi-stakeholder-collaborations/cognitive-impairment-detection-and-earlier-diagnosis.

Finally, as noted earlier, many of the nonphysician care providers discussed in this article are also the providers of dementia-capable services to whom physicians should refer older individuals with diagnosed dementia and their families. If recommendations from this article are adopted, organizational relationships between physicians and the health systems they work in, on the one hand, and nonphysician care providers on the other hand, will strengthen and develop two-way referral and communication pathways and increase the likelihood that older adults living with dementia and their families will receive the valuable dementia services and supports described in other articles in this journal issue.

Practice Recommendations

The seven practice recommendations listed below are intended to promote the involvement of nonphysician care providers in kickstarting the cognition conversation, detecting cognitive impairment, supporting older adults with cognitive impairment to obtain a diagnostic evaluation, and helping them and their families be aware of and understand a dementia diagnosis.

1. *Make information about brain health and cognitive aging readily available to older adults and their families*. Within their scope of practice and training, nonphysician care providers who work with older adults and their families in community or residential care settings should either talk with them or refer them to other

experts for information about brain health, changes in cognition that commonly occur in aging, and the importance of lifestyle behaviors and other approaches to maintain brain health. They should suggest print and online sources of additional information as appropriate.

2. *Know the signs and symptoms of cognitive impairment, that signs and symptoms do not constitute a diagnosis of dementia, and that a diagnostic evaluation is essential for diagnosis of dementia*. All nonphysician care providers who work with older adults in community or residential care settings should be trained to recognize the signs and symptoms of cognitive impairment. They should be trained that signs and symptoms are not sufficient for a diagnosis of dementia and that a diagnostic evaluation must be conducted by a physician who can make the diagnosis.
3. *Listen for concerns about cognition, observe for signs and symptoms of cognitive impairment, and note changes in cognition that occur abruptly or slowly over time*. Depending on their scope of practice, training, and agency procedures, if any, nonphysician care providers who work with older adults in community or residential care settings should listen for older adults' concerns about dementia and observe for signs and symptoms of cognitive impairment and changes in cognition. As appropriate and in accordance with agency procedures and respect for individuals' privacy, nonphysician care providers should communicate with coworkers about observed signs and symptoms, changes in cognition, and concerns of older adults and family members about the older adult's cognition. Depending on their scope of practice and training, they should encourage the older adult and family to talk with the individual's physician about the signs and symptoms, changes in cognition, and older adult and family concerns.
4. *Develop and maintain routine procedures for detection of cognition and referral for diagnostic evaluation*. Administrators of organizations that provide services for older adults in community or residential care settings and self-employed care providers should develop and maintain routine procedures for assessment of cognition. They should, at a minimum, maintain an up-to-date list of local memory assessment centers and physicians, including neurologists, geriatricians, and geriatric psychiatrists, who can provide a diagnostic evaluation for older adults who do not have a primary care physician or have a primary care physician who does not provide such evaluations. Ideally, nonphysician care providers and organizations that work with older adults should partner with physicians, health plans, and health care systems to establish effective referral procedures to ensure that older adults with signs and symptoms of cognitive impairment can readily receive a diagnostic evaluation.
5. Use a brief mental status test to detect cognitive impairment *only if*:
   - such testing is within the scope of practice of the nonphysician care provider, and
   - the nonphysician care provider has been trained to use the test; and
   - required consent procedures are known and used; and
   - there is an established procedure for offering a referral for individuals who score below a pre-set score on the test to a physician for a diagnostic evaluation.
6. *Encourage older adults whose physician has recommended a diagnostic evaluation to follow through on the recommendation*. Within their scope of practice, training, and agency procedures, if any, nonphysician care providers who work with older adults in community or residential care settings and are aware that an older adult's physician has recommended a diagnostic evaluation should encourage the older adult and family, if appropriate, to follow through on the recommendation. They should talk with the older adult and family about the reasons for and importance of getting a diagnostic evaluation and provide print and online sources of additional information.
7. *Support better understanding of a dementia diagnosis*. Within their scope of practice, training, and agency procedures, if any, nonphysician care providers who work with older adults in community or residential care settings and are aware that the older adult has received a dementia diagnosis but does not understand the diagnosis (or the older adult's family does not understand the diagnosis) should encourage the older adult and family to talk with the diagnosing physician. The care provider should also offer print and online sources of additional information as appropriate.

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Conflict of Interest

None reported.

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Review Article

Person-Centered Assessment and Care Planning

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Abstract

The quality of dementia care rendered to individuals and families is contingent upon the quality of assessment and care planning, and the degree to which those processes are person-centered. This paper provides recommendations for assessment and care planning derived from a review of the research literature. These guidelines build upon previous recommendations published by the Alzheimer's Association, and apply to all settings, types, and stages of dementia. The target audience for these guidelines includes professionals, paraprofessionals, and direct care workers, depending on their scope of practice and training.

Keywords: Dementia, Evaluation, Interdisciplinary, Person-centered care, Quality of life

This paper provides practice-oriented guidelines for person-centered assessment of persons living with dementia, their family members, and care partners. It is one in a series of articles in this supplement issue and is intended to complement these other papers by building on the definition of person-centeredness provided by Fazio, Pace, Flinner, and Kallmeyer (2018) and providing recommendations for assessments that support the practices described in the subsequent papers.

Part one of this paper begins with the core concepts of person-centeredness informed by the philosophies of Kitwood (1997) and Brooker (2005). Two additional approaches are then introduced to provide a clear philosophical and practical foundation for comprehensive, person-centered assessment: Mast's (2011) approach to whole person assessment and Molony's (2010) work on at-homeness. These perspectives view assessment as an ongoing, dynamic approach to care.

Part two of this paper provides recommendations for assessment based on a review of literature published since the 2009 Alzheimer's Association (Alz Assoc). Recommendations for assessment and care planning are supported by national and international dementia care guidelines; published quality indicators; literature related to the process and/or outcomes of person-centered care; literature written by persons living with dementia and care partners; and literature published in core journals relating to specific domains of dementia assessment.

Part three discusses the evidence-based recommendations for care planning and transforming assessment data into action. Taken together, the assessment guidelines in this paper provide a foundation for the interventions described in the subsequent papers in this supplement issue.

Overview of Person-Centered Assessment

In his seminal work on dementia, Kitwood (1997) highlights three core elements of personhood: relationship, uniqueness and embodiment. According to Kitwood, relationship implies recognition, trust, and respect, and

prioritizes the experience of the person. Kitwood references Martin Buber's concept of I-Thou relationships to convey true meetings with another in a spirit of openness, full acceptance, presence, and sense of new possibility. Kitwood (1997) points out that unfortunately:

> …a man or woman could be given the most accurate diagnosis, subjected to the most thorough assessment, provided with a highly detailed care plan and given a place in the most pleasant surroundings – without any meeting of the I-Thou kind ever having taken place"(p. 12).

This statement highlights the fact that assessment and care planning are processes that are informed not only by published research and clinical expertise, but also by the possibilities that emerge *in the moment*, during authentic human encounters with individuals living with dementia and their families. Person-centered assessment must therefore incorporate openness to the experience and relationship unfolding in the present moment. The word assessment often conveys a goal-oriented, task-centric set of activities, but in a person-centered context, assessment begins with valuing the experience of being present with another human being, trying to understand that person's experience, and coming to know the uniqueness of the person.

The purpose of assessment and care planning is to support the individual and family to live the best possible life, with dementia. The key components of person-centered dementia care described by Fazio and colleagues in this issue (p. 10) correspond to assessment modalities. *Personhood and relationship-based care* align with assessment approaches that convey respect and seek to understand the subjective experience of the individual living with dementia. I*ndividualized care and meaningful engagement* is practiced during assessment by prioritizing information about individual preferences, needs, values, routines, sources of joy and personal meaning. *Relationship-based care and positive social environments* are supported by identifying care partners and assessing their needs for support, information and resources. In residential care settings, this includes assessing staff needs, resources, satisfaction, and person-centered communication skills.

Mast (2011) describes an approach to whole person dementia assessment that combines nomothetic and idiographic perspectives. Nomothetic approaches utilize empirical studies with groups of people living with dementia to identify general principles and evidence-based strategies that may apply broadly to other persons in similar situations. The assessment recommendations found in the research literature and reviewed in this paper typify the nomothetic approach. Idiographic approaches rely on in-depth assessment of the individual in the context of his/her experiential, autobiographical and social world. Using this approach, assessment includes gathering information about life history; accomplishments, losses, significant experiences, hopes, dreams, preferences, important roles, and ways of dealing with previous challenges or stressful situations (Mast, 2011). The assessment also includes information about the significant people in the person's life, including the primary care partner and others. Mast points out that this information may not be obtained in one sitting, but is gathered across multiple encounters over time. In order to make the information useful for planning care, it must be documented, shared with other care providers, and periodically revisited and updated.

Molony (2010) conducted a metasynthesis of studies on the meaning of home that included papers focusing specifically on persons living with dementia (Wiersma, 2008; Zingmark, Norberg, & Sandman, 1993, as cited by Molony, 2010). Molony describes home as an experiential place of empowerment, refuge (comfort, warmth, and ontological safety), lived relationship (with persons, animals, meaningful places, cherished possessions, time, and ideas), and self-reconciliation (maintaining selfhood in the context of transition or loss). Understanding and assessing personalized meanings of home, and the processes by which home is experienced, built, shared, sustained, or lost, extends the concept of person-centered care more broadly into physical, social, and environmental domains. At-homeness is potentially threatened by medical crises and thus Kitwood's focus on embodiment, Molony's discussion of the lived body and traditional medical approaches to health and physical assessment are consistent with person-centered assessment.

Taken together, the core components of person-centered care as informed by Kitwood, Brooker, Fazio et al., Mast and Molony, call for an intentional preassessment phase to prepare the assessor to enter *the experience of the person* living with dementia and their care partner(s) by asking three self-reflective questions: (a) How will I demonstrate empathy and respect this person's uniqueness and wholeness while inquiring about the challenges of the disease/diagnosis? (b) How will I demonstrate that I value therapeutic alliance and partnership with this person and care partner(s)? (c) How will I demonstrate therapeutic optimism (for quality of living, if not for cure) and foster hope?

Qualitative studies examining the experience of persons living with dementia draw attention to the role of the care provider's attitude in shaping the person's outlook on dementia (Frank & Forbes, 2017). Simple strategies of therapeutic communication should not be undervalued in the assessment process. It is important to recognize that internalized stigma or therapeutic pessimism may adversely affect assessment process and outcomes (Wolverson, Clarke, & Moniz-Cook, 2016).

Recommendations for Assessment and Care Planning

A review of practice guidelines published after 2009 was conducted to update evidence-based recommendations related to assessment content, frequency, methods,

measures, and outcomes. Wiener, Gould, Shuman, Kaur, and Ignaczak (2016) conducted a detailed analysis of 37 practice guidelines that included medical and psychiatric guidelines from diverse national and international sources including the American Medical Directors Association, the American Psychiatric Association, the American Psychological Association, the British Columbia Ministry of Health, the European Federation of Neurological Sciences and many others. Global reviews and panel summaries such as those by Callahan et al. (2014) and Mitchell and Coleman (2015) as cited by Wiener et al. (2016) were also reviewed. Some of these guidelines were setting-specific, discipline-specific, or domain-specific. Six primary assessment domains were uniformly identified as essential to assessment: cognitive status, functional abilities, behavioral symptoms, medical status, living environment, and safety. There is consensus in the literature that dementia must be distinguished from delirium and depression, and that reliable and valid instruments must be used that are designed to detect changes in cognition, function and behavior. Many guidelines recommend integrating systematic pain assessment tools that are appropriate for seniors and/or persons living with dementia. Wiener and colleagues (2016) also recommend assessment for indicators of abuse, neglect or inability to live alone including repeated hospitalizations, medication misuse, malnutrition, wandering from home. Recommendations specific to home and community settings highlight the need to assess caregiver health and signs of strain or stress, and to identify family member needs for education, support and services.

Guidelines for frequency of assessment are based on setting, with primary care assessment recommended at a minimum every 6–12 months and more often if changes in behavior, cognition, or function occur. Frequency of assessment in residential long-term care is guided by regulation, including key times such as: upon admission, after return from a hospital stay, and with significant changes in condition, function or behavior. Direct caregivers provide important assessment data in these settings, in addition to professional assessments using the MDS 3.0. All evidence-based guidelines stress the need for ad hoc assessment whenever behavioral changes occur, including an in-depth investigation of antecedents and contributors to behavioral and psychological symptoms of dementia (BPSD). Behavioral changes necessitate inquiry into unmet needs, stressors in the physical and social environment (including loneliness, boredom and isolation), and most importantly, underlying physical or psychiatric comorbidities. In these scenarios, referral to a health professional for comprehensive health assessment is recommended (Wiener et al. 2016).

A few of the guidelines reviewed by Wiener and colleagues (2016) recommend system-level incentives and supports needed to promote documentation and tracking of cognition, function and symptoms, provide training for caregivers, and establish standardized protocols for pain assessment and management. In acute care settings, the National Institute for Health and Clinical Excellence (2007), as cited by Wiener and colleagues (2016) recommend referral to a liaison service that specializes in assessment and treatment of dementia.

Ngo and Holroyd-Leduc (2015) conducted a systematic review of 39 practice guidelines published from 2008 to 2013. There is significant overlap with the recommendations provided by Wiener et al., with increased emphasis on regular, serial assessment of activities of activities of daily living and cognition to evaluate and document changes over time. Serial assessment for BPSD is recommended every 3 months, and medication changes, adherence and effects are to be assessed during every visit. Assessment for vascular risk factors is also recommended.

Additional published guidelines were obtained through the AHRQ and ClinicalKey databases. Multiple authors suggest that care plans should incorporate individual values, cultures, and needs, and should promote the maintenance of function and independence to the greatest degree possible. Specific assessment domains not already highlighted include the living environment, physical exercise, recreational activities, signs of abuse or neglect, caregiver needs, advanced directives, decision making, and plans for end-of-life care. While it is beyond the scope of this review to provide detailed recommendations for each of these facets of assessment, guidance is available for individualized assessment and management related to bathing, driving, mealtime difficulties, oral hygiene, nursing care (all settings), and care planning (National Guideline Clearinghouse, 2013; Clinical Key, 2017). The Gerontological Society of America (GSA) recently published a guideline outlining a four-step process for earlier detection and diagnosis called the KAER toolkit (GSA, 2017). The toolkit is primarily intended for primary care providers, but the associated appendices and tools provide efficient, valid, recommended tools for professional assessment in multiple settings.

Callahan and colleagues (2014) reviewed evidence-based models of dementia care and identified key components for assessment and care planning. Assessment domains not already highlighted include goals of care, driving, home safety, and use of substances. The review also highlights the importance of using each assessment opportunity to evaluate the outcomes of previous therapeutic interventions. The authors recommend consideration of referral to a specialty memory care practice for ongoing evaluation and management. Additional recommendations include educating the individual and family about diagnosis, care options, and community resources. This implies that pre-existing knowledge has been assessed.

Two performance measure sets for dementia care were included in this review. The American Academy of Neurology (AAN), American Geriatrics Society (AGS), American Medical Directors Association (AMDA), American Psychiatric Association (APA), and Physician Consortium for Performance Improvement® (PCPI™)

published quality measures to improve outcomes for persons with dementia (AMA, 2011). The International Consortium for Health Outcomes Measurement (ICHOM, 2017) brought together patient representatives, clinician leaders and registry leaders from all over the world to identify a comprehensive set of outcomes and case-mix variables for all providers to track. These standards are applicable to all types and stages of dementia. Table 1 depicts a comparison of the domains and topics recommended in these documents. These sources provide strong support for regular comprehensive assessment, with an emphasis on health, function, clinical, caregiver and safety domains. While there is some focus on the person living with dementia and care partner, the *experience of the person* living with dementia has not been a central focus in most research-based guidelines and quality measures.

To provide additional data for this review, evidence from individual research studies was gathered by searching in PubMed, CINAHL, SocINDEX, PsychINFO, and Social Work Abstracts for articles published since 2000, using various combinations of search terms including: dementia, assessment, whole person, strengths, strengths-based, needs assessment, person-centered or person centred care, nutrition assessment, symptom assessment, risk assessment, health assessment, health impact, quality of life, self-assessment, and geriatric assessment. This search yielded additional search terms that were then included in a PubMed search. After eliminating duplicates, non-English language papers and articles that were not research-based, a total 885 abstracts were reviewed. Since the goal of this paper was not to conduct a systematic review, the 108 papers selected for full text review and data extraction were prioritized based on the quantity and quality of evidence that included person-centered care or quality of life and/or experiential data from persons living with dementia or care partners, and/or publication in a core clinical, nursing or gerontological journal. Research-based articles were also included that provided elaboration of assessment recommendations given less detail in other works.

This scoping search revealed that BPSD, pain, quality of life, safety, and risk are more frequent topics for study in the professional literature than the process or outcomes of

Table 1. Assessment Data Needed to Support Quality Measures[a]

Assessment focus	PCPI	ICHOM (Specific instruments or measures are in bold)
Demographics		*Baseline*—Age, sex, level of education; Annually - living status and location, smoking status, alcohol use, BMI
Clinical status	Dementia severity	*Baseline*—Type of dementia (**ICD classification**), *Annually*—Level of dementia (**Clinical Dementia Rating Scale**)
Associated clinical history	Depressive symptoms	*Baseline*—history of head injury; Annually—cardiovascular event incidence, comorbidities (including hypertension, diabetes, high cholesterol, depression)
Medication variables		Total number of medications prescribed, documentation of any prescribed acetyl-cholinesterase inhibitors, N-methyl-D-aspartate (NMDA) receptor antagonists, antipsychotic drugs, antidepressants, anticonvulsants, or hypnotics
Symptoms	Neuropsychiatric symptom assessment; identification of potential triggers/precipitants and consequences; search for treatable, contributory causes	Neuropsychiatric symptoms (**Neuropsychiatric Inventory [NPI]**)
Function—cognitive	Cognitive assessment (using reliable and valid instrument or formal neuropsychological evaluation)	Cognitive function (**Montreal Cognitive Assessment [MOCA]**)
Function—daily living	Social function, Activities of Daily Living (using reliable and valid scale)	
Quality of life		*Baseline and 6-monthly* - Overall quality of life and wellbeing (**Quality of Life-AD [QOL-AD]** and **Quality of Wellbeing Scale-Self-Administered [QOLWS-SA]**)
Care partner/caregiver	Caregiver health assessment	Carer quality of life (**EuroQoL-5D or SF-12 or VR-12**)
Care provision		Need for 24-hr care
Safety	Home safety evaluation; driving risk	Falls
Other	Advance care plan, identification of surrogate decision-maker	Hospital admissions

Note: BMI = Body mass index; ICHOM = International Consortium for Health Outcomes Measurement; PCPI = Physician Consortium for Performance Improvement.

[a]Assessed annually unless otherwise stated.

person-centered assessment and care. The search for evidence was therefore extended to include texts and audiovisual media written or hosted by persons/families living with dementia. These sources provided insight into the process of assessment and underscored the importance of supporting dignity, autonomy and the voice of the person living with dementia. A synthesis of key assessment topics is provided in Table 2, and a summary of updated recommendations for assessment and care planning are included at the end of this paper.

Assessment Process

Feasibility and Scope

Regular, comprehensive assessment is recommended at baseline and interim reassessments are recommended in all settings at least every 6 months (Wiener et al., 2016). Time-pressed clinical environments require prioritization and the use of toolkits to increase efficiency. The first priority is to detect issues that detract from quality of life or prevent the person from living fully with dementia. This includes detection of hidden medical illness or pain or sources of excess disability and assessment of the degree of engagement in enjoyable activities. The presence of caregiver challenges should also be assessed as these may increase risk for institutionalization. More frequent reassessment is indicated in the context of recent medication changes, changes in health or behavior, living alone, driving, unstable or multiple comorbid conditions, bothersome symptoms, care partner stress, individual or care partner health concerns, recent hospitalization, or emergency department visits (Kales, Gitlin, & Lyketsos, 2014). There is considerable variability in cognitive and physical function in persons with Alzheimer's disease and other forms of dementia have different patterns of progression that would warrant more frequent assessment. The care partner's wellbeing and ability to provide support commensurate with the person's needs, may also change over time. A person-centered approach will tailor the frequency of assessment to the individual and family situation.

Persons living with dementia may become fatigued by cognitive and functional demands throughout the day and experts, including persons living with dementia, recommend that when possible, assessments be conducted during times of day when the person is at peak performance, in an environment free from distractions and competing demands.

Table 2. Comprehensive Person-Centered Assessment

Experience of the person/care partner
- Strengths/factors that support wellbeing including experiences of at-homeness
- Challenges/unmet needs
- Living situation and care needs
- Advance planning and awareness of resources (including education, support, palliative care)
- Caregiver health, unmet needs, stress
- Care dyad's knowledge about diagnosis, care options, and community resources

Function and Behavior
- Neurocognitive function
- Decisional capacity
- Physical function (including activities of daily living [ADL], instrumental activities of daily living [IADL])
- Psychological, social and spiritual activity and wellbeing
- Everyday routines, activities (including personal care, exercise, recreational activity, sleep)
- Behavioral changes, symptoms

Health Status and Risk Reduction
- Comorbidities (medical/psychiatric)
- Health indicators (e.g., pain, nutritional status, oral health)
- Medications (over-the-counter, prescription, supplements)
- Safety and risk reduction

Outcomes of Therapeutic Interventions

Sources of Information

Sources of information for the assessment include interviews with the person living with dementia, interviews with the care partner (and/or health care proxy if applicable), clinical records, prior assessments and observations. Observation, functional measurement and physical assessment provide objective data. The perspective of the person living with dementia should be prioritized in all assessments (de Medeiros & Doyle, 2013). Individuals living with dementia often report being ignored or infantilized (Bryden, 2016; Ellenbogen, 2012; Specht, Taylor, & Bossen, 2009). Using a life review approach, and asking about strengths and abilities before focusing on losses and disabilities, recognizes the person as someone who is a whole person. This forms a basis for a therapeutic partnership between the professional and the person living with dementia (Mast, 2011). Research has shown that even in late stages of dementia when people tend to "live in the moment," responses to simple questions about their well-being and feelings are possible (Kolanowski, Litaker, Catalano, Higgins, & Heineken, 2002). When the caregiver or other person is serving as a health care proxy, the viewpoint of the person living with dementia should still be sought, and preferences noted, including those expressed through verbal and nonverbal means (Bangerter, Abbott, Heid, Klumpp, & Van Haitsma, 2016). Repeat observations over time and/or behavior and symptom diaries are particularly useful for this purpose.

The majority of nonpharmacological treatments and care practices that have demonstrated efficacy in randomized controlled trials have targeted the person/care partner dyad and/or family caregivers (Maslow, 2012). It is therefore essential that family members also be included in the assessment process. In residential or institutional settings, direct caregivers who spend a great deal of time with

the person are essential informants to collect data about usual routines, preferences, sources of joy, and sources of discomfort or frustration. Caution should be used when relying exclusively on proxy report (family or staff) for subjective experiences such as pain or quality of life, which covary with caregiver variables and may not always agree with ratings from the person living with dementia (Conde-Sala et al., 2013; Herr, Coyne, McCaffery, Manworren, & Merkel, 2011). Reliable and valid observational measures and consultation with multiple informants may be of greatest benefit in these situations.

Preparation for the Assessment

Comprehensive assessment is supported by having reliable and valid assessment instruments (e.g., the Montreal Cognitive Assessment, the Neuropsychiatric Inventory), algorithms and toolkits (e.g., Medicare Annual Wellness Visit Algorithm and Toolkit for Assessment of Cognition; Cordell et al., 2013, KAER Toolkit; GSA, 2017), and resources regarding issues of frequent concern (e.g., Alzheimer's Association materials regarding wandering and driving safety). Print and on-line resources assist the individual and family in understanding the disease, planning for the future, dealing with situational challenges, anticipating and mitigating risks, enhancing meaningful engagement, and promoting healthful practices. Table 3 contains links to resources that support person-centered assessment.

Assessment Content

The goal of systematic assessment is to identify opportunities to support personhood, reduce health risks, optimize function, and identify comorbidities that may be impacting health, function and quality of life. Priority assessment topics that support positive person-centered care include factors that are relevant to living well with dementia, such as maintaining a sense of identity, agency, belonging, purpose, and positive emotional expression (Wolverson et al., 2016). This would include asking explicit questions about sources of joy, personally meaningful experiences of at-homeness and exploring the activities, environments, care practices and relationships that support the person's strengths and/or minimize distress.

Assessment of the Experience of the Person/Care Partner

Living with dementia is dynamic and situational and therefore what "matters" at any particular time in the course of the person's experience will change as the disease progresses, the person's perspective changes, and challenges occur that may threaten equilibrium and/or provide opportunities for growth (Taylor, 2007). The person living with dementia and care partners exist in a world of shifting salience where some things show up in the foreground as more important at a given time, and other things take the background. This means that person-centered assessment and care planning is an ongoing process, and not a one-time, finite task. A focus on the experience of the person will also guide setting-specific differences in assessment. The experience of living in the community poses challenges to autonomy, self-care, instrumental activities of daily living, and positive engagement with the social world. The experience of the person/care-partner dyad is particularly salient in this setting. This calls for proactive, systematic assessment from home, and community-based service providers. The experience of discomfort or disability related to undetected or undertreated physical and mental health conditions calls for the use of high-quality relational skills, listening, and strategic use of screening tools to identify these issues in primary care settings. In residential long-term care settings, the experience of the person living with dementia is often overwhelmed by organizational, staff, regulatory, and task-driven processes. In order to prioritize experiential assessment in these settings, leadership practices, organizational policies, culture building efforts, person-centered assessment tools, staff development activities, and quality improvement processes must all be aligned with the philosophy, goals, and practices described later in this paper.

Strengths and Facilitators of Wellbeing

In routine assessment, it is preferable to inquire about strengths, abilities, and successful self-care and caregiving approaches prior to assessing deficits and/or inquiring about alterations in personality, cognition or behavior (Judge, Yarry, & Orsulic-Jeras, 2010; Specht et al., 2009). While periodic symptom and behavioral inventories are useful to identify triggers for more in-depth assessment and care planning, they may also foster internalized stigma and fear. Using an assessment approach that focuses on the individual's experience conveys that the person living with dementia and their family are partners whose input is solicited, valued, and used in the plan of care.

Assessment of psychosocial and emotional health includes inquiry into overall positive and negative mood and affect, preferences for daily activities, pleasant events, quantity of social interactions, and the quality of relationships with significant people and animals (Mast, 2011). Assessment tools such as the Preferences for Everyday Living Inventory (PELI) (Van Haitsma et al., 2013) and the Pleasant Events Schedule (Logsdon & Teri, 1997) may be used to identify opportunities to enhance autonomy, meaningful engagement and psychosocial wellbeing. Persons living with dementia share the needs of all people to express emotions, fears and opinions, play or have fun, satisfy curiosity, give and receive affection, feel a sense of accomplishment, and engage in spiritually meaningful and faith-based activities. Wolverson and colleagues (2016) provide an overview of assessment tools related to these constructs of positive well-being.

Table 3. Resources for Person-Centered Assessment

Type	Source (All sites Accessed 26 October 2017)
Comprehensive resources (including all topics below)	http://www.alz.org; https://www.nia.nih.gov/health/alzheimers
Legal and financial planning and financial capacity	
Hospice and palliative care	http://www.nhpco.org/
Family care	https://www.caregiver.org/
Dementia subtypes and young-onset dementia information	http://www.theaftd.org/; https://www.lbda.org/; http://www.alz.org/i-have-alz/if-you-have-younger-onset-alzheimers.asp)
Living fully with dementia	http://daanow.org/
Primary care providers—system-level resources	https://www.thepcpi.org/pcpi/media/PCPI-Maintained-Measures/Dementia-Cognitive-Assessment-Updated-meas-wksht-FINAL.pdf; http://www.alz.org/careplanning/downloads/cms-consensus.pdf; https://www.geron.org/images/gsa/kaer/gsa-kaer-toolkit.pdf
Advance planning and serious illness conversations	http://theconversationproject.org/
Behavioral measures and resources for care planning	The Commonwealth Fund and The John A. Hartford Foundation Nursing Home Toolkit: www.nursinghometoolkit.com Rothschild Person-centered Care Planning Task Force *Guideline*: http://www.ideasinstitute.org/PDFs/Process_for_Care_Planning_for_Residnet_Choice.pdf; Support Health Activities Resources Education (SHARE) model: http://www.benrose.org/Research/share.cfm; WeCareAdvisor™ online interactive tool (Kales et al., 2017): http://ummentalhealth.info/2015/08/10/new-web-based-tool-called-wecareadvisor-aims-to-provide-support-for-caregivers-of-those-with-dementia/; Alzheimer's Navigator: https://www.alzheimersnavigator.org/; Care to Plan (CtP) online tool (Gaugler, Reese, & Tanler, 2016)
Safety and risk reduction (falls, driving, home safety)	https://www.alz.org/national/documents/brochure_stayingsafe.pdf; https://www.patientsafety.va.gov/professionals/onthejob/falls.asp; https://www.cdc.gov/steadi/; http://alz.org/care/alzheimers-dementia-and-driving.asp; https://www.thehartford.com/resources/mature-market-excellence/publications-on-aging)
Pain assessment	http://www.americangeriatrics.org/health_care_professionals/clinical_practice/clinical_guidelines_recommendations/ Chan, Hadjistavropoulos, Williams, & Lints-Martindale, 2014; Warden, Hurley, & Volicer, 2003

The wellbeing of care partners and caregivers strongly influences wellbeing and behavioral function of persons living with dementia. Therefore, caregiver wellbeing, self-efficacy, and perception of unmet needs should be a component of every assessment (Jennings et al., 2016). Assessment tools have been developed to explore caregiver values and preferences, caregiver relationships, consequences and rewards of giving care, caregiver skills, abilities, and the motivation to provide needed care (Whitlatch, Judge, Zarit, & Femia, 2006).

Challenges and Unmet Needs

Asking about current challenges and unmet needs (person living with dementia and care partner) facilitates empathy, enables tailored interventions, and informs the care planning process. Unmet needs commonly reported in the literature include: home maintenance, food, daytime activity, socialization, psychological distress, vision/hearing, self-care, and accidental self-harm. Persons living alone have more unmet needs than others (Miranda-Castillo, Woods, & Orrell, 2010).

Designing person-centered approaches requires a detailed assessment of environmental and caregiving features that either support or detract from function, independence, and safety (Gitlin, Marx, Stanley, & Hodgson, 2015). For community dwellers, an in-home assessment is recommended to identify safety concerns, environmental barriers to function and additional assessment data that may not be shared in more formal clinical settings (e.g., over-the-counter medications and supplements, pet-related concerns and living conditions). For persons living in residential care settings, the ability to observe the person's usual activity within their residence offers a great deal of information about abilities, preferences, social interactions, stressors, and person–environment fit (Brooker, 2005; Gaugler, Hobday, & Savik, 2013).

Reports of caregiver distress during any assessment occasion warrant referral to a team member with dementia-specific expertise in order to conduct a more in-depth assessment of needs, dyadic interaction, home environments, and opportunities to enhance function and safety. As the disease progresses and caregiving support needs are increased, the assessment of caregiver wellbeing and

the balance of care provision between informal supporters and family caregivers versus formal/paid care providers become increasingly salient. The literature recommends assessment for neglect and abuse (physical, financial, emotional, or sexual), particularly in high-risk situations including aggressive behaviors and BPSD and caregiver variables including anxiety, depression, social isolation, low education, and emotional problems (Wiglesworth et al., 2010).

The evidence supports the need to assess and address caregivers' personal needs, including physical and psychological health, and the need to manage their own lives (McCabe, You, & Tatangelo, 2016). Assessing caregiver needs and awareness of community and on-line resources is particularly important for minority populations who experience disparities in diagnosis and follow-up care (Cooper, Tandy, Balamurali, & Livingston, 2010).

Cognitive Function and Decisional Capacity

Sudden or unexpected declines in cognition or function warrant referral to a health care provider to identify physical and mental health conditions that if undetected, may result in excess disability and cognitive dysfunction. Delirium (acute, potentially reversible cognitive impairment) is more common in persons with dementia (Morandi et al., 2012) and a high index of suspicion is recommended for this life-threatening condition (Inouye, Westendorp, Saczynski, Kimchi, & Cleinman, 2014). Serial assessment using reliable and valid cognitive assessment tools (by professionals with appropriate training and scope of practice) is recommended to identify potential acute changes in cognition or function. (Wiener et al., 2016). Two recent systematic reviews of instruments to detect delirium may be useful to clinicians trained in their administration (Morandi et al., 2012; Wong, Holroyd-Leduc, Simel, & Straus, 2010) and some researchers recommend that family members be educated to recognize delirium (Paulson, Monroe, Mcdougall, & Fick, 2016).

Cognitive function should be assessed in a manner that optimizes success and preserves dignity (Bryden, 2016). The assessor needs to understand not only the presence of cognitive and functional changes, but also the impact on the person living with dementia and care partners, and the implications for the goals, relationships, daily living, and engagement (Brooker, 2008). It is important to recognize different cultural views of cognitive impairment and the acceptance of dementia as a diagnosis, and to use cognitive assessment tools that have been validated in populations for whom English is not the first language (Wiener et al., 2016).

Cognitive assessment also supports person-centered care planning by guiding recommendations for activities and setting up appropriate expectations tailored to the person's function (Agostinelli, Demers, Garrigan, & Waszynski, 1994). For example, deficits in executive function may warrant task simplification, cueing, and activity-specific strategies. Deficits in language and communication may benefit from demonstration, hand-over-hand techniques, and specific strategies recommended by speech and occupational therapists (Gitlin, Winter, Dennis, Hodgson, & Hauck, 2010). Tailoring activities to the person's neurocognitive abilities and strengths may preserve dignity, prevent excessive stress-inducing demands, and prevent excess dependency, boredom, and learned helplessness.

Cognitive function includes the capacity to make decisions. Assessment of decisional capacity is most frequently discussed in the research literature in relation to medical treatment decisions. Decisional capacity (a clinical assessment) is distinct from competence (a legal determination) and is decision-specific. Involvement in everyday decision making is associated with quality of life and may include choices about living environments, types, and amount of support for daily activities and planning for a future of diminished capacity or function. (Menne, Judge, & Whitlatch, 2009). Capacity assessment tools have been developed for treatment-related decisions Grisso, Appelbaum, & Hill-Fotouhi. (1997) and everyday decisions (Lai et al., 2008). A specialized case of capacity assessment involves capacity for sexual decision making (Wilkins, 2015). Illness may temporarily alter capacity and reassessment is indicated after appropriate treatment. Even in situations of diminished capacity, a person-centered approach supports that the values and wishes of the person living with dementia be sought, and included in the consideration of options (Mezey, 2016).

Physical Function

Functional independence is a component of health-related quality of life (Barbe et al., 2017) and is associated with care partner wellbeing and caregiving time (Razani et al., 2014). Functional assessment includes both basic (bathing, dressing, grooming, mobility, toileting, feeding) and instrumental activities of daily living (managing finances, shopping, cooking, managing medications, housework, using transportation). Performance-based measures are recommended, in addition to obtaining data from multiple sources (e.g., person, care partner, direct observation, and measurement).

Functional assessment includes inquiry into any changes in day-to-day social, occupational, recreational, or physical function. Financial capacity and driving ability are sensitive but particularly important domains in the early phases of the disease, and it is recommended that these be discussed candidly with the person living with dementia and the care partner (Frank & Forbes, 2017; Sudo & Laks, 2017).

Psychosocial Assessment

Whereas neurocognitive and functional assessments are often focused on detecting deficits or sources of illness and

disability, assessment of psychosocial and emotional health focuses more on aspects of life that contribute to wellbeing. Qualitative studies emphasize two important themes related to quality of life: connectedness and agency (O'Rourke, Duggleby, Fraser, & Jerke, 2015). Relationships with family, friends, long-term care staff, and other residents all contribute to the sense of connectedness in addition to harmonious relationships with place. Individualized meanings of home may be assessed and used as a basis for planning discrete experiences to improve quality of living (Molony, 2010). Assessment of the person's ability to experience autonomy and control, to set and meet achievable goals, and to maintain spiritual connections are essential to inform person-centered care planning (Frank & Forbes, 2017).

Everyday Routines

Part of assessing day-to-day function and planning person-centered care includes reviewing daily habits, preferences, routines, and responses to various personal care activities. Evidence-based guidelines are available for assessment and care planning related to person-centered bathing, dressing, and oral care. (Crandall, White, Schuldheis, & Talerico, 2007; Zimmerman, Sloane, Cohen, & Barrick, 2014).

Behavioral Symptoms

Behavioral symptoms have been conceptualized as a form of communication and expressions of unmet needs (Algase et al., 1996) and/or a reflection of lower tolerance for stressors in the physical and psychosocial environment (Hall & Buckwalter, 1987). A recent framework proposed by Kales and colleagues (2015) includes the quality of interaction between the caregiver and person living with dementia.

Behavior is universally acknowledged by researchers and families living with dementia as an essential component of assessment. Behavioral symptoms increase the burden of care for family and formal caregivers, often precipitate institutionalization and account for one-third of all dementia-related costs (Herrmann et al., 2006; Toot, Swinson, Devine, Challis, & Orrell, 2017). Common behavioral symptoms include aggression, agitation, and apathy (Kales et al., 2015). A whole-person assessment of behavior is the first step in understanding what these symptoms may signify so that the response is appropriate and person-centered. Careful assessment may identify triggering conditions or contexts that can be modified to reduce the likelihood of distress. In addition, assessing what aspect of the symptom is most distressing for the individual and caregiver will support individually tailored treatment strategies. This type of assessment is incorporated into successful models of care (Gitlin, Winter, Dennis, Hodgson, & Hauck, 2010).

Once the behavior is well-characterized and untreated medical conditions are excluded as a possible cause, the second step is to assess for modifiable causes of the symptom. These precipitants then become targets for intervention. The investigation of these triggers involves astute observation of behavioral patterns. Behavioral logs can assist in identifying triggers that commonly include medications, pain, comorbidities, lost functional abilities, boredom, poor communication, task-focused care, and environmental characteristics such as noise, lighting, temperature, and crowding (Gilmore-Bykovskyi, Roberts, Bowers, & Brown, 2015). The WeCare™ web-based application provides individually tailored guidance for caregivers and families assessing and managing behavioral symptoms (Kales et al., 2017).

Kolanowski Boltz and Galick (2016) conducted a recent scoping review of causes or determinants of behavioral symptoms. A number of causes were common across several behavioral symptoms: neurodegeneration, type of dementia, severity of cognitive impairments, declining functional abilities, caregiver burden, poor communication, and boredom. These findings have implications for further assessment and care planning to support functional independence, improve communication, and prevent boredom.

Health Status and Risk Reduction

Comorbidities

Co-occurring health conditions such as heart failure, diabetes or lung disease may amplify cognitive, functional, and behavioral challenges in persons living with dementia. Thorough investigation for co-occurring conditions may prevent disability and distress (Wiener, 2016). These investigations include assessment of vision, hearing, oral health, communication, swallowing, nutrition, hydration, substance use, sleep, oxygenation, skin integrity, sexuality, continence, bowel function, and mobility and signs of infection or pain.

Older age, more chronic health conditions, polypharmacy, reduced mobility, advanced dementia, and/or communication impairments warrant a more comprehensive approach to physical assessment to identify undetected sources of illness or distress. There is a gap in the literature regarding the best methods to conduct a sensitive physical assessment in persons with dementia. The first author's clinical experience suggests that a person-centered approach includes modification of the usual head to toe, palpation-before auscultation approach. Using less intrusive assessment techniques first (e.g., observation, resting auscultation), providing simple instructions and explanations, using a calm reassuring tone of voice and nonverbal communication strategies, are helpful in completing the assessment, particularly for persons in advanced phases of dementia. Referral to interdisciplinary colleagues for vision, hearing, and nutritional assessment is helpful when these team members are available. Vision loss may contribute to visual misinterpretation, nonrecognition and hallucinations. Vision screening has been shown to be feasible even in moderate to advanced dementia (Chriqui, Kergoat,

Champoux, Leclerc, & Kergoat, 2013). Inspection for wax impaction is part of routine geriatric assessment and is particularly important to prevent avoidable hearing loss in persons living with dementia.

Depression is common in early-stage Alzheimer's disease. A recent meta-analysis found a pooled prevalence of major depression of 30.3% (Goodarzi, Mele, Roberts, & Holroyd-Leduc, 2017) with a higher prevalence when criteria specifically developed for depression in dementia were used. While screening tools such as the PHQ-2 may be used mild stages of the disease, Goodarzi and colleagues (2017) found that the Cornell Scale for Depression in Dementia (CSDD) and Hamilton Depression Rating Scale (HDRS) had higher sensitivity and discriminatory ability than other instruments. Both of these scales include interview with persons with dementia and their caregivers. If a more in-depth assessment for depression is indicated, referral to a provider with mental health, geriatric, and/or dementia expertise is recommended.

Medications

Medications are a frequent contributor to cognitive dysfunction and a careful medication review is universally endorsed in the literature. Assessment includes identification of high alert medications and potentially inappropriate medications, as well as any medication usage or medication management challenges (American Geriatrics Society [AGS], 2015; Johnell, 2015). While additional studies are needed to support predictive validity, the Mini-cog and Medi-cog screening assessments have demonstrated clinical utility in identifying the need for more assessment and support related to medication management and may be used by well-trained assessors (Anderson et al., 2014).

Safety and Risk Reduction

One of the most valuable types of support for persons and care partners is planning for risk reduction. Persons living with dementia in early to middle phases are at increased risk for harm related to financial mismanagement (Dong, Chen, & Simon, 2014), medication-related adverse events (Wucherer et al., 2016), driving (Rapoport, Cameron, Sanford, & Naglie, 2017), falls (deRuiter et al., 2017), wandering, elopement, and getting lost (Ali et al., 2016). Recommendations for community-based care include providing a referral to the Alzheimer's Association and providing information about resources such as MediAlert® and the Safe Return® program, and the Alzheimer's Navigator (an individually tailored assessment and management program available from the Alzheimer's Association. Tools are available in the literature to support home safety assessment to identify opportunities to reduce the likelihood of avoidable injury (Tomita, Sumandeep, Rajendran, Nochaiski, & Schweitzer, 2014).

Table 4 identifies safety issues cited in the literature that need to be periodically assessed to provide anticipatory guidance and reduce risk (Amjad, Roth, Samus, Yasar, & Wolff, 2016). Persons living with dementia point out that skillful, empathetic communication strategies are needed to prevent these assessments from being conveyed as prophecies of a feared future, acknowledging that each person's disease and trajectory are unique (Taylor, 2007).

A person-centered approach requires that safety not be narrowly constructed to mean only physical safety. The person's integrity may be threatened by risk-averse approaches that discount threats to personhood and dignity (ontological safety). Frank discussions about risk tolerance and risk mitigation are essential. The Alzheimer's Association website has tools and resources to assist professionals in assessing and promoting safety while optimizing autonomy, including strategies to promote restraint-free care. Another excellent resource is the Rothschild Foundation guide for care planning processes (Calkins & Brush, 2016) which was designed for nursing home settings and provides numerous clinical examples, quality improvement tools and templates to support care planning around risk-related activities while honoring individual preferences.

The range of safety-related topics illustrate the need for situational flexibility between wide-ranging, scoping assessment and in-depth, targeted assessment. In addition to driving safety, areas that are frequently in need of more detailed assessment include: nutrition (Abdelhamid et al., 2016), pain (Beer et al., 2010), oral care (Delwel et al., 2017), falls (de Ruiter, de Jonghe, Germans, Ruiter, & Jansen, 2017) and planning for restraint-free care (Kopke et al., 2012). Restraint-free care is supported by all of the assessment practices recommended in this paper. Learning each person's life history, values, habits, and preferences and conducting skillful assessment of contributors to wandering,

Table 4. Safety and Risk Reduction

Community dwellers
- Driving problems
- Money management or financial exploitation
- Medication management problems
- Wandering or getting lost
- Cooking, appliance or power equipment problems
- Spoiled food or non-food
- Attending medical visits alone
- Difficulty responding to crisis/emergency
- Unsafe storage/use of firearms

Persons living with dementia in all settings
- Care partner/caregiver stress/strain
- Smoking problems or use of alcohol or other substances
- Behavioral symptoms (suspicious or accusative behavior; verbal or physical aggression)
- Threats to hurt oneself or suicidality
- Falls
- Mistreatment or neglect
- Risk for restraints

behavioral symptoms, delirium, and falls, may reduce the need for restraints. System-wide policies for restraint-free care are recommended to guide this assessment and to raise awareness of preventable risk factors.

Advance Planning

While systematic reviews confirm that early attention to advance planning maximizes autonomy and increases the likelihood that the person living with dementia will have individual preferences and wishes honored, there is a gap in translating this knowledge into practice (Robinson et al., 2010). The Institute for Healthcare Improvement and The Conversation Project have developed supportive materials for serious illness conversations tailored to the particulars of Alzheimer's disease (Bernacki & Block, 2014). Assessment of the individual and family's knowledge and attitudes related to palliative care and symptom management (distinct from hospice care), inform the care planning process and may prompt referral to interdisciplinary team members for ongoing education and support (e.g., social worker, care manager, Alzheimer's Association, and/or palliative care team).

Advanced dementia poses particular challenges for assessment. If the disease has affected the individual's ability to communicate, care providers must have a high index of suspicion and vigilance in detecting delirium, illness, discomfort, hunger, constipation, impaction, urinary retention, infection, fear, grief, loneliness, and boredom. Skin breakdown, dehydration, swallowing difficulties, and aspiration are common threats to wellbeing that require timely detection and management. The more advanced the disease and/or the greater the number of comorbidities, the more frequent assessment should occur to identify potentially remediable causes of suffering (Mitchell et al., 2009).

The Alzheimer's Association End-of-Life Care Practice Guidelines (2007) contain detailed information and recommendations about decision making, planning, symptom management, and end-of-life care. Researchers have identified essential components of family-centered care at end of life and intensive individualized comfort care (Lopez, Mazor, Mitchell, & Givens, 2013; Lopez & Amella, 2012).

Turning Assessment into Action

A new Medicare Cognitive Assessment and Care Planning billing code (G0505) took effect in January of 2017 that provides reimbursement to practitioners for a clinical visit that results in a comprehensive care plan for persons with a documented cognitive impairment. The rules require a multidimensional assessment that includes cognition, function, safety, neuropsychiatric and behavioral symptoms, medication reconciliation, and assessment of caregiver needs. Transdisciplinary, collaborative care approaches are increasingly being recommended and evaluated (Galvin, Valois, & Zweig, 2014). Collaborative assessment and care management may be particularly useful in reducing disparities in dementia care quality among caregivers with lower educational attainment (Brown, Vassar, Connor, & Vickery, 2013). In any team-based approach, there needs to be agreement on who is accountable for coordinating and documenting assessment findings and follow-up actions.

Team care planning includes medical, nursing, direct care/personal care providers, care partners and other family, social workers, occupational therapists, physical therapists, speech therapists, registered dieticians, and pharmacists (Wiener et al., 2016). This may require use of technologies to facilitate team collaboration, use of asynchronous written or electronic input and/or a care coordinator accountable for linking with all other team members, sharing and integrating all perspectives. If not already done, a list of strategies, approaches, therapies, and joy-enhancing activities should be gathered from family members, care providers, and all members of the team. This list must be frequently re-evaluated, revised, and used with sufficient flexibility to accommodate situational changes in the individual's health, preferences and needs.

The person living with dementia should be involved in the care planning process and may need support in having their "voice" (including verbal and nonverbal communication) heard. The information obtained during whole-person assessment is used to plan care that meets the goals of the person living with dementia and their caregivers. Unfortunately, information contained in care plans does not always get shared with care providers in a systematic way. This is a barrier to person-centered care because many of the preferences and needs of residents are known to direct care workers as a result of their daily contact (Abbott, Heid, & Van Haitsma, 2016). All staff must be included in the care planning process, particularly those who spend the most time with the person. This includes personal care assistants in community-based settings. Care plan implementation requires the use of tools to capture and distribute person-centered information to workers at the point of care (Van Haitsma et al., 2014).

Others involved in the process include persons who care about, care with and/or care for the person with dementia. Using person-centered conceptual models to guide care and person-centered language in all documentation are two strategies that will increase the likelihood of person-centered planning. A number of outstanding resources are available to assist with care planning (see Table 3). The Dementia Action Alliance, a grassroots advocacy organization, provides white papers to support these practices (available at: http://daanow.org/).

Experiential, functional, behavioral, and health assessment provide the basis for ongoing care and referrals to other members of the interdisciplinary team. The outcome of comprehensive assessment is an interdisciplinary plan for function-focused care, rehabilitation, modification of tasks and environment, and activity-specific recommendations to improve engagement, enhance function, optimize choice,

autonomy and comfort during personal care and decrease person/care partner stress (Galik, Resnick, Hammersla, & Brightwater, 2014; Gitlin et al., 2015). Published guidelines recommend that care plans specifically address family well-being and the needs of caregivers and incorporate the person's choices about the goals of care and end-of-life wishes.

Specific goals included in the plan include strategies to build on strengths, promote success, honor personhood, and support function (physical, cognitive, psychosocial, and spiritual). A quality assurance and performance improvement (QAPI) audit may be used to review whether plans of care respect the person's unique preferences, consider the experience of the person and family, and focus on what really matters to the person and those who care deeply about them. The care planning process implies frequent reassessment about whether previous goals and preferences are being met and if not, what revisions need to be made (Van Haitsma et al., 2015). Lack of goal achievement or behavioral challenges indicate a need for more comprehensive assessment and problem-solving leading to small individually-tailored trials with frequent checks to evaluate success. Consultation with advanced practice clinicians or dementia care experts may be sought if they have not previously been included in the process. It is particularly important to evaluate whether pharmacologic interventions are having the intended effect and providing benefits that outweigh the risks.

The time spent performing a comprehensive assessment and creating a holistic, person-centered plan will be wasted if that plan is not documented and shared in a manner that guides day-to-day care and experiences for the person and care partners. A study by Kolanowski, Van Haitsma, Penrod, Hill, & Yevchak (2015) found that certified nursing assistants in the nursing home setting did not have access to written information and/or the information that was available was out of date or too time-consuming to read.

Person-centered care interventions have demonstrated effectiveness in clinical trials (Brooker et al., 2016; Kim & Park, 2017) but organizational barriers frequently prevent the implementation of these strategies. Future work is needed to create and sustain supportive environments that enable implementation of these practices.

Summary

As discussed throughout this manuscript, person-centered assessment and care planning focus on the unique needs and characteristics of the person. At present, many persons living with dementia do not receive person-centered assessment and care planning because of programmatic, organizational, and regulatory requirements and professional and provider practices that reflect the needs of staff and settings, more than the needs of the person with dementia. The following recommendations are intended to increase the use of assessment and care planning practices that focus on the needs of the person in a wide array of care settings, across types and stages of dementia, and conducted by professionals, paraprofessionals, and direct care workers, depending on their scope of practice and training.

1. Perform regular, comprehensive person-centered assessments and timely interim assessments.

   Assessments, conducted at least every 6 months, should prioritize issues that help the person with dementia to live fully. These include assessments of the individual and care partner's relationships and subjective experience and assessment of cognition, behavior, and function, using reliable and valid tools. Assessment is ongoing and dynamic, combining nomothetic (norm-based) and idiographic (individualized) approaches.

2. Use assessment as an opportunity for information gathering, relationship-building, education, and support.

   Assessment provides an opportunity to promote mutual understanding of dementia and the specific situation of the individual and care partners, and to enhance the quality of the therapeutic partnership. Assessment should reduce fear and stigma and result in referrals to community resources for education, information and support. Assessment includes an intentional preassessment phase to prepare the assessor to enter the experience of the person living with dementia and their care partner(s).

3. Approach assessment and care planning with a collaborative, team approach.

   Multidisciplinary assessment and care planning are needed to address the whole-person impact of dementia. The person living with dementia, care partners and caregivers are integral members of the care planning team. A coordinator should be identified to integrate, document and share relevant information and to avoid redundancy and conflicting advice from multiple providers.

4. Use documentation and communication systems to facilitate the delivery of person-centered information between all care providers.

   Comprehensive, high-quality assessment is of benefit only if it is documented and shared with care providers for use in planning and evaluating care. Information must be current, accessible, and utilized.

5. Encourage advance planning to optimize physical, psychosocial and fiscal wellbeing and to increase awareness of all care options, including palliative care and hospice.

   Early and ongoing discussion of what matters, including values, quality of life and goals for care, are essential for person-centered care. The person living with

dementia's preferences and wishes should be honored in all phases of the disease, even when proxy decision making is required. The individual and family should be referred to health care team members to provide ongoing education and support about symptom management and palliative care.

Further research is needed to inform the assessment process. Models of care are needed that balance the nomothetic and idiographic approaches to assessment in a person-centered, yet cost-effective manner. Future research is needed to investigate contributors to wellbeing and positive relationships in care partner dyads. Additional research is also needed to validate strategies for ensuring that best practices in person-centered assessment and planning are carried over to implementation at the point of care in both community-based and residential settings. The National Health Service Quality Outcome Framework in the United Kingdom explicitly lists "Ensuring that people have a positive experience of care" as a quality standard (National Institute for Health and Care Excellence, 2013). This places the experience of the person living with dementia in the center of quality improvement efforts. A future challenge will be to integrate and measure outcomes of the relational processes needed to establish and sustain an "I-Thou" relationship, and support personhood, as envisioned by Kitwood.

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Conflict of Interest

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Review Article

Ongoing Medical Management to Maximize Health and Well-being for Persons Living With Dementia

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Abstract

Background and Objectives: Persons living with dementia have complex care needs including memory loss that should be taken into account by providers and family caregivers involved with their care. The prevalence of comorbid conditions in people with dementia is high and, thus, how primary care, community providers and family caregivers provide best practice care, person-centered care is important.

Research Design and Methods: Care providers should understand the ongoing medical management needs of persons living with dementia in order to maximize their quality of life, proactively plan for their anticipated needs, and be as well prepared as possible for health crises that may occur.

Results: This article provides eight practice recommendations intended to promote understanding and support of the role of nonphysician care providers in educating family caregivers about ongoing medical management to improve the wellbeing of persons living with dementia.

Discussion and Implications: Key among these are recommendations to use nonpharmacological interventions to manage behavioral and psychological symptoms of dementia as the first line of treatment and recommendations on how to best support the use and discontinuation of pharmacological interventions as necessary.

Keywords: Caregiving-formal, Dementia, Evidence-based practice, Person-centered care

In this article, we address the ongoing medical care that most people living with dementia need over the course of the disease. Persons living with dementia have complex care needs including memory loss, for example, that may impede their ability to take medicines on a regular basis or communication difficulties that make it more difficult for them to report symptoms that they may be experiencing (Bunn et al., 2014). Persons living with dementia can have many of the same comorbid conditions that persons without dementia have, but frequently have more encounters with acute care providers, including doctors and nurses at hospitals and emergency departments. A recent systematic literature review by Bunn and colleagues (2014) suggests that significant numbers of people with dementia have a comorbid health condition, such as diabetes, visual impairment, or stroke. Because this was a large review of over 65 studies, prevalence numbers varied, however, as Bunn and colleagues (2014) report the prevalence of type

2 diabetes ranged from 6% to 39% in people with dementia; similarly 3% of hospitalized older adults in the United Kingdom to 34% of community dwelling older adults in a U.S. sample had a history of stroke and dementia. Two studies reported the prevalence of dementia in people with visual impairment recruited via eye clinics. In one 19% of people with macular disease had dementia and in the other 20% of people with glaucoma had memory impairment and 22% impaired executive functioning.

There may be a variety of factors that contribute to this finding. For example, people with dementia may be less likely to attend regular appointments or to notice or report relevant symptoms and they may be more reliant on caregivers to manage and facilitate appointments. It is also possible that clinicians may be more reluctant to investigate and treat individuals with dementia either because of the difficulties involved in securing cooperation or because treatments are considered inappropriate for older patients with multiple comorbidities. In addition, if dementia is symptomatic, then the dementia can become clinically dominant and detract from the management of other conditions like diabetes mellitus (Bunn et al., 2014). It is useful for nonphysician care providers to understand how care ideally should be provided to persons with dementia in order to maximize their quality of life, proactively plan for their anticipated needs, and be as well prepared as possible for health crises that may occur.

As reviewed earlier in this special issue, the number of persons affected by Alzheimer's disease and other dementias is projected to increase over the coming decades. With these increases, we can expect to see a greater demand for services for persons living with dementia across all health care settings, though it might be expected that this demand will be greatest in those venues that most commonly provide care to persons living with dementia today. Some of these settings, such as memory care centers and long-term care centers including nursing homes, have long-standing experience in providing care to large numbers of persons living with dementia; whereas in other settings, including primary care offices, medical specialists' offices, hospitals, and emergency departments, more preparation will be needed to address the unique care needs of persons living with dementia as their numbers increase.

For clarity, this article uses the terms, physician, medical care provider, primary care provider, and acute care provider, to refer to physicians and medical care providers including nurse practitioners and physician assistants who work in primary care offices, medical specialist offices, hospitals, and emergency departments. It uses the terms, family, family members, and caregivers to refer to relatives, friends, and neighbors who provide care for a person living with dementia. Lastly, it uses the terms, nonphysician care provider and community or residential care provider, to refer to individuals who work in area agencies on aging, aging and disability resource centers, information and referral agencies, senior centers, senior housing, personal care homes, assisted living facilities, nursing homes, home health agencies, homemaker and personal care agencies, care management agencies, adult day centers, pharmacies, and public health and community nursing agencies. Examples might include pharmacists; social workers, physical, occupational, and speech therapists. Nonphysician care providers also include self-employed geriatric care consultants, family counsellors, and home care aides.

Understanding Common Comorbidities

It is important for nonphysician care providers who work in community and residential care settings to remember that persons living with dementia have medical care needs in addition to care needs related to the dementia. Typically, medical care for the person living with dementia is provided by a family medicine physician or internist, who often works with a neurologist or psychiatrist depending on the person's needs. Persons living with dementia may see several doctors, therefore, having a consistent relationship with a primary care provider can help coordinate care and potentially prevent unnecessary hospitalizations. Family caregivers should expect that physicians and medical care providers across all health care settings should provide care to persons living with dementia in a manner that respects their personhood, takes into account the variable ability of individuals living with dementia to participate in or direct their health care, and reflects the high likelihood concerned family members should be involved and included in any medical decision making. Like other older adults, persons living with dementia commonly suffer from high blood pressure, heart disease, diabetes, as well as other conditions that become more common with age. Care for these common conditions should not be provided in isolation from the person's dementia but rather take the person's dementia into account (Bunn et al., 2014; Schubert et al., 2006).

Medical issues can worsen cognition, and many people living with dementia have other conditions that can and do impact cognition. Unfortunately, it can be difficult to recognize when the person living with dementia is ill. Persons living with dementia are known to be less likely to report symptoms or by the time they are asked about them, the symptoms have passed, and they can't give an accurate report. Often, the only symptom one can see is the worsening of confusion or behaviors, which makes it very difficult to know if this is due to the progression of the underlying dementia or if there is a new problem to be addressed. When there is a significant and sudden change in cognition and behavior, it is important that the person with dementia, their caregiver and involved nonphysician care providers report this to the person's primary care provider quickly.

In order to assure that persons living with dementia and their caregivers receive medical care and other services that are consistent with their goals of care, they need to be first offered an explanation of the condition, its prognosis, and potential treatment options, including pharmacologic and nonpharmacologic approaches. Evidence to date suggests

that only a minority of persons living with dementia are recognized as having the condition by their primary care providers and that their caregivers experience increased levels of stress, depression, and mortality (Boustani, Sachs, & Callahan, 2007; Fowler, 2012; McKhann et al., 2011). There are evidence-based programs that support the process of identifying and diagnosing persons with dementia, provide on-going support to them and their caregivers, and help address their on-going and evolving biopsychosocial needs (Callahan et al., 2014; LaMantia et al., 2015; Tan, Jennings, & Ruben, 2014). Speaking with persons living with dementia and their caregivers about the diagnosis of dementia should not be done in a hurried manner, but rather should be approached with sensitivity and in a manner that recognizes the particular needs of each individual (Wilkinson & Milne, 2003). Further, speaking with persons living with dementia and their caregivers about the diagnosis and its prognosis does not need to be done in an overly negative manner that removes hope. Instead, an approach that acknowledges and incorporates the many advances that have been made in addressing the medical and social needs of the person living with dementia and their caregivers is recommended.

Persons living with dementia and their family members often fear that after the diagnosis, their physician will abandon them because there are currently no disease modifying treatments available (Boustani et al., 2011; Fowler et al., 2012). Physicians and other medical care providers can offer important education and psychosocial support to both the person with dementia and the family caregiver (Austrom & Lu, 2009; Callahan et al., 2011; McKhann et al., 2011). Medical care providers also have a unique opportunity to educate the person living with dementia and their family members about what to expect over the course of disease. Indeed, the needs of persons with dementia can be expected to change over time. Early on, medical providers, nonphysician care providers, and caregivers may need to provide little additional support than that which is given to persons without dementia, however with time the amount of support should be titrated gradually in a personalized manner that responds to the individual's unique pattern of increasing need and respects his or her autonomy (Callahan, 2017). Medical providers can, additionally, provide referrals to available support services and can monitor judgment and safety issues so that the person living with dementia can remain independent and community-dwelling for as long as possible (Boustani et al., 2011; Callahan et al., 2012; Farran et al., 2007; Schulz et al., 2003). Nonphysician care providers can play an instrumental role in supporting person living with dementia and their care partners after they have been diagnosed by their physician.

Addressing Behavioral and Psychological Symptoms of Dementia

One of the more common complications that can arise in the care of persons living with dementia is the development of behavioral disturbances. Such symptoms are thought to occur in between 75% and 98% of community dwelling individuals and can become more common as the dementia progresses. Symptoms can include agitation, wandering, resistance to care, combativeness, nighttime arousals that interfere with sleep and caregivers' sleep, and psychotic symptoms (Ballard & Waite, 2006; Fung et al., 2012; Sink, Covinsky, Newcomer, & Yaffe, 2004; Teri et al., 2000). It is important that families and nonphysician care providers bring these symptoms to the physician's attention so that the symptoms may be evaluated thoroughly and a plan for their management developed.

In evaluating the person's behavioral disturbance, it is important that the context in which the behavior occurs is considered. This information is most often obtained from family members or a nonphysician care provider. These individuals may be most able to describe whether this is a continuation of an old behavior that should come to medical attention for some other unrelated reason or describe accurately if this is a new or worsening symptom. A useful framework for physicians in making an evaluation of a new symptom is that initially developed by Sharon Inouye (Inouye, 1999; Inouye & Charpentier, 1996) to describe delirium. This framework consists of predisposing factors inherent to the individual which set the stage upon which precipitating factors then cause the concerning behavior to occur. In this model, examples of predisposing factors could include the stage of the person's dementia, the presence of chronic comorbid illnesses like congestive heart failure or chronic obstructive pulmonary disease, and sensory impairments like decreased hearing ability or decreased vision caused by cataracts, glaucoma, or macular degeneration for example. Precipitating factors might include the use of sedating or stimulating medications, the presence of untreated pain, exposure to frightening or disturbing stimuli, the inability of the individual to get adequate rest, the removal of the person from his or her usual environment or normal routine, and the development of delirium (Inouye, 1999).

In a recent study by Kerns and colleagues (2017), family caregivers and nurses of persons with dementia living in the community and in residential care, were interviewed for their perceptions on the use of both nonpharmacological interventions and medications for behavioral disturbances (Kerns, Winter, Winter, Kerns, & Etz, 2017). Caregivers were able to identify three major issues regarding medications for persons with dementia including (a) barriers exist for nonpharmacologic therapies and these should be addressed; (b) medications have few barriers, and seem generally effective and safe; and (c) when nonpharmacologic measures fail, medications, including antipsychotics, may be necessary and appropriate to relieve the person with dementia's distress. This study highlights the important voice that caregivers, both family members and nurses, can bring to person-centered care (Kerns, Winter, Winter, Kerns, & Etz, 2017).

As noted above, medications can be the cause of newly developing behavioral disturbances among persons living with dementia. The astute family member and nonphysician care provider should be suspicious when a new or concerning behavior occurs soon after a new medication has been started. Similarly, concern should be raised if the person living with dementia develops new behavioral symptoms and may not be receiving their medications as they have been prescribed, either because the medicine is being taken at the wrong dose or it is being taken too frequently, not frequently enough, or at the wrong times. As adults age, their bodies process medications differently than they did when they were younger and as a result, there are medications that some persons living with dementia have taken for years but no longer tolerate as their body ages and as their brains become more vulnerable with the worsening of their condition. Of particular concern is the use of anticholingeric medications in older adults and the negative impact on cognitive function. A review of the literature by Boustani and colleagues (2008) found that prescribing anticholinergics to older adults can lead to acute cognitive impairment and might even lead to chronic cognitive deficitis (Boustani, Campbell, Munger, Maidment, & Fox, 2008). Given changes in responses to medication over time, it is very important for family members and/or nonphysician care providers to attend routine doctors' appointments with the person living with dementia; to make sure that they bring all medications, supplements, and herbs with them to the appointments whether these are prescribed or taken over-the-counter; and that they discuss with the person's physician whether all of the medications continue to be needed. The physician should welcome this type of information and these types of conversations as they help the family and nonphysician care providers deliver care that is personalized and appropriate to the needs of the person living with dementia. Physicians and other medical care providers that are not welcoming or supportive of person-centered care for the person living with dementia and participatory care with the family caregiver, may not be the most appropriate provider for the person with dementia and caregiver dyad.

Family caregivers and nonphysician care providers should expect that the medical provider will start with the lowest effective dose of a medication then reevaluate the person living with dementia for anticipated side effects and effectiveness of the medication before deciding whether to continue the medicine, increase its dose, or discontinue it. A useful tool to consult when evaluating the need to start, continue, or discontinue a medication for an older adult and particularly those with dementia is the Beers List (AGS, 2015). This list, originally developed by physician Mark Beers in 1991 and updated most recently in 2012, includes 34 medicines and classes of medicines that are "potentially inappropriate" in older adults. Examples of these include benzodiazepines, like lorazepam which may be used to address anxiety but can increase the risk of falls or confusion in an older adult, or anticholinergic medications, like diphenhydramine which may be used to treat allergic symptoms in an urgent or emergent situation but can cause confusion or fatigue in a vulnerable senior and should not be used for treating either sleep issues or anxiety. Asking medical providers about the necessity of all prescribed medicines and understanding the indication for their use can be an important way for family caregivers and nonphysician care providers to be effective advocates for persons living with dementia.

While medicines are clearly an important precipitant of behavioral disturbances among older adults, there are other important causes to consider. Pain is obviously still experienced by persons living with dementia though in more advanced stages of the condition the person's reporting of pain may be impaired, take a different form, or be unrecognized by others. In this situation, the report of a family caregiver or nonphysician care provider about increased irritability or grimacing during certain activities or at certain times of the day can be an important clue to pain's role in the person's behavior. To overcome the difficulty of the person living with dementia communicating their pain, it has been recommended that observational scales that help gauge the level of person's pain be used. One such example, the PAINAD scale asks providers to observe and rate person's outward behaviors across six domains that may correlate with the presence of pain: Breathing, negative vocalizations, facial expression, body language, and consolability (https://www.healthcare.uiowa.edu/igec/tools/pain/PAINAD.pdf). While any observational pain scale may rely to some extent on the skill of the observer and so necessarily require some training on the part of the examiner, this approach nonetheless remains a valid attempt to overcome the communication difficulties that many persons living with dementia experience as the condition advances (Rosenberg & Lyketsos, 2011). Research by Husebo and colleagues (2011) that measured and treated pain in a large sample of nursing home residents with late stage dementia, showed that significant results in reducing pain and agitation were found with a relatively simple intervention and protocol that has been long approved by the American Geriatrics Society (1998). Developing an effective approach to the management of pain among persons living with dementia does not need to be complicated or to rely on the use of powerful pain control medications such as opioids; pain can potentially be controlled with milder medications that do not come with significant side effects at usual doses. Similarly, there is evidence that the use of acetaminophen, the main ingredient in a common over-the-counter pain medicine, can decrease agitation among persons living with dementia (Corbett et al., 2012).

Other common causes of behavioral disturbances among persons living with dementia can include exposure to frightening stimuli, sleep disruption, and the development of delirium. Frightening or misunderstood stimuli can lead to behavioral disturbances that occur with bathing

or with cleaning after toileting. Others, whether brought on by persons that remind the older adult of an unpleasant former acquaintance or that cause confusion, can take more detective work to identify. In either event, identifying the cause and thus the meaning of the concerning behavior can be the first step in developing a plan to manage it (Rasin & Barrick, 2004).

Sleep disruptions are common and can be exacerbated by disruptions in person's normal internal 24-hr clock, the circadian rhythm (Deschenes & McCurry, 2009; Dauvilliers, 2007). Cross-sectional studies have suggested that approximately 25%–35% of persons with Alzheimer's disease have problems sleeping, and most likely due to the progressive deterioration and loss of neurons in the suprachiasmatic nucleus (Dauvilliers, 2007). Unfortunately, medications commonly used to treat negative behavioral symptoms of dementia and to slow disease progressions, often result in negative side effects that affect sleep and wakefulness (Dauvilliers, 2007; Wu & Swaab, 2007). Setting a consistent schedule, promoting a regular nighttime routine, finding a comfortable sleeping space without excess noise, temperature, or light can all be initial steps that families and nonphysician care providers take to address this issue (Deschenes & McCurry, 2009; Wu & Swaab, 2007). Finally, delirium is a condition in which persons, particularly those with dementia or other conditions which make their brains more vulnerable, typically display new and fluctuating symptoms of inattention and either disorganized thinking or altered levels of consciousness. If this condition is suspected, it is recommended that a family member or nonphysician care provider bring the condition to the medical provider's attention, as further medical testing and observation may be warranted.

Nonpharmacologic Interventions

Behavioral and psychological symptoms of dementia (BPSD) may become necessary. BPSD is a term used to describe a heterogeneous range of psychological reactions, psychiatric symptoms, and behaviors occurring in people with dementia of any etiology (Finkel & Burns, 2000). Managing BPSD is critical because the incidence of these have been shown to result in premature institutionalization, increased financial cost, increased caregiver burden, poor quality of life for the person with dementia and their family caregiver as well as increased nursing stress (de Vugt et al., 2005; Draper et al., 2011; Herrmann et al., 2006; International Psychogeriatrics Association, 2000). The majority of persons living with dementia (75%–98%) develop some behavioral or psychiatric symptoms at some point in their illness (Ballard & Waite, 2006; Fung et al., 2012; Sink, Covinsky, Newcomer, & Yaffe, 2004; Teri et al., 2000).

When providing care for a person living with dementia, nonpharmacological interventions are preferred and should be tried first. Research on the effectiveness of nonpharmacological interventions has increased over the past few years and the interventions discussed below have shown positive impact on both the person living with dementia and the family caregiver. Indeed, a recent systematic review of systematic reviews in this area, found that while methodologies and sample sizes vary, music therapy and behavioral management techniques proved most beneficial overall (Abraha et al., 2017). In addition, Gitlin, Kales, & Lyketsos (2012) stress that nonpharmacologic interventions need to be included as first-line treatment for behavioral disturbances, or in conjunction with pharmacologic treatments if necessary.

Activity and recreation have been shown to be beneficial to the person living with dementia. Encouraging participation in daily chores and maintaining hobbies and shared past activities have been shown to improve mood, reduce agitation, and improve quality of life for persons living with dementia. Twenty to sixty minutes of activity daily with skill level and interest well matched to that of the person living with dementia have been shown to have the most benefit (de Oliveira et al., 2015; Kolanowski, Litaker, & Buettner, 2005).

Educating family caregivers has been shown to be as effective at reducing agitation as medications (de Oliveira et al., 2015; Teri et al., 2000). Among the important things for family caregivers to learn is that a person living with dementia does not behave in these ways intentionally. Rather, the behaviors are manifestations of a brain disorder, and caregivers should not take personally anything the person living with dementia says or does (Guerriero Austrom, Lu, & Hendrie, 2013). Knowing this can help avoid conflicts, anger, and subsequent feelings of guilt. Persons living with dementia cannot be held responsible for their behaviors, but all behavior has a purpose. It is up to the family caregiver to look for that underlying purpose. For example, a person living with dementia may be agitated and wander around the house because he has forgotten where the bathroom is and he needs to use it. Or a person with dementia may constantly disrobe because she is too hot. The family caregiver should not blame the person living with dementia for these behaviors but should remain calm, try to figure out what is causing the behavior, and redirect the person living with dementia while protecting his or her dignity (Guerriero Austrom et al., 2013; Whitlatch, Judge, Zarit, & Femia, 2006). Nonphysician care providers can help to remind family caregivers that the person with dementia is no longer acting with volition. Several psychosocial educational programs have been shown to be effective in increasing caregiver knowledge and understanding of person's with dementia's behaviors and challenges (Burns et al., 2003; Falcão, Bras, Garcia, Santo, & Nunez, 2015; Gitlin et al., 2012) leading to improved outcomes for both caregivers and patients. Care providers are encouraged to direct family caregivers to available resources (http://www.alz.org/care; https://www.nia.nih.gov/alzheimers; https://cicoa.org/services/careaware; http://www.actonalz.org/dementia-friendly-toolkit).

A person living with dementia will need care for many years. Successful caregiving is based on understanding the caregiver's emotional response to the disease, to the person living with dementia, and to the behaviors, which all change over time. Families must endure an ongoing grief process as they strive to cope with the demands of caregiving while watching the psychological death of their loved one and the death of that individual's personality—that quality or assemblage of qualities that makes a person who he or she is. Many caregiving families fail to realize that grief is an appropriate response when caring for a person with dementia (Austrom & Lu, 2009; Ott, Sanders, & Kelber, 2007; Schulz et al., 2012). Nonphysician care providers play an important role in supporting families as they grieve.

Exercise programs also have been shown to be beneficial in reducing agitation. In one study, persons with dementia who participated in a 3-week group exercise program for 30 min per day (15 min of aerobic exercise and 15 min of resistance training) showed reduced agitation (Aman & Thomas, 2009; de Oliveira et al., 2015).

Pharmacologic Interventions

Despite best intentions, pharmacologic management of the behavioral and psychological symptoms of dementia (BPSD) may become necessary. BPSD is a term used to describe a heterogeneous range of psychological reactions, psychiatric symptoms, and behaviors occurring in people with dementia of any etiology (Finkel & Burns, 2000). Managing BPSD is critical because the incidence of these have been shown to result in premature institutionalization, increased financial cost, increased caregiver burden, poor quality of life for the person with dementia and their family caregiver as well as increased nursing stress (de Vugt et al., 2005; Draper et al., 2011; Herrmann et al., 2006; International Psychogeriatrics Association, 2000). As many as 90% of persons living with dementia develop some behavioral or psychiatric symptoms at some point in their illness (Ballard & Waite, 2006; Fung et al., 2012).

It is important for nonphysician care providers to understand the basics of medications used to treat symptoms in person living with dementia. There is a role for the use of medications in the management of the progression of persons' dementia as well the management of their comorbid illnesses. Any time that a medication is going to be used in an older adult, a careful assessment of the risks and benefits of the medication's use is warranted with due consideration given to the goals of the person's care and the stage of their dementia. Dementia-specific medications, such as acetylcholinesterase inhibitors and NMDA agonists, have received approval from the U.S. Food and Drug Administration (FDA) to treat cognitive symptoms associated with Alzheimer's disease. These medications are prescribed with an aim of decreasing the rate of cognitive decline associated with the disease. No medications are currently approved for the treatment of the behavioral and psychological symptoms associated with Alzheimer's disease. Indeed, any medications prescribed by a physician for treatment of these symptoms are "off label," an approach in which a provider administers a medication for a reason other than the one for which the medicine was approved for use by the FDA.

Common medications that are used "off label" to treat the behavioral and psychological symptoms of dementia include antidepressant medicines, which are thought to target mood disturbances and agitation, benzodiazepines to target anxiety, and antipsychotic medications for the treatment of hallucinations, agitation, and aggressive behavior. It should be noted that there has been particular concern raised by the use of antipsychotic medications among persons with dementia given research that is shown an increased risk of stroke and death associated with their use (Douglas and Smeeth, 2008; Gill et al., 2007; Schneeweiss, Setoguchi, Brookhart, Dormuth, & Wang, 2007). As a result, the FDA has issued a "black box warning" that warns providers about the increased risks that accompany use of these medicines. Careful evaluation, discussion with caregivers, and monitoring of persons with dementia would be warranted if use of antipsychotic medications were to be initiated. As with any medication started for an older adult, it is recommended that the need for continued use of these medications is reviewed periodically, that attempts be made to decrease their dose, and their use be discontinued when possible. As always, nonpharmacologic approaches to the management of dementia symptoms are preferred and it should be considered that the concurrent use of nonpharmacologic approaches may decrease or eliminate the need for use of prescribed medications to address concerning behaviors. It is important for nonphysician care providers to understand the basics of medications used to treat symptoms in person living with dementia.

Crisis Planning and Management

Compared to older adults without dementia, persons with dementia visit the emergency department (ED) more frequently, are hospitalized more often, return to the ED within 30 days of an initial ED visit at higher rates, and are at higher risk of death in the six months after an ED visit than persons without dementia (LaMantia, Stump, Messina, Miller, & Callahan, 2016). These data underscore the vulnerable state of persons living with dementia who develop an acute illness. Preparing for a crisis before it occurs can be an important step that caregivers and community care providers take to ensure that persons living with dementia receive optimal care.

One of the most important steps that family caregivers can and should take to ensure that they are able to represent the person living with dementia is to participate in advance care planning discussions early in the state of the illness, while substantive conversations about wishes can

still be had. While many states recognize the right of family members to make medical decisions for loved ones when they can longer speak for themselves and have established clear hierarchies of precedence for delegating decision making powers among relatives, not every state does so. As a result, it can be useful to establish a durable health care power of attorney designation early on in the course of the person's illness. Forms to complete these designations are often available through state and local governments, local hospitals, and elder care attorneys. Forms frequently need to be notarized and may need to be filed with a local authority, depending on the jurisdiction, so it is recommended to verify the appropriate procedures for setting this in place with an entity familiar with local laws and regulation. For individuals who learn that they are to be or seek to become someone's health care power of attorney, it is important that they speak with the person living with dementia about their health care values and wishes so that the person's values and decisions can be represented if/when that time comes. While these conversations may be difficult to initiate, they are critical to have and many guidelines and materials are available on-line to help advise people on how to approach these (http://www.alz.org/care/alzheimers-dementia-legal-documents.asp; http://www.nia.nih.gov/alzheimers/legal-and-financial-issues-people-alzheimers-disease- resource-list). Nonphysician care providers can be a support to families as they navigate the process.

End-of-life Care

From these conversations, it may become clear that the person living with dementia may wish to place limitations on the type of care that they receive if they were to become ill. In some areas, it may be possible to discuss end-of life care decisions with the physician or other medical care provider whether or not the person with dementia and their health care representative wish to put in place a do not resuscitate order often called a DNR, that would direct emergency services personnel not to start resuscitation in the event that the person living with dementia were to experience cardiac arrest or needs assistance in breathing. Importantly, these orders still allow Medical care providers to offer treatments that would keep the person living with dementia comfortable, but without interrupting the natural course of events. If a person were to have more specific ideas about the type of care they would like to receive, in many states they may elect to complete Physician Orders for Life-Sustaining Treatment (POLST) with their provider (Hickman, Nelson, Smith-Howell, & Hammes, 2014). These forms, when completed, help delineate what types of care persons with serious illnesses seek to receive and forego towards the end of their lives.

Beyond these considerations, caregivers may wish to keep critical materials, including lists of medications, active medical conditions, names of treating providers, together in a folder that is easily accessible and can be brought to the emergency department or hospital if the person with dementia needs emergency care. Given that persons with dementia may have a hard time navigating an emergency department or staying in a hospital room on their own, it may be necessary for their caregivers to stay by their bedside to serve as their advocate, provide comfort to them, and explain to them what is happening. Such tasks can be exhausting and many caregivers find it helpful to establish a network of friends and family who potentially can rotate serving in these roles if extended medical care is needed. Negotiating networks of people who would be willing to step in if the need were to arise ahead of time can be useful to maximize the likelihood that these tasks do not fall back on one person, who may become easily overwhelmed. Again, nonphysician care providers can be a huge support to families as they plan for end of life care and decisions.

Summary and Conclusions

On-going medical management for persons living with dementia is complex and can last for many years. Helping persons living with dementia and their family caregivers negotiate the medical maze over the course of the disease can reduce stress, improve care and the quality of life for both persons with dementia and their caregivers.

Recommendations for ongoing medical management to maximize health and well-being for persons living with dementia

Nonphysician care providers who work with persons living with dementia and their families in community or residential care settings should:

1. Take a holistic, person-centered approach to care and embrace a positive approach to the support for persons living with dementia and their caregivers that acknowledges the importance of individuals' ongoing medical care to their well-being and quality of life. Nonphysician care providers must adopt a holistic approach to providing care and ongoing support to the person living with dementia and their family caregivers. They should work to reduce existing barriers to coordination of medical and nonmedical care and support. Adopting a positive approach towards care can reduce real or perceived messages of hopelessness and helplessness and replace these with positive messages and an approach that encourages persons living with dementia and their caregivers to seek support and care over the course of the disease.
2. Seek to understand the role of medical providers in the care of persons living with dementia and the contributions that they make to care. Nonmedical care providers and family caregivers should work with medical providers towards developing a shared vision of care to support the person living with dementia.
3. Know about common comorbidities of aging and dementia and encourage persons living with dementia and their families to talk with the person's physician about how to manage comorbidities at home or in residential care

settings. Common comorbidities can negatively impact a person living with dementia, and conversely, a diagnosis of dementia can make the treatment and management of comorbid conditions quite challenging. Nonmedical care providers should encourage persons living with dementia and their families to report acute changes in health and function to the person's physician, and to let the physician know about difficulties they encounter in managing acute and chronic comorbidities at home or in a residential care facility.

4. Encourage persons living with dementia and their families to use nonpharmacologic interventions for common behavioral and psychological symptoms of dementia first. Increasing evidence suggests nonpharmacological interventions are effective at managing behavioral and psychological symptoms of dementia. Community care providers should encourage persons with dementia and their families to try these interventions first before considering pharmacological treatments.
5. Understand and support the use of pharmacological interventions when they are necessary for the person's safety, well-being, and quality of life. Although nonpharmacological interventions are preferred, there are times when pharmacological treatment is warranted for behavioral and psychological symptoms. It is important for community care providers to understand that pharmacological treatment can have value for the person living with dementia in certain situations and to help them and their family caregiver to accept such treatment. Community care providers should also understand the general principles for starting and more importantly, ending pharmacological treatments and encourage the person living with dementia and family caregivers to ask their medical providers for regular medication reviews and to consider the discontinuation of medications when appropriate.
6. Work with the person living with dementia, the family, and the person's physician to create and implement a person-centered plan for possible medical and social crises. It is helpful for persons living with dementia and their caregivers to have a plan in place should a medical or social crisis occur, such as an illness, hospitalization or the death of a caregiver. Having a plan in place will help the person's physician and community care providers provide care and support that reflects the preferences of the person living with dementia and reduce stress for family members and care providers who have to make decisions for the person during a crisis.
7. Encourage persons living with dementia and their families to start end-of-life care discussions early. Persons living with dementia and their caregivers should understand options available for care during the later stages of Alzheimer's disease. Having discussions early with the person's physician and other care providers and communicating the preferences of the person and family across care settings can make the transitions during the progression of dementia more manageable.

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Conflict of Interest

None reported.

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Review Article

Meeting the Informational, Educational, and Psychosocial Support Needs of Persons Living With Dementia and Their Family Caregivers

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Abstract

Background and Objectives: Meeting the unique and changing needs of individuals living with Alzheimer's disease and their family caregivers can be very challenging given the dynamic and often unpredictable nature of the disease. Effective programs are available to help families manage the challenges they will face.

Research Design and Methods: This article first describes the educational, information, and support needs of individuals living dementia and their family caregivers across all stages of Alzheimer's. Next, we describe the variety of services and program models targeted to the needs of individuals living with Alzheimer's disease or other types of dementia and their families.

Results: These programs can help ensure that person- and family-centered care is maintained from time of first symptoms through end-of-life.

Discussion and Implications: We end with our recommendations for maintaining person- and family-centered care through the provision of targeted information, education, and support to individuals and their families.

Keywords: Alzheimer's disease, Person-centered care, Psychosocial, Social support

The prevalence of dementia has increased dramatically over the past decades. Likewise, there is a growing need for quality education and support programs to help individuals living with dementia, family caregivers, and professionals (Black et al., 2013; Peeters, Van Beek, Meerveld, Spreeuwenberg, & Francke, 2010). Families are often unprepared to confront the complex emotions and challenges that often accompany a dementia diagnosis. Individuals living with dementia and their care partners also face obstacles to effective communication and when trying to manage the changing levels of care and decision making that are required over time. As individuals living with dementia are diagnosed earlier and more accurately, we can expect more families to enter the social service system earlier in the disease process. In preparation, it is imperative that adequate person- and family-centered systems, programs, and resources are in place to address the unique needs of individuals living with dementia and the family members who care for them.

Whether an individual is in the midst of a diagnostic process, or has received a diagnosis, the terms dementia and memory loss are often presented in a manner synonymous with inevitable deficit and decline and thus, can be stigmatizing (Harman & Clare, 2006). Due to a lack of understanding of the diagnosis and poor access to quality information, education, and support, individuals living with dementia often begin their adjustment to their diagnosis by being told that they cannot or should not do certain things, such as driving or continuing to work. Family caregivers,

with their limited understanding of the disease, have difficulty making sense of the changes the individual living with dementia is experiencing (Robinson, Clare, & Evans, 2005).

An estimated 25% of individuals with dementia are living alone with no one to care for them (Alzheimer's Association, 2016). For others, family caregivers are often involved with their care from the onset of symptoms, through diagnosis, relocation to skilled care, and end-of-life. Caregivers can be spouses, partners, adult children, parents, other relatives (siblings, aunts, nieces/nephews, in-laws, and grandchildren), friends, or neighbors. According to the Alzheimer's Association (2016), in 2015, over 15 million family caregivers provided over 18.1 billion dollars of unpaid care. Negative health effects for caregivers are widely documented in the literature and include higher levels of depression, compromised physical health, and decreased quality of life (Etters, Goodall, & Harrison, 2008; Perkins et al., 2012; Pinquart & Sörensen, 2007).

When an individual living with dementia can no longer make decisions for him/herself, it is not uncommon for the caregiver to begin to make decisions on their behalf. In turn, for the individual living with dementia, the window of opportunity to be an active participant in their own care begins to close (Menne & Whitlatch, 2007; Whitlatch & Feinberg, 2003). Ultimately, the core of the individual's identity can be lost (Maslow, 2013). As the symptoms of dementia other chronic conditions progress, care partners often begin to provide help with instrumental activities of daily living (IADLs) such as shopping, making appointments, and providing transportation. Eventually, caregiving demands increase and ultimately care partners are providing assistance with personal activities of daily living (PADLs, e.g., bathing, dressing, and toileting), oftentimes with no backup plan in place if the caregiver becomes ill or can no longer provide care (Pearce, Forsyth, Boyd, & Jackson, 2012).

Many qualitative studies report a clear need for greater support after receiving a dementia diagnosis for both the individual living with dementia and their family caregiver (Bunn et al., 2012). In addition to not knowing what types of supports exist, families face many challenges to receiving this desperately needed education and support. Many in need of help experience difficulty in knowing which sources of information are accurate and of good quality; many also suffer a lack of knowledge of and guidance on how to access them (National Academies of Sciences, Engineering, and Medicine, 2016).

The purpose of this paper is to describe the broad categories of educational, information, and support needs of individuals living dementia and their family caregivers across the three stages of Alzheimer's (i.e., early, middle, and late stages). Further, we will provide a description of specific services and program models that have been developed and tested (i.e., evidence-based), thus ensuring individuals living with Alzheimer's disease or other types of dementia and their families have the most effective person- and family- centered support available to them. Lastly, we will present updated practice recommendations that summarize the most current knowledge and person- and family- centered strategies in education, information, and support programs and services for individuals living with dementia and their family caregivers.

Developing Evidence-based Person-Centered Programs

Research findings increasingly document that education, information, and psychosocial programs and support can contribute to the quality of life of both care partners, improve mental health outcomes for caregivers, and delay relocation to long-term care settings for individuals with dementia (see review by Smits et al., 2007). Evaluations of these programs vary greatly; some have an established evidence base documenting their effectiveness while others have very little research supporting their design, evaluation, and efficacy (see also Wiener et al., 2016 for additional information on Models of Dementia Care). Throughout this paper we provide descriptions of programs that take a person- or family-centered perspective and have a documented evidence base confirming their effectiveness. For our purposes, here we follow the definition of an established evidence-base practice model developed as part of the Hartford Foundation funded project "Decision Support Tool for Dementia Caregiving Programs." The work group for this project has compiled a list of the latest nonpharmacological, evidence-based programs for persons with dementia and their caregivers (Maslow, 2016). The original criteria for designation as an evidence-based practice model includes the following (adapted from Maslow, 2016):

(a) use in an evaluation of a community-based population;
(b) the intervention is nonpharmacological;
(c) the intervention has positive outcomes in at least one U.S.-based randomized control trial (RCT);
(d) positive outcomes for the person with dementia, the family caregiver(s) or both;
(e) outcomes are reported for the person with dementia and the family caregiver(s);
(f) has been or is being replicated/translated at least once in the United States.

Programs that meet these six criteria are designated as evidence-based practice models. As well, we note the translation status of each program per Maslow (2016).

Education and Information

Education and information about dementia can include a variety of topic areas such as information about disease progression, pharmacological options, risk factors (genetic and environmental), stress management for both care partners, managing behavioral and psychological symptoms of dementia (BPSDs), and available and appropriate services. Access to the various types of information, education, and appropriate services across the different stage

of Alzheimer's can vary, with evidence suggesting that caregivers find it most difficult to access information in the early stages (Lilly, Robinson, Holtzman, & Bottorff, 2012; for information about the stages of Alzheimer's visit http://www.alz.org/alzheimers_disease_stages_of_alzheimers.asp). To be most useful, information for both the individual living with dementia and caregiver must target their current needs and situation rather than take a "one size fits all" approach (Etters et al., 2008; Lauriks et al., 2007; Van Mierlo, Meiland, Van der Roest, & Dröes, 2012). Information presented "off time", that is, when the individual living with dementia or care partner is not ready to hear it, could cause unnecessary stress for either person (Orsulic-Jeras, Whitlatch, Szabo, Shelton, & Johnson, 2016).

However, appropriate and accurate education and information about the disease is "[u]ndisputably effective" (p968; Sörensen, Duberstein, Gill, & Pinquart, 2006) and has significant positive effects on burden, depression, and subjective well-being. Selwood, Johnston, Katona, Lyketsos, & Livingston (2007) note that education alone is not enough to improve outcomes, unless presented in conjunction with other strategies targeted to the unique needs of the individual living with Alzheimer's, the caregiver, and broader family. These authors note in their review that mental health improved for care partners who learned behavioral management techniques individually (as opposed to in group settings), and learned coping strategies (individually or group-based delivery format).

Other types of information that are useful for individuals living with dementia and care partners address the future care needs of the individual, and decision making around how these needs will be met as the disease progresses. Understanding future care needs is another type of information critical for families who have accepted the disease and understand its progression. They are ready to plan for the future and willing to discuss decisions together. Practitioners can support these families by providing a safe, open, and nonjudgmental environment that facilitates discussion about what the individual living with dementia values for their care (e.g., not being a burden, being safe) and who they want to help them once they need assistance (Orsulic-Jeras et al., 2016). Care partners who understand their relative's care values can make more informed decisions about care as the disease progresses. These decisions are critical to ensuring person- and family-centered care throughout the course of dementia because they reflect the individual's and caregiver's values and preferences for care (Whitlatch & Feinberg, 2003). Planning for incapacity is very important to individuals living with dementia and their family caregivers as they face legal and financial decisions about many aspects of their lives. Targeted legal and financial information is also very important to individuals living with dementia and their care partners as they try to manage their resources in order to ensure that their housing, support, health, social, and financial needs are met. In addition, it is critical for practitioners to provide guidance about how to recognize and avoid financial scams and other exploitive efforts that target vulnerable older populations.

Support Options

In addition to meeting the education and information needs of families, professionals have numerous options for providing or referring families to appropriate supportive services and programs across the disease trajectory.

Support Groups

Support groups have been found to be helpful to families in decreasing isolation and increasing social support (Chien et al., 2011; Logsdon, McCurry, & Teri, 2007). Support groups encourage care partners and individuals living with dementia to share personal experiences and learn from others, while fostering engagement and socialization. Groups can be led either by a professional or peer, can target the individual living with dementia and/or the family caregiver, and bring together similar kin groups of attendees (e.g., spouses, adult children, men, women, etc.). Web-based, online, and phone groups rather than in-person support groups are also available in some communities (Berwig et al., 2017; Topo, 2009). Research on the effectiveness of support groups is mixed (i.e., no strong evidence base) with some studies showing great gains by participants and other studies showing less promise (Pinquart & Sörenson, 2006).

Counseling

Families report positive outcomes from their experiences meeting individually with counselors, social workers and other clinicians who provide individual, dyadic, and family counseling and/or psychotherapy (Vernooij-Dassen, Joling, van Hout, & Mittelman, 2010). Examples of this type of support include cognitive behavioral therapy, psychodynamic therapy, and other techniques designed mainly to help deal with BPSDs in the middle to late stages (see section below). Individual and family counseling protocols are often one element of a multicomponent intervention (see Multi-Component section below).

Respite

Respite is a service primarily designed to provide a break or time away from caregiving as a strategy for ensuring that care partners gets relief from their care responsibilities. Respite can be provided by a professional, friend, or family member who provides companionship and/or supervision for the individual or takes him/her out of the home. Ideally, respite provides the care partner the opportunity to run errands, exercise, visit with friends or family, or engage in other pleasant or enriching activities that promote caregiver self-care and improve well-being. Likewise, home health workers or aides provide respite when they care for the individual because they provide supervision

during their visit. Adult day programs provide a safe and enriched environment for individuals living with dementia while simultaneously providing respite for the care partner who may use the time to go to work. In addition, caregivers who take advantage of adult day programs show improved outcomes such as increased levels of the beneficial stress hormone DHEA-S (Zarit et al., 2014). Again, the evidence base documenting respite's effectiveness is mixed with few studies using a RCT.

Care Coordination Programs

Care coordination programs (also referred to as Case Management, Care Consultation, Managed Care, Collaborative Care, and Care Counseling) provide information, coaching, and emotional support to family caregivers and, in some cases, the individual living with dementia. These programs can be conducted online, by phone, or in-person, and are designed to provide education and information about the disease, referral to appropriate programs, recommended strategies for coping with stress, advice about self-care, and care planning. Care coordination can provide regular assessment of the individual's and caregiver's strengths and changing needs, and offer strategies for coping with new stressors. This model of support, assessment, and reassessment is in-line with recommendations put forth by Fazio et al. and Molony et al. (this issue) which focus on the importance of adjusting practices based on the individual's and caregiver's changing needs and preferences.

Multicomponent Interventions

Multicomponent interventions include more than one treatment modality such as information and education, individual and family counseling, support groups, and self-help training. In their review of multicomponent programs, Brodaty and Arasaratnam (2012) discuss that multicomponent programs that included a combination of skills training, education of the caregivers, activity planning, environmental redesign, caregiver support, caregiver self-care, or exercise for the caregiver can significantly reduce BPSDs.

Alternative Therapies

Also available to individuals with dementia and their family care partners are alternative therapies such as yoga, meditation, life review, physical exercise, aromatherapy, bright light, music, and art. A number of research studies show promising findings for the use of alternative therapies (Douglas, James, & Ballard, 2004) including improved caregiver depression, anxiety, and perceived self-efficacy (Waelde, Thompson, & Gallagher-Thompson, 2004). Music interventions are available to families across the three stages of Alzheimer's with promising findings reported for decreased anxiety and reduced agitated behaviors for the individual (Lin et al., 2011; Sherratt, Thornton, & Hatton, 2004; Sung, Lee, Li, & Watson, 2012). While both the individual with dementia and his/her care partner are often encouraged to participate, research suggests that outcomes are stronger when the caregiver plays a more active role in the program through role playing and other interactive exercises (Pinquart & Sörensen, 2006).

Education, Information, and Support Interventions Across All Stages of Alzheimer's Disease

Early Stage of Alzheimer's Disease

A diagnosis of Alzheimer's or other dementia brings about many significant and unexpected life changes. One significant change is the transition from a familial relationship between two caring individuals (such as spouse or adult child) to that of a ***care dyad***. Thoughts about what lies ahead can become overwhelming for the person who is transitioning into the role of care partner. Care partners often experience stress during this postdiagnosis period due to a lack of information and knowledge about the diagnosis, and limited access to formal resources and support (Ducharme et al., 2011; Robinson et al., 2005).

The initial or early-stage postdiagnosis is often characterized by few visible symptoms of the disease. The individual living with Alzheimer's is still quite independent and does not require much if any assistance. However, challenges with daily tasks combined with the fear of future impaired functioning can threaten the individual's self-identity, future independence, and perceived views and expectations of normal aging (Clare, 2003; Harman & Clare, 2006; Steeman, Tournoy, Grypdonck, Godderis, & De Casterlé, 2013).

Early-Stage Education and Information

The need for information and education about the disease, symptoms, treatment, and prognosis are high during this stage (Peeters et al., 2010; Van Mierlo et al., 2012). Programs and resources are needed to help newly diagnosed and early-stage individuals living with Alzheimer's and their families cope with the impact of the disease. However, individuals and care partners may have different information needs as they begin to accept the diagnosis and seek out information about symptoms, progression, and treatment options. In addition, readiness to receive information and support may vary within a family and, in turn, may impact the willingness and/or ability of family members to accept help (Orsulic-Jeras et al., 2016).

Information about services is often less emphasized during this early stage because the individual's level of need for personal assistance is minimal. However, research shows that when asked to look back to the early stages of their relative's dementia, later stage caregivers believe they would have benefited from receiving relevant information earlier on (Boots, Wolfs, Verhey, Kempen, & de Vugt, 2015). In addition, retrospectively, some care partners felt that being introduced earlier to information that was hopeful or

empowering would have helped them be more open to asking for help. This early-stage paradox creates a challenge in trying to support early-stage families who often struggle to accept changes due to fear of stigma.

Online Resources

One of the largest unmet needs reported by care partners of individuals living with early-stage dementia is the lack of high quality and available information, education and support services that are tailored to meet the unique needs of families, rather than take a "one size fits all" approach (Gaugler & Kane, 2015; Rudzicz & Polgar, 2016). One strategy for addressing the unique needs of families is to provide an assessment that ensures that a comprehensive picture of the individual's and care partner's needs, preferences, and strengths is obtained. See Molony et al. (this issue) for more information about assessment and care planning.

Care to Plan Tool. The Care to Plan Tool is one example of a needs assessment that generates a tailored support recommendation (Gaugler, Reese, & Tanler, 2016). Although the Care to Plan tool shows positive feasibility and acceptability for care partners, it remains unclear how the use of the tool affects *outcomes* for individuals living with dementia and care partners. However, although there is no established evidence base for Care to Plan, preliminary findings show promise in linking tailored support that could potentially improve the care planning process for both care partners. Care to Plan has not undergone any translational studies to date.

Early-Stage Support Options

The early stage of Alzheimer's provides a unique opportunity for the individual and caregiver to learn more about available resources that can help them in the future. Supportive services that provide transportation, delivery of groceries and meals, and access to technology (e.g., mobile phone, internet, on-line shopping) can be helpful in preserving the autonomy of the individual living with dementia.

Support Groups

A growing body of research has documented the effectiveness of early-stage support groups (Logsdon et al., 2010). There are existing support groups developed for early-stage families in many, but certainly not all, communities. Challenges exist with service delivery of these programs, mainly around engaging families in rural and minority communities as well as involving both care partners. Organizations such as the Alzheimer's Association have been successful in establishing both staff and volunteer-led support groups that serve individuals living with dementia *and* their care partners. Although few early-stage support groups have undergone rigorous evaluation, a handful of studies have been conducted. These studies have found a decrease in isolation, increase in social support, and ability to accept the diagnosis, cope with symptoms, improve quality of life, and enhance family communication (Logsdon et al., 2007; Logsdon et al., 2010; Snyder, Jenkins, & Joosten, 2007). Memory Club, one example of an early-stage dyadic group intervention, has showed promise in supporting both care partners (Gaugler et al., 2011; Zarit, Femia, Watson, Rice-Oeschger, & Kakos, 2004). With time set aside to work together as well as separately, Memory Club participants are given the opportunity to have discussions about their care situations as well as plan for the future. The group format encourages Memory Club participants to create and maintain a community of supportive peers which is critical to the well-being of both the individual living with dementia and care partner. Although many early-stage groups are available in the community and some have reported positive outcomes, few translational studies exist that support their effectiveness in community settings.

Technology-Based Supports

Internet-based interventions offer support for families in an efficient and cost-effective way (Boots, Vugt, Knippenberg, Kempen, & Verhey, 2014; Lauriks et al., 2007). Online support interventions include health coaching, counseling, stress management, and specific caregiver support. In addition, telecare and telehealth interventions are used to facilitate the delivery of health information and care options from a distance using a variety of technologies (Lorenz, Freddolino, Comas-Herrera, Knapp, & Damant, 2017). These types of interventions can assist with care management when there are multiple family members who are providing care from a distance.

Telehealth interventions have also been found to improve coping skills for care partners of individuals living with Alzheimer's (Chi & Demiris, 2015). In addition, telehealth interventions can be effective in reaching isolated populations, specifically rural individuals living with Alzheimer's and their care partners (Clancy Dollinger & Chwalisz, 2011). Despite these promising findings, many telehealth programs (home telehealth in particular) face barriers to sustainability due to a variety of programmatic challenges (e.g., lack of person- or family-centered outcomes, evidence of cost effectiveness; see Radhakrishnan, Xie, & Jacelon, 2016). Funding of technology-based programs through client payment and/or government subsidies is also challenging although family caregivers report being willing to pay privately for services that support family members with dementia (Schulz et al., 2016).

Overall, telehealth, online, and other technology-based programs have the potential to broaden the reach of support for families facing the challenges of Alzheimer's who might otherwise not have access to useful and timely resources. Note: Many interventions mentioned in this paper have technology-based and/or telehealth components that are not described here but will be identified in other sections. Although a handful of telehealth interventions have shown

promising results, none to our knowledge have conducted translational studies to date.

Care Planning for the Future

Families in the early stage can benefit from discussions about future care and values for care as they plan for the time when the individual living with dementia is no longer able to voice his or her preferences (Orsulic-Jeras et al., 2016). Thus, knowing the individual living with dementia is crucial to person- and family-centered care in the early stage if his/her voice is to be heard and honored through the later stages.

SHARE Program. Other than a few of the early-stage dyadic support groups, few interventions exist which are designed to elicit discussions that clarify *both* care partners' values and preferences for care and develop a future plan of care based on these preferences. One exception is the SHARE Program (Support, Health, Activities, Resource, and Education; formerly referred to as Early Diagnosis Dyadic Intervention; Whitlatch, Judge, Zarit, & Femia, 2006). SHARE takes advantage of the unique opportunity in early-stage Alzheimer's when the individual with dementia can assume an active role in discussing care values and preferences for the future. The core of this intervention centers on the individual's care values and preferences, and the care partner's perceptions of those care values and preferences Whitlatch, Heid, Femia, Orsulic-Jeras, Szabo, & Zarit (in press). After the individual's care values and preferences are understood, the SHARE protocol works with the individual living with dementia and caregiver to develop a plan of care for the future (Orsulic-Jeras et al., 2016). SHARE's proactive approach focuses on empowerment and self-efficacy for both care partners with a strong emphasis on giving the individual living with Alzheimer's a voice in planning their own care. Allowing care partners the opportunity to hear, acknowledge, and validate the individual's preferences gives them a starting point from which to frame discussions on decision making and future care planning. This strategy helps to build a network of support and identify opportunities for meaningful engagement.

SHARE has been translated multiple sites across the United States and also in the Netherlands. Adaptations of the SHARE intervention include persons with chronic conditions, heart failure, and SHARE in a group setting.

Driving Safety for Individuals Living with Alzheimer's Disease

One of the greatest threats to the autonomy and personhood of an individual living with Alzheimer's is losing the ability to drive (Snyder, 2005). Individuals living with Alzheimer's often rely on the support of family and/or friends to assist in making decisions about driving safety (Carter et al., 2015). In turn, families seek help from professionals, but often find that professionals are also unprepared to give driving advice (Adler, 2010; Stern et al., 2008). Physicians report feeling that they are unprepared to offer families legal advice on driving cessation, even though they are often the first professional contact families reach out to for driving advice (Perkinson et al., 2005). To address this significant deficiency in the early-stage service system, several organizations have developed literature to provide education to families regarding driving safety and when it is time to "put away the keys." The Alzheimer's Association Dementia and Driving Resource Center is an online tool that provides information and suggestions about how to discuss driving safety with care partners and persons living with dementia (http://www.alz.org/care/alzheimers-dementia-and-driving.asp).

Despite the availability of printed educational material for families about driving, research suggests that simply providing reading material may not be adequate for informing families about how and when to limit and ultimately stop the individual from driving (Stern et al., 2008). As a result, several psychoeducational driving groups have been developed by researchers in order to provide more support to families (Meuser, Carr, Berg-Weger, Niewoehner, & Morris, 2006; Stern et al., 2008; Zarit et al., 2004). Windsor and Anstey (2006) discuss various interventions developed to provide support to families after driving cessation. In addition, families could benefit from information about senior transportation options in their communities as an alternative to the person living with dementia continuing to drive and risk hurting him/herself or others. Understanding and accepting the individual's changing reality and identity can be challenging to the individual, care partner, and family and friends, but it is essential to providing person- and family-centered care that reflects the individual's preferences and values for care.

Middle Stage of Alzheimer's: Increased Need for Care and Support

During the middle stage of Alzheimer's, individuals living with dementia begin to require more assistance with IADLs such as shopping, housekeeping, taking care of finances, food preparation, taking medication, using the telephone, and accessing on-line resources. As the disease progresses, individuals living with Alzheimer's also require help with more personal activities (PADLs) such as bathing, dressing, toileting, eating, and grooming.

The increasing dependence of the individual for help with IADLs and PADLs often brings about higher levels of stress and burden for the caregiver. The need for supportive services and help from other family/friends becomes high during the middle stage. Discussions about changing living arrangements and possible relocation in the future may be initiated by the caregiver or other family members, or more commonly, are made reactively as a result of an unexpected emergency or crisis that occurs for either care partner (e.g., severe fall, unexpected health crisis).

Middle-Stage Education and Information

Similar to the needs of families in the early stage of Alzheimer's, the information and education needs of families in the middle stage is significant. Information and education are most effective if targeted to meet the unique needs of each family. In their meta-analysis of over 100 studies of dementia caregiver interventions, Pinquart & Sörensen (2006) note that education has a positive and significant effect on burden, depression, subjective well-being, the individual's symptoms, ability and knowledge. The individual living with dementia's increasing dependency and changes in behaviors (e.g., wandering, agitation, sexual disinhibition) during the middle stage of Alzheimer's can be stressful and exhausting for the caregiver. Thus, in addition to needing information about the disease and its progression, families in the middle stage can be helped by learning how to manage the individual with dementia's unpredictable and changing behaviors. Programs that help families to manage BPSDs are described below (see also Sörensen et al., 2006 who provide additional description of caregiver need and potential interventions and resources that could be useful.)

Middle-Stage Support Options

As noted, growing evidence indicates that psychosocial programs and support can contribute to the quality of life of both care partners, improve mental health outcomes for caregivers, and delay relocation to long-term care settings for individuals with dementia (see review by Smits et al., 2007). Evaluations of these programs vary greatly; some have an established evidence base documenting their effectiveness and others have very little research supporting their design, evaluation, and efficacy (see also Wiener et al., 2016 for additional information on Models of Dementia Care). Next, we provide descriptions of middle-stage programs that take a person- and family- centered perspective many of which have a documented evidence base confirming their effectiveness.

Management of BPSDs

One of the most distressing symptoms of dementia are the BPSDs that first surface during the early stage of Alzheimer's and reach their peak in number and intensity during the middle or late stage. Currently, there is neither consensus nor an established evidence base concerning the techniques that are universally effective for helping family caregivers to manage and cope with BPSDs. Yet, promising practices do exist. In their review of psychological interventions for caregivers, Selwood et al., 2007 found that behavioral management techniques taught to individual care partners rather than groups of caregivers decreased caregiver depression over both the short- and long-term. Individual and group strategies for coping with BPSDs decreased distress and depression over the short- and long-term. Teaching "principles" was found to be less effective than learning and practicing what to do (i.e., role playing and problem solving) when working with specific behaviors. Nonpharmacological interventions are available to manage wandering specifically although the effectiveness in decreasing wandering behaviors is not universal (see Robinson et al., 2006 for a review). Mounting evidence indicates that nonpharmacologic interventions to help caregivers manage BPSDs can be as effective as or more effective than pharmacological strategies in reducing BPSDs (Brodaty & Arasaratnam, 2012) and decreasing the caregiver's negative reactions to the behaviors.

Advanced Caregiver Training (ACT). This evidence-based program helps care partners to recognize and manage BPSDs. Behaviors can be caregiver based, individual living with dementia based, and/or environmentally based (Gitlin, Winter, Dennis, Hodgson, Hauck, 2010a, b). Sessions provide education, strategies to improve communication, and information about the importance of physical and mental engagement for both care partners. The ACT intervention has been fully translated to date.

Caregiver Skill Building. The Caregiver Skill Building program (CSB) is designed to help caregivers manage and cope with BPSDs by learning about the causes of these behaviors and how to respond in an optimal manner (Farran, Gilley, McCann, Bienias, Lindeman, & Evans, 2007). This 5-week group intervention also provides telephone support weekly for 7 weeks. The program first addresses simpler and less distressing BPSDs and then moves on to those that are more upsetting. Group booster sessions (6 and 12 months) and phone contacts are also available as needed. The effectiveness of CSB is not firmly established and no translational studies have been conducted to date.

Care Coordination Programs

As noted, care Coordination programs provide information, coaching, and emotional support to family caregivers and, in some cases, the individual living with dementia.

Benjamin Rose Institute Care Consultation. BRI Care Consultation is an evidence-based phone-delivered coaching and support program (Bass et al., 2014). BRI-CC helps caregivers to develop an action plan that recognizes the family's personal strengths and resources, and draws upon resources in the community and available through their health plan. This person- and family- centered program is delivered in partnership with Alzheimer's Association chapters and a managed care health system or a Veteran's Administration Medical Center. BRI Care Consultation provides information, referral, and guidance for both care partners and improves access to medical and nonmedical services. Moreover, critical to BRI Care Consultation are the on-going interactions with Care Consultants that encourages regular re-evaluation of referrals, changing

information needs, and family support that can inform changes to the dyad's action plan. Numerous translational studies have been conducted.

CarePRO Care Partners REACHING OUT. This evidence-based group intervention empowers family caregivers of individuals living with Alzheimer's disease through education, skill building, communication, and self-care strategies (Coon et al., 2016). Research indicates the feasibility of CarePro and high levels of "caregiver perceived benefit." (p.9; Coon et al., 2016). English and Spanish versions of CarePRO are available. Currently translational studies are underway in Arizona and Nevada.

Dementia Care Consultation. A dementia care consultation intervention based in the community for family caregivers (Fortinsky, Kulldorff, Kleppinger, & Kenyon-Pesce, 2009). Care consultants meet individually with caregivers and persons living with dementia over 12 months to develop and adjust care plans. Referring primary care physicians receive copies of care plans and incorporate them as needed. Preliminary RCT findings are promising (e.g., delayed relocation to skilled living environments, increased caregiver efficacy, lower depression, and decreased caregiver burden). We are aware of no translational studies that have been conducted to date.

New York University Caregiver Intervention (NYU-CI). This multicomponent evidence-based intervention teaches spouse caregivers how to manage the stress of providing care for individuals living with Alzheimer's disease (Gaugler, Roth, Haley, & Mittelman, 2008; Gaugler, Mittelman, Hepburn, & Newcomer, 2010; Mittelman et al., 1993). Treatment modalities for the caregiver include education about the disease, referrals to services, individual and family counseling, support groups, and telephone counseling. Originally developed for spouse caregivers, NYU-CI is also available for adult child caregivers. NYU-CI has been shown to delay the decision to relocate the individual into a skilled care environment for spouse and adult child caregivers (Mittelman et al., 1993). Numerous translational studies for the NYI-CI intervention have been conducted.

Powerful Tools for Caregivers. Based on the Chronic Disease Self-Management Program, Powerful Tools is designed to help caregivers develop the "tools" to maintain their health and lessen the stress of providing care (Kuhn, Hollinger-Smith, Presser, Civian, & Batsch, 2008). Six weekly classes help caregivers learn how to reduce stress, communicate their needs to family members and service providers, and address difficult emotions. Powerful Tools has an established evidence base, with numerous translational studies published to date.

Savvy Caregiver and Savvy Caregiver 2: Distance Dementia Caregiver Education Programs. Savvy Caregiver is a 12-hr psychoeducational evidence-based program (six 2-hr group sessions) that introduce family caregivers and caregiving professionals to the caregiving role, providing them with the knowledge, skills, and approaches to carry out the role, alerting them to self-care issues, and using problem solving skills to manage BPSDs (Kally et al., 2014; Lewis, Hobday, & Hepburn, 2010). Savvy 2 is advanced training (4 weeks) for caregivers who completed the initial program, but want added support and information to meet the challenges of more advanced dementia. Participants reported feeling more confident as caregivers and overall better communicators. The Savvy Caregiver program has conducted translational studies.

Skills2Care. The evidence-based Skills2Care program (formerly REACH ESP) is a home-based program for community individuals living with dementia and their family caregivers with the goal of reducing caregiver burden through: information about the disease, education about the impact of the home environment, and supporting caregivers to make environmental modifications (Gitlin, Winter, Dennis, Hodgson, & Hauck, 2014). Five 90-min home visits and one 30-min telephone contact are conducted over 6 months. The Skills2Care program is fully translated.

Alternative Therapies

Alternative therapies are increasingly viewed as a viable option for providing support and coping strategies to individuals living with Alzheimer's and their caregivers. Music therapy has been found to increase levels of well-being, improve social interactions (Lord & Garner, 1993), and reduce agitation in individuals with dementia (Gerdner, 2000). Aromatherapy also has shown to be useful for individuals living with dementia and effective in reducing agitation, as well as better tolerated than neuroleptics or sedatives (see Douglas et al., 2004 for a review). Finally, Korn et al., 2009 have examined the effect of Polarity therapy on the well-being of American Indian and Alaska Native family caregivers.

Exercise provides health benefits to individual with dementia and their caregivers including reduced falls, improved mental health, improved sleep, mood, balance, gait, and decreased daytime agitation (Dawson, Judge, & Gerhart, 2017; King et al., 1997). Additional studies show varying results where weekly exercise plus phone support did not lead to improvements in depression, anxiety, or burden (Castro, Wilcox, & O'Sullivan, Baumann, & King, 2002). However, the RDAD program (Reducing Disability in Alzheimer's Disease; Menne et al., 2014; Teri et al., 2003) has shown very positive results and has published numerous translational studies. RDAD consists of 12 1-hr

sessions in the home which helps promote exercise and physical activity in persons living with dementia and their caregivers. Moreover, caregivers learn approaches for managing BPSDs which is associated with a decrease in unmet needs (Menne et al., 2014).

Overall, these alternative programs embrace a person- and family- centered philosophy because they provide ongoing support and meaningful engagement, and help build caring and engaging relationships. In addition, they respond to and, in turn, target the unique needs of individuals living with dementia, their caregivers, and other family members. More research is needed, however, to identify the most promising modalities (For additional information about Alternative Therapies that enhance person- and family-centered care see Scales, Zimmerman, & Miller, this issue)

MultiComponent Interventions

Multicomponent programs for individuals living with middle-stage dementia and their caregivers show encouraging results. This model of support is especially effective for positive outcomes (e.g., delaying relocation of individuals with dementia to long-term care settings) if participants are "exposed to all components" (Brodaty & Arasaratnam, 2012).

Care of Persons With Dementia in Their Environment (COPE). The COPE program is a multicomponent evidence-based intervention that engages both care partners to support the strengths of the individual with dementia by reducing environmental stressors and enhancing caregiver skills (Gitlin, Winter, Dennis, Hodgson, & Hauck, 2010). Treatment components include, but are not limited to: individual living with dementia deficits and capabilities, home environment, caregiver communication, caregiver-identified concerns, caregiver education about medications, pain, and reducing stress, and information about healthy activities. A translational study of the COPE intervention is currently underway.

Resources for Enhancing Alzheimer's Caregiver Health (REACH 2). This home- and evidence-based program addresses five areas of caregiver stress: safety, self-care, social support, emotional well-being, and BPSDs (Belle et al., 2006; Lykens, Moayad, Biswas, Reyes-Ortiz, & Singh, 2014). Caregivers are provided training and counseling for 6 months (9 1.5-hr sessions). Intervention strategies include providing information, role playing, stress management techniques, problem solving, and telephone support. REACH 2 is delivered in-person, over the phone, and through structured telephone support group sessions. Lykens et al. (2014), note that their trial in Northern Texas (where REACH 2 was conducted in both English and Spanish) produced positive outcomes for caregiver depression and burden. Numerous translational studies on the REACH intervention have been published.

Advances in Technology

New developments in technology and web-based programs offer families innovative strategies for providing assistance and support to individuals and their care partners from a distance and managing their health care. Consumer Health Information Technology (CHIT) includes electronic technologies caregivers, individuals living with dementia and other family can access and interact with and that have the potential to use health and other personal information to tailor care plans, and individualize programs (Dyer, Kansagara, McInnes, Freeman, & Woods, 2012). A review of the use of CHIT by caregivers of adults with chronic conditions found that "on-line peer –support groups and chat rooms were both the most used and valued components of any website, application, or intervention" (page 2; Dyer et al., 2012). The authors note the importance of anonymity to these users as well.

In general, these online multicomponent interventions have the potential to improve knowledge, skills, and coping, while enabling meaningful engagement and caring relationships and support for caregivers and individuals living with dementia. They hold great promise for families in rural settings and those with additional chronic health conditions that do not allow them to leave their home. Moreover, individuals who are distrustful of institutions because of historical prejudice and injustice may feel more comfortable accessing support and services that are offered in a more confidential manner. In turn, a more supportive person- and family- centered environment is created which respects individual differences and supports families and individuals regardless of cultural background, sexual orientation, gender identity (Moone, Crogham, & Olson, 2016), and socioeconomic status.

Late stage of Alzheimer's: Relocation to Assisted Living or Skilled Care and End of Life Care

Not different from families during previous stages of Alzheimer's, families in the late stage have a significant need for information about the illness and its prognosis as well as support. Stress for both the individual living with dementia and the family caregiver can be high during this stage. Understanding how the disease will progress can help alleviate some of this stress because it helps families to know what to expect in the future and, in turn, prepare for the future. Referring back to earlier discussions about the individual's care values and preferences could ensure that decisions made are in line with individual living with dementia's earlier stated preferences for care (Orsulic-Jeras et al., 2016).

Late-Stage Education and Information

During the late stage, when the individual living with Alzheimer's care needs become too great for the caregiver

to manage, families often begin to consider whether to continue in-home care or relocate the individual with Alzheimer's to an alternate care setting (e.g., assisted living, skilled care). This decision can be very distressing to caregivers and individuals who may have not discussed the possibility of relocating to a care setting.

On the other hand, some families may have promised their relative that they would never relocate him or her to a long-term care setting. This promise can be unrealistic as the individual living with dementia's care requirements intensify and the caregiver's ability to meet these needs becomes increasingly challenging or even impossible. Yet, oftentimes caregivers do not understand that many individuals living with dementia are open to discussing the possibility of relocating to a long-term care setting if their care needs become too burdensome (Whitlatch, 2010). As a result, it is critical for families to have an understanding of available alternate living environments from assisted living and skilled care to hospice.

Late-Stage Support Options

Research indicates that the transition from home to skilled setting can be stressful for persons living with dementia and caregivers. Compared to their in-home caregiving peers, caregivers with relatives in skilled care environments report providing less hands on assistance (PADLs), and experience more guilt (Aneshensel, Pearlin, Mullan, Zarit, & Whitlatch, 1995). Caregivers who adopt manageable visiting routines are often better adjusted than caregivers who, for example, visit daily, stay for long periods of time, and continue to provide a significant amount of personal care (Aneshensel et al., 1995). Moreover, families often work to establish relationships with long-term care and assisted living staff with the hope that this will ensure that the individual living with dementia will receive the best care possible. Interventions that help caregivers and individuals with dementia adjust to the skilled care environment could help alleviate the stress of relocation (Gaugler & Kane, 2015). See article by Hirshman and Hodgson (this issue) which goes into great detail about transitions in care.

Regardless of whether or not the individual with dementia relocates to a long-term or supportive environment, his or her dementia will progress and the need for end-of-life care will become more salient. However, no matter the speed or course of progression to end-of-life, or whether the individual remains at home or relocates to a care setting, the educational and informational needs about care-related decisions are high as is the need for support for both the individual and caregiver. Shared decision making around end-of-life practices that are based on the individual's earlier stated preferences, are critical to ensuring person- and family-centered care.

Families during the final stage require significant support and can be helped by programs targeted to their unique needs as they enter into end-of-life and hospice care. As during the earlier stages of Alzheimer's, individual, dyadic, family counseling, and support groups can help alleviate the stress families feel during this time. Involving other family members/friends in care can be helpful to the individual with dementia and family caregiver by lessening their stress and isolation (Dening, Jones, & Sampson, 2013). Not all support is necessarily helpful or desired, and family members must respect the preferences of both the individual with dementia and caregiver. Yet, few programs exist which specifically target the unique needs of families facing end-of-life care for individuals with Alzheimer's disease.

End-of-Life Care

Throughout this paper, we advocate for the provision of education, information, educational materials, and support in the early stages of Alzheimer's. We encourage a focus on encouraging discussion of the individual's values and preferences for care with their caregivers when the individual's voice can still be heard (Dening et al., 2013; Orsulic-Jeras et al., 2016). One of the primary challenges of advanced Alzheimer's end-of-life care is the dependence upon family members to make critical health care decisions when the individual is no longer able (Caron, Griffith, & Arcand, 2005a). In addition, it is possible that if those early-stage supports are in place, individuals may be able to remain at home longer. However, in many family care situations, the individual's symptoms and health care needs are far too advanced to take advantage of the benefits of early intervention. Indeed, family caregivers are increasingly providing help with multiple and complex medical tasks (e.g., using monitors, providing wound care, managing multiple medications, preparing special diets; Reinhard & Levine, 2012), As a result, remaining at home may not be a viable option (Mittelman, Haley, Clay, & Roth, 2006).

Research indicates that a diagnosis of Alzheimer's or related dementia increases the likelihood of relocation to a skilled care setting (Gaugler, Yu, Krichbaum, & Wyman, 2009; Mittelman et al., 2006). Once the individual is living in a nursing home, the challenges for family caregivers include not knowing what role they should assume and how to obtain information about the individual's care (Caron, Griffith, & Arcand, 2005b). Thus, it is important to continue to provide counseling and supportive interventions to those caregivers who have chosen relocation to a skilled or supportive setting as the best option.

Palliative Care Approach

Evidence suggests that individuals with dementia receive less than adequate end-of-life care in comparison to those who are cognitively intact (Dening et al., 2013; Sampson, Ritchie, Lai, Raven, & Blanchard, 2005). Although many practitioners favor the option of providing palliative services for individuals living with dementia at the end-of-life, there are very few evidence-based interventions available (Jones et al., 2016). There is also recognition that a palliative approach is consistent with the principles of

person- and family-centered care because it preserves the values and identity of the individual, even in the advanced stages (Kydd & Sharp, 2016). Thus, we strongly encourage that palliative approaches not only be considered for individuals living with dementia, but that future research focuses on the development of person- and family- centered interventions tailored to the unique strengths and challenges of living with and caring for an individual with Alzheimer's disease.

Advanced Illness Care Teams. Advanced Illness Care Teams (AICTs) help health care facilities to improve the quality of care for residents with advanced dementia (Chapman & Toseland, 2007). AICTs embrace a "holistic" approach for working with nursing home residents that focuses on four categories of wellness, including medical, meaningful activities, psychological health, and behavior. AICTs can help skilled facilities to improve planning and service delivery for residents before a crisis occurs. AICTs can also help staff increase their understanding of resident and family member/surrogate needs.

PEACE Palliative Excellence in Alzheimer Care Efforts. The goal of the palliative care PEACE program is to enhance end-of-life care of persons with dementia (Shega et al., 2003). PEACE focuses on advance planning, palliative care, person- and family-centered care, and family support. Individuals with dementia and their family caregivers discuss care options important for the optimal care of the individual with dementia. PEACE also works to integrate palliative care practices into primary care specifically within the geriatrics practice of the University of Chicago. Feedback from participants is provided to physicians which further enhances quality care. Initial feasibility and acceptability of the program is promising.

Residential Care Transition Module. Residential Care Transition Module is a six-session intervention designed to help families cope with the emotional and psychological stress associated with relocating a family member living with dementia into a residential care setting (Gaugler, Reese, & Sauld, 2015). Caregivers enrolled in the program reported less emotional distress at follow-up (4 and 8 months). Given the dearth of placement interventions, the promising findings suggest that psychosocial support can help families manage emotional distress associated with the relocation of an individual with dementia into a residential long-term care setting. The team is currently conducting an RCT with over 200 caregivers.

Concluding Remarks and Recommendations for Ensuring Person- and Family- centered Care Over the Course of Alzheimer's Disease

Individuals living with Alzheimer's disease and their families have unique information, education, and support needs that change as the symptoms of Alzheimer's progress. Practitioners working with these families need a variety of programs, tools, and materials to ensure that person- and family-centered care is maintained from the time of first symptoms through the late stages of Alzheimer's and end of life. This review has described the variety of education, information, and support needs of individuals living with dementia and their families across the disease continuum as well as the services and programs currently available to meet these needs (see Table 1. Resource List). This review highlights a variety of unmet needs and a lack of available and person- and family-centered evidence-based programming for families in the early and late stages of Alzheimer's. Likewise, we see that specific groups of

Table 1. Resource List

Disease condition	National organization(s)	Fact sheets
Alzheimer's disease	http://www.alz.org/	http://www.alz.org/alzheimers_disease_what_is_alzheimers.asp http://www.alz.org/alzheimers_disease_10_signs_of_alzheimers.asp#signs http://www.alz.org/alzheimers_disease_stages_of_alzheimers.asp
Creutzfeldt-Jakob disease	http://www.cjdfoundation.org/	https://www.ninds.nih.gov/Disorders/Patient-Caregiver-Education/Fact-Sheets/Creutzfeldt-Jakob-Disease-Fact-Sheet
Dementia with Lewy bodies	https://www.lbda.org/	https://www.caregiver.org/dementia-lewy-bodies
Frontotemporal dementia	http://www.theaftd.org/	http://www.ftdtalk.org/factsheets/
Huntington's disease	http://www.hdsa.org/	https://www.ninds.nih.gov/Disorders/All-Disorders/huntingtons-Disease-Information-Page
Parkinson's disease	http://www.pdf.org/ http://www.parkinson.org/	http://www.parkinson.org/sites/default/files/PD%20Dementia.pdf
Vascular dementia		http://www.alz.org/dementia/vascular-dementia-symptoms.asp http://www.stroke.org/we-can-help/survivors/stroke-recovery/post-stroke-conditions/cognition/vascular-dementia

individuals and family caregivers have fewer information and support options available to them because of geography (i.e., rural areas and distance caregiving) or minority status (e.g., cultural background, LGBTQ, or other marginalized groups). Our review highlights the need for translation of proven research programs into practice in real world delivery systems (see Gitlin, Marx, Stanley, & Hodgson, 2015). We also find that many individuals and their families could benefit from technology-based programs that improve access to and acceptance of services and support. We also find that it is beneficial to have a clear understanding of the individual's preferences for the provision of their care. Understanding these preferences helps individuals and their families adapt to the changing symptoms and challenges they will likely face. Early planning could prevent future stress, enhance quality of life, and ensure person- and family-centered care for individuals living with dementia who might otherwise question whether their preferences were understood and would be honored in the future. While the number of evidence-based person-and family-centered services and supports is growing, there remain large gaps in programming which currently fail to meet the unique needs of individuals living with Alzheimer's disease and their families. We offer the following recommendations as a strategy for ensuring person- and family-centered care from time of diagnosis through end of life.

Information, Education, and Support Recommendations

1. ### Provide Education and Support Early in the Disease to Prepare for the Future

   Intervening during the early stages creates opportunities to identify, meet, and, in turn, honor the changing and future care needs and preferences of individuals living with dementia and their family caregivers. Discussing the individual's care values and preferences early in the disease can aid in planning during the moderate and advanced stages, as well as at end of life. Early intervention gives individuals living with dementia a voice in how they are cared for in the future, while giving their caregivers piece of mind when making crucial care-related decisions.

2. ### Encourage Care Partners to Work Together and Plan Together

   In recent years, interventions have been developed that bring together individuals living with dementia and their family caregivers, rather than working with each person separately. This person- and family-centered approach supports, preserves, and validates the individual living with dementia's care values and preferences while acknowledging the concerns, stressors, and needs of the caregiver. By discussing important care-related issues earlier on, the individual with dementia's desires and wishes for their own care will remain an important part of their caregiver's decision-making process as the care situation changes.

3. ### Build Culturally Sensitive Programs That Are Easily Adaptable to Special Populations

   It is very important to design effective evidence-based programming that is sensitive to the unique circumstances of families living with dementia, such as minority, LGBT, and socially disadvantaged populations. However, many minority or socially disadvantaged families living with dementia do not seek out or accept support from non-familial sources. Highlighting multicultural issues when training professionals and providing guidance for reaching out to these special populations will lead to more effective programs that embrace the unique needs of all care partners.

4. ### Ensure Education, Information, and Support Programs are Accessible During Times of Transition

   There are many transitional points throughout the disease trajectory that have variable effects on both care partners. For example, transitioning from early to middle to late stage often introduces new symptoms and behaviors that, in turn, increase care partners' questions and concerns about what to expect in the future. Progression through the various stages of dementia also brings about other types of transitions, such as changes in living arrangements or care providers (i.e., from in-home to nursing home care). Providing education, information, and support that honor the individual with dementia's values and preferences during these transitions will be reassuring to caregivers as they make hard choices on behalf of the individual living with dementia.

5. ### Use Technology to Reach More Families in Need of Education, Information, and Support

   Supportive interventions and programs that use technology (such as Skype, Facetime, etc.) to reach those in need of services are expectedly on the rise. As technology continues to advance and become more accessible and reliable, delivering programs using electronic devices (computer, table, and smart phone) could help reach more families. These programs would be especially useful in rural communities where caregivers and individuals living with dementia are often isolated with little access to supportive services.

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Conflict of Interest

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Review Article

Progressive Support for Activities of Daily Living for Persons Living With Dementia

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Abstract

Background and Objectives: Dementia is accompanied by increasing need for support in activities of daily living (ADLs). This brief report/literature review summarizes the practices to care for early stage, middle stage, and late stage ADL needs (dressing, toileting, and eating/nutrition), and examines commonalities across ADL needs and the extent to which practices are reflected in guidelines and/or evidence.

Research Design and Methods: A review of the grey and peer-reviewed literature, using some but not all procedures of a systematic review. Key terms were identified for ADLs overall and for each of the 3 ADLs, and a search was conducted using these words in combination with (a) dementia, Alzheimer's disease, and similar terms, and (b) practices, interventions, guidelines, recommendations, and similar terms. Searches were conducted using databases of peer-reviewed literature as well as the Grey Literature Reports and Google search engine. Sources were included if they provided evidence or recommendations on interventions to address ADL functioning for dressing, toileting, and feeding for persons living with dementia.

Results: As cognitive and functional impairment increases, the number of care practices and themes that embody care practices increases. The majority of practices are evidence-based, and most evidence is incorporated into guidelines.

Discussion and Implications: Virtually all practices reflect person-centered care principles. Five recommendations summarize the evidence and recommendations related to providing support to persons living with dementia in relation to dressing, toileting, and eating/nutrition.

Keywords: Dressing, Eating, Person-centered care, Toileting

Dementia is a progressive disease, accompanied by progressive need for support in the conduct of activities of daily living (ADLs); from first to last, the need for supportive care generally follows the order of bathing, dressing, grooming, toileting, walking, and eating (Cohen-Mansfield, Werner, & Reisberg, 1995). This order is consistent with that of the Functional Assessment Staging Test (FAST) for dementia, which (for example) identifies challenges with dressing beginning in moderate dementia, and with toileting occurring in moderately severe dementia (Reisberg, 1988); need for support in eating typifies severe dementia. Making the need for support even more evident, loss of independence in ADLs is associated with poorer quality of life (Chan, Slaughter, Jones, & Wagg, 2015); therefore, it is especially important to understand guidelines for care and evidence-based strategies to promote ADL function—which must reflect practices related to not only the ADL itself, but also to the level of diminished cognitive capacity of the person living with dementia.

This report summarizes the grey and peer-reviewed literature regarding guidelines and evidence-based dementia

care practices for one early stage, one middle stage, and one late stage ADL loss: dressing, toileting, and eating/nutrition. The discussion highlights the nature of person-centered care that cuts across all three ADLs regardless the level of cognition, and provides summative recommendations emanating from the data. Consequently, this paper is of special interest to care providers, policy makers, and researchers who strive to improve the well-being of people living with dementia.

Research Design and Methods

To conduct the grey and peer-reviewed literature search, key terms were identified for ADLs overall (e.g., ADLs, function) and for each of the three ADLs (e.g., dressing, clothing; toileting, continence; eating, drinking), and a search was conducted using these words in combination with (a) dementia, Alzheimer's disease, and similar terms, and (b) practices, interventions, guidelines, recommendations, and similar terms. Searches were conducted using databases of peer-reviewed literature (Cochrane Library, Psycinfo, Pubmed, and Google Scholar) as well as the Grey Literature Reports (New York Academy of Medicine) to identify books, reports, newspaper articles, and other non-peer reviewed materials. Additional searches used the Google search engine to identify guidelines and quality improvement initiatives of relevant organizations. Publications were also identified through reference lists of studies already included in the review. Sources were included if they provided evidence or recommendations on interventions to address ADL functioning for dressing, toileting, and feeding for individuals living with dementia. Sources were excluded if they did not address care for individuals living with dementia or if they could not be accessed through the university library database.

For each of the three ADLs, the literature was summarized to describe the practice and identify whether it derived from a guideline and/or evidence. Additionally, evidence was graded based on the Johns Hopkins Nursing Evidence-Based Practice Model (http://www.hopkinsmedicine.org/evidence-based-practice/_docs/Appendix%20C%20image.jpg), a widely used classification system:

- Level I: experimental studies, randomized controlled trials (RCTs), systematic reviews of RCTs;
- Level II: quasi-experimental studies, systematic reviews of a quasi-experimental studies with or without RCTs;
- Level III: nonexperimental studies, systematic reviews nonexperimental studies with or without quasi-experimental studies and/or RCTs.

Then, within each ADL, the material was organized into themes, which are summarized in the text that follows. Tables provide the specific practices, and the Supplementary Appendix provides the data from the research citations, presented in alphabetical order by author within type of ADL.

Of note, many of the methods detailed above follow standards for a systematic review, but the grading we used to critique the articles did not meet the standards of a systematic review, in that (for example) bias and precision were not rated, nor was a meta-analysis conducted. Therefore, the methods are best considered a literature review, and not a systematic review.

Results

A total of 59 relevant sources were identified, some of which referred to more than one care practice. The material included a combination of evidence-based guidelines (i.e., guidelines that were largely evidence based; n = 7 sources; Alzheimer's Australia WA, 2009; Alzheimer's Association, 2009a, 2009b; Dementia, The NICE-SCIE Guideline on Supporting People with Dementia and Their Carers in Health and Social Care, 2007; "Detection, Diagnosis and Management of Dementia, n.d."; Encouraging eating: Advice for at-home dementia caregivers, 2006; "Preventing and managing resistance when attending to activities of daily living, n.d.;" guidelines lacking an identified evidence-base (n = 6; ALZLIVE; Anderson, 2017; "Dementia; The dining experience," 2016; "Helping persons with dementia with eating, n.d.;" Kyle, 2012; "Toileting (for dementia)," 2012); and peer-reviewed research evidence (n = 46). Of the evidence that existed (46 sources, which included systematic and literature reviews) the majority was Level II evidence (n = 21), followed by Level III evidence (n = 15), and then Level I evidence (n = 10). Table 1 lists the themes that summarize the guidelines and evidence for each ADL, and indicates the one common theme related to all areas: person-centered assessment and care.

Table 1. Themes Summarizing Guidelines and Evidence to Provide Support for Dressing, Toileting, and Eating/Nutrition for Persons With Dementia

Dressing	Toileting	Eating/nutrition
Dignity/respect/choice	Dignity/respect	Dignity/respect/choice
Dressing process	Toileting process	Dining process
Dressing environment	Toileting environment	Dining environment
	Health/biological considerations	Health/biological considerations
		Adaptations/functioning
		Food/beverage/appetite

Note: Common Theme: Person-centered assessment and care.

Dressing

Three themes, based on 20 practices, summarize the guidelines and evidence related to dressing: *dignity/respect/choice* (e.g., respect individual style and culture), *dressing process* (e.g., simplify clothing routines), and *dressing environment* (e.g., dress in a comfortable and safe area). Nineteen of the practices are included in guidelines (ten with and nine without an evidence base), and one practice is based on evidence that has not yet been incorporated into guidelines. None of the evidence is Level I; instead, it is primarily Level III (nine practices), and to a lesser extent Level II (four practices, two of which also have Level III evidence). Simple verbal instructions for dressing (e.g., Lancioni et al., 2009) and sequential arrangement of clothing (e.g., Namazi & Johnson, 1992), both with Level II evidence, relate to improved ability to dress and decreased need for assistance. An example recommendation that does not have a clear evidence base is to gather information regarding personal style preferences (Alzheimer's Association, 2009b). Table 2 lists the themes and practices, indicates whether they are a guideline and/or have an evidence base, the level of evidence (if relevant), and the related sources/citations. The Supplementary Appendix provides information about the evidence itself.

Toileting

Four themes, based on 21 practices, summarize the guidelines and evidence related to toileting: *dignity/respect* (e.g., promote privacy), *toileting process* (e.g., maintain a pattern of bathroom visits), *toileting environment* (e.g., make the bathroom easy to find and use), and *health/biological considerations* (e.g., engage in constipation prevention). Sixteen of the 21 practices are included in guidelines (nine with and seven without an evidence base); five of the practices are based on evidence that has not been incorporated into identified guidelines. Five practices are supported by Level I evidence: positive reinforcement and reassurance (which are part of multi-component interventions), verbal reminders to use the bathroom (e.g., Schnelle et al., 1983), graded assistance (Doody et al., 2001), patterns of bathroom visits (e.g., Ouslander et al., 2005) and avoiding caffeine and fluids in the evening (Engberg, Sereika, McDowell, Weber, & Brodak, 2002); all practices relate to a decrease in incontinence episodes. There also is strong evidence (Level II) for use of a urinary alarm (Lancioni et al., 2011), and consulting a physician for pharmacologic treatments (Tobin & Brocklehurst, 1986). Table 3 includes guidelines and evidence related to toileting, and the Supplementary Appendix provides information about the evidence.

Eating

Six themes, based on 33 practices, summarize the guidelines and evidence related to dressing: *dignity/respect/choice* (e.g., engage the individual in the mealtime experience), *dining process* (e.g., provide verbal prompts or physical cues), *dining environment* (e.g., provide a quiet, relaxing, and homelike atmosphere), *health/biological considerations* (e.g., maintain dental checkups and oral health), *adaptations/functioning* (e.g., use adaptive devices/utensils), and *food/beverage/appetite* (e.g., make snacks available and visible). Twenty-eight of the 33 practices are included in guidelines (20 with and eight without an evidence base); five of the practices are based on evidence that has not been incorporated into identified guidelines. Twelve practices are supported by Level 1 (or less rigorous) evidence, 5 by Level II (or less rigorous) evidence, and eight by only Level III evidence. For example, there is strong evidence that verbal prompts and encouragement increase eating and weight (a practice that is part of multi-component interventions; e.g., Simmons et al., 2008) and that playing music during meals decreases agitation and increases consumption (e.g., Thomas & Smith, 2009). See Table 4 for the guidelines and the Supplementary Appendix for evidence related to eating.

Discussion and Implications

The practices identified in this review highlight that cognitive issues in Alzheimer's disease and other dementias are increasingly relevant to ADL support as the disease progresses. For example, decline in the ability to independently dress can be improved by sequentially organizing the closet (Namazi & Johnson, 1992), a cue that requires more cognitive capacity than most practices recommended for toileting and eating. That said, given individual differences in the timing of cognitive and ADL loss, cognitive capacity is still indicated for some toileting practices—albeit fewer—such as to engage in physical therapy for incontinence (Hägglund, 2010).

Common themes across all practices included *dignity/respect/choice*, the *care process*, and the *care environment*. With the progressive loss of cognitive and ADL function, the number of themes and care practices increases: 20 practices (three themes) for dressing; 21 practices (four themes) for toileting; and 33 practices (six themes) for nutrition. These results highlight the trend that as cognitive functioning becomes more impaired, the amount and complexity of care needs increase.

Of the 74 practices, the majority (50) were evidence-based (68%), with most evidence being level III (the least rigorous) followed by level II; all but 11 evidence-based practices were incorporated into guidelines. Relatedly, the 63 practices that were included in guidelines were primarily evidence-based (62%). Conversely, 38% of the practices included in guidelines lacked supporting evidence. These unsupported guidelines largely offered pragmatic advice (such as attending to nonverbal cues to use the bathroom), or related to basic human values, such as dignity. One could argue, then, that the practicality and principles of these guidelines offsets the need for "evidence" of their value.

Table 2. Dressing Guidelines and Evidence

Theme	Recommendation	Guideline	Evidence base	Source/citation	Number of evidence based citations, by level of evidence[a]		
					I	II	III
Dignity/respect/choice	Respect individual style and cultural preferences	x	x	Alzheimer's Association, 2009b; Tips for helping a person with dementia to dress, n.d.; Mahoney, Coon, & Lozano, 2016			1
	Gather information on personal style preferences from the person with dementia and his/her family	x		Alzheimer's Association, 2009b			
	Lay out two outfits to encourage freedom of choice	x		Alzheimer's Australia WA, 2009			
	Ensure dirty clothes are promptly removed	x		Alzheimer's Australia WA, 2009			
	Use a "dignity" or "modesty cape" to ensure the person is covered while dressing	x		Alzheimer's Australia WA, 2009			
	Use clothing as a conversation starter to engage the person	x		Alzheimer's Association, 2009b			
	Engage the person by name and explain all actions before progressing	x		Alzheimer's Australia WA, 2009			
	Provide encouragement and positive reinforcement for as much independence as possible	x	x	Tips for helping a person with dementia to dress, n.d.; Alzheimer's Australia WA, 2009; Cohen-Mansfield et al., 2006; Rogers et al., 1999		1	1
	Do not debate or argue	x	x	Tips for helping a person with dementia to dress, n.d.; Mahoney, LaRose, & Mahoney, 2015; Mahoney, Coon, & Lozano, 2016			2
Dressing process	Simplify routines	x	x	Alzheimer's Association, 2009b; Tips for helping a person with dementia to dress, n.d.; Alzheimer's Australia WA, 2009; Mahoney, LaRose, & Mahoney, 2015			1
	Organize dressing process (or closet) sequentially	x	x	Alzheimer's Association, 2009b; Tips for helping a person with dementia to dress, n.d.; Alzheimer's Australia WA, 2009; Namazi & Johnson, 1992		1	

Table 2. *Continued*

Theme	Recommendation	Guideline	Evidence base	Source/citation	Number of evidence based citations, by level of evidence[a]		
					I	II	III
	Give short verbal instructions (following graded levels of assistance) on dressing	x	x	Alzheimer's Association, 2009b; Tips for helping a person with dementia to dress, n.d.; Alzheimer's Australia WA, 2009; Engelman, Mathews, & Altus, 2002; Lancioni et al., 2009; Namazi & Johnson, 1992; Rogers et al., 1999		4	
	Use gentle physical prompting (following graded levels of assistance) as needed	x	x	Alzheimer's Australia WA, 2009; Cohen-Mansfield et al., 2006; Namazi & Johnson, 1992		1	1
	Label drawers with the type of clothing they contain	x		Alzheimer's Australia WA, 2009			
	Plan for sufficient time to dress	x	x	Alzheimer's Association, 2009b; Tips for helping a person with dementia to dress, n.d.; Alzheimer's Australia WA, 2009; Dementia, The NICE-SCIE Guideline on Supporting People with Dementia and Their Carers in Health and Social Care, 2007; Cohen-Mansfield et al., 2006			1
	Play familiar music to encourage movement	x		Alzheimer's Australia WA, 2009			
	Choose comfortable, simple (e.g., zippers and velcro instead of buttons and ties) dressing options and weigh the pros and cons of each	x	x	Alzheimer's Association, 2009b; Tips for helping a person with dementia to dress, n.d.; Cohen-Mansfield et al., 2006; Mahoney, LaRose, & Mahoney, 2015			2
	Use comfortable, nonslip shoes	x		Alzheimer's Association, 2009b			
Dressing environment	Dress in a comfortable and safe area (e.g., bathrooms may increase falls risk)	x	x	Alzheimer's Australia WA, 2009; Cohen-Mansfield et al., 2006			1
	Consider caregiver safety (e.g., use an adjustable bed to reduce bending)		x	Cohen-Mansfield et al., 2006			1

Note: [a]Level I: experimental studies, randomized controlled trials (RCT), systematic reviews of RCTs; Level II: quasi-experimental studies, systematic reviews of the same in combination with RCTs; Level III: nonexperimental studies, systematic reviews of the same in combination with more rigorous designs, and qualitative studies.

Table 3. Toileting Guidelines and Evidence

Theme	Recommendation	Guideline	Evidence base	Source/citation	Number of evidence based citations, by level of evidence[a]		
					I	II	III
Dignity/respect	Assess for signs of leakage or incontinence	x		Alzheimer's Association, 2009b			
	Use adult diapers or pads to prevent accidents		x	Ouslander, Zarit, Orr, & Muira, 1990			1
	Do not chide or argue		x	Andrews, 2017			1
	Promote privacy	x		Preventing and managing resistance when attending to activities of daily living, n.d.			
	Provide positive reinforcement and reassurance to maintain personal dignity	x	x	Alzheimer's Association, 2009b; Detection, Diagnosis and Management of Dementia, n.d.; Engberg et al., 2002; Lancioni et al., 2011; Schnelle et al., 1983	2	1	
Toileting process	Talk to family to assess urinary and bowel patterns	x		Alzheimer's Association, 2009b			
	Be aware of and plan to avoid circumstances surrounding accidents	x		Alzheimer's Association, 2009b			
	Pay attention to nonverbal cues of needing to use the bathroom	x		Preventing and managing resistance when attending to activities of daily living, n.d.; Toileting (for dementia), 2012			
	Encourage independence by using graded assistance as needed	x	x	Detection, Diagnosis and Management of Dementia, n.d.; Toileting (for dementia), 2012; Doody et al., 2001	1		
	Provide verbal reminders to use the bathroom	x	x	Detection, Diagnosis and Management of Dementia, n.d.; Andrews, 2017; Doody et al., 2001; Engberg et al., 2002; Hägglund, 2010; Ouslander et al., 2005; Schnelle et al., 1983	4		2
	Help maintain pattern of bathroom visits (e.g., on a timed schedule)	x	x	Alzheimer's Association, 2009b; Detection, Diagnosis and Management of Dementia, n.d.; Toileting (for dementia), 2012; Andrews, 2017; de Codt et al., 2015; Doody et al., 2001; Hägglund, 2010; Ouslander et al., 1990	1	1	3

Table 3. *Continued*

Theme	Recommendation	Guideline	Evidence base	Source/citation	Number of evidence based citations, by level of evidence[a]		
					I	II	III
	Use a urinary alarm system for reminders		x	Lancioni et al., 2011		1	
	Use nonrestricting clothing	x	x	Preventing and managing resistance when attending to activities of daily living, n.d.; Andrews, 2017			1
	Allow sufficient time; do not rush the person	x		Toileting (for dementia), 2012; Dementia, The NICE-SCIE Guideline on Supporting People with Dementia and Their Carers in Health and Social Care, 2007			
Toileting environment	Make the bathroom easy to find and use (e.g., with a sign labeled with a word or photo)	x	x	Preventing and managing resistance when attending to activities of daily living, n.d.; Toileting (for dementia), 2012; Andrews, 2017; Namazi & Johnson, 1991			2
	Remove objects that can be mistaken for a toilet (e.g., planters)	x	x	Toileting (for dementia), 2012; Andrews, 2017			1
Health/biological considerations	Engage in constipation prevention - exercise, high fiber diet, hydration, correct posture and use of foot stools, abdominal massage	x	x	Alzheimer's Association, 2009b; Kyle, 2012; Andrews, 2017; Ouslander et al., 2005			2
	Consult a physician for pharmacologic options		x	Tobin & Brocklehurst, 1986		1	
	Use laxatives under health professional guidance	x		Alzheimer's Association, 2009b			
	Engage in bladder training through physical therapy or pelvic floor exercises		x	Hägglund, 2010			1
	Eliminate caffeine and fluids in the evening if urinary accidents at night are an issue	x	x	Toileting (for dementia), 2012; Engberg et al., 2002	1		

Note: [a]Level I: experimental studies, randomized controlled trials (RCT), systematic reviews of RCTs; Level II: quasi-experimental studies, systematic reviews of the same in combination with RCTs; Level III: nonexperimental studies, systematic reviews of the same in combination with more rigorous designs, and qualitative studies.

Table 4. Eating/Nutrition Guidelines and Evidence

Theme	Recommendation	Guideline	Evidence base	Source/citation	Number of evidence based citations, by level of evidence[a]		
					I	II	III
Dignity/respect/choice	Allow individual to choose meal time or adjust it based on agitation or disorientation	x		Alzheimer's Association, 2009a; Dementia, The Dining Experience, 2016			
	Offer food choices		x	Perivolaris, LeClerc, Wilkinson, & Buchanan, 2006; Simmons et al., 2008	1	1	
	Engage individual in the mealtime experience/preparation to stimulate appetite	x	x	Alzheimer's Association, 2009b; Dementia, The Dining Experience, 2016; Ball, 2015; Johansson et al., 2015			2
	Avoid confrontation		x	Ball, 2015			1
Dining process	Maintain familiar dining routines	x	x	Alzheimer's Association, 2009b; Encouraging Eating: Advice for at-home dementia caregivers, 2006; Ball, 2015; Johansson et al., 2011; Johansson et al., 2015			3
	Facilitate social eating with others	x	x	Dementia, The Dining Experience, 2016; Encouraging Eating: Advice for at-home dementia caregivers, 2006; Amella, Grant, & Mulloy, 2008; Ball, 2015; Jensen, Rekve, Ulstein, Skovdahl, 2016; Johansson et al., 2015; Perivolaris et al., 2006; Reed, Zimmerman, Sloane, Williams, & Boustani, 2005	1	1	4
	To avoid overeating, limit access between meals, maintain a schedule, and monitor intake	x		Alzheimer's Association, 2009b			
	Provide ample time to eat	x	x	Dementia, The Dining Experience, 2016; Encouraging Eating: Advice for at-home dementia caregivers, 2006; Bunn et al., 2016; Jensen et al., 2016		1	1
	Model the sequence of eating in the meal	x	x	Helping persons with dementia with eating, n.d.; Jensen et al., 2016			1
	Serve family style meals		x	Altus, Engelman, & Mathews, 2002; Amella, Grant, & Mulloy, 2008; Bunn et al., 2016; Charras & Frémontier, 2010		3	1

Table 4. *Continued*

Theme	Recommendation	Guideline	Evidence base	Source/citation	Number of evidence based citations, by level of evidence[a]		
					I	II	III
	Provide verbal prompts/encouragement or physical cues if person cannot eat or drink on their own at a slow pace	x	x	Alzheimer's Association, 2009b; Ball, 2015; Bergland, Johansen, & Sellevold, 2015; Chang & Lin, 2015; Coyne & Hoskins, 1997; Liu et al., 2015a, 2015b; Perivolaris et al., 2006; Simmons et al., 2008	3	2	2
	Sit level, make eye contact, and speak with the person when assisting	x		Alzheimer's Association, 2009a, 2009b			
	Encourage independence when possible	x	x	Alzheimer's Association, 2009a, 2009b; Jensen et al., 2016; Johansson et al., 2011; Johansson et al., 2015			3
	Play music during meals to decrease agitation	x	x	Dementia, The Dining Experience, 2016; Amella, Grant, & Mulloy, 2008; Bunn et al., 2016; Goddaer & Abraham, 1994; Ho et al., 2011; Lin, Huang, Watson, Wu, & Lee, 2011; Thomas & Smith, 2009; Perivolaris et al., 2006; Ragneskog, Kihlgren, Karlsson, & Norberg, 1996	1	6	1
Dining environment	Provide a quiet, relaxing, and homelike atmosphere; reduce distracting stimuli (e.g., phone calls or extra dishes, etc on the table)	x	x	Anderson, 2017; Helping persons with dementia with eating, n.d.; Dementia, The Dining Experience, 2016; Encouraging Eating: Advice for at-home dementia caregivers, 2006; Bergland, Johansen, & Sellevold, 2015; Jensen et al., 2016; Johansson et al., 2015; Liu et al., 2015a, 2015b; Reed et al., 2005	1		4
	Ensure the dining area is well lit	x	x	Dementia, The Dining Experience, 2016; Amella, Grant, & Mulloy, 2008; Brush, Meehan, & Calkins, 2002		1	1

Table 4. *Continued*

Theme	Recommendation	Guideline	Evidence base	Source/citation	Number of evidence based citations, by level of evidence[a]		
					I	II	III
	Use colored plates to provide contrast and make the food easier to see	x	x	Alzheimer's Association, 2009b; Dementia, The Dining Experience, 2016; Amella, Grant, & Mulloy, 2008; Ball, 2015; Bergland, Johansen, & Sellevold, 2015; Brush, Meehan, & Calkins, 2002; Dunne et al., 2004		2	3
Health/biological considerations	Maintain dental checkups and oral health	x		Encouraging Eating: Advice for at-home dementia caregivers, 2006			
	Consult with a physician on supplements such as vitamins and herbs	x	x	Alzheimer's Association, 2009b; Lauque et al., 2004	1		
Adaptations/ functioning	Provide functionally-appropriate foods and beverages (e.g., match texture to swallowing capability)	x	x	Alzheimer's Association, 2009b; Ball, 2015; Bergland, Johansen, & Sellevold, 2015; Jensen et al., 2016			3
	Adapt foods (e.g., finger foods) and provide assistance when utensils can no longer be used	x	x	Alzheimer's Association, 2009b; Encouraging Eating: Advice for at-home dementia caregivers, 2006; Ball, 2015; Liu et al., 2015a, 2015b	1		1
	Ensure seating addresses balance issues	x		Alzheimer's Association, 2009b			
	Help the individual sit comfortably with good posture	x	x	Alzheimer's Association, 2009b; Amella, Grant, & Mulloy, 2008; Simmons et al., 2008	1		1
	Use adaptive devices/utensils as needed	x	x	Alzheimer's Association, 2009b; Dementia, The Dining Experience, 2016; Encouraging Eating: Advice for at-home dementia caregivers, 2006; Amella, Grant, & Mulloy, 2008; Ball, 2015; Johansson et al., 2015; Perivolaris et al., 2006		1	3
	Engage the person in feeding skills training (e.g., spaced retrieval, Montessori techniques) or the caregiver in feeding care programs		x	Lui, W., 2015, Bunn et al., 2016	1	1	

Table 4. *Continued*

Theme	Recommendation	Guideline	Evidence base	Source/citation	Number of evidence based citations, by level of evidence[a]		
					I	II	III
Food/beverage/ appetite	Provide opportunity to drink fluids	x		Alzheimer's Association, 2009a			
	Make snacks available and visible to promote eating	x	x	Alzheimer's Association, 2009b; Bunn et al., 2016; Simmons et al., 2008	1	1	
	Offer nutritionally and culturally appropriate foods	x	x	Alzheimer's Association, 2009a, 2009b; Amella, Grant, & Mulloy, 2008; Jensen et al., 2016; Liu et al., 2015a, 2015b	1		2
	Offer nutrient-dense foods	x		Alzheimer's Association; Anderson, 2017			
	Prepare food to maximize acceptance based on taste (e.g., sweet foods) and preference	x	x	Alzheimer's Association, 2009a; Anderson, 2017; Encouraging Eating: Advice for at-home dementia caregivers, 2006; Bergland, Johansen, & Sellevold, 2015; Jensen et al., 2016			2
	Try favorite foods and nutrient-dense ones prior to supplement use	x	x	Alzheimer's Association; Simmons et al., 2008	1		
	Promote activities to encourage appetite	x		Alzheimer's Association, 2009b			
	Help the individual access prepared food services (e.g., Meals on Wheels) if necessary		x	Johansson et al., 2011			1

Note: [a]Level I: experimental studies, randomized controlled trials (RCT), systematic reviews of RCTs; Level II: quasi-experimental studies, systematic reviews of the same in combination with RCTs; Level III: nonexperimental studies, systematic reviews of the same in combination with more rigorous designs, and qualitative studies.

The 11 evidence-based practices that are not explicitly incorporated into guidelines are of three types: those that convey basic principles of dementia care (i.e., do not chide or argue [regarding toileting]; avoid confrontation [regarding eating]); those that are already generally accepted practice (i.e., use adult diapers or pads; offer food choices); and those that may merit inclusion in guidelines so as to promote use (e.g., consider caregiver safety [when dressing]; use a urinary alarm system for reminders; engage in feeding skills training).

Throughout all practices runs a central theme: person-centered care. Not only is *dignity/respect/choice* common for all ADLs, but practices embodied in other themes also recognize the individual—such as what constitutes "sufficient time to dress" (ALZLIVE; Alzheimer's Association, 2009b), or an individual's own "nonverbal cues" conveying need to use the bathroom (Toileting (for dementia), 2012), or what constitutes a "familiar" mealtime routine (Johansson, Sidenvall, & Christensson, 2015). In fact, no one-size-fits-all approach was recommended in any guideline or evidence, and the importance of tailoring support to the individual's preferences and needs was stressed by virtually all sources. These recommendations reflect the importance of a person-centered approach to promote function throughout the life of person living with dementia (Fazio, Pace, Flinner, & Kallmer, 2018).

Results from this review suggest the following five practice recommendations, with related brief explanations.

1. Support for ADL function must recognize the activity, the individual's functional ability to perform the activity, and the extent of cognitive impairment.

   Dementia is a progressive disease, accompanied by progressive loss in the ability to independently conduct ADLs. Needs for supportive care increase over time—such as beginning with support needed for dressing, and later toileting, and later eating—and must address both cognitive and functional decline as well as remaining abilities.

2. Follow person-centered care practices when providing support for all ADL needs.

   Not only are dignity, respect, and choice a common theme across all ADL care, but the manner in which support is provided for functionally-specific ADLs must attend to the individualized abilities, likes and dislikes of the person living with dementia.

3. When providing support for dressing, attend to dignity, respect and choice; the dressing process; and the dressing environment.

   In general, people living with dementia are more able to dress themselves independently if, for example, they are provided selective choice and simple verbal instructions, and if they dress in comfortable, safe areas.

4. When providing support for toileting, attend to dignity and respect; the toileting process; the toileting environment; and health and biological considerations.

   In general, people living with dementia are more able to be continent if, for example, they are monitored for signs of leakage or incontinence, have regularly scheduled bathroom visits and access to a bathroom that is clearly evident as such, and avoid caffeine and fluids in the evening.

5. When providing support for eating, attend to dignity, respect and choice; the dining process; the dining environment; health and biological considerations; adaptations and functioning; and food, beverage and appetite.

In general, people living with dementia are more likely to eat if, for example, they are offered choice, dine with others and in a quiet, relaxing, and homelike atmosphere, maintain oral health, are provided adaptive food and utensils, and offered nutritionally and culturally appropriate foods.

Supplementary Material

Supplementary data are available at *The Gerontologist* online.

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Conflict of Interest

None reported.

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Review Article

Evidence-Based Nonpharmacological Practices to Address Behavioral and Psychological Symptoms of Dementia

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Abstract

Background and Objectives: To draw from systematic and other literature reviews to identify, describe, and critique nonpharmacological practices to address behavioral and psychological symptoms of dementia (BPSDs) and provide evidence-based recommendations for dementia care especially useful for potential adopters.

Research Design and Methods: A search of systematic and other literature reviews published from January 2010 through January 2017. Nonpharmacological practices were summarized to describe the overall conceptual basis related to effectiveness, the practice itself, and the size and main conclusions of the evidence base. Each practice was also critically reviewed to determine acceptability, harmful effects, elements of effectiveness, and level of investment required, based on time needed for training/implementation, specialized care provider requirements, and equipment/capital requirements.

Results: Nonpharmacological practices to address BPSDs include sensory practices (aromatherapy, massage, multi-sensory stimulation, bright light therapy), psychosocial practices (validation therapy, reminiscence therapy, music therapy, pet therapy, meaningful activities), and structured care protocols (bathing, mouth care). Most practices are acceptable, have no harmful effects, and require minimal to moderate investment.

Discussion and Implications: Nonpharmacological practices are person-centered, and their selection can be informed by considering the cause and meaning of the individual's behavioral and psychological symptoms. Family caregivers and paid care providers can implement evidence-based practices in home or residential care settings, although some practices require the development of more specific protocols if they are to become widely used in an efficacious manner.

Keywords: Behavioral and psychological symptoms of dementia (BPSD), Nonpharmacological, Dementia care, Recommendations, Evidence, Review

Behavioral and psychological symptoms of dementia (BPSDs) are among the most distressing sequelae of Alzheimer's disease and related dementias. They include agitation, aberrant motor behavior, anxiety, irritability, depression, apathy, disinhibition, delusions, hallucinations, and sleep or appetite changes (Cerejeira, Lagarto, & Mukaetova-Ladinska, 2012). Up to 97% of persons living with dementia experience at least one BPSD, the most common being apathy, depression, irritability, agitation, and anxiety (Steinberg et al., 2008). BPSDs result from changes in the brain in relation to characteristics of the social and physical environment, as explained by three complementary conceptual models described below. In the material that follows, the focus is on modifiable factors in the social

and physical environment, which is not to minimize the important role of unmodifiable neurodegeneration associated with dementia (Kales, Gitlin, & Lyketsos, 2015).

The competence-environmental press framework conceives of BPSDs as reflecting the interplay of cognitive capacity and external environmental stressors; simply stated, environmental forces influence ("press" on) an individual's psychological state and evoke a behavioral response (Lawton & Nahemow, 1973). For example, when confronted with bath water that is an uncomfortable temperature, a person living with dementia may strike out rather than convey discomfort through words. The progressively lowered stress threshold model expands the concept of press. It suggests that environmental antecedents produce stress, which is met by a coping response that is compromised by the progressive impact of dementia; BPSDs emerge as environmental demands exceed stress-tolerance or coping thresholds (Hall & Buckwalter, 1987). A behavioral example explained by this model is an individual who becomes agitated in response to an environment made noisy through overhead speakers and persistent talk.

The needs-driven dementia-compromised behavior model conceives of BPSDs as an attempt to communicate an unmet need; they reflect a response to antecedent environmental or social stimuli based on person-specific characteristics such as personality and cognitive and functional status (Algase et al., 1996). Within this framework, BPSDs are considered meaningful expressions, ranging from disengagement (e.g., apathy) to mild discomfort (e.g., pacing) to urgent need (e.g., physical aggression). As an example, a person living with dementia who "wanders" may be communicating the need to leave a situation that is causing mild anxiety. If the need is not addressed, symptoms will persist and may become more severe (Kovach, Noonan, Schlidt, & Wells, 2005), perhaps escalating from wandering to exit seeking.

Understanding the triggers of BPSDs has allowed for the development and testing of social and environmental practices (i.e., interventions or treatments) to reduce or eliminate those symptoms. Such practices are especially desirable given that antipsychotic and other psychotropic medications are generally contraindicated for the treatment of BPSDs; not only is there is limited evidence of benefit (Sink, Holden, & Yaffe, 2005), but the use of antipsychotic medications to treat this population is associated with higher risk of myocardial infarction (Pariente et al., 2012), stroke (Douglas & Smeeth, 2008), and mortality (Kales et al., 2012). In fact, regulations state that antipsychotic medications should be considered to treat BPSDs only in instances when the symptoms present a danger, and only after "medical, physical, functional, psychological, emotional, psychiatric, social and environmental causes have been identified and addressed" (CMS, 2013). Similarly, physical restraints are contraindicated to address BPSDs, as they can result in injury and negatively affect cognition, mood, and opportunities for social interaction (Scherder, Bogen, Eggermont, Hamers, & Swaab, 2010).

It is recommended that practices to address BPSDs build from broader dementia care principles, which include simplifying tasks (breaking each task into simple steps, using verbal and/or tactile prompts); communicating clearly and calmly and allowing sufficient time for the individual's response; aligning activities with the individual's preference and capacity and providing support as needed; and engaging with the individual in a simplified environment that is free from clutter and distractions, using visual cues for orientation (Gitlin, Kales, & Lyketsos, 2012). Family caregivers and formal care providers of people living with dementia often need education/training about these principles, as well as how to recognize BPSDs, their triggers, and strategies to alleviate them (Spector, Orrell, & Goyder, 2013).

To date, a number of systematic and literature reviews have identified evidence-based nonpharmacological practices to address BPSDs. Consistent with the conceptual approaches described above, these reviews have highlighted the utility of identifying characteristics of the social and physical environment that trigger or exacerbate BPSDs. However, not all reviews have focused specifically on outcomes related to BPSDs (e.g., one systematic review examined "health outcomes" that included BPSDs; Zimmerman et al., 2013) and others have been specific to settings of care (e.g., a Cochrane review of dementia special care units; Lai, Yeung, Mok, & Chi, 2009). Furthermore, few of the reviews present and summarize the conceptual underpinnings of the individual practices, which is important information for considering when, why, and for whom a practice may be effective. Furthermore, there has been limited attention to the investment required for each practice, in terms of time requirements (such as for training and implementation), the need for specialized care providers, and equipment and capital resource requirements, all of which are important in the context of crafting recommendations for dementia care.

Therefore, the intent of this article is to serve as an applied review of the literature that summarizes evidence-based nonpharmacological practices to address BPSDs, describes the practices in some detail, critiques them in terms of their investment requirements, and derives related recommendations for dementia care. Other reviews have not typically provided information to help potential users understand the conceptual basis underlying practices or the time investment necessary to implement them; consequently, this article is unique in its relevance for potential adopters.

Design and Methods

To identify evidence-based nonpharmacological practices to address BPSDs, a search of systematic and other literature reviews published in English from January 2010 through January 2017 was conducted. The 2010 start date focused this review on the most up-to-date assessments of a body of literature that has been growing for several decades; the majority of reviews have been published since 2010, but most cover evidence published since 1990 or earlier. Search

terms included "systematic (or literature) review," "dementia (or Alzheimer's disease)," "behavioral and psychological symptoms of dementia" (and synonyms), and "interventions" (and related terms). Search databases included PubMed, CINAHL, PsycINFO, AgeLine, and Cochrane. As needed, articles identified from the reference lists of the reviews were themselves reviewed for clarification or more information; additionally, so as to be inclusive, a small number of individual studies on BPSD practices that were identified during the search but not yet evaluated in systematic reviews were included in this review and synthesis. Review articles that addressed the experiences and outcomes of caregivers themselves were not included, although we recognize the essential link to the experiences and outcomes of the person living with dementia (Gitlin, Marx, Stanley, & Hodgson, 2015). As a literature review and synthesis, this article presents evidence that has already been evaluated using a priori inclusion criteria and standards of rigor rather than replicating existing systematic review efforts. It does not evaluate the qualities of the reviews themselves, but it is important to note that they all met the standards of peer review.

The identified BPSD practices were summarized to describe the overall conceptual basis of each practice, the practice itself, and related evidence. Then, the evidence base for each practice was critically reviewed by the authors to determine apparent/likely acceptability to participants, reported/potential harmful effects, potential elements of effectiveness, and investment required. As the included reviews used different criteria to search and evaluate the strength of the evidence, the intention in this article was to broadly summarize the findings across the reviews for potential adopters rather than specifically quantify the number of Level I, Level II, and Level III studies on each practice. Thus, the size of the evidence base for each practice was heuristically characterized as small (when the systematic reviews that were summarized in this review tended to identify fewer than five studies meeting inclusion criteria and supporting the BPSD practice in question), moderate (5–10 studies), or large (more than 10 studies); to note, these categories served as a general guide for summarizing the extent of the evidence rather than precise quantifications. The main conclusions from the evidence were characterized as positive (if positive effects were reported across the reviews), mixed (if negative effects were also identified), or preliminary (if the evidence base was too small to evaluate). Investment was rated as low, moderate, or high, in relation to time needed for training and implementation, specialized care provider requirements, and equipment or capital requirements, based on an adaptation of an existing framework. As shown in Table 1, low investment requires <2 hr of training and <15 min to implement, no specialized care provider requirements, and material purchases <$100 with no environmental modification; high investment requires >4 hr of training and >60 min to implement, a specialized care provider, and material purchases >$500 with ongoing cost >$100/month and extensive environmental modification; and moderate involvement lies between the two extremes for all categories (Seitz et al., 2012). Overall, the literature itself did not quantify the investment required of each practice, so the authors used their judgment based on these criteria.

The Results section presents the practices, conceptual basis, evidence, and implementation; Tables 2–4 provide additional details regarding evidence.

Results

From the database search, 197 articles reporting evidence-based nonpharmacological practices to treat BPSDs were reviewed, and 14 single articles were also reviewed for their detail on particular practices. The practices that were identified have been classified here in three overarching categories: sensory practices (aromatherapy, massage, multisensory stimulation, and bright light therapy), psychosocial practices (validation therapy, reminiscence therapy, music therapy, pet therapy, and meaningful activities), and structured care protocols (bathing and mouth care).

Sensory Practices

Normal aging is associated with gradual decline across the five senses—visual, auditory, kinesthetic, olfactory, and

Table 1. Criteria to Rate Investment Required for Nonpharmacological Practices to Treat BPSDs

	Low investment	Moderate investment	High investment
Time required for training and implementation	<1 hr of training <15 min to implement	1–4 hr of training 15–60 min to implement	>4 hr of training >60 min to implement
Specialized care provider requirements	None	Implemented by usual care provider but requires specialized knowledge	Not implemented by usual care provider
Equipment or capital resources	Material purchase <$100 with no ongoing cost No environmental modification	Material purchase $100–$500 Ongoing cost <$100/month Some environmental modification	Material purchase >$500 Ongoing cost >$100/month Extensive environmental modification

Note: BPSDs = behavioral and psychological symptoms of dementia.

Table 2. Sensory Practices

Practice	Description	Summary of evidence	Assessment of implementation and investment
Aromatherapy	Administration of scented oils (e.g., lavender or lemon balm), via diffusion, patches, or skin cream, to induce calm and positive affect.	Moderate evidence base Evidence is mixed; indicates positive effect on agitation More high-quality research required, using consistent implementation protocols and outcome measures	Well accepted by participants No known harmful effects Autonomic nervous system regulation and social/physical contact may be key elements of effectiveness Low investment (minimal time, usual caregiver, modest resources)
Massage	Tactile or therapeutic touch applied to back, shoulders, necks, hands, or feet by qualified massage therapist or by trained staff or family members, to induce calm and positive affect.	Small evidence base Evidence indicates positive effects on agitation, aggression, anxiety, depression, disruptive vocalizations More high-quality research required, using consistent implementation protocols and outcome measures and conducted with larger samples	Well accepted by participants No known harmful effects, although individual preference regarding physical touch should be assessed and honored Physiological response and social/physical contact may be key elements of effectiveness Low investment (minimal time, usual caregiver, modest resources)
Multisensory stimulation	Stimulation of multiple senses through a combination of light effects, calming sounds, smells, and/or tactile stimulation, to overcome apathy or induce calm.	Large evidence base Evidence indicates positive effects on agitation, anxiety, apathy, depression More high-quality research required, using consistent implementation protocols and outcome measures and conducted with larger samples	Well accepted by participants No known harmful effects Social contact may be key element of effectiveness Moderate investment (moderate time, usual caregiver, moderate resources)
Bright light therapy	Exposure to simulated or natural lighting designed to help promote synchronization of circadian rhythms with environmental light–dark cycles.	Moderate evidence base Evidence is mixed, showing both positive and negative effects More high-quality research required, especially with natural lighting	Degree of acceptance varies by light source Some potential for harmful effects Change to circadian rhythm may be key element of effectiveness Moderate investment (moderate time, usual caregiver, low or moderate resources)

gustatory—which can lead to loss of independence, social isolation, disorientation and confusion, safety risks, and other adverse outcomes (Raina, Wong, & Massfeller, 2004; Schneider et al., 2011). Sensory change is also specifically associated with cognitive impairment, although the nature and degree of this association is still under investigation (Behrman, Chouliaras, & Ebmeier, 2014). Older persons living with dementia are therefore particularly vulnerable to sensory deficits, which can reduce their capacity to interpret and manage the demands of their environment (consistent with the progressively lowered stress threshold model described in the Introduction). An individual who has trouble seeing, for example, may be easily startled and distressed by noises that are not clearly identifiable, leading to anxiety or agitation.

Sensory practices comprise a range of techniques for correcting sensory imbalances, increasing alertness, reducing anxiety and agitation, and enhancing quality of life (Fitzsimmons, Barba, & Stump, 2014; Strøm, Ytrehus, & Grov, 2016). Prominent among these tested techniques are aromatherapy, massage, multisensory stimulation (MSS), and bright light therapy. It is recommended that sensory practices are supported by basic care practices that help minimize confusion and enhance orientation, such as ensuring that individuals have functional hearing aids and eyeglasses, and that the care environment is well-lit and easily navigable (Behrman et al., 2014); together, these practices can help individuals better tolerate the press from their environment.

Table 3. Psychosocial Practices

Practice	Description	Evidence	Assessment of implementation and investment
Validation therapy	Individual or group practice designed to validate the perceived reality and emotional experience of the individual.	Small evidence base Evidence is mixed; some evidence of positive effects on agitation, apathy, irritability, night-time disturbance More high-quality research required on the specific effects on BPSDs	Well accepted by participants No known harmful effects, although care providers should ensure that negative emotions are not exacerbated through validation Alleviating negative feelings and enhancing positive feelings may be key elements of effectiveness Low investment (minimal time, usual caregiver, modest resources)
Reminiscence therapy	Individual or group practice designed to induce positive affect through a focus on happy memories, often using photographs or other prompts.	Moderate evidence base Evidence indicates positive effects on mood, depressive symptoms More high-quality research required on the specific effects on BPSDs	Well accepted by participants No known harmful effects, although care providers should help focus reminiscence on positive memories Increasing well-being and providing pleasure and cognitive stimulation may be key elements of effectiveness Moderate investment (moderate time, usual or special caregiver, modest resources)
Music therapy	Receptive or participatory activities designed to promote well-being, foster sociability, create familiarity, and reduce anxiety.	Moderate evidence base Evidence indicates positive effects on a range of BPSDs, including anxiety, agitation, and apathy, particularly with personalized music practices More high-quality research with larger samples required	Degree of acceptance varies by participant's preference for music No known harmful effects Promoting well-being and sociability, aiding reminiscence, reducing anxiety/stress, and providing distraction may be key elements of effectiveness Moderate investment (moderate time, usual or special caregiver, modest resources)
Pet therapy	Structured or unstructured time with animals, primarily dogs, to promote well-being, socialization and emotional support, and sensory stimulation.	Small evidence base Evidence is preliminary, with some evidence of positive effects on agitation, apathy, disruptive behavior Stuffed or robotic pets may be an effective substitute for live animals More high-quality research with larger samples and consistent implementation protocols required	Degree of acceptance varies by participant's preference for contact with animals Negative outcomes may include allergic reactions, hygiene concerns, or anxiety/agitation Socialization/bonding, emotional support, and sensory stimulation may be key elements of effectiveness Low to moderate investment (minimal to moderate time, usual or special caregiver, modest to moderate resources)
Meaningful activities	Provision of activities designed to enhance quality of life through engagement, social interaction, and opportunities for self-expression and self-determination.	Moderate evidence base Evidence is mixed, but shows some positive effects on agitation; larger effect sizes for activities that are individually tailored Some evidence for positive effect of physical exercise activities on agitation and depressive symptoms More high-quality research with larger samples and longer duration required	Degree of acceptance varies by appropriateness of activity No known harmful effects, except for expected risks associated with physical engagement in activities Enhancing quality of life, social interaction, and opportunities for self-expression and self-determination may be key elements of effectiveness Low to moderate investment (moderate time, usual or special caregiver, modest resources)

Note: BPSDs = behavioral and psychological symptoms of dementia.

Table 4. Structured Care Protocols

Practice	Description	Evidence	Assessment of implementation and investment
Mouth care	Structured protocols for providing mouth care that include person-centered communication and interaction strategies as well as technical skills.	Small evidence base Evidence is preliminary; one study found positive effects on care-resistant behaviors More high-quality research required	Well accepted by participants No known harmful effects Reducing threat, anxiety, fear, and pain may be key elements of effectiveness Low investment (low time, usual caregiver, modest resources)
Bathing	Structured protocols for providing bathing care that include person-centered communication and interaction strategies as well as technical skills.	Small evidence base Evidence indicates positive effects on agitation, aggression, irritability, anxiety More high-quality research required, using consistent implementation protocols and outcome measures	Well accepted by participants No known harmful effects Reducing fear and pain may be key elements of effectiveness Low investment (low time, usual caregiver, modest resources)

Aromatherapy

Aromatherapy is based on the long-standing practice of using scented oils, such as lavender or Melissa oil (lemon balm), to "regulate body activities by control and activation of the autonomic nervous system and the neuroendocrine system" (Press-Sandler, Freud, Volkov, Peleg, & Press, 2016). Given the link between smell and memory, the scent of essential oils (aromatic compounds found in seeds, bark, stems, roots, flowers, and other plant parts) can potentially improve an individual's mood if linked to positive memories; even as olfaction decreases, however, essential oils may have a direct effect on the brain (Behrman et al., 2014).

A number of studies have tested the efficacy of aromatherapy for agitation and aggression in dementia. In these studies, the practice has been administered using room diffusion, sachets, a patch, or skin cream; and dosage has ranged from 3 min to 24 hr for a period of 2–360 days (Strøm et al., 2016). Recent reviews of the moderate evidence base for aromatherapy in dementia have found mixed results (Forrester et al., 2014; Livingston et al., 2014; Press-Sandler et al., 2016; Strøm et al., 2016). For example, one descriptive analysis of randomized controlled trials concluded that applying oil closer to the olfactory system was associated with positive outcomes, whereas the type of oil or duration of treatment made no explanatory difference (Press-Sandler et al., 2016). A different review of practices for agitation in nursing homes (Livingston et al., 2014) found that aromatherapy has not been effective when assessors are masked to the treatment.

Despite the need for more large-scale efficacy trials, current evidence indicates that aromatherapy is well accepted by participants with no harmful effects. Social and physical contact may be a key therapeutic element in aromatherapy practices, such as when scents are provided through the application of a hand cream (Ballard, O'Brien, Reichelt, & Perry, 2002). Our review of aromatherapy suggests that required investment is low, given minimal time needed for learning and implementation, no need for a specialized care provider, and modest resource requirements.

Massage

As a nonverbal means of communication or connection, massage may help offset the social isolation that triggers negative affect and related behaviors (Behrman et al., 2014). Through tactile connection, a person living with dementia may feel comforted and cared about, especially in residential care environments where touch tends to be instrumental and task specific (Gleeson & Timmins, 2004); by the same token, massage may help familiarize the person with his/her care provider and thereby reduce resistance to personal care (Fitzsimmons et al., 2014). Touch may also incur a physiological response, for example a sense of reassurance or calm mediated by the production of oxytocin, and meaningful sensory stimulation may help counteract cognitive decline (Hansen, Jorgensen, & Ortenblad, 2006).

Massage may be applied to different parts of the body, including back, shoulders, neck, hands, or lower legs and feet, using slow or large strokes, rubbing or kneading, noncontact therapeutic touch, or acupressure (Hansen et al., 2006). A small evidence base shows positive results for the effectiveness of massage in helping reduce agitation, aggression, stress, anxiety, depression, and disruptive vocalizations in the immediate or short term (Kales et al., 2015; Moyle, Murfield, O'Dwyer, & Van Wyk, 2013; Randall & Clissett, 2016; Staedtler & Nunez, 2015; Strøm et al., 2016; Hansen, Jorgensen, & Ortenblad, 2006).

Massage appears to be well accepted by participants; it is recommended that individual preference be assessed, however, as the increased stimulation may increase agitation (O'Neil et al., 2011). Our review suggests that minimal investment is required to implement massage practices (minimal time demands, no need for a specialized care provider, and few capital resources). However, the diversity of massage techniques and outcomes suggests that development of specific protocols would be beneficial to enhance

the consistent application and effectiveness of touch-based practices (Moyle et al., 2013). Web-based training modules may be especially beneficial in this regard (Tuohy, Graham, Johnson, Tuohy, & Burke, 2015).

Multisensory Stimulation

Originating in the learning disabilities field (Burns, Cox, & Plant, 2000), MSS is designed to provide "a stress-free, entertaining environment both to stimulate and to relax" (Sánchez, Millán-Calenti, Lorenzo-López, & Maseda, 2013, p. 7), which does not require cognitive processing or short-term memory (Behrman et al., 2014). Because MSS environments are designed to be explored by the individual in his/her own way, MSS is also intended to promote control and autonomy, which may otherwise be denied to persons living with dementia.

MSS involves the stimulation of multiple senses through a combination of light effects, calming sounds, smells, and/or tactile stimulation (Sánchez et al., 2013). Practices have ranged from three sessions (in total) to daily sessions over 15 months, averaging 30 min/session. A leading example of MSS is Snoezelen, a model that includes music, aroma, bubbles, fiberoptic sprays, and projected images (O'Connor, Ames, Gardner, & King, 2009). Other MSS approaches include sensory gardens (Goto, Kamal, Puzio, Kobylarz, & Herrup, 2014) and the incorporation of sensory stimulation into daily care routines (Van Weert, van Dulmen, Spreeuwenberg, Ribbe, & Bensing, 2005; Whall et al., 1997). From the large but diverse body of research on MSS practices, there is positive evidence for the effects of MSS on reducing short-term anxiety, agitation, and apathy (Baker et al., 2003; Millán-Calenti et al., 2016; Sánchez et al., 2013). As with aromatherapy and massage, evidence also suggests that part of the therapeutic benefit of individualized MSS practices may be the dyadic interaction involved (Maseda et al., 2014).

MSS appears to be well accepted, with no negative effects. Different from the other sensory practices, however, our review suggests that moderate investment in resources and time is required. Once resources are secured, care provider time is the primary ongoing cost. As with massage, there is a need for more clearly defined protocols and care provider training to implement MSS (Bauer, Rayner, Koch, & Chenco, 2012).

Bright Light Therapy

Normal aging is associated with changes in the circadian sleep-rest cycle that may result in fragmented nocturnal sleep, including multiple and prolonged awakenings, and increased daytime sleep (Forbes, Blake, Thiessen, Peacock, & Hawranik, 2014). In persons living with dementia, these sleep disturbances tend to be exacerbated by degenerative changes in the suprachiasmatic nuclei (SCN) of the hypothalamus, which generates the circadian rhythm, and can result in BPSDs such as agitation and sundowning. Bright light therapy is designed to promote the synchronization of circadian rhythms with environmental light-dark cycles through stimulation of the SCN (Behrman et al., 2014). This practice may be particularly important for nursing home residents, who otherwise receive limited exposure to bright light (Sloane et al., 2007).

Light therapy can be delivered through a light box, a light visor, ceiling-mounted light fixtures, "naturalistic" lighting that simulates twilight transitions (Forbes et al., 2014), or exposure to natural bright light (Dowling et al., 2008). Practices have ranged from 2,500 to 10,000 lux exposure for 1–2 hr for 10 days to 2 months (Brasure et al., 2016). The evidence base for bright light therapy is moderate but shows mixed results. One recent review found insufficient evidence to recommend light therapy for reducing sleep disturbance or other BPSDs, such as agitation (Forbes et al., 2014); another review found low-strength evidence showing that bright light therapy is similar to standard light in managing agitation and aggression (Brasure et al., 2016). Other reviews have found no efficacy for light therapy and that it may actually worsen agitation (Livingston et al., 2014), although others have found positive effects on agitation and sleep (Cabrera et al., 2015), and mixed results for depression (Hanford & Figueiro, 2013).

Overall, the evidence suggests that bright light therapy may have some therapeutic benefit for reducing agitation, depression, and/or sleep disturbance in some individuals living with dementia, although further research is required. Monitoring is critically important to ensure that bright light does not increase agitation. Our review suggests that bright light therapy requires moderate investment (as it can be administered by the usual care provider with additional time and with low to moderate capital investment). Acceptability may be increased and investment requirements decreased by using natural light (opening windows, going outdoors) or ambient light rather than individual light boxes, which are more expensive and less usable with mobile individuals (Hickman et al., 2007).

Psychosocial Practices

As described in the Introduction, a number of conceptual models explain the emergence of BPSDs as an interaction between an individual's neurological changes and their surrounding environment. Individuals living with dementia may experience anxiety, for example, because memory problems render their surroundings unrecognizable, especially in residential care settings where daily interactions are not supported by long-term memories. Psychosocial practices are specific strategies intended to create a person-centered environment (see Fazio, Pace, Flinner, & Kallmyer, 2018) to help prevent or alleviate BPSDs and improve overall quality of life (Testad et al., 2014; Vernooij-Dassen, Vasse, Zuidema, Cohen-Mansfield, & Moyle, 2010); in this context, they are consistent with the person-centered focus of the needs-driven dementia-compromised behavior model. Prominent practices of this type include validation

therapy, reminiscence therapy, music therapy, pet therapy, and meaningful activities.

Validation Therapy

Rooted in Rogerian humanistic psychology (Livingston, Johnston, Katona, Paton, & Lyketsos, 2005), validation therapy focuses on accepting the reality of the person living with dementia. By focusing empathically on the emotional content of a person's words or expressions, the aim of validation therapy is to alleviate negative feelings and enhance positive feelings.

Validation therapy is implemented through a number of communication techniques, including using nonthreatening words to establish understanding; rephrasing the person's words; maintaining eye contact and a gentle tone of voice; responding in general terms when meanings are unclear; and using touch if appropriate (Mitchell & Agnelli, 2015). The evidence base for validation therapy is small and shows mixed findings. A recent review of personalized psychosocial practices for BPSDs (Testad et al., 2014) identified two validation therapy studies: one study of validation therapy and sensorial reminiscence therapy conducted twice weekly for 12 weeks, with each session lasting 45–60 min, found significant improvements for behavioral disturbance compared to controls (Deponte & Missan, 2007); the other study, which included both individual (20 min, three times per week) and group sessions (45–60 min weekly), found decreased agitation, apathy, irritability, and night-time disturbance (Tondi, Ribani, Bottazzi, Viscomi, & Vulcano, 2007). However, several other reviews found insufficient evidence for the efficacy of validation therapy in reducing BPSDs (Livingston et al., 2005; O'Connor et al., 2009; O'Neil et al., 2011).

Although the evidence base for validation therapy is underdeveloped, the concept of honoring the feelings of the person living with dementia has face validity as part of person-centered dementia care (Kitwood, 1997). Validation therapy is a low investment practice, as it can be integrated into care by usual care providers after modest investment in communication training. Negative effects appear minimal, although there may be risk that an individual's feelings of distress could be exacerbated through validation therapy if care providers are not sufficiently prepared to both honor and alleviate those feelings.

Reminiscence Therapy

Reminiscence therapy involves discussion of past events and experiences with the aim of increasing well-being and providing pleasure and cognitive stimulation (Cabrera et al., 2015). It relates to Erikson's theory of psychosocial development, in which the final "wisdom" stage (posited as age 65 years and older) is characterized by retrospection, or looking back over one's life (Kasl-Godley & Gatz, 2000). The approach is also based on the concept that older memories are more enduring than recent memories (Cammisuli, Danti, Bosinelli, & Cipriani, 2016). Introduced in the 1980s, reminiscence therapy has been considered by some to be "one of the most popular psychosocial interventions in dementia care" (Cotelli, Manenti, & Zanetti, 2012).

Reminiscence therapy can be conducted with an individual or in a group, guided by either free recall (through conversation), specific stimuli (e.g., photographs, music), or a life-review method (often by creating a life-history book). Reminiscence therapy has been tested in 30- to 60-min sessions, one to two times per week for 3–8 weeks (Testad et al., 2014). There is a moderate base of evidence supporting its positive effects on mood, depression, and agitation or distress in the short term; however, the evidence is limited by sample size and heterogeneity, lack of blinded post-treatment assessment, and lack of information about adherence (Cabrera et al., 2015; Cammisuli et al., 2016; Cotelli et al., 2012; Huang et al., 2015; Testad et al., 2014). One review found strongest evidence for the benefit of reminiscence therapy in improving mood and depressive symptoms, with four studies reporting significant benefits compared to control (Testad et al., 2014).

As with validation therapy, reminiscence therapy fits well within a broader, person-centered approach that aims to recognize and honor the individual (Mitchell & Agnelli, 2015). In residential care settings, learning about each person's personal history and meaningful events is considered important for combatting isolation and loneliness (Huang et al., 2015). Validation therapy requires moderate investment in training and implementation time; an optional expenditure is the cost of audio-visual aids, such as film projectors or music players (Lazar, Thompson, & Demiris, 2014). There is no evidence of adverse effects of reminiscence therapy (Woods, Spector, Jones, Orrell, & Davies, 2005), although the onus is on care providers to guide reminiscence toward positive memories, rather than negative memories that may cause distress.

Music Therapy

Music may help prevent or alleviate distressing symptoms of dementia in a number of ways. As a leisure activity, music is thought to promote well-being and fosters sociability in part by offsetting the isolation that can result from progressive loss of verbal ability (Cammisuli et al., 2016). Furthermore, because musical memory is generally retained longer than other memories, music can facilitate reminiscence and potentially reduce anxiety through general mind activation and specific memory triggers (Spiro, 2010). Consistent with the progressively lowered stress threshold model, music may reduce stress by creating a sense of familiarity and regularity in the environment (Behrman et al., 2014).

Broadly, musical activities can be classified as either receptive (listening to music) or participatory (making music; Mitchell & Agnelli, 2015). Practices include personalized music delivered through iPods or as part of daily care, or group sessions using prerecorded music or delivered by staff or music therapists (Chang et al., 2015). They have generally been implemented for up to

1 hr, two to three times per week, for an average of 10 weeks (Ueda, Suzukamo, Sato, & Izumi, 2013). A number of reviews have found a moderate evidence base supporting the positive effects of music therapy on the short-term reduction of a range of BPSDs, including anxiety, agitation, and apathy (Cammisuli et al., 2016; Chang et al., 2015; Gómez-Romero et al., 2017; Kales et al., 2015; Konno, Kang, & Makimoto, 2014; Livingston et al., 2014; Millán-Calenti et al., 2016; Strøm et al., 2016; Ueda et al., 2013). A recent meta-analysis concluded that individual music therapy provided once a week and group music therapy provided several times a week are optimal for reducing disruptive behaviors, anxiety, and depressive mood (Chang et al., 2015). Another review of music therapy for agitation found evidence for individualized music practices and interactive modalities (e.g., clapping, singing, and dancing; Millán-Calenti et al., 2016). A number of other studies have supported the efficacy of personalized or preferred music (Doody et al., 2001; Garland, Beer, Eppingstall, & O'Connor, 2007; Sung, Chang, & Lee, 2010).

Music therapy appears to be an enjoyable and effective approach to alleviate BPSDs and create well-being. Our review suggests that investment is moderate, as time and training are required to set up and sustain a music program; more resources are required over the long term for group sessions led by a music therapist than for individualized recorded music sessions. Music therapy does not appear to have adverse effects although, and as with other BPSD practices, a personalized approach is recommended so that the practice aligns with the individual's preference.

Pet Therapy

Pet therapy, also known as animal-assisted therapy, has been used for several decades to treat mental and physical health disorders, including in dementia, intending to promote socialization and emotional support, sensory stimulation, and enhanced well-being (Bernabei et al., 2013). Physiologically, quiet interaction with an animal can help lower blood pressure and increase production of neurochemicals associated with relaxation and bonding, which may in turn reduce BPSDs (Filan & Llewellyn-Jones, 2006).

Pet therapy in dementia, most often involving dogs, has been tested daily or one to two times per week for 30–90 min for 1–12 weeks, in a structured or unstructured format (Bernabei et al., 2013). In small studies, it has reduced agitation and disruptive behavior, increased social and verbal interactions, and decreased passivity (Bernabei et al., 2013; Brodaty & Burns, 2012; Filan & Llewellyn-Jones, 2006; Strøm et al., 2016). Preliminary studies using a robotic dog or cat—which may be more feasible to implement by reducing maintenance costs, but does require initial capital investment—have shown positive increases in mood and decreased agitation (Bernabei et al., 2013; Petersen, Houston, Qin, Tague, & Studley, 2017). Overall, there is a small and preliminary evidence base for pet therapy, with most studies using quasi-experimental or repeated measure within-participant designs (Livingston et al., 2014; O'Neil et al., 2011).

Although the evidence is too preliminary is too preliminary to permit specific recommendations, our review suggests that pet therapy is a practice that requires minimal to moderate investment, depending on the initial or ongoing costs of acquiring and/or caring for the animal. Specialized training and resource allocation may be required to care for and handle the animal or to contract with an outside agency, unless stuffed or robotic pets are used in place of live animals. Negative outcomes may include allergic reactions, hygiene concerns, or anxiety/agitation among some individuals, such as those who had negative experiences with animals in the past.

Meaningful Activities

The provision of individualized, meaningful activities is considered an important element of person-centered care and may help prevent or alleviate BPSDs by enhancing overall quality of life through engagement, enhanced social interaction, and opportunities for self-expression and self-determination (Han, Radel, McDowd, & Sabata, 2016). By contrast, lack of meaningful activity is cited by persons living with dementia and family members as one of the most "persistent and critical" unmet needs (Trahan, Kuo, Carlson, & Gitlin, 2014). The importance of tailoring activities is noted as particularly important for ensuring that individuals are able to fully participate and benefit, regardless of their cognitive capacity or functional abilities (Trahan et al., 2014).

These practices comprise a range of leisure and social activities, also known as recreational activities, usually tailored to the individual's preferences, cognitive and functional abilities, lifelong habits and roles, and memories and past experiences (Han et al., 2016). Overall, the evidence base for individualized activities is moderate, with mixed findings. A recent review found that nonindividualized meaningful activities reduced mean agitation levels in the short run, with mixed findings about the additional benefit of individualizing activities according to functional level and interest; there was a lack of evidence about longer-term effect (Livingston et al., 2014). Other reviews have found more support for individually tailored activities (Brodaty & Burns, 2012; de Oliveira et al., 2015); however, evidence is still insufficient to draw conclusions about the comparative effectiveness of practices tailored to different characteristics (Brasure et al., 2016). As a specific type of activity, there is some evidence for the effectiveness of exercise programs (including endurance, strength training, and/or general physical activation; Fleiner, Leucht, Förstl, Zijlstra, & Haussermann, 2017) on agitation and depressive symptoms for individuals living with dementia, although effect sizes are small and the evidence is limited by heterogeneous designs, small samples, and short practices (Barreto, Demougeot, Pillard, Lapeyre-Mestre, & Rolland, 2015; Brett, Traynor, & Stapley, 2016; Forbes, Forbes,

Blake, Thiessen, & Forbes, 2015; Potter, Ellard, Rees, & Thorogood, 2011).

Like other nonpharmacological practices for BPSDs, the provision of meaningful activities is consistent with the broader aims of person-centered care. Investment required for implementation varies depending on the type of activity, but in most cases will be low to moderate; meaningful activities take time, but can often be facilitated by regular care providers or informal caregivers without extensive additional training.

Structured Care Protocols

Personal care routines can trigger a range of negative feelings and experiences for individuals, including pain or discomfort, fear, and embarrassment (O'Connor et al., 2009); the needs-driven dementia-compromised behavioral model suggests that BPSDs represent meaningful expressions of these feelings and experiences. Good mouth care, for example, is important for maintaining or improving quality of life and reducing risk of morbidity and mortality; however, practices such as tooth brushing are often resisted by persons living with dementia due to pain and/or the intimate and potentially intrusive nature of the practice (Zimmerman, Sloane, Cohen, & Barrick, 2014). Similarly, bathing can create embarrassment or anxiety as well as discomfort, including due to arthritic pain experienced during movement (Dunn, Thiru-Chelvam, & Beck, 2002). Structured care protocols, adapted to an individual's needs and preferences, may help family caregivers and care providers implement care in a person-centered and technically proficient way that avoids or minimizes pain and other behavioral triggers. Of course, in all instances, pain itself should be assessed—such as through facial cues, body movements, and/or vocalizations—and appropriately addressed, including with medication if indicated (Achterberg et al., 2013; Husebo, Ballard, & Aarsland, 2011; Kovach et al., 2006; Pieper et al., 2013).

Mouth Care

Anticipated resistance to daily mouth care (e.g., tooth brushing or mouth swabbing) is one of the reasons that oral hygiene tends to be neglected for people living with dementia, especially in residential care settings (Zimmerman et al., 2013). Anxiety or agitation during mouth care may be the manifestation of a limbic threat identification and fear response, a response that is progressively less mediated by cortical control in cognitive impairment (Jablonski, Therrien, & Kolanowski, 2011). Using mouth care protocols that include person-centered strategies for approaching, communicating with, and touching the individual, along with technical skills, may help reduce threat and thereby minimize resistive behaviors.

This review found that the evidence base for the effect of mouth care protocols on global or individual BPSDs is small and preliminary. One review (Konno et al., 2014) found evidence from one pilot study that mouth care using an ability-focused, threat-reduction approach administered over a 2-week period significantly improved care-resistant behaviors (Jablonski et al., 2011). Findings from another evidence-based practice, 'Mouth Care without a Battle', suggest that care providers who have been trained to use a mouth care protocol feel more able to effectively address behavioral responses during care (Zimmerman et al., 2014).

From the limited evidence, our assessment is that little investment is required to implement structured protocols to prevent or minimize BPSDs during mouth care. Minimal capital expenditures include appropriate toothbrushes and other mouth-care supplies. However, training is required to ensure that family caregivers and other care providers are well prepared to implement the protocol appropriately, effectively, and consistently. No harmful effects have been identified.

Bathing

An intimate activity inscribed by cultural norms and individual preferences, bathing is the personal care task associated with the highest frequency of behavioral expressions of distress for persons living with dementia (Gozalo, Prakash, Qato, Sloane, & Mor, 2014). As with mouth care, distress during bathing may signify a fear response that may potentially be alleviated by implementing person-centered strategies and skills.

A range of bathing protocols have been tested for a duration of 2–6 weeks, with a primary focus on providing person-centered showers or bed baths (depending on the individual's preference) and enhancing the bathing environment through preferred music or calming sounds. Results from this small evidence base suggests that bathing protocols show positive results in reducing agitation, aggression, irritability, and anxiety as well as physical discomfort (Konno et al., 2014; O'Connor et al., 2009; Pieper et al., 2013), but more high-quality studies are required (Kales et al., 2015).

Our review suggests that implementing structured protocols for bathing requires minimal investment, given that they can be incorporated into ongoing care by usual staff, with some training and support. No harmful effects have been identified.

Discussion

A large body of research indicates that a range of sensory practices, psychosocial practices, and structured care protocols can be effective to some extent in addressing BPSDs, thus aligning with the causal mechanisms described in the competence-environmental press framework, the progressively lowered stress threshold model, and the needs-driven dementia-compromised model. Although the evidence base for virtually every practice requires further development, it was possible to identify a conceptual justification for the

potential effectiveness of each one (e.g., meaningful activities conceptualized as addressing a critical unmet need for social engagement expressed through anxiety or apathy). Furthermore, all can be implemented with minimal to moderate investment of time and resources, and depending on the investment required, most of the practices can be implemented by family caregivers in home-based settings as well as by paid care providers in other settings, suggesting a good likelihood of "management continuity" (Haggerty et al., 2003) across care settings. Broadly speaking, enhanced continuity of care is associated with reduced health care use, cost, and complications (Hussey et al., 2014). In dementia specifically, continuity of care may also help promote the "continuation of self and normality" that has been articulated by individuals and their families as the core of person-centered care (Edvardsson, Fetherstonhaugh, & Nay, 2010).

Two caveats are noted regarding use of evidence-based practices to address BPSDs. First, conceptual models of BPSDs indicate that practices should reflect environmental press as experienced by the individual, his/her experience of stress and coping reaction(s), and his/her specific unmet need(s). Considered this way, practices should be responsive to the perspective of the person living with dementia, support his/her sense of self, promote individualization and relationship building, and structure an environment that promotes well-being (Fazio et al., 2018). In sum, nonpharmacological practices to treat BPSDs are recommended to be person-centered. For example, the potential for validation or reminiscence therapy to evoke distressing memories for a particular individual requires careful consideration, and pet therapy may only be acceptable to individuals who are comfortable around animals. However, little literature has specifically examined outcomes in relation to the extent to which practices have been individually chosen and tailored, which seems an area important for future study; in fact, it may be the lack of individualization that in some cases is responsible for inconclusive evidence. For this reason, it is important that systems be put in place to evaluate the effectiveness of practices and allow for change as needed. The process of selecting and monitoring practices to evaluate their individual effectiveness is usefully captured by the Describe, Investigate, Create, Evaluate (DICE) cycle for the person-centered management of BPSDs (Kales, Gitlin, & Lyketsos, 2014).

Second, many practices for BPSDs lack readily accessible evidence-based protocols for administration. The absence of such protocols means that family caregivers and other care providers do not have sufficient guidance to implement practices that are likely to be efficacious as part of their caregiving efforts. Given that many of the manuscripts reviewed for this article were derived from research that used standardized protocols, creating a toolkit of evidence-based practices for BPSDs seems an easy next step to improve the quality of life of people living with dementia. Once such protocols are available, care providers are advised to adhere to the protocols of administration to ensure that practices are used. That said, the protocols themselves may need to evolve over time, given the progressive nature of dementia and the individualized nature of BPSDs.

An additional consideration relates to the investment required to enact the practices. The typology used in this article (Seitz et al., 2012) provides general categories of time investment (combining time for training and implementation) and equipment or capital costs (combining initial and ongoing costs). It is conceivable, however, that more finite figures or a different classification would better describe "investment" for a given user. For example, a practice that requires >4 hr of training is considered to be a high investment, but if it may be implemented in <15 min, a user might then rate it as a moderate, or perhaps low, investment. Indeed, the developers suggest that if a practice does not meet all criteria within a category, it may best be assigned to the next lowest category. Therefore, consideration and ratings of investment are best individualized, which is consistent with the overall person-centered focus of care provision.

Based on this synthesis of findings from previous systematic reviews, and a critical consideration of implementation and investment required to implement evidence-based practices to address BPSDs, the following five practice recommendations are suggested:

1. Identify characteristics of the social and physical environment that trigger or exacerbate behavioral and psychological symptoms for the person living with dementia.

   BPSDs result from changes in the brain in relation to characteristics of the social and physical environment; this interplay elicits a response that conveys a reaction, stress, or an unmet need and affects the quality of life of the person living with dementia. The environmental triggers of BPSDs and responses to them differ for each person, meaning that assessment must be individualized and person-centered.

2. Implement nonpharmacological practices that are person centered, evidence based, and feasible in the care setting.

   Antipsychotic and other psychotropic medications are generally not indicated to alleviate BPSDs, and so nonpharmacological practices should be the first-line approach. Practices that have been developed in residential settings and which may also have applicability in community settings include sensory practices, psychosocial practices, and structured care protocols.

3. Recognize that the investment required to implement nonpharmacological practices differs across care settings.

   Different practices require a different amount of investment in terms of training and implementation, special-

ized caregiver requirements, and equipment and capital resources. Depending on the investment required, some practices developed in residential settings may be feasible for implementation by caregivers in home-based settings.

4. Adhere to protocols of administration to ensure that practices are used when and as needed, and sustained in ongoing care.

   Protocols of administration assure that there is a "guideline" for care providers as they strive to alleviate BPSDs. These protocols may evolve over time, responsive to the particular components of the practice that are most effective for the person living with dementia.

5. Develop systems for evaluating the effectiveness of practices and make changes as needed.

   The capacity and needs of persons living with dementia evolve over time, and so practices to alleviate BPSDs also may need to evolve over time. Therefore, it is necessary to routinely assess the effectiveness of the practice and, if necessary, adapt it or implement other evidence-based practices.

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Conflict of Interest

None reported.

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Review Article

Long-Term Care Workforce Issues: Practice Principles for Quality Dementia Care

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Abstract

Purpose : This article is one in a series of articles in this supplement addressing best practice for quality dementia care. The Alzheimer's Association, in revising their Dementia Care Practice Recommendations for 2017 has identified staff across the long-term care spectrum as a distinct and important determinant of quality dementia care. The purpose of this article is to highlight areas for developing and supporting a dementia-capable workforce.

Methods : The Alzheimer's Association Principles For Advocacy To Assure Quality Dementia Care Across Settings provide a framework to examine interventions to support the dementia care workforce in long-term care settings. Evidence-based approaches that represent these principles are discussed: (a) staffing, (b) staff training, (c) compensation, (d) supportive work environments, (e) career growth and retention, and (f) engagement with family.

Results : Although not all settings currently require attention to the principles described, this article proposes these principles as best practice recommendations. Recommendations and future research considerations to further improve the lives of those who live and work in nursing homes, assisted living, hospice, and home care, are proposed. Additional areas to improve the quality of a dementia care workforce person-centered care information, communication and interdepartmental teamwork, and ongoing evaluation are discussed.

Keywords: Dementia, Person-centered care, Long-term care, Home- and community-based care and services

Direct care providers (DCPs) play a vital role in the provision of long-term care (Graf, Cignacco, Zimmermann, & Zuniga, 2016) and dramatically shape the daily lives of persons with dementia (Squires et al., 2015). For the purpose of this article, the term long-term care will be used to encompass nursing homes, assisted living, residential care, hospice, and home health environments. DCPs are the "hands-on" workers in long-term care and are identified specifically as the nurses, nursing assistants or nurse's aides, medication aides/technicians, personal care, home health, and hospice aides. DCPs assist with all aspects of physical care, offer meaningful activities, and hold in their hands the quality of care and quality of life of individuals with dementia. Through their close contact with persons with dementia, DCPs gain a knowledge of the individual with dementia, preferences, behaviors, and functioning, and are often the first to notice physical changes, signs of illness, pain, or decline (Jansen et al., 2017).

Each person who works in a long-term care organization, through their interactions can influence the long-term care experience and quality of life of individuals with dementia and their families. The DCPs collaborate with other staff who are important to the lives of the individuals with dementia and include those who work in dietary, housekeeping, activities, social services, therapy, admissions, and other departments (Gilster, 2006; Hunter, Hadjistavropoulos, Thorp, Lix, & Malloy, 2016).

Demand for Dementia Care Providers

There are 47 million people worldwide diagnosed with dementia and 9.9 million new cases each year (World Health Organization Media Center, 2017). Currently, there are an estimated 5.5 million Americans with Alzheimer's disease and dementia and the incidence is expected to increase to 7.1 million in 2025 as the number of people 65 and older surges. More than 80% of the care of individuals with dementia is provided by unpaid care providers (Alzheimer's Association, 2017a). However, the ratio of the number of family caregivers to recipients is decreasing. In 2010, there were seven caregivers for every older person needing assistance and the number is expected to drop to 4:1 in 2030. The number of unpaid caregivers is not sufficient to meet the increasing number of older adults in need of care, creating an even greater demand for paid DCPs (Redfoot, Feinberg, & Houser, 2013).

Increasing numbers of people with dementia will require more caregivers, both family caregivers as well as long-term care providers. The need for paid care providers will continue to increase from 3.27 million in 2014 to 4.56 million in 2024. At the same time the number of those who comprise the bulk of the care providers, women between the ages of 25 and 64 is anticipated to remain the same (Gao, Tilse, Wilson, Tuckett, & Newcombe, 2015).

The growing demand and ability to retain care providers continues to challenge the long-term care industry. Turnover is widespread, in home care, hospice, and residential care environments and ranges from 40% to well over 100% (Banaszak-Holl, Castle, Lin, Srivastava, & Spreitzer, 2015). Unless significant changes are made in long-term care the future looks bleak as the demand for DCPs will outpace the supply.

Methods: A Framework for a Quality Dementia Workforce

The Alzheimer's Association (AA) posited that the "single most important determinant of quality dementia care across all care settings is direct care staff," (Alzheimer's Association, 2017b). The Alzheimer's Association Principles For Advocacy To Assure Quality Dementia Care Across Settings provide a framework to examine interventions to support the dementia care workforce in long-term care settings (Table 1). Search terms included "dementia" OR "Alzheimer's" AND "staff" and each of the following terms: (a) levels (OR deployment OR numbers); (b) training (OR education OR teaching); (c) compensation (OR salary OR benefits); (d) work environments (OR practice environment); (e) career growth (OR advancement); (f) family engagement (OR family and partnership); and (g) hiring. Interventional research focused on direct care workers, and published between 2000 and the present were included, representing nursing home, assisted living, residential care, home care and hospice settings.

Results

Staffing Levels

Staffing requirements for DCPs in long-term care environments providing dementia care vary by the setting, state, and country. Federal mandatory staffing requirements exist for registered nurses and licensed practical nurses in nursing homes, yet there is no minimum requirement for state tested/certified nursing assistants, though many states have established additional staffing requirements for these facilities (Harrington, 2010). Residential care, including assisted living facilities (RC/AL) are licensed by the respective state agencies, though most states do not specify minimum staffing levels or ratios in dementia care (Carder, 2017).

Beyond meeting any mandatory DCP staffing numbers required in organizations serving persons with dementia, there is a growing awareness of the need to deploy DCPs in a manner that aligns with resident routines and needs (Cohen-Mansfield & Bester, 2006). Nursing assistants have reported the important role that flexible schedules have in contributing to individualized care (Curry, Porter, Michalski, & Gruman, 2000). Further, flexible schedules may be useful in decreasing turnover and therefore in avoiding the costs associated with frequent hiring and training (Weale, Wells, & Oakman, 2017).

For example, the Adards Nursing Home in Tasmania, Australia promotes flexibility as a central management principle in working with both residents and staff members. Flexibility in regard to residents is manifested in their ability to control the time they get up, eat, go outdoors, and go to sleep, with access to multiple opportunities for activities that are common to people who live in the outside community (Cohen-Mansfield & Bester, 2006). The routines of staff members are flexible in that they are encouraged to eat

Table 1. Long-Term Care Workforce Issues: Principles for Advocacy to Assure Quality Dementia Care Across Setting

- *Staffing levels* should be adequate to allow for proper care at all times—day and night.
- Staff should be sufficiently *trained* in all aspects of care, including dementia care.
- Staff should be adequately *compensated* for their valuable work.
- Staff should work in a supportive atmosphere that appreciates their contributions to overall quality care. Improved *working environments* will result in reduced turnover in all care settings.
- Staff should have the opportunity for *career growth*.
- Staff should *work with families* in both residential care settings and home health agencies.

Note: Adapted from Alzheimer's Association (2017b).

meals with residents, converse and spend time walking with them, or engage in other activities with them. Flexible staff schedules, including shorter hours, support this approach. The flexibility and part-time assignments have positively impacted turnover, staff recruitment, absenteeism, and sick leave. Since the facility opened in 1991, the average tenure of staff members is 7.2 years, and the average turnover rate for those years has been 10% (Cohen-Mansfield & Bester, 2006). This is in marked contrast to the turnover rates of 50%–100% reported in the United States (Castle, 2005; Mukamel et al., 2009).

Staff Training

Unlike other illnesses, the unique characteristics of dementia, such as impaired communication, disorientation, confusion, and behavioral changes demand training for DCPs to increase understanding and strategies for caregiving (Alzheimer's Association, 2017a). Care providers working with persons with dementia have identified the need for sufficient training (Pitfield, Shahriyarmolki, & Livingston, 2011). Several literature reviews have described the benefits of dementia training, including a positive approach to dementia and less work-related stress (Barbosa, Nolan, Sousa, & Figueiredo, 2017; Islam, Baker, Huxley, Russell, & Dennis, 2017). Training can be categorized based on three types of targeted outcomes: staff outcomes, patient outcomes, and organizational outcomes.

Further, DCPs and staff require an understanding of the concept of person-centered care in an effort to deliver high quality care for individuals with dementia (Kim & Park, 2017). The fundamentals of person-centered care, best practice, and approaches to care are discussed within this supplement in the article on person-centered care, outlining the essential components for care and training (Fazio, Pace, Flinner, & Kallmyer, 2018). Recognizing the person with dementia as a unique individual, with a distinctive life story assists the care providers to view people with dementia as a whole person, not simply a task or person with a disease (Gronhdal, Persenius, Baath, & Helgesen, 2017).

Training and Staff Outcomes

Spector, Revolta, and Orrell (2016) conducted a systematic review that examined the effect of staff dementia (Type 1) training upon staff outcomes in care homes, nursing homes and assisted living. They found that most training programs incorporated person-centered principles and aimed to improve communication between care staff and residents. Staff outcomes included knowledge, attitude, self-efficacy, burnout, and job satisfaction. In these studies which varied in methodological quality, knowledge showed the greatest increase. Stress and burnout showed more variation as outcomes. There was no association between training intensity and outcomes.

Recent studies have examined innovative training approaches. A Norwegian study examined the effectiveness of the Dementia ABC educational program (Rokstad et al., 2017). In addition to written materials, the intervention includes multidisciplinary reflection groups and workshops. The positive impact was evident in scores of patient-centeredness and job satisfaction. The Ladder to the Moon Culture Change Studio Engagement Program (CCSEP) is a staff training approach based on the Positive Psychology framework that uses theatre- and film-based activities. In qualitative responses staff reported an improved sense of teamwork, more positive attitudes towards residents, as well as some concerns about using theatrical intervention (Guzmán, Wenborn, Ledgerd, & Orrell, 2017a). Quantitative responses revealed an increase in positive interactions post intervention, and a significant increase in the building relationship techniques in the care setting. Survey responses also indicated that the intervention did not significantly affect the happiness or job satisfaction of care home staff (Guzmán, Wenborn, Swinson, & Orrell, 2017b).

Training and Resident/Patient Outcomes

In a review of 19 studies, McCabe, Davison, and George (2007) found no effect of staff training upon outcomes in residents with dementia. However, in a later systematic review of 20 studies that focused specifically on training interventions to reduce behavioral and psychological symptoms of dementia (BPSD), Spector, Orrell, and Goyde (2013) found evidence that training had some positive impact upon BPSD and improved the interaction between staff and residents. Training was also found to impact the way staff behaved towards residents (Spector et al., 2013).

No links were found between the theoretical orientation of training programs and their effectiveness. However, studies did demonstrate that training that incorporated the support of management was more likely to be effective (Spector et al., 2013). For example, Burgio and colleagues (2002) supplemented four weeks of behavior management training of nursing assistants, which included hands-on training, with formal staff management (FSM) implemented by nursing supervisors (a Type III intervention). The components of the FSM system included (a) a clear and specific description of behavioral skills, (b) CNA self-monitoring, (c) LPN monitoring of CNA skill performance, (d) verbal and written performance feedback to CNAs, and (e) CNA incentives for achieving established performance criteria. The behavior management skills training program improved CNAs' ability to interact with nursing home residents who experienced BPSD, and the residents showed sustained reductions in agitation. Also, the FSM system was more effective for maintaining communication skills 6 months after training (Burgio et al., 2002).

The STAR intervention, a Type IV intervention, consists of two 4-h workshops augmented by four individualized on-site consultations and three leadership sessions. The intervention reported improved resident outcomes in assisted living (Teri, Huda, Gibbons, Young, & van

Leynseele, 2005). STAR demonstrated reduced levels of affective and behavioral distress compared with control residents. Additionally, the staff reported less adverse impact and reaction to residents' problems ($p < .05$) and more job satisfaction ($p < .10$) compared with control staff.

Landreville, Dicaire, Verreault, and Levesque (2005) reported a reduction in BPSD with the use of 8 h of class instruction followed by 8 h of weekly supervision by the trainers (Type IV intervention). In addition to supervisory support, care planning has been a critical complement to some training programs. In a large cluster randomized trial, Chenoweth and colleagues (2009) demonstrated that dementia care mapping along with patient-centered care training and leadership engagement, was associated with less agitation in persons with BPSD (Type IV intervention). Falls were less in the sites that used mapping alone but falls increased in the sites that used patient-centered care alone (Chenoweth et al., 2009). More recently, the OASIS educational program, also a Type IV intervention, targeted all NH staff (direct care and nondirect care), engaged supervisory staff and used a train-the-trainer model that emphasizes reframing behavior and care plans that capitalize on resident strengths (Tjia et al., 2017). The nursing homes that implemented OASIS experienced a reduction in antipsychotic use in persons with dementia, but the improvement was not sustained.

Although undetected pain is a common problem in persons with dementia (Husebo, Wilchterberg, & Flo, 2016), it has rarely been the focus of training programs. PAIN-Dem training was delivered to care staff from three care homes in South London, along with guidance to supervisors and resources to encourage improved pain management over 4 weeks (Type IV intervention). Although staff demonstrated improved pain management behavior, there was no improvement in pain outcomes (Petyaeva et al., 2017).

DCPs and staff in community based and long-term care environments specifically request additional training and the chance to be involved in the development of the training programs (Talbot & Brewer, 2016). Staff desire more practical learning methods and application, as well as training that is relevant to their daily work including real life situations and solutions (Bishop, 2014; Kolanowski, Van Haitsma, Penrod, Hill, & Yevchak, 2015; Stanyon, Griffiths, Thomas, & Gordon, 2016; Talbot & Brewer, 2016).

Training and Organizational Outcomes

In a study of training requirements and outcomes, Trinkoff found that training for certified nursing assistants above the mandated federal requirement led to less adverse events, pain, falls with injury and depression. A strong association between the number of inservice hours and quality indicators suggested a link between ongoing training and quality of care (Trinkoff, Storr, Lerner, Yang, & Han, 2016). There is a need to make training relevant and accessible for DCPs and all staff, in all long-term care environments. Additional research is needed to evaluate organizational strategies that support and engage DCPs in training, orientation, and education, as well as determine the impact of training on staff stress, satisfaction, and retention, and effect on persons with dementia.

Compensation

The "monetary needs" of nursing assistants working in long-term care settings for older people with dementia was identified in qualitative work as an important reason to work in long-term care (Sung, Chang, & Tsai, 2005). This finding is consistent with early studies (Garland, Oyabu, & Gipson, 1988; Monahan & McCarthy, 1992). Compensation in wages, the provision and payment of health insurance is a concern for DCPs in regard to satisfaction, recruitment, and retention in all sectors of long-term care (Howes, 2008; Kemper et al., 2008; Paraprofessional Healthcare Institute, 2013; Probst, Baek, & Laditka, 2010). However, Squires and colleagues (2015) found in a systematic review that organizational factors such as workload, resources, and individual factors such as autonomy and empowerment to be greater predictors of job satisfaction than satisfaction with salary/benefits. Meaningful work was more important than hourly wages with intent to leave for residential DCPs (Gao et al., 2015). Stone and colleagues (2017) found that intent to leave for home care workers was dependent upon the overall household income level over the federal poverty level and the provision of health insurance though hourly wages were not. Thus, though compensation is important, it is only one of the expressed needs of DCPs across settings (Stone et al., 2017).

Supportive Work Environment

Many challenges exist for DCPs in the provision of care to persons with dementia while at the same time meeting the many expectations and demands of families (Coates & Fossey, 2016; Zimmerman et al., 2005). DCPs have reported that the work environment influences their experience as well as those of the residents in long-term care residences. A national survey conducted in the Netherlands found that person-centered care is beneficial to the nursing staff, specifically when the nursing staff feel supported by their supervisor (Willemse et al., 2015). Qualitative reports indicate that efforts to provide individualized care are supported by supervisors who provide hands-on help working with residents, are open to new ideas, and policies that promote an inclusive approach to care planning (Cohen-Mansfield & Bester, 2006; Curry et al., 2000). Further, phenomenological research conducted by Law, Patterson, and Muers (2017b) suggests the need for supervisors to support strong and supportive relationships between health care assistants and residents. They suggest opportunities for staff to explore their emotional reactions through reflective practice groups or clinical supervision in order to reduce

any adverse impact on care provision (Law et al., 2017b). This recommendation is corroborated by earlier work conducted by Edvardsson, Sandman, Nay, and Karlsson (2009) with nursing staff in residential dementia care. The researchers identified that in addition to staff age and educational level, perception of the caring environment and opportunity to have discussions of difficulties and ethics at work were salient predictors of job strain (Edvardsson et al., 2009).

Career Growth and Retention

In an integrative analysis of reports, articles, and website information on the labor market for dementia care, researchers found that the main reason for quitting a care job was lack of job satisfaction. Dementia care workers describe a lack of appreciation and dissatisfaction about the quality of care they were able to provide as the major sources of job dissatisfaction (Vernooij-Dasssen et al., 2009).

In contrast, a mixed method study with Australian nurses in acute, subacute, community, and residential health care settings reported reasonable satisfaction (Chenoweth, Merlyn, Jeon, Tait, & Duffield, 2014). Nurses who felt valued and supported by the organization and their colleagues were more positive about their work. Perceived facilitators of job satisfaction were education, training, supervision, mentoring opportunities, and appropriate compensation.

There is also evidence that management practices used to empower certified nurse assistants (CNAs) and nurses can increase retention and improve resident outcomes (Brannon & Mor, 2005). LEAP ("Learn," "Empower," "Achieve," "Produce"), a comprehensive long-term care workforce development initiative, aims to educate, empower, and retain long-term care nurses and CNAs (Hollinger-Smith & Ortigara, 2004). LEAP consists of two modules. One module is a 6-week (18 h total) workshop targeting nurse managers and charge nurses to develop essential roles of leader, care role model, clinical expert, and care team builder. The second module is a 7-week (14 h total) workshop focused on career development for CNAs. LEAP demonstrated increases in leadership effectiveness, work empowerment, job satisfaction, and perceptions of the organizational climate. Improvements in quality indicators, reduced number of health deficiencies, and decreased nurse and CNA turnover were also reported (Hollinger-Smith & Ortigara, 2004).

In anticipation of a pending workforce shortage to care for an aging population, human resource experts recommend traditional practices to recruit and retain quality staff, including benefits packages, reward and recognition, and flexible scheduling (Jarousse, 2011). Additionally, they recommend behavior-based interviewing and peer interviewing to build effective, long-term teams. Sung and colleagues (2005) recommend the use of a screening process to assess job motivation and attitudes toward persons with dementia. Researchers at the Indiana University Center for Aging Research have developed an innovative method of screening for critical abilities expected in the frontline care provider position, the Care Coordinator Assistant (Cottingham et al., 2014). They created a new screening process, building on the multiple mini interview (MMI) format to evaluate the ability to express "caring" and empathy. The Care Coordinator Assistant MMI is comprised of six stations that simulate frequently encountered, challenging scenarios in persons with dementia. The interviewer then evaluates the candidate's responses and abilities. Overall, the six-station MMI, with two to three items per station, provided factorial valid measures and good predictive ability. Additionally, the interviewers reported that the process was not burdensome and was helpful in discriminating between candidates (Cottingham et al., 2014).

Orientation to include dementia education before a new employee is assigned to provide care for a person with dementia enhances their understanding of the disease and improves their ability to provide care and interact in a more appropriate fashion (Talbot & Brewer, 2016). Additional topics recommended at orientation include person-centered dementia care, behavioral strategies, alternatives to medication, abuse and neglect, and safety (Alzheimer's Association, 2017c). Providing dementia training in an orientation has been found to benefit not only the organization, but indicates to the new employee that the organization recognizes their importance, and has proven beneficial to staff retention (Gao et al., 2015; Gilster, 2006; National Nursing Home Quality Improvement Campaign, 2016).

Engagement With Family

Effective partnership with families is recognized as an integral role in the care of persons with dementia (Robison et al., 2007). Hennings, Froggatt, and Keady (2010) conducted a systematic review of families' experiences with end of life care in care homes. They found that families wanted frequent contact, empathy, reassurance, and engagement in decision-making with support along the way. Graneheim, Johansson, and Lindgren (2014) examined families' experiences of transition into long-term care through a meta-ethnographic study incorporating a systematic literature search. Families wanted staff to show genuine concern for them and their family member, to consider the family member's views, and facilitate family's ability to influence the plan and delivery of care (Graneheim et al., 2014).

Law, Patterson, and Muers (2017a) extended this line of inquiry with a systematic review that identified that families want consistent, knowledgeable staff who interact well with both them and the person with dementia. The authors conclude that staff education should focus not only on the clinical and practical needs of persons with dementia but also how to interact and partner with families (Law et al., 2017a). Robison and colleagues (2007) studied an intervention to improve staff and family communication in nursing home dementia units, and found that the program Partners

in Caregiving was an effective method to increase support to staff, families, and residents. Many families of persons with dementia enjoy participating in the provision of information such as life stories to encourage DCP's ability to recognize and value the person with dementia (Grøndahl, Persenius, Bååth, & Helgesen, 2017).

Documenting, sharing life stories can be an opportunity to engage residents, families, and staff and particularly important in caring for persons with dementia who have lost their ability to share such information and communicate their needs and desires. Life stories is a way to offer staff insight into the world of the person with dementia before the disease and can enhance the DCPs and staff's ability to connect, interact, and create improved strategies for caregiving. Grøndahl found in a systematic review that creating life stories, recording and sharing aspects of a person's past and present life and using that information for planning and providing care was beneficial for the person with dementia, the family, DCPs, and staff. Staff attitude towards persons with dementia improved and the process of creating life stories was enjoyable and enhanced their relationship with the person with dementia. However, in one study the staff perceptions did not improve significantly (Grøndahl et al., 2017).

Supportive relationships may be enhanced through the use of consistent assignments, a model supported by many national organizations including Advancing Excellence, The American Health Care Association and Leading Age (National Nursing Home Quality Improvement Campaign, 2016). Consistent assignments are offered as a method to enhance close personal relationships and quality of life, as DCPs come to know the person not simply as an "assignment," but as an individual with a unique life and history (Corazzani et al., 2015; Roberts, Nolet, & Bowers, 2015). Further, Castle found that consistent assignments have been found to decrease staff turnover in residential care environments (Castle, 2011), while Stone and colleagues (2017) determined that consistent assignments in home care workers increased job satisfaction and was associated with a lower intent to leave (Stone et al., 2017).

Additional Considerations to Improve Quality Dementia Care Workforce

DCPs are the foundation of long-term care, as they provide the "service" in nursing homes, assisted/residential care, home care and hospice. Yet the industry struggles to create environments that address their needs and desires. Turnover is high in all positions and extremely costly to all organizations. Monetary compensation and benefits, while important, are not the only answer (Stone et al., 2017). It is more than just a job; for many it is a calling (Pfefferle & Weinberg, 2008).

Need for Continued Research in Leadership

The leader and the culture of an organization play a dominant role and significantly impact the quality of dementia care and quality of life for the people who live and work in long-term care settings (Stanyon et al., 2016). Leaders set the tone, establish the culture of the organization and influence success or failure (Siegel, Bakerjian, & Zysberg, 2017). Requirements and training for leaders, often referred to as administrators, executive directors, directors, etc., vary by setting and location for nursing homes, residential care, assisted living, home care, and hospice care. For instance, nursing home administrators and administrators in RC/AL are subject to state licensure, certification, training requirements, and continuing education although the amount and scope vary widely by state. Only 21 states require the RC/AL administrator to be licensed or certified and the required annual hours of continued education ranges from no requirement to 40 h (Carder, 2017). As of 2018, the administrators of home health agencies with certificates of participation for Medicare and Medicaid are required to be a licensed physician, a registered nurse or have an undergraduate degree with experience in health administration coupled with at least 1 year of administrative or supervisory experience (Centers for Medicare and Medicaid, 2017a).

A culture supporting quality person-centered dementia care requires stable, dedicated leadership, and workforce (Koren, 2010). Nursing home administrator turnover is common and ranges from 41% to 45%. A high rate of administrator turnover is associated with high numbers of deficiencies (Geletta & Sparks, 2013) increased DCPs turnover (Castle, 2005) and the quality of care (Castle, 2001; Geletta & Sparks, 2013; Stolee et al., 2005).

The importance of this single person and their effectiveness in long-term care settings has not received a great deal of attention (Dana & Olson, 2007; Donoghue & Castle, 2009). There is a need for continued research in leadership in long-term care settings to determine reasons for leader turnover and what may need to be done to prepare leaders for the future to improve DCP and staff competencies (Singh & Schwab, 2000).

Need for Systems to Collect and Disseminate Person-Centered Information

Care providers and staff want life history information to enable them to respond to the "individual" with dementia and to establish approaches to care and behaviors (Grøndahl et al., 2017). However, barriers to providing quality person-centered dementia care include the inability for DCPs and staff to secure information about the person with dementia, mechanisms for communicating that information to colleagues and the time to do so. Currently, much of this information is communicated verbally, and often the staff lack the time for communicating this information (Kolanowski et al., 2015). Systems need to be created that

support a communication process to facilitate the exchange of this person-centered information to DCPs and staff and to share changes in the person with dementia as they occur over time. An expectation within the CMS Dementia Focused Survey Guide is the gathering and dissemination of person-centered care information to DCPs and staff (Centers for Medicare and Medicaid Services, 2015).

Encouraging Communication and Interdepartmental Teamwork

Interdepartmental meetings that engage staff in all departments have been shown to enhance a sense of team and community, an open mindedness and support for one another regardless of their role (Guzman et al., 2017a). Graf found the strongest predictors of job satisfaction and overall quality of care were collaboration with nursing home director, director of nursing, colleagues and staff resource adequacy (Graf et al., 2016). Coates found usefulness in proving opportunities to reflect with colleagues to promote thought and problem solving, encourage all to look at solutions through the eyes of another person or the person with dementia (Coates & Fossey, 2016). The ability of an organization to enhance interdisciplinary staff participation and interdepartmental collaboration can be accomplished through routinely scheduled all-inclusive staff meetings and in-service programs (Smythe, Jenkins, Galant-Miecznikowska, & Bentham, 2017). Offering meetings and inservices on all shifts for all departments provides an opportunity for all staff to attend, enhances communication, participation, and relationships between departments (Gilster, 2005).

Ongoing Evaluation of Programs

To ensure a quality care dementia workforce and environment requires an ongoing process to measure continuous quality improvement (Koren, 2010). Quality care, assessment and evaluation programs, processes, and systems continues to challenge the industry (Mills et al., 2017). The most recent initiative to improve quality care is the Quality Assurance and Performance improvement plan (QAPI) is effective November of 2018. QAPI expands the process of quality assurance to put practices in place to improve care and services. Elements of the process serve to include and engage all stakeholders in the program, create a learning organization, leadership role in ensuring stakeholder input and involvement and creating a systematic approach to determine problems, causes, appropriate interventions, and data driven decisions (Center for Medicare and Medicaid Services, 2017b). The implementation of QAPI may very well augment some of the other areas that DCPs and staff have indicated they desire in their work; including a focus on education, involvement in the decision process, the availability of information, team work, a learning environment, and collaboration.

Conclusion

Training has received considerable attention as the unique characteristics of dementia and resulting behaviors need to be understood by those who provide care. While the quality and quantity of training programs has been examined, more needs to be done to determine how to maintain knowledge and practice over time and how to garner leadership and management support for training programs.

Critical to person-centered dementia care is "knowing the person," the human being, father, golfer, mother, bank president, university professor, and researcher. The use of life history or stories may influence the ability of staff to see the whole person, as a human being with a rich history and life versus an individual with dementia who is difficult to care for and time consuming. However, systems and processes need to be in place to not only secure the information but to develop mechanisms to share and make accessible the information with all DCPs and staff.

Professionals and nonprofessional groups in varied environments such as nursing homes versus home care and in other countries present different job needs and desires (Banaszak-Hall et al., 2015). They also fall under varied regulations internationally, nationally, and by state. It is important to note that while organizations may not be required and/or staff are not asking for dementia specific programs as recommended in this article, such programs may still be beneficial. Training, respect and appreciation, communication, participation in decision making, support programs, teamwork and caring, and engaged leadership have all been cited individually as desires, and such programs may prove important for all long-term care settings to promote a quality dementia care workforce. Research on a combination of programs that address these issues may be beneficial.

Increasing numbers of people living with dementia and decreasing resources makes it essential to determine what motivates DCPs to work across the long-term care spectrum and what programs are necessary to retain them. Organizations need to address the desires of DCPs and outcomes of research to promote best practice. Creating a competent dementia care workforce is clearly complex and requires a deep inquiry into the multiple needs and desires of DCPs and staff. There will likely not be one program or strategy that solves the workforce issue.

Practice Recommendations for Staffing

1. **Provide a thorough orientation and training program for new staff, as well as ongoing training**

   A comprehensive orientation should be provided that includes the organization's vision, mission, and values, high performance expectations, and person-centered dementia training. This training is essential for new staff, and should be included in ongoing education for all staff members.

2. **Develop systems for collecting and disseminating person-centered information**

   It is important that all staff know the person living with dementia as an individual. Establish procedures for collecting person-centered information that includes choices, preferences and life history. It is also essential that an effective process be developed to share this information with all staff.

3. **Encourage communication, teamwork, and interdepartmental/interdisciplinary collaboration**

   An organization should promote staff participation and interdepartmental/interdisciplinary collaboration through routinely scheduled inservice programs and meetings. Training is most effective when designed to include ongoing education, communication, and support. Offering inservices and conducting meetings on all shifts are important, and will impact attendance, participation, and facilitate relationships between staff.

4. **Establish an involved, caring, and supportive leadership team**

   Creating a person-centered "community" is not possible without service-oriented leaders, managers, and supervisors. It is also vital that the leadership team be vision-driven, open, and flexible. High performing leaders know that staff are the foundation of success, and when staff are valued, recognized, and feel served themselves, they in turn will more likely value and serve others.

5. **Promote and encourage resident, staff, and family relationships**

   Encouraging relationships among persons living with dementia, staff, and families is central to person-centered care, and is fostered in part by implementing consistent staff assignment. The involvement of all parties in planning care, activities, education, and social events may cultivate successful relationships as well.

6. **Evaluate systems and progress routinely for continuous improvement**

   It is important that an organization routinely collect and evaluate information on all staff processes, including hiring, orientation, training, and satisfaction. Analysis of the data should be used to evaluate the effectiveness of all systems and identify areas for improvement. In addition, leaders should share this information with staff, and act upon the results.

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Review Article

From Research to Application: Supportive and Therapeutic Environments for People Living With Dementia

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Abstract

The evidence about the role the designed and built environment plays in supporting individuals living with dementia has been steadily mounting for almost 40 years. Beginning with the work of M. Powell Lawton at the Weiss Pavilion at the Philadelphia Geriatric Center, there are now dozens of researchers who are exploring how the environment can be either supportive and therapeutic, indeed even serving as a prosthetic for various changes in cognition, or be a barrier to independent functioning and high quality of life. Two recent literature reviews published on the impact of environmental factors and characteristics on individuals living with dementia clearly delineate evidence that the environment can have a therapeutic or a debilitating impact on individuals living with dementia. Rather than duplicate these excellent reviews, this article puts the knowledge gleaned from this research into the shifting context that is long-term care. This article begins with an exploration of the evolution of approaches to the design of spaces for individuals living with dementia from traditional or medical models, to special care units (SCUs), to person-centered care (PCC), which is the organizing theme of this supplemental issue. A novel, person-centered way of conceptualizing the domains of environmental systems is then presented and used as the framework for structuring recommendations and creating supportive and therapeutic environments for individuals living with dementia. Although there are distinct pathophysiological and behavioral manifestations of different forms of dementia, there is almost no evidence that suggests alternative environmental characteristics are better for one type of dementia over another. Thus, this article will refer to "individuals living with dementia" as opposed to Alzheimer's disease or other specific forms of dementia. Further, this article only addresses residential environments: homes in the community, independent and assisted living residences and nursing homes. It does not address other settings, such as hospitals or hospice, or work and public community spaces, such as stores. It is recognized that individuals living with dementia do spend time in all these spaces, and fortunately, there is growing interest in creating more dementia-friendly communities, but they will not be addressed in this article. Most of the research that has been done has focused on shared residential settings, so that will be the primary focus on this article.

Keywords: Alzheimer's disease, Assisted living facilities, Environment (i.e. ergonomics), Falls, Nursing homes, Person-centered care, Quality of life

History of Settings for Individuals Living With Dementia

The history of environments for individuals living with dementia can be traced through several distinct routes. As stated above, the earliest theoretical work in this arena was conducted by M. Powell Lawton, who with his colleague, Lucille Nahemow, developed the most widely cited theory in environmental gerontology: the Ecological Model of Competence Press (Lawton & Nahemow, 1973; Lawton, 1983). See Scales, Zimmerman, and Miller (2018) in this issue for a deeper description of this model. By the mid-1990s, several notable environment-gerontology designers and researchers had developed distinct but related versions of "therapeutic goals" that could be used to guide the development of environments—both physical and social/programmatic (see Table 1) (Calkins, 1988; Cohen & Weisman, 1991; Parker et al., 2004; Weisman, Lawton, Sloane, Calkins, & Norris-Baker, 1996; Zeisel, Silverstein, Levkoff, Lawton, & Holmes, 2003). The earliest was developed in 1986 by Lawton, and the most recent was published in 2004 (Parker et al., 2004). There is significant overlap in many of the concepts put forth by these different authors: Awareness & Orientation appear on all versions except one, and Support for Physical Functioning/Daily Activities is in every set. It is worth noting that several of these were not developed specifically for individuals living with dementia, but for older adults in general (Lawton, 1986; Parker et al., 2004)—yet the constructs remain consistent between those for older adults and those for individuals living with dementia. These therapeutic goals were used as the basis for creating supportive environments, conducting research, and developing new assessment tools, such as the Professional Environmental Assessment Protocol (Lawton et al., 2000; Parker et al., 2004; Zeisel et al., 2003).

An alternative way to examine the history of environments for individuals living with dementia is by examining the actual care settings. The focus in this section of the paper will be on shared residential settings, as they have been specifically designed for these individuals, as opposed to homes in the community which generally are not—though many of the principals are translatable. Lawton also oversaw the development of the first specialized care unit for people living with dementia. (A note about language: The term "unit" reflects older, more institutional language and will be used in this article when referring to areas, primarily in nursing homes, that were designed under that care model. Newer designs that seek to de-institutionalize and create households that reflect the homes people have come from will be referred to as either households or living areas.) The Weiss Pavilion at the Philadelphia Geriatric Center was the first purpose-built nursing home for individuals who are living with dementia (Lawton, Fulcomer, & Kleban et al., 1984). It was a radical departure from the 60-bed, double-loaded corridor design that was typical at the time, and featured an open plan with rooms for 40 residents (most in rooms shared by 2-persons) around the perimeter with central social spaces easily visible from virtually anywhere. All of the goals Lawton had developed in 1986 were clearly used as a basis for this design: there was clear visibility to all important spaces to support orientation, the open plan allowed for superior negotiability, the ability to see other people and what was going on was designed to encourage social integration; and they worked to de-institutionalize the esthetics of the setting with plants and trellis work separating spaces (Lawton et al., 1984). Lawton estimated that this design increased the cost of construction by about 10%. But the evaluation of the Weiss institute demonstrated that "everyday behavior, including participation in enriched activities and social behavior, did not show a decline in parallel with the decline in basic functions" (Lawton, 1986, p. 131). This was the first solid evidence that the design of the built environment has an impact on the functioning (physical and social) of individuals living with dementia. Following this, a growing number of (primarily) nursing homes across the country started creating their own specialized environments for people with dementia, such that the term special care unit (SCU) was in wide use by the late-1980s. Unfortunately, many of these SCUs were nothing but a traditional unit with the doors locked to prevent what was termed "elopement." Staffing might be not consistent, they may or may not have been given any extra dementia-focused training, and the programming might or might not have been tailored to the abilities and preferences of the residents living there. There were of course exceptions, but also real concerns over the benefits residents might (or might not) be getting for the extra costs associated with many of these units.

It was almost 10 years before there were other examples of specially designed dementia care settings, and the first and best-known examples were for assisted living. The Corinne Dolan Center at Heather Hill (Chardon, Ohio, opened in 1989) and Woodside Place (Oakmont, Pennsylvania, opened in 1991) were two early exemplary models, in part because both were subjected to rigorous evaluation research (Namazi et al., 1991; Hoglund, Dimotta, Ledewitz, & Saxton, 1994). These two model care communities radically changed the standard of shared residential settings for individuals living with dementia: they were based on households of 10–12 residents (with two to three households per building), each household had a kitchen, dining room, and living room that reflected familiar spaces one might find at home (vs. the large multipurpose spaces common in more traditional long-term care settings), and each provided direct and largely uncontrolled access to substantial outdoor gardens and walking paths (Day & Calkins, 2002). Out of these designs and the accompanying research, a new approach to how to create care settings for individuals living with dementia was born. It was now possible to see concrete examples of how the therapeutic goals that had been developed were actually expressed in the design of the built environment. Through the 1990s and into the 2000s, increasing numbers of nursing homes and assisted living communities were built or converted existing units into household-based designs. And in the beginning, the vast majority of professionals (design and medical) continued to believe that these individuals who

Table 1. Therapeutic Goals for Settings Designed for Individuals Living With Dementia

	Lawton (1986)	Calkins (1988)	Cohen & Weisman (1991)	Weisman, Lawton, Sloane, Calkins, & Norris-Baker (1996)	Zeisel et al. (2003)	Parker et al. (2004)
Domains	Safety	Safety	Safety & Security	Safety & Security	Exit Control	Safety & Health
	Orientation	Wayfinding & Orientation	Wayfinding & Orientation	Awareness and Orientation	Walking Paths	
	Negotiability (increase functionality in ADLS)	Competence in Daily Activities	Support Functional Abilities	Support Functional Abilities	Autonomy Support	Support for Physical Frailties
	Aesthetics		Stimulation & Change	Regulation & Quality of Stimulation	Residential Character Sensory Comprehension	
			Autonomy & Control	Opportunities for Personal Control	Outdoor Freedom	Choice and Control
				Provision of Privacy		Privacy
	Social Integration	Privacy & Socialization	Social Contact & Privacy	Facilitation of Social Contact	Individual Space Common Space	
	Personalization	Personalization	Ties to the Healthy & Familiar	Continuity of Self		Personalization
						Normalcy & Authenticity
			Adapt to Changing Needs			
						Connection to Community & Awareness of Outside World
						Comfort
						Support for Cognitive Frailties

Adapted from Lawton et al., 2000.

are living with dementia had distinct and unique needs that other residents in long-term care did not have (Weisman, Kovach, & Cashin, 2004).

But that too began to change. Although care and environments might (with a stress on *might*) be better for those individuals living in these specially designed settings, these settings accommodated a small minority of all individuals living in long-term care, and many of them were subjected to highly institutional buildings (and care practices). Why do just a small number of people living with dementia deserve to live in a place that feels more like home? Shouldn't everyone? Aren't the therapeutic goals that were largely developed primarily for individuals who are living with dementia be equally applicable to any individual? Increasingly, the answer to these questions is being seen as "yes," and this reflects the growing person-centered care movement in long-term care (which is addressed in other articles in this issue).

Segregation Versus Integration

Although the development of segregated living areas solely for individuals living with dementia continues, there is also increasing discussion that segregation—whether as a separate living area within a larger care community or as a free-standing memory care building—contributes to the stigma that is currently attached to having diagnosis of dementia. A more person-centered approach is one that allows individuals who are living with dementia to live in rooms or apartments alongside individuals who do not currently have dementia (Powers, 2017a). Beyond the ethics of stigmatization, integration makes sense given the statistics that 40–42% of assisted living residents and 61% of nursing homes residents have moderate-to-severe cognitive impairment (Alzheimer's Association, 2017). It has been argued that all long-term care staff should be dementia-capable, and all environments should be supportive of the needs of individuals living with dementia. But it is often

the stigma, brought on by the fear of developing dementia that makes people not currently diagnosed want to separate themselves from individuals living with the symptoms of dementia (Lachs et al., 2016; Powers, 2014; Teresi, Holmes, & Monaco, 1993). Indeed, there is even research on the stigma of being a caregiver for individuals living with dementia (Walmsley & McCormack, 2016). This line of reasoning, however, is by no means absolute. There are also individuals living with dementia who may not want the changes they are experiencing to be seen and potentially judged by others; they may be more comfortable in a setting with people who are at a similar cognitive and functional level as they are (Gilster, S., Personal communication, 2017). There is mixed evidence about whether segregated living areas result in better outcomes. Marquardt, Buettner, and Moyzek (2014) in a recent literature review identified six studies with improved behavioral outcomes and five studies with no benefit on behavioral scores of segregated living areas. A recent Cochrane review (Lai, Yeung, Mok, & Chi, 2009) suggests there is a lack of evidence for better clinical outcomes, and other studies demonstrate an increased risk of elder-to-elder aggression or mistreatment (Lachs et al., 2016) and potentially higher antipsychotic use in segregated units (Cadigan, Grabowski, Givens, & Mitchell, 2012; Powers, 2017b). Kok, Berg, and Scherder's (2013) literature review of the topic suggests that longitudinally, residents in SCUs demonstrated greater neuropsychiatric diagnoses, displayed more deteriorations in behavior and resistance to care, as well as less decline in activities of daily living (ADLS), compared to individuals not residing in SCUs. Van Haitsms, Lawton, and Kleban (2000), in a well-designed and controlled study, found there were poorer outcomes for individuals who lived on the segregated living area than for a matched sample of residents who lived in integrated living areas. Thus, the evidence that exists about the benefits of segregation versus integration is somewhat contradictory. See also the discussion under safety versus autonomy, in the following, for a discussion of whether secured units are considered a form of restraint. It is recommended that both living options be available, to accommodate people who prefer not to be segregated or to have to necessarily relocate as their abilities change (which is common with segregated living areas), and people who prefer to live with others who are experiencing similar changes. Having both options available lets people choose—but *only if* the living areas are equally supportive. Regardless of location, it is the care community's deep adoption of person-centered care values and practices, including staff training, the approach to programming and activities and having a supportive environment, that will ultimately make the setting successful—a place where individuals living with dementia care be comfortable, feel at home, have their preferences honored, and be in meaningful relationships with those around them.

The Merger of SCU and PCC Values

Just as there were several versions of therapeutic goals listed in Table 1 for settings for individuals living with dementia (Calkins, 1988; Lawton, 1986; Cohen & Weisman, 1991; Weisman, 1998; Zeisel et al., 2003), so too are there many conceptualizations of goals or Practice Recommendations, as they are being referred to them in this series of articles, supporting person-centered care values and practices (Harris, Poulsen, Vlangas, 2006; DHFS, 2006; Geboy & Meyer-Arnold, 2011; Koren, 2010; Pioneer Network, 2017; Weiner, Ronch, & Lunt 2013). Although there is significant conceptual overlap between the Practice Recommendations, each article in this issue has its own set of Practice Recommendations based on the different foci of that article. Previous versions of the Alzheimer's Association Best Practices documents have primarily followed a therapeutic goal framework, similar to those in Table 1. Although useful, this approach can lead to a noncohesive approach to design because there is no overarching conceptual framework that links all the therapeutic goals together. Person-centered care can, however, provide a more cohesive foundation that links the different recommendations together in a more meaningful way. The therapeutic goals are still inherent in these Practice Recommendations, but they are now subservient to higher level, person-centered goals. For example, awareness and orientation are important *because* they serve to increase individuals' comfort within a given setting. This article accepts the person-centered care values that are articulated in the first article of this issue (Fazio, S., Pace, D., Flinner, J., & Kallmyer, B. 2018), which include: know the person with dementia; recognize and accept the person's reality; identify and support ongoing opportunities for meaningful engagement; build and nurture authentic, caring relationships; create and maintain a supportive community for individuals, families, and staff; evaluate care practices regularly and make appropriate changes. Based on an extensive literature review of both research and gray literature conducted over a period of years (Calkins, Brush, & Abushousheh, 2015), a set of five overarching practice recommendations which reflect core person-centered values is proposed, each of which addresses a number of different specific design strategies for home and shared residential settings.

1. Create a sense of community within the care environment
2. Enhance comfort and dignity for everyone in the care community
3. Support courtesy, concern, and safety within the care community
4. Provide opportunities for choice for all persons in the care community
5. Offer opportunities for meaningful engagement to members of the care community

Create a Sense of Community With and Within the Care Environment

The first practice recommendation is more than just physical design-related but provides an overall framework for considering settings for individuals living with dementia. This fundamental principle suggests that designing

settings that provide continuing opportunities for individuals living with dementia to continue to be engaged with their community—with friends and church/synagogue/mosque, with shopping and restaurants, with working and volunteering—demonstrates that they deserve to continue to be considered an important part of the fabric of the community, not people to be shunned and set apart (Swaffer, 2016). This is the basis for the dementia-friendly communities movement, which is gaining traction in the United States. Unfortunately, one of the realities in the United States is that many shared residential settings for older adults are "set apart" from the community, either physically (located long distances from residential neighborhoods) or functionally (not offering any reason for people other than good friends and family to visit; Green & Calkins, 2003). Research clearly shows that the vast majority of people want to age in an age-integrated neighborhood, with children and younger people close by (Merrill Lynch, 2016). Our society still has a strong ageist bias that devalues older adults, which is compounded when considering someone who might also be living with dementia (Burgener & Berger, 2008). But a person-centered approach to care is fundamentally based on a conviction that each and every person can be equally valued and appreciated and have their personhood respected, regardless of age or ability (Geboy & Meyer-Arnold, 2011). And one way to do that is to bring people together in creative and meaningful ways.

Examples include care communities that are creating restaurants open to nonresidents/visitors, or include exhibit space that local artists use for their shows, both of which can bring many people into the care community who do not have any other connection there (AIA, 2016). Some offer meeting space for local groups, whereas others have an on-site day care that not only serves the children of staff but parents in the neighborhood, bringing them into contact with the care community on a regular basis. Every time someone who does not have a relative or friend who lives in the care community crosses the threshold, it is an opportunity to create community. Some of these ideas require dedicated space, but not all. In a traditional care community, individuals living with dementia would likely be excluded from any or all of these events and spaces. But a care community that deeply adopts person-centered care values and practices will find ways to include individuals who are living with dementia (Zeisel, 2009). From an environmental perspective, the design of these (and other) spaces needs to consider the amount of ambient stimulation in the room or area. Highly stimulating environments (visually or acoustically) tend to be overwhelming to individuals living with dementia (Hall & Buckwalter, 1987). Providing ways to control direct sunlight (which produces glare) and including surfaces with high noise reduction coefficient values can help tremendously. Since some individuals living with dementia experience stress or distress in unfamiliar environments (Lawton et al., 2000), providing some smaller spaces that accommodate fewer people will better support their participation.

Enhance Comfort and Dignity for Everyone in the Care Community

The related concepts of comfort and dignity are at the core of person-centered care values but vary in one important way. Comfort is fundamentally how an individual feels, and dignity is more related to how they are treated. Both are something that some individuals living with dementia sometimes find difficult or lacking. In research, comfort is often stated as the avoidance of *dis*comfort. Although there is certainly evidence of underdiagnosed pain in individuals living with dementia (Worcester, 2008), it is important to recognize that discomfort is not just physical; there is also mental discomfort, which Cohen-Mansfield suggests is expressed as agitation or behaviors labeled as challenging or aggressive (Cohen-Mansfield, Thein, Marx, Dakheel-Ali, & Jensen, 2015). A person-centered approach would argue that avoiding discomfort, while important and laudable, is not the same as being truly comfortable. Translating this to the design of the environment, Calkins (2013) suggests that an ideal shared residential setting is one where the resident feels "at home"—which signifies a deep level of comfort. However, because of changes in cognitive processing abilities and recent memory, even places (homes) that a person knows well and has lived in for years may seem unfamiliar or be perceived of as potentially threatening, and therefore be uncomfortable. People who relocate to a shared residential setting may not remember that the decision to move was based on their needing increasing levels of assistance, so they too are often uncomfortable. In the context of environmental design for shared residential settings, enhancing comfort and dignity translates into creating familiar environments such as households (vs units), providing appropriate personal space, and supporting orientation to time, place and activity, each of which is addressed in the following paragraphs.

Creating a *Household* is one core strategy for moving away from traditional institutional or medical model approaches to adopting the values of person-centered care such as supporting meaningful engagement that have purpose and are familiar. Although not exclusive to settings for individuals living with dementia, a household is often the main design part for memory care settings. Although there is no single widely accepted definition of a household, Abushousheh, Proffitt, and Kaup (2011) achieved consensus with a wide stakeholder group on the following definition:

> A household is a small grouping (typically 10–20) of residents and their dedicated staff with the purpose of fostering self-directed relationship-based life. The household has pleasing homey spaces with a functional kitchen at its hub - nurturing daily life, responding to individual residents, and fostering community life. It

is intimately-sized with clear boundaries and a variety of spaces typical of home, including the flexibility of private and shared bedroom spaces as desired by the residents.

A household includes clinical best practices, the tasks and routines and pleasures of daily life, cutting edge technologies to encourage life choices and promote functionality, mobility, wellness and growth.

Household life is facilitated by an empowered self-led team of residents and staff. Deep knowing, reflective of true home, fosters a good life for everyone and is supported by the resources of the organization. The organization has been redesigned to position households and their leadership with the autonomy and accountability to respond to individual resident needs, as well as, the responsibility to create meaningful household life. In other words, the households, together as a team with the Administrator and Director of Nursing Services, become the vehicle for all operational decisions and administration, replacing the traditional department structure.

The environmental aspects of this definition include a relatively small number of residents (10–20), living together with house-based rooms (kitchen, living room, and dining room), and being distinct (meaning it has everything it needs to operate independently) from adjacent households or living areas. The importance of spaces that are familiar, such as a kitchen, is that they help individuals recognize the space and often what types of activities are appropriate for that space (Wrublowsaky, 2017). Large multipurpose spaces do not convey that type of information to people in the setting. There is a growing body of research that shows that designs that reflect these characteristics are associated with a broad range of positive outcomes such as less distress or agitation, greater social engagement, maintenance of functional abilities, and more individualized care (honoring residents' preferences), whereas larger traditional units are associated with greater agitation, faster cognitive decline, and more resident conflicts (Marquardt et al., 2014; Hutchinson et al., 1996; Suzuki, Kanamori, Yasuda, & Oshiro, 2008; Reimer, Slaughter, Donaldson, Currie, & Eliasziw, 2004). Funaki, Kaneko, and Okamura (2005) found that having an opportunity to engage in household-related activities resulted in a significant improvement in quality of life. There is also evidence that more home-like environments have positive impacts on staff morale, which might translate into secondary positive outcomes for residents (Parker et al., 2004).

Along with creating the scale and spaces of a home, it is important to create an enriched environment that provides positive distractions and things to do, such as tactile art or interesting views and access to the outdoors, with opportunities to explore the setting and find props that support different kinds of activities that might be engaging (Bourgeois, Brush, Elliot, & Kelly (2015). Research on the positive impact of these types of environmental characteristics is sparse because they are often part of the whole household or enriched environment. However, the evidence that exists has shown that a more home-like environment is associated with deeper engagement in social interaction, activities of daily living, reduction in excess-walking episodes, and higher autonomy in food and hydration intake (see Chaudhury, Cooke, Cowie, & Razaghi, 2017 for an excellent summary). From a design perspective, the environment should maximize perceptual clarity and reduce perceptual noise (e.g. visual clutter or signage that is only for staff; Hall & Buckwalter, 1987; Orfield, 2015). In both shared residential and home environments, setting out clear props that indicate a room's use, such as keeping the dining room table at least partially set with a place mat and glass of water, can help with understanding the purpose of this space and encourage the individual living with dementia to participate in daily household activities such as setting or clearing the table.

Territoriality is an issue in shared bedrooms, which are common in shared residential settings. The most common bedroom design in nursing homes (and many assisted living communities) places the headboard of both beds on the same wall, with a piece of fabric (misnamed a "privacy curtain") between them. This means that the person in the bed by the window must always trespass through the space or territory of the person who stays in the bed closest to the hallway. For someone who may not understand why they are living with a "stranger," why that person keeps coming into their space, possibly going through their belongings (or what they think are their belongings), this situation, which relates to the person-centered value of accepting the person's reality, can cause significant discomfort. There is some evidence that there is greater resident-to-resident aggression when residents live in this type of shared room versus being in either a private room or what is referred to as an enhanced shared room (Figure 1), where each individual has their own clearly defined space, with a window, that has equal access to the door and bathroom (Calkins & Cassella, 2007). There is a clear need for more research on this type of room design, in terms of benefits to residents and staff (Chaudhury et al., 2017).

Awareness and Orientation skills become compromised in dementia, making it more difficult for individuals living with dementia to rely on memory to find their way from one location to another. Tying to the person-centered value of accepting the person's reality, a therapeutic environment is one that provides a variety of meaningful cues to support orientation. A "signage system" is not the same as an orientation system, which uses many more elements beyond signs (Brawley, 2006; Silvis, 2011). For people still living at home in the community, making sure that frequented destinations are visually accessibly (easily visible) and distinctive is important. The front of the house or the door of the apartment might need to have a unique and personally meaningful/recognizable element added so it stands out

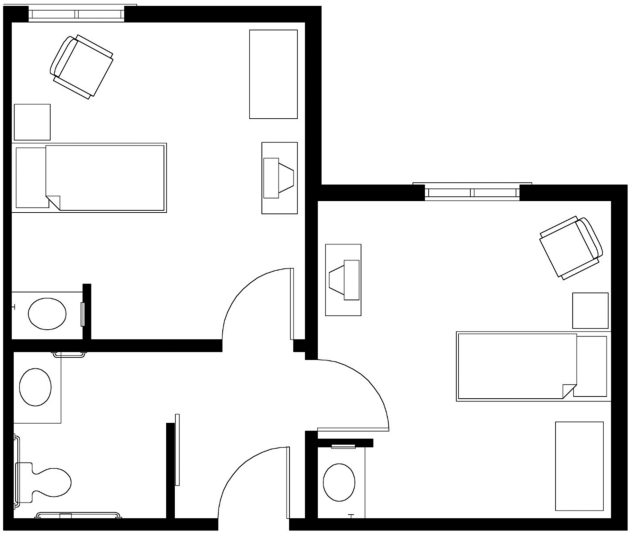

Figure 1. Enhanced shared-bedroom. Credit: Gaius Nelson, Nelson Tremain Partnership, P.A.

visually from its neighbors. An open floor plan not only makes it easier for the individual living with dementia to find a destination but also makes it easier for the care partners to see where the person is. This same principal of visual cues is also applied in shared residential settings where often bedroom or apartment entrances have a case or shelf for residents to display personal mementoes. There is some research that suggests that it is the meaningfulness of the items that is most critical in having these display areas be effective (Namazi, 1990; Namazi, Rosner, & Rechlin, 1991; Nolan, Mathews, Truesdell-Todd, & VanDorp, 2002; Gibson, MacLean, Borrie, & Geiger, 2004). Other researchers have found that buildings or living areas with simple plans that have few required changes in direction or open plans, support better orientation (Marquardt & Schmieg, 2009; Brush & Calkins, 2008). There is also strong evidence, albeit from only one study, that direct visibility of the desired destination may have a profound impact on successful destination finding: a study from the Corinne Dolan Center found an eightfold increase (from 37 to 285) in use of the toilet when it was directly visible (not behind a door or curtain and in high contrast with the surrounding walls and floor; Namazi & Johnson, 1991). Color, in and of itself, has not been shown to be an effective wayfinding cue (Cooper, Mohide, & Gilbert, 1989).

Orientation to activity is more naturally supported in a household design, because the combination of smaller scale and familiar spaces such as a kitchen and dining room are more easily understood by individuals living with dementia over more traditional medical model designs (Cohen & Weisman, 1991; Calkins, 2009; Elmståhl, Annerstedt, & Ahlund, 1997; Marquardt & Schmieg, 2009). While having props, such as place settings in the dining room, can help with orientation, a more person-centered approach would also include the residents setting the tables themselves (Bourgeois, Brush, Elliot, & Kelly, 2015). Orientation to time is supported with views to the outside, as well as large face, high-contrast clocks.

Support Courtesy, Concern, and Safety in the Care Community

Another essential tenet of person-centered care is that of respect for others. Although in many ways the concepts of courtesy and concern would seem to be more person-based (how people treat one another), there are environmental correlates as well. Settings should be pleasant (noninstitutional) with visual and physical access to engaging but safe outdoor spaces, support privacy of confidential information and security of personal space, provide sufficient support for the individual living with dementia and, as needed, care partners, to maneuver and be successful while completing personal care activities, and provide systems that support a sense of security, while also ensuring that sometimes necessary safety features may also need to be in place.

The environment can be designed to *Support Functional Abilities* in individuals living with dementia, often in subtle, unobtrusive ways. For example, dressing is a complex activity that requires significant decision-making skills (what clothes to pick out, making sure all the necessary items are gathered, knowing in what order clothes should be donned, managing different closures systems [buttons, zippers, shoelaces, etc.]). Several studies have examined environmental strategies to support more independent dressing (Beck, Zgola & Shue, 2000; Calkins, 2012; Cohen-Mansfield et al., 2006; Sabata & Pynoos, 2005). Calkins (2012) demonstrated that limiting the number of choices, presenting clothes in the order in which they were to be put on and providing other prosthetic supports in an assistive wardrobe can increase independence in dressing substantially. Similarly, setting up personal care items around the sink with clearly labeled items and eliminating unnecessary and potentially distracting items, supports successful self-care (Brush, Calkins, Bruce, & Sanford, 2012). The bathroom should be highly visible, both during the day and at night, which supports both orientation and maximizing functional abilities. Making grab bars readily available and in the best location is also important. The standard ADA design with the toilet 18″ from the wall and a grab-bar along the back wall does not support how most older adults transfer (AIA, 2012). Recent research identifies that having the centerline of the toilet at least 24″ from the wall and having two bi-lateral grab bars, placed 14″ off center, 30″ above the floor, is the most preferred configuration for both independent and assisted transferring (Lee, Sanford, Calkins, & Barrick, 2017). Ensuring that lighting is sufficient and even throughout a space will also serve to support functional independence. The Illuminating Engineering Society guidelines for *Lighting and the Visual Environment for Seniors and the Low Vision Population* has recently been revised (IES, 2016) and should be followed in settings for individuals living with dementia.

Balancing Safety with Autonomy in a person-centered manner is a delicate balance between supporting remaining independence and choices for the individual, while recognizing that sometimes systems need to be in place to mitigate risks for individuals living with dementia. This relates to two person-centered values of know the person (what's important to the individual) and accept the person's reality (in terms of their inability to judge the dangerousness of a given situation). Whether living at home or in a shared residential setting, at some point in the course of the disease the individual may lose the ability to recognize risks. Individuals getting lost is a major concern in all settings. A typical non–person-centered response to this is to simply lock the doors so people cannot go out. This is not considered the best solution, especially from a person-centered perspective. First, "locking people in" is what our society does to criminals, and individuals who are living with dementia are not criminals and should not be treated as such (Swaffer, 2016). Second, there are important physical and psychological benefits to spending time outside on a regular basis (Brawley, 2006; Zeisel & Tyson, 1999). Third, particularly in nursing homes but also for home and community-based service providers, creating a secure living area is now viewed as a restraint according to CMS' Rules of Participation (DHHS, 2016), and should only be applied when specifically needed for an individual, and only for as long as necessary. Having a diagnosis of dementia does not mean that the individual is necessarily at risk for walking away, and being "placed" on a unit or living area that is secure is only appropriate for individuals who have a known propensity for walking away, otherwise it is considered involuntary seclusion. One study (Parker et al., 2004) found that a "culture of safety and health requirements could be creating risk-averse environments which act against quality of life" (p .941). There is some evidence that when people are actively engaged in activities that they find interesting and appropriate to their cognitive and functional levels, they are less likely to spend time walking around (what we used to call wandering) or walking away (what was called elopement; Geboy & Meyer-Arnold, 2011; Futrell, Melillo, Remington, & Schoenfelder, 2010). First, individuals living with dementia need to be actively engaged in the decision about whether they want to move to a secured living area. They should not be "placed" by family or staff without being a part of that decision-making process. If they show or indicate that they do not want to live there but have a repeated pattern of walking away, there are two options. One is to try to find a different care community that has the programming and staffing that will help the individual be comfortable and not want to walk away, or, in what should be rare cases, a doctor's order for the individual to live on the secure living area may be necessary. This is an example where the safety of the individual and the preferences of the individual may not be able to be equally accommodated. It is a value decision of the whole care team (including the person living with dementia and his or her chosen care partners) as to which set of values will be honored. Having frank discussions (and documenting the discussions) early in the course of the disease about what an individual might want in the future can make these later decisions easier to address (see Fortinsky & Maslow article in this issue for more information on this).

Every setting for individuals living with dementia should have direct and relatively unrestricted access to a secure outdoor area which provides individuals the opportunity to choose whether to be inside or outside. Consideration should be given as to when doors (to the outside or to other areas of the care community) need to be secured (inclement weather and perhaps at night) and when people can freely choose whether to remain in this living area or go to a different place in the care community. This requires effective communication with staff across the community, and possibly with neighbors and local shop owners for people still living in the community. Finally, there is an increasing variety of technology systems that can be tailored to the needs or preferences of individual residents: some will secure a door when an individual with the device approaches it, others are simply locational systems that can easily let staff see residents' locations. These should be used with caution as they can be considered a form of restraint, and devices that are large and stigmatizing should be avoided.

Falls are another common safety concern (though this is not unique to individuals living with dementia). In home environments, common risk factors include rugs and slippery flooring, changes in level (steps and thresholds), poor lighting and clutter. Recommendations include eliminating all rugs (even if they are secured to the floor, the height transition can be a problem for someone who has a shuffling gait); adding high-contrast slip-resistant material to flooring, especially where people are transferring their weight, such as around a tub, shower, or stairs; ensuring the lighting is sufficient and even throughout a space and using motion-sensor lighting to assist in navigating at night (especially from bed to bathroom); creating a clear path through the house with stable furniture that can be leaned on for support (Warner, 1998). The Fall Prevention Center at USC (no datea, no dateb) has a variety of resources on environmental strategies to reduce fall risk at home. Grab bars or handrails in hallways and bathrooms are much more common in shared residential settings, but they can also be implemented in the home environment. One home-based study found that a handrail along a wall covered with family photos allowed the individual living with dementia to have necessary support for balance while looking at the familiar images (Gitlin, Liebman, & Winter, 2003). There is some interesting research that shows that individuals with Alzheimer's disease have a reduced contrast perception ability (it has not been tested with other forms of dementia; Gilmore & Levy, 1991; Gilmore, Groth, & Thomas, 2005), meaning they need higher visual contrast to maximize function in any visual task. Thus, high contrast is important when considering safety and functionally supportive

features, such as thresholds and steps, between floors and walls, and at place settings in the dining room. Research found that increasing lighting and using brightly colored dishes increased independent caloric intake by as much as 500 Kcal over a 3-day calorie count (Brush, Meehan, & Calkins, 2002). However, high-contrast patterns should be avoided on flooring. The floor is a functional surface and should have minimal or low-contrast patterning: avoid the use of border and inset patterns and make sure there is contrast between the floor and the wall. There is also clear evidence that a significant proportion of falls occur at night when people are trying to get to the bathroom in the dark. Research by Figueiro (2008) has shown that amber-colored night lights do not disturb the circadian rhythm the way regular incandescent or fluorescent lighting does, which can cause people to have trouble falling back asleep. Figueiro recommends amber-colored LED lighting in the bathroom, either on motion sensors or on all night, or around the bathroom doorway to create a clear path from bed to toilet (see Figure 2). All of these modifications are appropriate for both home and shared residential settings.

There are times when it may be appropriate to limit access to unsafe items. What needs to be secured, and when and how, can be very individualized, and care should be taken not to assume that because someone has a diagnosis of dementia they are immediately incapable of using any potentially hazardous item. Someone who has spent a lifetime cooking may be perfectly capable of using a sharp knife safely well into later stages, whereas another individual might try to use a knife or a saw to cut open a can of beans because they can no longer use a can opener. Common items that may eventually be secured and used only with supervision include cleaning chemicals, sharp utensils (kitchen, workshop, garden), potentially hazardous appliances such as a gas stove. When securing items, it is best to be as inconspicuous as possible: do not put an obvious lock on a cabinet, which not only can cause frustration but also reinforces to the individual living with dementia that this is yet another skill or capability they have lost. Instead, either remove the item, or make the security inconspicuous. Replace gas or electric stoves with an induction cooktop, which are much safer to use (reduced fire and burn hazard). Move harsh cleaning chemicals to a different secured cabinet, and put safe or green cleaning products in more accessible areas. In shared residential living areas, because there are likely individuals at different stages of dementia, unsafe items are more often made inaccessible. Caregivers should not assume that none of the residents could no longer use a sharp knife safely, but consider that this might be a supervised activity. Knives should be kept in a secured drawer in the kitchen, which allows staff to access them as appropriate, but keeps safe the residents who should not have independent access to them. Codes for nursing homes require that stove in a domestic kitchen serving 30 or fewer residents have a separate power switch that is on a timer, located in a cabinet (or similar) that only staff can access, and that there be smoke alarms and fire extinguishers readily available. These safety features are also appropriate for assisted living communities that have residential kitchens.

Figure 2. Amber LED lights to outline the bathroom door. Credit: Dennis Guyon, Lighting Research Center, Rensselaer Polytechnic Institute.

Provide Opportunities for Choice for All Persons in the Care Community

CMS, in its new Rules for Participation, makes it quite clear that nursing home residents' choices are to be honored to the greatest extent possible (DHHS, 2016). Although much of this focuses on resident preferences related to delivery of care, it also expressly refers to offering the resident choices from which to make meaningful decisions. Therefore, designing spaces and places that accommodate different levels of activity and types of stimulation, that are meaningfully varied in terms of size, scale, and décor, and that include both indoor and outdoor areas, gives people choices about where and how they want to spend their time. This construct is generally thought of more in relation to shared residential settings, in part because many traditional care settings offer virtually no choices for the residents: there may be only one common shared multipurpose room that serves for meals and activities, and staff encourage residents to spend their time there or sitting in front on the nursing station, so they are easily visible. While being able

to see where residents are and what they are doing is not necessarily bad, limiting residents' ability to have meaningful options of where to spend time is. Ideally, every setting should provide a full continuum from private to semi-private to semi-public to public spaces, and individuals can choose where, when, and how to spend their time (Cohen & Weisman, 1991; Zeisel, 2009).

Spaces need to be meaningfully different: having two or three rooms that each accommodates six to eight people and have essentially the same furniture and décor is NOT meaningfully different. There are times when people want a quiet conversation with one other person, and times when 12 to 15 people might gather for an event. Choice is also limited when all the furniture (especially chairs) are the same size: people come in different sizes, and thus find different styles and sizes of furniture comfortable. Not every space should be on the household: having locations in other areas of the building or complex can give people a greater sense of freedom, which is important. One care community in western Ohio is comprised of 6 to 8 different buildings, and the residents, who are all living with dementia, routinely go from one building to another, often without being accompanied by staff, though staff may communicate with each other that someone is on their way over. Sometimes, the residents walk to the convenience store that is just down the road. The people who work in the shop know the residents who visit and make sure they are headed in the right direction when they leave; sometimes calling the care community with a heads up that someone is on their way back. These individuals are living a normal life with respect to their rights and abilities, in an environment that supports their making meaningful choices. They like where they live and have no desire to leave it.

Although bedroom configurations were discussed previously, the issue of being able to have privacy was not addressed. People may desire privacy for a variety of reasons—maybe just a chance to be alone or a chance to have a private conversation with a family member or friend or staff. Sexual activity among elders in long-term care settings is often ignored (as an uncomfortable topic) and yet care communities are having to address this issue on a regular basis (Doll, 2012). The issue is more complex when the individuals are living with dementia (and the ethical issues surrounding this will not be addressed in this chapter), but from an environmental perspective, it is important for the care community to plan how they will accommodate this activity. If all the bedrooms are private, this is not an (environmental) issue. However, if there are shared rooms, then accommodations must be made. One community made an arrangement with a local hotel for conjugal visits between residents and their nonresident partner/spouse. Other communities may have a guest suite that is available for visitors that can also be used for this activity.

In supporting the person-centered value of supporting opportunities for meaningful engagement, the choice to spend time outside is also important, as is having different options for how to engage with the outdoor space. Some people are more passive observers, whereas others want to explore, or garden, or take walks along a path, or sit and soak up the sun. This likely varies as much between individuals as it does by stage of dementia. Having both sun and shade is preferred; nontoxic plantings that might attract butterflies or hummingbirds, and container pots that can be moved around to create larger or smaller social spaces all create different options and choices for residents (Brawley, 2006; Tyson, 2002). A few small porcelain or cement animal figurines that are moved around the garden by staff can create an opportunity for exploration every day. Some residents may want to garden from a seated position at a raised bed, whereas others still want to dig more deeply into the soil and feel they are really working. Flexible seating has benefits, but be sure it does not compromise necessary safety features (e.g., enable people to climb over a fence). There is a growing body of research that suggests that spending time outdoors can reduce agitation and aggression (Murphy, Miyazaki, Detweiler, & Kim, 2010; Gonzalez & Kirkevold, 2014).

Offer Opportunities for Meaningful Engagement to Members of the Care Community

Just having choices about where to spend time does not necessarily guarantee that people will know what to do, how to engage in activities, or relate to others. A study by Bergland and Kirkevold (2008) on thriving in a nursing home suggests that relationships need to be positive and meaningful. Relationships—especially meaningful relationships—do not develop while sitting and watching television, they develop by doing things together, especially things that bring out memories, conversation, and sharing together (Kane, Lum, Cutler, Degenholtz, & Yu, 2007). Although few studies explore social relationships related to dining and kitchens, Chaudhury, Hung, Rust, and Wu (2016) found that having the elements of a domestic kitchen (refrigerator, microwave, coffee maker) facilitated not only resident independence but also social interaction. Anecdotally, this is one of the reasons why residential kitchens that allow residents and staff and family to work together, preparing the meals that are the sustenance of life, are becoming increasingly common. Design features that support active engagement include a lowered (30″ high) section of counter that faces the kitchen or a table with chairs in the center of the kitchen. Eating a meal requires a lot of concentration (Brush, Meehan, & Calkins, 2002) and can be more difficult if the environment is noisy (people talking, dishes clinking, loud ice machines) or visually chaotic (staff bustling about quickly trying to get everyone served). Small scale dining rooms for 20 or fewer individuals can help keep the level of stimulation manageable (Hall & Buckwalter, 1987) and enable people to not only enjoy the meal but converse with others.

Every activity is an opportunity for meaningful engagement, even personal care activities. In a traditional unit, the daily activity program typically consists of one to two large group "events" a day, led by someone in the activities department, which residents are often only passively engaged in (Orsulic-Jeras, Judge, & Camp, 2000). In a care community that has deeply adopted person-centered care values, every day is seen as an opportunity to try something new and different. Some person-centered communities use a learning circle (Action Pact, 2001) where each person is offered a chance to express her or himself and talk about something of importance. This type of sharing requires a space large enough to accommodate everyone sitting in a circle and is best when there is no background noise. Some communities use this to determine what the residents want to do that day (choice and self-determination), but to be effective, there also needs to be lots of props available to do these activities. Easily accessible storage, some of which might be highly visible and some of which might be less visible, is essential: almost no care community ever says they have enough storage (Bourgeois, Brush, Elliot, & Kelly, 2015). Meaningful engagement is also facilitated when chairs are placed close enough and at right angles to facilitate successful conversation. It is much more difficult to talk with someone who is sitting beside you, facing the same way, than it is to talk with someone who is at right angles to you (Calkins, 1988). Several small conversational clusters of chairs, which look out over an interesting view (inside or outside), with easy props such as books, magazines or personal photo albums, can also support relationship development.

Similar practice recommendations apply to the home environment: having easy access to items that support engagement and sharing with others is important. In the study by Gitlin and colleagues mentioned previously, it was having a wall full of family photographs that was sufficiently interesting for reminiscing which made having the handrail along the wall important. Whenever guests came to visit, the individual living with dementia would bring them to the wall, stand there and talk about each photo.

Conclusion

The designed environment is clearly a resource that can support functional abilities, meaningful relationships, and high quality of life for individuals living with dementia, yet is often still considered only the backdrop in front of which "real life" actually takes place. We need to consider both how the environment is designed by architects, interior designers and landscape architects, as well as how it is activated by the people in the setting. Care partners and caregivers generally are not trained to think about the importance of turning on a light, or closing curtains to reduce glare, or eliminating unnecessary background noise, all of which either contribute to excess disabilities or support more independent functioning in individuals living with dementia. Furthermore, although many studies still lack from small sample sizes, poor controls, and insufficient detail about the environmental characteristics being studied, the body of research on the specific impacts of different environmental features and characteristics continues to grow. More rigorous studies, especially ones with larger sample sizes, appropriate control groups, and multiple sites, are needed.

The growing focus on person-centered care values and practices will spur greater innovation, in large part based on an increasingly active role that individuals living with dementia are and will continue to take. There are increasing numbers of forums that individuals living with dementia are taking control of—organizations, blogs, books, and websites to name a few. But this has not yet translated into the design of the environment: we have not yet seen enough involvement of people with early-stage dementia being actively engaged in planning their living environments, either at home or in shared residential communities. Although no individual can honestly know what the future will hold and how they will perceive their world when they are deeper into their condition, getting their insights at an early stage is a critical, but currently missing, step. Finally, given the statistics on the percentages of people who are developing dementia as they age, *everyone* has the opportunity to give consideration to the thought of where and how they want to live, should they develop dementia. Write it down—one day you might need it. Each of the Practice Recommendations in this chapter provides a person-centered framework for creating supportive and therapeutic environments for individuals living with dementia.

Practice Recommendations for Fostering a Person-Centered Therapeutic and Supportive Environment

1. Create a sense of community within the care environment.

   The care community includes the person receiving care, their family and other chosen care partners, and professional care providers. The environment should support building relationships with others as a result of sharing common attitudes, interests, and the goals of the individuals living with dementia, their caregivers, and other care providers.

2. Enhance comfort and dignity for everyone in the care community.

   It is important that members of the care community are able to live and work in a state of physical and mental comfort free from pain or restraint. Environments are designed to maintain continuity of self and identity through familiar spaces that support orientation to place, time, and activity.

3. Support courtesy, concern, and safety within the care community.

   Members of the care community should show politeness and respect in their attitudes and behavior toward each other. Doing so includes creating a supportive environment that does not put unnecessary restrictions on individuals and helps them feel comfortable and secure, while also ensuring their safety. The environment compensates for physical and cognitive changes by maximizing remaining abilities and supporting caregiving activities.

4. Provide opportunities for choice for all persons in the care community.

   The culture of the care community supports a range of opportunities for all persons to make decisions concerning their personal and professional lives, as well as their health and welfare. The environment can provide opportunities for self-expression and self-determination, reinforcing the individual's continued right to make decisions for him/herself.

5. Offer opportunities for meaningful engagement to members of the care community.

   Relationships are built on knowing the person, which itself is based on doing things together. An environment that provides multiple, easily accessible opportunities to engage in activities with others supports deeper knowing and the development or maintenance of meaningful relationships.

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None reported.

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Review Article

Evidence-Based Interventions for Transitions in Care for Individuals Living With Dementia

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Abstract

Background and Objectives: Despite numerous, often predictable, transitions in care, little is known about the core elements of successful transitions in care specifically for persons with dementia. The paper examines available evidence-based interventions to improve the care transitions for persons with dementia and their caregivers.

Research Design and Methods: A state-of-the-art review was conducted for research published on interventions targeting transitions in care for persons living with dementia and their caregivers through January 2017.

Results: Our review revealed seven evidence-based interventions to postpone/prevent or reduce care transitions specific to persons living with dementia. Effective approaches appear to be those that involve the individual and caregiver in establishing goals of care, educate the individual and caregiver about likely transitions in care; provide timely communication of information about the individual, create strong inter professional teams with competencies in dementia care, and implement evidence-based models of practice.

Discussion and Implications: Five essential features for consistent and supported care transitions for persons with dementia and their caregivers are recommended. Findings reinforce the need for additional research and adaptation of evidence-based transitions in care interventions.

Keywords: Alzheimer's disease, Care coordination, Transitional care

Background and Significance

Currently 5.5 million people are estimated to be living with Alzheimer's disease, a number expected to reach close to 14 million by 2050 (Alzheimer's Association, 2017). Among individuals living with dementia in the U.S., transitions between acute and subacute health care settings and home and community settings are common (Figure 1). In a nationally representative sample of older adults diagnosed with dementia, most (89.2%) had at least one or more hospital stays and 54.9% had at least one stay in a nursing home in the past year (Callahan et al., 2015). In a second study, researchers found that 19% of nursing home residents living with cognitive impairment experienced one or more health care transitions (e.g., transfer to a hospital or move to a different nursing home) and an average of 1.6 transitions in the last 90 days of life (Gozalo et al., 2011).

Transitions in care for persons living with dementia include movement across settings and between providers increasing the risk of receiving fragmented care and experiencing poor outcomes such as hospital-acquired complications, morbidity, mortality, and excess health care expenditures (Phelan, Borson, Grothaus, Balch, & Larson, 2012). Among Medicare beneficiaries living with a diagnosis of Alzheimer's disease, 77% have three or more additional chronic conditions and 95% have at least one additional chronic condition (Centers for Medicare & Medicaid, 2016). Persons living with dementia, in comparison to those without dementia, have greater odds of having potentially

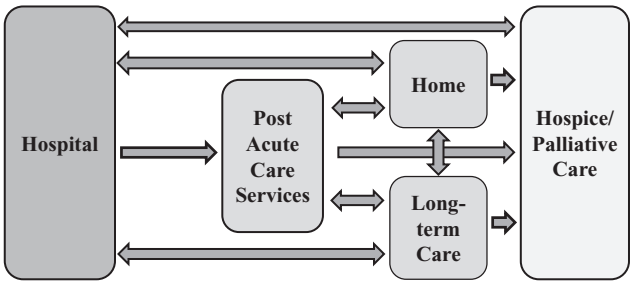

Figure 1. Common transitions in care across and between settings and providers.

avoidable hospitalizations for their chronic conditions such as diabetes and hypertension (Lin, Fillit, Cohen, & Neumann, 2013). In one recent study, experiencing new or worsening symptoms such as voice/speaking problems, urinary tract infections, blood pressure, delusions/hallucinations, falls, and "other organ specific" symptoms (e.g., diabetes, chest pain, vomiting, head injury) increased the odds of using acute care services two- to sevenfold for persons living with dementia (Sloane et al., 2017). It is estimated that 15% of hospitalizations for persons aged 65 years and older living with dementia are potentially avoidable (Lin, Rane, Fillit, Cohen, & Neumann, 2016). The resulting fragmentation in care and poor care coordination leads to many under-detected, under-evaluated, and unmet needs for persons living with dementia and their caregivers.

Transitions in care are often unnecessary, unplanned, and stressful not just for the person living with dementia but the family as well (Boltz, Chippendale, Resnick, & Galvin, 2015; Shankar, Hirschman, Hanlon, & Naylor, 2014). When an individual has to move between care settings there is a risk for a breakdown in communication, confusion about medication, lack of follow-up care, inaccuracies in information exchange, ineffective coordination of care between care providers, and inadequate patient and caregiver preparation (Gilmore-Bykovskyi, Roberts, King, Kennelty, & Kind, 2016; Kable, Chenoweth, Pond, & Hullick, 2015; Laugaland, Aase, & Barach, 2012; Shankar et al., 2014). A substantial percentage of transitions in care may be prevented by shifting care from institution to community and could result in billions of dollars in Medicare and Medicaid savings (Harrington, Ng, Laplante, & Kaye, 2012).

As the person living with dementia and their caregiver are the only common factor across levels and sites of care, a person-centered model to transitional care is viewed as a best practice to preventing adverse events and improving care quality. A "person-centered" approach considers the needs, goals, preferences, cultural traditions, family situation, and values of the person with dementia while integrating the family caregiver as an essential partner whose needs and preferences are also considered (Feinberg, 2012).

Transitional care—the planning and implementation of a move between care settings—offers an opportunity to focus on person- and family-centered care. Whereas there has been an increased emphasis in person-centered models of care transition in trials with cognitively intact older adults from hospital to home, much less attention has been paid to individuals living with dementia experiencing transitions in care between the hospital and home or residential settings and delaying moves to residential settings. Consequently, clinicians are not trained in best practices for transitional care, organizations do not have processes in place to facilitate smooth care transitions, and persons with dementia and their caregivers are not aware of the likelihood of common care transitions. The purpose of this paper is to provide an overview of available evidence-based interventions to improve transitions in care for persons living with dementia and their caregivers and provide practice recommendations for improving transitions in care going forward.

Methods

A state-of-the-art review was conducted for research published on transitions in care for persons living with dementia and their caregivers through January 2017 (Grant & Booth, 2009). A search for evidence-based intervention studies or systematic reviews was completed in several electronic databases: PubMed, CINAHL, PsycINFO, EMBASE, ProQuest, and Google Scholar. Search terms included common terms for transitions in care and dementia—("transitional care" or "care coordination" or "transfer delay" or "placement") and ("Lewy Body disease" or "dementia" OR "amnestic, cognitive disorders" or "frontotemporal dementia" or "Alzheimer's disease" or "cognitive impairment")—and articles were limited to the English language. The Cochrane Collaborative was also searched for systematic reviews of any interventions that aimed to reduce, postpone, or prevent transitions in care for persons with dementia.

Each author independently reviewed title and abstract of all identified papers, applying the following inclusion criteria: (a) testing an evidence-based intervention targeting transitions in care; (b) sample includes adults with Alzheimer's disease or other dementias; and (c) present transitions (e.g., decrease resource use, delay placement) outcomes. The reference lists of articles were also reviewed for additional relevant intervention literature. Duplicates were removed from the lists and a total of 130 papers remained for review. Of the 130 papers, 123 were excluded for one of the following reasons: no evidence-based intervention tested (n = 14), did not report care transitions outcomes for persons living with dementia (i.e., persons with

dementia excluded) (n = 109). The remaining seven papers were retained for this analysis.

Results

Table 1 offers a summary of the limited available data on evidence-based, patient-interventions targeting transitions in care for persons living with dementia and their caregivers. All seven of the interventions are multicomponent and focus on delaying or avoiding unnecessary transitions and reported evidence of support for individuals living with cognitive impairments. All but one intervention were tested in the United States. Two of the seven interventions begin during a hospitalization (Transitional Care Model, Dementia Caregiver Training Program), three interventions begin in the community at home (MIND at Home, Partners in Care, NYU Model), and two occur in the long-term care setting (Geriatric Team Intervention, Goals of Care Intervention). Below each evidence-based intervention is briefly described based on its delivery characteristics (e.g., psychosocial/educational or care coordination). Key transitional care delivery characteristics are *italicized* for emphasis.

Psychosocial/Psychoeducational Interventions Shown to Delay or Postpone Care Transitions

The New York University (NYU) Caregiver Intervention

The NYU Caregiver intervention is a comprehensive support and counseling program for caregivers designed to postpone or prevent nursing home placement of persons with Alzheimer's disease (Mittelman, Haley, Clay, & Roth, 2006). Key delivery characteristics of this intervention include an *interprofessional care team*, *prompt communication* of assessment findings, *caregiver education* and support in establishing *goals of care*. Comprehensive assessments at intake and follow-up provide information about the changing physical and emotional health and social support needs of the primary caregiver and the problems associated with dementia care. After the initial assessment two individual and four family counseling sessions are held with the primary focus being improving social support for the caregiver and helping the family understand the nature of dementia and the difficulties it presents. After the six counseling sessions, caregivers and participating family members are encouraged to telephone the counselor and to participate in the support groups whenever they need additional advice and support. Spousal caregivers in the intervention group experienced a 28.3% reduction in the rate of nursing home placement of the person living with dementia in comparison to the control group (p = .03) that received a limited intervention of project newsletters twice a year and a call from a counselor to "check in" every four months (Mittelman et al., 2006). In recent years, the model has been adapted to work with adult children (Gaugler, Reese, & Mittelman, 2013) and is in the process of being implemented on a larger scale (Mittelman & Bartels, 2014).

Prince Henry Hospital Dementia Caregiver Training Program

This 10-day program is delivered to persons with dementia during psychiatric hospitalization to delay nursing home placement. Dyads of persons living with dementia and a caregiver (most often spouses) were enrolled and both stayed in the inpatient setting to receive the 10-day intervention. Key intervention characteristics provided by an *interprofessional team* (focus of key clinician in brackets) to *educate and support caregivers* over the 10 days include: (a) a focus on reducing caregiver distress (social worker/occupational therapist); (b) combating isolation (psychiatrist); (c) decreasing guilt (psychiatrist); (d) supporting new ways of thinking (psychologist/occupational therapist); (e) coping skills (psychologist/occupational therapist); (f) fitness (physiotherapist/dietician); (g) medical assessment (psychiatrist); (h) review of community services (welfare officer); (i) planning for *goals of care* (psychiatrist); and (j) behavioral symptoms (entire team). The intervention demonstrated delays in institutionalization in participants for persons living with dementia in comparison to study participants who were randomly assigned to only receive a respite stay at the hospital (p = .04) (Brodaty, Gresham, & Luscombe, 1997).

Goals of Care Intervention

This is a two-session intervention delivered to decision makers of persons living with dementia in the nursing home setting (Hanson et al., 2016; Hanson et al., 2017). *Caregivers* for the person living with dementia first view an 18-min "*Goals of Care*" decision aid video followed by a structured discussion with the *interprofessional team* at the nursing home. The decision aid video provides a variety of information on: dementia, supporting function, improving comfort, goals of prolonging life, treatments consistent with each care goal, and how to prioritize goals. Each decision makers then received a print copy of the decision aid and guide entitled "Questions to Consider in Care Planning." The caregivers in the control group were shown a video about dementia and had a traditional care plan meeting with nursing home staff. All staff at the nursing homes were provided with training on how to have goals of care discussions. Persons living with dementia in the intervention sites had half as many hospital transfers (e.g., emergency department or hospitalization) compared to those in the control condition (p = .02) (Hanson et al., 2017). Family members in the "Goals of Care" group rated the quality of communication higher than the control group (p = .05).

Table 1. Evidence-Based Care Transitions Interventions Evaluated with Persons Living with Dementia and/or Their Caregivers

Author (year)	Setting	Intervention	Design	Description of the intervention(s)	Sample	Transition in care-specific outcomes
Psychosocial/Psychoeducational Interventions						
Mittelman et al. (2006)	Home	New York University (NYU) Model	RCT	Enhanced counseling and support intervention versus usual care	406 spousal caregivers of individuals with a diagnosis of dementia	Time to placement for the spouses of the caregivers who completed the NYU enhanced counseling and support intervention group was over 1.5 years longer than that of the usual care group (HR: 0.717; $p = .03$).
Brodaty et al. (1997)	Psychiatric Hospital	Dementia Caregiver Training (DCT) Program[a]	RCT	10 day intensive psycho-educational program for caregivers. Two-thirds of the caregivers received the DCT program either immediately after randomization or after a short waitlist versus control group (no intervention)	96 caregivers of older adults diagnosed with dementia	Time to placement was statistically significantly delayed among those persons living with dementia whose family caregivers received the DCT intervention in comparison to persons living with dementia whose family caregiver was in the control group (log rank test: 4.35, $p = .04$).
Hanson et al. (2017)	Nursing Home	Goals of Care (GOC) Intervention	Cluster RCT	GOC video with structured care planning discussion versus informational video and standard care planning	22 nursing home; 302 nursing home residents with severe to advanced dementia and their family caregiver	Nursing home residents in the GOC group had half as many hospitalizations compared to the control group (Relative risk: 0.45; $p = .02$). Family members in the GOC group rated their overall quality of communication with nursing home staff higher (score: 6.0) than the control group (score: 5.6; $p = .05$) at three months. By 9 months, family members in the GOC group rated the quality of end-of-life care communication with nursing home staff higher (score: 3.9) than the control group (score: 3.1; $p = .03$).

Table 1. *Continued*

Author (year)	Setting	Intervention	Design	Description of the intervention(s)	Sample	Transition in care-specific outcomes
Care Coordination Interventions						
Naylor et al. (2014)	Hospital to Home	Transitional Care Model (TCM)	CER	Augmented Standard Care (ASC) versus Resource Nurse Care (RNC) versus TCM	202 hospitalized older adults with a diagnosis of dementia or significant cognitive deficits in orientation, recall or executive function and 202 family caregivers	Time to first rehospitalization was longest for those in the TCM, followed by RNC and then ASC, with 25% of the TCM group rehospitalized by day 83 versus day 58 in the RNC group and day 33 in the ASC group. Rehospitalization or death was accelerated for both the ASC and RNC groups by a factor of 1.75 and 1.93, respectively, in comparison to the TCM group (p = .05 and p = .02, respectively.)
Samus et al. (2014)	Home	MIND at Home	RCT	Dementia care coordination versus usual care	303 community dwelling older adults that met criteria for dementia or cognitive disorder not otherwise specified (DSM-VI-TR) and a reliable study partner	The MIND at Home group had a significant delay in time to all-cause transition from home and the adjusted hazard of leaving the home was decreased by 37% (HR: 0.63; p = .01) and remained in their home 51 days longer (log rank test: 4.1; p = .02) compared to the control group.
Bass et al. (2014)	Home	Partners in Dementia Care (PDC)	RCT	Care coordination program versus usual care	328 veterans with a diagnosis of dementia in their medical record	The PDC group with greater cognitive impairment at 6 months postenrollment and more behavioral symptoms at baseline had fewer hospitalizations (–0.29 and –0.26, respectively; p = .01, both) and among those with behavioral symptoms at 6 months post enrollment had fewer emergency department visits (–0.27; p = .02) in comparison to the control group.

Table 1. *Continued*

Author (year)	Setting	Intervention	Design	Description of the intervention(s)	Sample	Transition in care-specific outcomes
Bellantonio et al. (2008)	Assisted Living	Geriatrics Team Intervention (GTI)	RCT	GTI consisted of four systematic inter professional geriatric team assessments during the first 9 months living in an assisted living community versus standard medical care.	100 older adults with dementia who relocated to an assisted living	Analyses of the primary outcomes revealed reductions in the risk of unanticipated transitions, including hospitalizations (45%), ED visits (12%) and nursing home placement (11%), as well as death (63%), for the GTI group versus standard care, though not statistically significant.

Note: CER = Comparative Effectiveness Research; CI = Confidence interval; HR = Hazards ratio; RCT = Randomized Control Trial.
[a]Australia.

Care Coordination Interventions Shown to Postpone Transitions in Individuals Living With Dementia

The Transitional Care Model (TCM)

The TCM is a rigorously tested comprehensive advanced practice nurse led model of care that starts in the hospital and continues through skilled nursing facilities and back to the community (Naylor et al., 1994; Naylor et al., 1999; Naylor et al., 2004). The TCM focuses on person-centered care; education and promotion of self-managed care; continuity, collaboration, and care coordination with all members of the *interprofessional team* (Hirschman, Shaid, McCauley, Pauly, & Naylor, 2015). In a recent comparative effectiveness trial, the hospital to home TCM was tested against other lower dose evidence-based hospital only interventions each designed to improve care transitions for persons living with cognitive impairment and their family caregivers. The TCM intervention consisted of visits by the advanced practice nurse in the hospital and at home to discuss *goals for care* and establish the care plan; a *collaborative visit* with the older adult, *caregiver* and at least one of their physicians; telephone calls and advanced practice nurse *availability 7 days a week for education and support* (Hirschman et al., 2015). The TCM supplemented care during the hospitalization, supported the discharge planning process and substituted for skilled home care nurses, when appropriate. The advanced practice nurses completed additional training on managing dementia and delirium in addition to the TCM educational training. Older adults who received the TCM had a longer time to first rehospitalization or death compared to the lower-dose hospital only interventions (TCM: 83 days; RNC: 58 days; ASC: 33 days) (McCauley, Bradway, Hirschman, & Naylor, 2014). The 30-day rehospitalization rates in this trial for the TCM group (9%) were half as much as those in the lower dose hospital only intervention groups (19% and 22%) (Naylor et al., 2014). Rehospitalization or death was accelerated for both the ASC and RNC groups by a factor of 1.75 and 1.93, respectively, in comparison to the TCM group (p = .05, p = .02, respectively) (Naylor et al., 2014). Findings from this trial were similar to prior randomized trials and comparative effectiveness research TCM studies with cognitively intact older adults (Naylor et al., 1999; Naylor et al., 2004; Naylor et al., 2013).

MIND at Home

The MIND at Home intervention is 18 months of care coordination designed to link persons living with dementia and their caregivers to community-based agencies, medical and mental health care providers, and community resources (Samus et al., 2014). MIND at Home is delivered by an *interprofessional team* who conduct comprehensive in-home dementia-related needs assessments and provide individualized plans to establish *goals of care* and implementation. The team uses six basic care strategies: resource referrals, attention to environmental safety, *dementia care education*, behavior management skills training, informal counseling, problem-solving, as well as on-going monitoring, assessment and *planning for emergent needs*. Each component of the intervention is based on best practice recommendations and evidence from prior research, and is combined for maximum impact. Results from the MIND at Home trial support that a home-based dementia care coordination included longer time to transition from home or death (remained in their home 51 days longer, p = .02) and reduced risk of leaving the home by 37% in comparison to the control group (Samus et al., 2014). More recent results demonstrated that MIND at Home participants had increased use of dementia-related outpatient medical care and nonmedical supportive community services, a combination that may have helped participants remain at home longer (Amjad et al., 2017).

Partners in Dementia Care (PDC)

The PDC model is a coaching model designed to support people living with dementia and their *caregivers* to generate an action plan that is in line with their preferences and *goals for care* (Bass et al., 2014; Judge et al., 2011). This model has been tested in the Veterans Administration (VA) health system. In a recent trial, each veteran in the PDC group worked with a care coordinator (a social worker, nurse, or other helping profession degreed individual) to develop the content and steps to be addressed in the *goals of care* (Bass et al., 2015). Copies of action plans were provided in writing by mail to the veteran and their family member and the detailed plan was kept in the VA medical record. The assessment and care plan were *revisited on an ongoing basis*. In comparison to the usual care group, the veterans in the PDC group with high baseline behavioral symptoms had 32.0% fewer hospitalizations and veterans in the PDC group with greater cognitive impairment at 6 months after the start of the intervention had 26.9% fewer hospitalizations (p = .01, both) (Bass et al., 2015). There were 28.6% fewer emergency department visits among veterans with more behavioral symptoms at 6 months in the intervention group in comparison to the unusual care group (p = .02) (Bass et al., 2015).

Geriatrics Team Intervention

This intervention consists of four systematic, *interprofessional assessments* conducted by a team of clinicians including a geriatrician or geriatrics advanced practice nurse, a physical therapist, a dietitian, and a medical social worker. The assessment was completed during the first 9 months of the person living with dementia moving to the assisted living. The geriatrician and geriatrics advanced practice nurse conducted medical and cognitive evaluations. The physical therapist evaluated physical function, gait, and balance and assessed the need for ongoing physical therapy and assistive devices. The dietitian evaluated nutritional status and provided dietary recommendations. The medical social worker assessed guardianship issues, long-term planning, and the psychosocial adjustment of the residents and families. Following assessments, the team, together with staff nurses, meet bimonthly to discuss the most recent assessments and establish *goals of care* with the primary care physician, the Assisted Living director, and *families*. Members of the team were available for *in-person or telephone consultation* with Assisted Living staff members throughout the study. While not statistically significant, individuals who received the intervention had a reduced risk of any unanticipated transition (13%), permanent relocation to a nursing facility (11%), emergency department visits (12%), hospitalization (45%) in comparison to persons living with dementia in the assisted living setting who received usual care (Bellantonio et al., 2008).

Discussion

With this review, we sought to summarize current evidence about interventions that improve transitions in care for persons living with dementia and their caregivers. In our review of the seven evidence-based interventions (see Table 1) that included transitions in persons living with dementia, successful interventions were those that included five key elements: (a) educating the individual and caregiver about likely transitions in care and ways to delay or avoid the transition; (b) providing timely communication of information among everyone involved, including the individual, caregiver and care team; (c) involving the individual and caregiver in establishing goals of care (person-centered); (d) comprising a strong collaborative interprofessional team; and (e) implementing evidence-based models of practice. Each evidence-based intervention targeted the individual living with dementia and a family caregiver and required the person or persons delivering the intervention to have a specific skill set (e.g., counselor, nurse, physician) or complete educational trainings to develop a set of competencies to work with the population, which sets these interventions apart from other transitional care interventions with cognitively intact older adults.

These key elements are in line with recent systematic reviews of best practices for care transitions for frail older adults without dementia (Allen, Ottmann, & Roberts, 2013; Chenoweth, Kable, & Pond, 2015; LaMantia, Scheunemann, Viera, Busby-Whitehead, & Hanson, 2010; Pimouguet, Lavaud, Dartigues, & Helmer, 2010; Ray, Ingram, & Cohen-Mansfield, 2015; Somme et al., 2012; Tam-Tham, Cepoiu-Martin, Ronksley, Maxwell, & Hemmelgarn, 2013). These reviews highlight the missing of persons living with dementia and their caregivers. Challenges that are unique to transitions among persons living with dementia include the need for dementia care expertise among the team, the reliance on the caregiver as an essential member of the team, the need for caregiver education and preparation, and the challenges of behavioral symptom management as part of the goals of care conversation. Nonetheless, these reviews suggest that the best outcomes for persons at high risk for care transitions, such as individuals living with dementia, are associated with care that is person-centered in that is coordinated, responsive, and tailored to individual needs and preferences. Thus, best practice recommendations involve successfully connecting medical, social and supportive care professional and caregivers over the course of dementia to achieve person-centered outcomes in transitions between care settings.

Moreover, while evidence-based transitional care intervention studies aimed at preventing transitions such as hospitalizations or rehospitalizations are numerous, our findings suggest that for most of these studies persons living with dementia were included in only a limited way or no detailed evidence of the impact of these interventions on transitions in care for persons living with dementia was published at the time of this search (through January 2017). It is likely that interventions such as Care Transition Intervention (Coleman, Parry, Chalmers, & Min, 2006); INTERACT II, (Ouslander, Bonner, Herndon, & Shutes,

2014); BOOST (Williams et al., 2014); and Project RED (Jack et al., 2009; Mitchell et al., 2014) are being used and adapted or modified for persons living with dementia in real world settings. Going forward, rigorous assessment and sharing of transitions outcomes from these efforts for persons living with dementia is needed. More attention needs to be put into well-conducted studies to understand the barriers and facilitators of adapting these interventions in dementia care practice.

Finally, most persons living with advanced dementia eventually move to long-term care settings, and for many this is the setting of death. However, there was a notable gap in the reviewed literature in terms of studies that examined transitions to palliative or end-of-life care. One Cochrane review on respite care found no evidence supporting the role of respite in delaying time to institutionalization (Lee & Cameron, 2004). Nonetheless, decisions about transitions should also be guided by the advance directives of the person living with dementia; if the individual or their surrogate decision maker so wishes, no transition may be the best decision. Any transition in care as life draws to a close is intrusive, stressful, and can negatively affect quality of life.

Limitations

While we aimed for a transparent, systematic, and pragmatic approach in this review, our conclusions are limited by factors common to literature reviews including the selection of search terms, the sources searched, and the inclusion criteria. The interventions included in this review represent the breath of approached, but may not represent the depth of evidence in transitional care interventions for persons living with dementia. For example, we did not assess each individual intervention for risk of bias or effect estimates. In addition, several strategies that have been suggested for preventing unnecessary hospitalizations were not found in our review. These include adaptations to the living environment and increasing participation in activities (Spijker et al., 2008). Our recommendations to follow are therefore grounded on the existing, albeit limited, evidence base.

Recommendations

In the course of the review, five themes emerged and were used to develop the following recommendations to guide transitional care interventions for persons living with dementia:

1. Prepare and educate persons living with dementia and their family caregivers about common transitions in care.

   Preparing and educating persons living with dementia and their caregivers about transitions in care should occur before, during and after transitions. Because family caregivers are integral to the care of individuals living with dementia, it is important to understand their need for information about common transitions, including across care settings, such as home to hospital or skilled nursing facility, nursing home to emergency department; within care settings, such as from an emergency department to an intensive care unit; or from one team of clinicians or care providers to another. For example tools are publically available from the Alzheimer's Disease Education and Referral Center (ADEAR) NICHE - Nurses Improving Care for Health System Elders and the Alzheimer's Association that can be provided to persons living with dementia and their caregivers to help them prepare for the possibilities of hospitalization (Alzheimer's Disease Education and Referral Center, 2017, NICHE, 2017b; NICHE, 2017c) and transition to rehabilitation or long-term care settings such as nursing homes or assisted living (NICHE, 2017a).
2. Ensure complete and timely communication of information between, across and within settings.

   Individuals living with dementia are frequently transferred across facilities without essential clinical information. Careful attention is essential to ensure a safe "handoff." Finding timely and standardized ways to share medical records and advance care planning forms between patients, caregivers, and providers throughout transitions is needed (Borson et al., 2016). Linking electronic health records across care settings also offers this potential. Open communication between providers, across settings, and within organizations or clinical practices is essential (both written and verbal). Assisting persons living with dementia and their caregivers in accessing and sharing information in a person- and family-centered way can help to avoid poor outcomes often associated with transitions in care (e.g., rehospitalizations, emergency department visits, medication errors, and caregiver stress). Information must be clinically meaningful, appropriate in amount; it should be communicated by a method useful to the receiving site of care. Achieving these objectives by using standardized forms or standardized approaches to communicate hand-offs can increase the accuracy of information and minimizes risk of error.
3. Evaluate the preferences and goals of the person living with dementia along the continuum of transitions in care.

   Revisiting preferences and goals for care, including treatment preferences, advance directives, and social and living situation, while the person living with dementia can participate is essential during transitions in care. If a person living with dementia is unable to participate, including caregivers or others who know the person well is vital. After any hospitalization or other significant change requiring a transition in care or level of care, a review and reassessment of the preferences and goals of the person living with dementia should include

an assessment of safety, health needs, and caregiver's ability to manage the needs of the person living with dementia. This requires improved competencies of the entire interprofessional team in conducting goals of care conversation, and more effective processes to ensure appropriate assessments are performed before the decision to move a person with dementia to another setting of care is made.

4. Create strong interprofessional collaborative team environments to assist persons living with dementia and their caregivers as they make transitions.

   Creation of a strong interprofessional collaborative team environment to support the person living with dementia throughout transitions in care is crucial. Each member of the team needs to have a basic set of competencies in the fundamentals of caring for individuals living with dementia at all stages and the needs of family caregivers (Burke & Orlowski, 2015). All of the evidence-based interventions described here were specifically designed to address the challenges for individuals living with dementia and other complex chronic conditions as well as the needs of their family caregivers. For example, in the MIND study case managers were trained in dementia care management over a 4-week period of time (Amjad et al., 2017; Samus et al., 2014), in another study, Naylor and colleagues (2014) developed a set of web-based education modules focused on how to manage the care needs of older adults living with dementia and their family caregiver as they transition from the hospital to home (McCauley et al., 2014). Furthermore, this type of work requires continuity of the same clinicians (whenever possible) to support the person living with dementia and their family as they move between providers and across setting. Every member of the health care team must be accountable and responsive to ensure the timely and appropriate transfer of responsibility to the next level or setting of care. Optimally clinicians from the sending site of care should maintain responsibility for individuals with dementia until the caregivers at the receiving site assume clinical responsibility.

5. Initiate/Use evidence-based models to avoid, delay, or plan transitions in care.

   The seven evidence-based models of care in this review focused on avoiding unnecessary transitions (such as hospitalization, or emergency department visits), delaying or supporting placement in residential care settings (such as nursing homes or assisted living communities). Although many evidence-based models have excluded or limited the inclusion of persons living with dementia, adaptations of these models should be considered whenever possible to improve transitions. Among the interventions that targeted hospitalizations and emergency department visits, it is important to note that these events are often tied to nondementia-related conditions. Furthermore, targeting avoidable hospitalizations or rehospitalization for persons living with dementia has the potential to interrupt poor outcomes more common with this population such as risk of delirium (Fick, Steis, Waller, & Inouye, 2013; Watkin, Blanchard, Tookman, & Sampson, 2012) and falls (Meuleners, Fraser, Bulsara, Chow, & Ng, 2016). As evidence-based models of care are adapted and modified to meet the needs of persons living with dementia transitioning between, across and within settings of care it is critical to share the findings from these adapted transitions in care models.

Conclusion

Taken as a whole, research on transitional care interventions for persons with dementia is in an early development stage. Most research on transitions in care has not focused on older adults with dementia, and our review revealed few trials testing interventions to postpone/prevent or reduce negative outcomes associated with care transitions specific to persons living with dementia. Nonetheless, the shift in dementia care from institution to community means that interventions to support or prevent/postpone transitions in care will continue to be common for persons living with dementia. At the same time, evidence is mounting that efforts to ensure continuity of care for individuals with dementia during care transitions results in improved outcomes for the individual and their caregivers.

As the population of individuals living with dementia continues to grow for the near future finding ways to best meet their needs and more fully understand care transitions from diagnosis to death are needed. Recommendations for best practices for transitions of care for high risk older adults currently exist in Clinical Practice Guidelines such as Transitions of Care in the Long-Term Care Continuum and Acute Change of Condition in the Long-Term Care Setting (e.g., INTERACT) (American Medical Directors Association (AMDA), 2010; Ouslander et al., 2014), and documents available through the National Transitions of Care Coalition (NTOCC). While these recommendations offer promising approaches for reducing unnecessary transitions (Ingber et al., 2017), this evidence needs to be expanded to consider if it meets the unique needs of persons living with varying stages of dementia and their caregivers.

It takes a team to prevent avoidable transitions and to safely manage necessary transitions in care for persons living with dementia. The evidence supports that when health care team members effectively communicate with each other across care settings and with caregivers, persons with dementia can be safely transitioned with minimal complications. When caregivers are educated about, and involved in, care transition decisions rehospitalizations rates and lengths of stay decline and nursing home admissions can be delayed (Gitlin & Wolff, 2011).

Putting these five recommendations into practice will require a shift in current health care policies and practices.

The growing need for services that reduce unnecessary transitions or support necessary transitions can act as drivers for program innovation. For example, most health care settings require infrastructure support to involve caregivers in care transitions, and is at the heart of new initiatives such as the AARP initiated "Caregiver Advise, Record, Enable (CARE) Act" (AARP, 2014). In addition, there is a need to compensate the health care team for the required time to adequately assess the needs of both persons living with dementia and caregivers or provide the necessary education to caregivers (Alzheimer's Association, January 2017). While implementing evidence-based transitional care interventions offers the potential for cost savings by avoiding care complications, this has yet to be realized or captured. As a result, changing reimbursement structures to support evidence-based transitional care will require policies (such as the "Health Outcomes, Planning, and Education [HOPE] for Alzheimer's Act" S. 857/H.R. 1559) that recognize the essential role of caregivers and the potential benefits for persons with dementia, their caregivers and society.

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Conflict of Interest

None reported.

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Conclusion

Improving Care Through Public Policy

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Without the development of a disease-modifying biomedical therapy, the number of people aged 65 years and older with Alzheimer's dementia may nearly triple, from 5.5 million to a projected 13.8 million, by 2050 (Alzheimer's Association, 2017). It is imperative that society be able to care for them. The practices featured throughout this supplement are just a few of the effective, individualized care models that can meet the needs and preferences of persons living with dementia, but more are required. We must be able to test, improve, and expand existing models and develop new ones.

Policy can be a powerful driver of this expansion and innovation. Promotion of standards and practices by the federal and state governments can extend the reach of high-quality care to more people in need. Indeed, with input from and robust advocacy by the Alzheimer's Association and its advocates, Congress unanimously passed the National Alzheimer's Project Act (Public Law 111–375) in December 2010, which President Barack Obama signed into law in January 2011, elevating Alzheimer's to a national policy priority.

This law required the creation of a strategic plan, the National Plan to Address Alzheimer's Disease ("National Plan"), to improve care, support, and treatment (U.S. Department of Health and Human Services, 2016). It is organized around five goals, two of which specifically address care and support: Enhance Care Quality and Efficiency (Goal 2) and Expand Supports for People with Alzheimer's Disease and Related Dementias and Their Families (Goal 3). The other three goals focus on research, public awareness, and progress of the National Plan. Various strategies and objectives were established to achieve Goals 2 and 3, spanning issues from workforce to education to care planning. Several of these are discussed in this article. The Advisory Council on Alzheimer's Research, Care, and Services ("Advisory Council") oversees the implementation of the National Plan and is composed of federal agency representatives and stakeholders like patient advocates, caregivers, and voluntary health association representatives, among others. The Advisory Council submits its annual recommendations to update the National Plan to the U.S. Secretary of the Department of Health and Human Services.

To help drive the implementation of Goals 2 and 3 of the National Plan, the Alzheimer's Association convened a workgroup with expertise in clinical care, long-term services and supports, dementia care and support research, and public policy. Ultimately, it identified public policies needed over a 10-year period to improve systems of care and support in its *Report on milestones for care and support under the U.S. National Plan to Address Alzheimer's Disease* ("Milestones") (Borson et al., 2016). The National Plan, the Milestones, and the federal and state policy efforts discussed below can improve care and support for individuals living with dementia and their caregivers by promoting adoption and implementation of the effective practices featured in this supplement and beyond.

Detection, Diagnosis, and Education

As has been noted, Alzheimer's and related dementias are underdiagnosed and when diagnoses are made, they are too often undisclosed by clinicians: studies suggest that fewer than half of individuals report being told of their diagnoses (Alzheimer's Association, 2015). Without detection and diagnosis, people living with dementia cannot get the help they need. Thus, education of clinicians and individuals as well as actions to improve diagnosis rates feature prominently in the National Plan and the Alzheimer's Association Milestones. Specifically, the Milestones workgroup recommends the increased use of public awareness campaigns to ensure that, by 2018, 80% of people aged 65 years and

older understand that dementia is not a normal sign of aging and are comfortable discussing memory problems with their health care providers. Furthermore, the workgroup recommends efforts to ensure that 70% of physicians are knowledgeable on the importance of detection, appropriate diagnosis, and patient disclosure by 2018; that figure should increase to 90% by 2022. Finally, both the National Plan and the Milestones devote strategies to ensure receipt of culturally sensitive education, training, and support materials. These recommendations and the policies discussed below can move us closer to the realization of these goals.

The Alzheimer's Association has long advocated for legislation to improve detection, diagnosis, and awareness of the disease. Because so many persons living with dementia are covered by the federally-funded Medicare and Medicaid programs (Alzheimer's Association, 2017), changes and improvements to these programs can have an enormous impact on beneficiaries with dementia. Although Medicare historically covered diagnostic evaluations, diagnosis cannot happen until impairment is *detected*; assessment was not a covered Medicare service. Thus, the Association offered detailed input on the creation of a new Medicare benefit under the Patient Protection and Affordable Care Act ("Affordable Care Act," "ACA") (Public Law 111–148), the Annual Wellness Visit (AWV). The AWV creates an incentive for clinicians in requiring an assessment to detect cognitive impairment. In its comments on the proposal, the Alzheimer's Association urged the Centers for Medicare & Medicaid Services (CMS) to include in the AWV assessments for safety, function, and depression; information and referrals for individuals and caregivers; and education for primary care providers on detecting cognitive impairment. The benefit went into effect in January 2011 and the Association developed guidance on how to conduct cognitive assessments to encourage utilization of the benefit by primary care providers consistent with its recommendations to CMS. This guidance, the Medicare Annual Wellness Visit Algorithm for Assessment of Cognition (Cordell et al., 2013), encourages review of patient health risk assessment information, patient observation, unstructured queries during the AWV, and suggested structured cognitive assessment tools for both patients and informants. Because the AWV remains underutilized, the Milestones workgroup has recommended identifying clinicians who have successfully incorporated the AWV into their practices and evaluating how they have increased its use as well as the cognitive assessment tools they have used. This information could, in turn, be used to increase adoption of the benefit and improve detection of cognitive impairment.

More recently, the Association, in conjunction with Congressional supporters, helped to develop the Health Outcomes, Planning, and Education (HOPE) for Alzheimer's Act (S. 857/H.R. 1559), which would have created a new benefit to cover comprehensive care planning services to Medicare beneficiaries and their caregivers following a diagnosis of Alzheimer's disease. Additionally, it would have required documentation of the diagnosis and care planning services in the beneficiary's medical record, as well as education of clinicians about the new benefit. Since its introduction in 2009, the bill saw strong bipartisan growth in the numbers of its cosponsors. In addition to advocating for the bill within Congress, the Alzheimer's Association pushed for stronger care planning efforts in discussions with CMS and before the Advisory Council, of which CMS is a member. Following that growth of bipartisan support for the HOPE for Alzheimer's Act in Congress, CMS approved a billing code, G0505, in November 2016, allowing clinicians to be reimbursed for the comprehensive assessment of beneficiaries with cognitive impairment and the development of care plans for them (Centers for Medicare & Medicare Services [CMS], 2016). In order to bill under this code, discussed below, clinicians must provide a cognition-focused evaluation and various assessments, and the care plan must include education and support for the individual and caregivers. The implementation of this code, effective January 2017, is a significant step in improving detection, diagnosis, and education.

Other federal agencies are also taking steps to close gaps in awareness and diagnosis consistent with objectives in the National Plan. The Health Resources and Services Administration, which educates health care professionals, has coordinated the development of a unified curriculum on Alzheimer's and related dementias for primary care providers. The National Institute on Aging, the primary federal research agency on dementia, developed a portal of resources for health professionals that include tools on assessment and care management, https://www.nia.nih.gov/health/alzheimers-dementia-resources-for-professionals (National Institute on Aging [NIA], 2017). The Administration for Community Living (ACL) has developed and disseminated educational materials specific to caregivers.

Additionally, federal agencies are working to improve awareness and detection of cognitive impairment beyond the National Plan and in nonclinical settings. Effective January 2018, CMS will require home health agencies to evaluate individuals' cognitive status as part of overall patient assessments (Centers for Medicare & Medicaid Services [CMS], 2017). The National Aging and Disability Transportation Center, a program of the U.S. Department of Transportation, has published information, tips, and resources for public transportation providers on dementia and the needs of riders living with dementia (National Aging and Disability Transportation Center, 2017).

In collaboration with the Alzheimer's Association, the Centers for Disease Control and Prevention (CDC) is taking a joint federal-state approach to awareness about dementia and brain health, the Healthy Brain Initiative: The Public Health Road Map for State and National Partnerships (Alzheimer's Association and Centers for Disease Control and Prevention, 2013). This road map outlines approaches

for state and local public health agencies and their partners to promote healthy cognitive functioning, address cognitive impairment, and meet the needs of care partners. The road map includes guidance on the development of effective policy at state and local levels. Implementation of the Public Health Road Map is a policy priority for Association chapters in the states.

Several state governments have also participated in public awareness campaigns to increase knowledge and understanding of Alzheimer's, to encourage early detection and diagnosis, and to train the general public on how to interact with persons with dementia.

- **Georgia:** In 2014, the Georgia Division of Aging Services, the Rosalynn Carter Institute for Caregiving, the Alzheimer's Association, and Georgia Public Broadcasting produced and aired "Alzheimer's: Hope For Tomorrow, Help For Today," which offered information for individuals with the disease and caregivers.
- **Oregon:** The Oregon State Unit on Aging, with a grant from the U.S. Department of Health and Human Services and matched by state and private funds, worked with the Alzheimer's Association, the Oregon Department of Human Services, and Oregon Care Partners to increase outreach, marketing, and training for staff of the statewide Aging and Disability Resource Connection (ADRC) system. Nearly all ADRC staff were trained to identify persons who may have dementia and provide appropriate information and assistance, options counseling, and care transitions.
- **New York:** The New York State Department of Health created 10 regional Centers of Excellence for Alzheimer's Disease to promote public awareness and train health care providers and students in detection, diagnosis, and treatment; to enhance the quality of dementia diagnoses; to provide comprehensive, community-based care and support; and to promote the benefits of participation in research.

These policy approaches to raising awareness about the disease, how individuals are affected by it, and encouraging detection are the first steps to connecting more people to the care and support they need.

Assessment and Person-Centered Care Planning

Because Alzheimer's and related dementias are degenerative and lack effective treatments, care planning is essential to affected persons and caregivers. It allows persons living with dementia to participate in decision making while they are still able, and it can reduce stress and confusion for those individuals and for family and friends. It can also lead to more effective care management by clinicians, many of whom do not feel that they have the necessary time and resources to care for individuals with such complex needs (Alzheimer's Association, 2016). And because needs and preferences can vary drastically between affected individuals and even day to day, it is all the more important that planning be tailored accordingly.

Assessment and Care Planning

The development of individualized care plans based on comprehensive assessments remains a primary policy focus at the national and state levels. In its 2016 update to the National Plan, the Advisory Council recommended that stakeholders enhance care planning and coordination by increasing the use of person-centered and caregiver goals, and improve measurement of those goals within 3 years. The Milestones workgroup recommended reimbursement for high-quality care planning immediately following a dementia diagnosis—the crux of the HOPE for Alzheimer's Act. As noted above, CMS has realized these recommendations, now providing that reimbursement.

To receive reimbursement under billing code G0505, a clinician must provide an extensive, individualized assessment that results in a care plan (Centers for Medicare & Medicaid Services [CMS], 2016). Specifically, the encounter must include:

- Cognition-focused evaluation including a pertinent history and examination;
- Functional assessment (e.g., Basic and Instrumental Activities of Daily Living), including decision-making capacity;
- Use of standardized instruments to stage dementia;
- Medication reconciliation and review for high-risk medications, if applicable;
- Evaluation for neuropsychiatric and behavioral symptoms, including depression, including use of standardized instrument(s);
- Evaluation of safety (e.g., home), including motor vehicle operation, if applicable;
- Identification of caregiver(s), caregiver knowledge, caregiver needs, social supports, and the willingness of caregiver(s) to take on caregiving tasks;
- Advance care planning and addressing palliative care needs, if applicable and consistent with beneficiary preference; and
- Creation of a care plan, including initial plans to address any neuropsychiatric symptoms and referral to community resources as needed (e.g., adult day programs, support groups); care plan shared with the patient and/or caregiver with initial education and support.

Physicians, physician assistants, and certain advanced practice nurses are eligible to bill under this code. To ensure robust use of the code, particularly by primary care practices who may not be equipped to meet the extensive assessment requirements, the Alzheimer's Association developed the Cognitive Impairment Care Planning Toolkit (alz.org/careplanning) containing suggested assessment tools and other resources that are applicable in primary

care settings. As of January 2018, the temporary G0505 code will transition to 99483 and the Advisory Council has recommended that CMS should annually report code data by state, region, and diagnosis. Implemented and communicated effectively, this policy achievement will have a profound, positive impact on thousands of beneficiaries and clinicians.

Person-Centered Planning

Although not a new concept, the fusion of person-centered care planning into state and federal policy is relatively recent and extends to individuals with a wide range of conditions and across the care continuum. Notably, Section 2402(a) of the Affordable Care Act requires states receiving federal funds to develop home- and community-based services (HCBS) that are person-centered and maximize independence and self-direction.

Recognizing the growing population of Medicare and Medicaid beneficiaries with a range of chronic conditions, including dementia, CMS has made significant changes to incorporate beneficiaries' needs and preferences into their care. In an overhaul of its regulation of long-term care facilities serving Medicare and Medicaid beneficiaries, CMS added to existing care planning requirements, directing nursing facilities to complete either a baseline care plan or a comprehensive care plan within 48 hr of admission (Centers for Medicare & Medicaid Services [CMS], 2016). Care planning must account for beneficiary goals, physician orders, therapy and social services, and discharge assessment and planning, among other areas. Finally, the interdisciplinary team must include participation of beneficiaries and their caregivers.

CMS and ACL have also engaged in a sweeping revision of the philosophy underpinning HCBS programs. In 2014, CMS updated its regulation governing Medicaid HCBS with an emphasis on person-centered planning, choice, self-determination, and community living. Several states serve persons with dementia through Medicaid waiver programs and raised questions on how to comply with the new rule. In response, CMS and ACL released guidance on wandering, discussed in detail below, and how facilities can employ a person-centered planning approach to ensure beneficiaries' safety, dignity, and autonomy (Centers for Medicare & Medicaid Services, 2016).

In addition to efforts to integrate the principles of person-centered planning into their HCBS programs, many states have incorporated this approach into their laws and regulations. Oregon's regulations on memory care communities are written to promote a "...positive quality of life….person directed care...dignity, choice, comfort, and independence..." (State of Oregon, Oregon Administrative Rules, 2016). They also require facilities to undergo a rigorous endorsement process that includes proof of care planning and a person-centered approach. For example, the initial application for endorsement must include a copy of the care planning tool and employee training curricula. Facilities are also required to develop and implement life enrichment and family support programs. Staff must be trained in person-directed care and services must be delivered in "a manner that promotes autonomy and dignity...and maintain[s] or enhance[s] the resident's remaining abilities for self-care." The Commonwealth of Virginia's current Dementia State Plan includes a review by the Alzheimer's Disease and Related Disorders Commission of "all state-funded services to ensure dementia-capable approaches and policies based on principles derived from the Person-Centered Care and Culture Change movements" (Commonwealth of Virginia Alzheimer's Disease and Related Disorders Commission, 2015).

Given the unique nature of dementia and how individuals experience the disease, assessments and care plans can improve the quality of life for affected persons and their caregivers. While those assessments and care plans must be tailored from person to person, the broad dissemination of policies promoting such an approach can help to reach more people in need.

Care Delivery, Coordination, and Transitions

The care needs of individuals living with dementia are complex. Alzheimer's and dementia can lead to memory loss, disorientation and confusion, and mood and behavior changes, all of which worsen over time. These compound the challenges of managing other health issues: Medicare beneficiaries with Alzheimer's disease and other dementias have twice as many hospital stays per year as other older people and they are more likely than those without dementia to have other chronic conditions (Alzheimer's Association, 2017). Their needs extend well beyond the medical: they need help with basic daily tasks and must consider safety issues like wandering. The needs of caregivers can be equally involved, as they must assist persons with dementia with these myriad tasks while trying to manage their own physical and emotional health. These challenges require specialized care that is coordinated among knowledgeable providers and across settings.

Care Delivery

Strategy 2.A of the National Plan is devoted to building a workforce with the skills to provide high-quality care. The Milestones workgroup expands on this strategy, recommending that, after identifying state and county level workforce needs, those targets be met by 80% of states and counties by 2025 (Borson et al., 2016). The workforce must also be adequate and well-trained within the many settings in which persons with dementia receive care: their own homes through home health agencies, adult day care centers, assisted living facilities, hospitals, nursing homes, and hospice. Staff must also be attuned to the cultural values and preferences of different races, ethnicities, and

populations that are disproportionately affected by various forms of dementia.

The use of hospice continues to increase among persons with dementia. Nearly half are in hospice care at the time of death, yet less than half of surveyed nursing homes have a palliative care program. Palliative care can improve quality of life, control costs, and enhance patient and family satisfaction. As the demand for hospice and palliative care grow, so does the need for an adequately trained workforce. First introduced in the 114th Congress, the Palliative Care and Hospice Education and Training Act (S. 693/H.R. 1676) would increase palliative care and hospice training for health care professionals through grants and career development awards, launch a national campaign to inform patients and families about the benefits of palliative care, and expand research on the delivery of palliative care.

Efforts to deliver more person-specific care have also escalated in residential settings. In its 2016 revision of the rules governing long-term care facilities, CMS now requires that long-term care providers assess their facilities, their populations, and the workforce necessary to meet the increasingly diverse needs of residents. Because so many nursing facility residents have some form of dementia, CMS also put in place particular provisions to improve their care. As mandated by the ACA, for example, CMS extended previous dementia training requirements. Dementia training will now be part of the annual in-service training of nurse aides rather than a single initial training on the topic. CMS also went beyond the mandate, requiring that all staff, contractors, and volunteers receive some dementia training consistent with their roles. Although the 12-hr minimum required under the rule to cover all in-service topics is insufficient, this is an important first step in improving care delivery in nursing facilities. This kind of training is also important to those providing care: studies show staff trained specifically in dementia care are able to provide better quality of life for residents and have increased confidence (Hobday, Savik, Smith, & Gaugler, 2010), performance (Burgio et al., 2002), and job satisfaction (Teri, Huda, Gibbons, Young, & van Leynseele, 2005).

Many individuals with Alzheimer's and related dementias prefer and are able to remain in their homes and communities, so it is important that people in the community—but who may not necessarily deliver care—understand dementia and how it affects individuals. In addition to resources like the information for public transit providers discussed above, more formal training is imperative, particularly in matters of safety. Wandering is a prominent safety issue for persons with dementia, and police are often called to assist an individual who has become lost and confused. Kevin and Avonte's Law would require the Department of Justice to award grants to state and local law enforcement or public safety agencies to develop and operate local programs to prevent wandering and to locate missing individuals with dementia or children with developmental disabilities. With advocacy by the Alzheimer's Association and other stakeholders, cosponsorship of the bill grew significantly in the 114th session of Congress.

Well-designed settings can be as beneficial to persons living with the disease and their families as informed providers and community members. With regard to residential long-term care and adult day facilities, CMS's 2016 HCBS guidance outlines the underlying reasons for wandering and exit-seeking, person-centered planning and staff training, and highlights environmental designs that are not only intended to deter wandering, but that can reduce overstimulation and promote community engagement. In the home, the new clinician billing code from CMS requires safety evaluations of the home and driving, if applicable. Inclusion of such elements in policy signals the importance of safe, suitable environments for this population regardless of setting.

Some states have directed specific efforts to ensure culturally-appropriate care delivery. The State of Minnesota developed an online dementia training to reflect the norms and values of diverse cultural groups. Experts offer a series of training sessions to aging community and health care stakeholders on the issue. New York State's Department of Health created a fund for the Alzheimer's Disease Caregiver Support Initiative for Underserved Communities. Contractors funded under the initiative provide support for caregivers of diverse underserved populations across the state in the form of outreach, intake and assessment, referrals, education, and beyond.

Coordination

As has been noted, the needs of persons with dementia are complex and managing them effectively requires extensive coordination among providers and across settings. Action Number 2.G.1 of the National Plan directs the Center for Medicare and Medicaid Innovation (CMMI) within CMS to evaluate and implement new models of care coordination for individuals with dementia and their caregivers. To this end, CMMI funded the UCLA Alzheimer's and Dementia Care Program under its first round of Health Care Innovation Awards. A nurse practitioner Dementia Care Manager coordinates a needs assessment and connections to community-based organizations, creation and revision of care plans, and 24-hr access to assistance in order to maximize patients' function, independence, and dignity; to minimize caregiver strain and burnout; and to reduce unnecessary costs. This program has continued to succeed beyond the CMMI funding. Additionally, the Johns Hopkins University Maximizing Independence at Home (MIND) model, known as MIND at Home, was funded under the second round of CMMI Health Care Innovation Awards. Seeking to systematically address the barriers to persons with Alzheimer's remaining in their homes, interdisciplinary teams link patients with community health agencies, medical providers, and community resources in the Baltimore area. CMMI should continue to

test dementia-focused demonstration projects so that those deemed effective can be disseminated nationwide consistent with the National Plan's objectives.

Transitions

Individuals living with dementia often move between nursing facilities, hospitals, and home (Callahan et al., 2012). In fact, Callahan and colleagues found that persons with dementia not only transition frequently between settings, but also experience more transitions than those without dementia. Furthermore, persons with dementia have increasing difficulty processing new information and stimuli, and disruptive situations like transitions can cause anxiety and agitation. For these reasons, the National Plan and the Milestones each devote a strategy to ensuring that people with Alzheimer's disease and related dementias experience safe and effective transitions between care settings and systems. National Plan Action Number 2.F.1 requires that CMS evaluate demonstration programs testing care transitions and Action Number 2.F.2 directs the Assistant Secretary for Planning and Evaluation, which advises the Secretary of the Department of Health and Human Services and coordinates National Plan efforts, to explore the intersection between health information technology and transitions of care. The Milestones workgroup concluded that after extensive data collection and baseline development, all preventable transitions should be reduced from the baseline by 30% by 2025.

Transitional care models featured throughout the ACA, acknowledging the relationship between transitions, care, and costs. CMS has begun to codify these practices accordingly. For example, in 2012, CMS finalized transitional care management billing codes to reimburse clinicians for the time and resources needed to orchestrate often complex transitions, and the agency continues to refine the codes to improve utilization (Centers for Medicare & Medicaid Services [CMS], 2013). It proposed the regular revision of individualized discharge plans used in hospitals and home health agencies in 2015, and the long-term care rule of 2016 makes changes to communications between providers, the types of information shared, and documentation requirements related to admissions and discharges (Centers for Medicare & Medicaid Services [CMS], 2015).

Because licensing and staffing requirements in institutional settings are regulated by state governments, state laws and regulations can influence training standards to a considerable extent. The Alzheimer's Association supports the following elements of comprehensive dementia care training for inclusion in state statutes and regulations:

- Require dementia training for all care providers employed by a facility or program in the state and who are involved in the delivery of care or have regular contact with persons with Alzheimer's or related dementias;
- Use a culturally competent training curriculum that incorporates principles of person-centered care and how to best address the needs of care recipients;
- Evaluate training through demonstration of skill competency and knowledge gained, as required by the appropriate state agency;
- Establish a system to support and enforce continuing education on dementia care;
- Allow portability of completed dementia care training across employment settings;
- Ensure trainers meet minimum requirements to qualify as instructors of dementia care curriculum; and
- Designate a state agency to formally monitor dementia training programs and ensure compliance with state dementia training requirements.

States vary significantly in their training requirements as determined by Justice in Aging in 2015 (Justice in Aging, 2015). With the support of the Alzheimer's Association, Justice in Aging surveyed the statutes and regulations of all 50 states, the District of Columbia, and Puerto Rico to determine their capability to serve the growing population of persons with dementia. Subsequently, Justice in Aging published a series of papers summarizing the results. In its final paper in the series, Justice in Aging highlighted Washington State's dementia training requirements as a model for other states, as they include multiple settings and provider types, state involvement in training content development and evaluations, detailed training objectives, demonstrated mastery of competencies, and continuing education (Justice in Aging, 2015). Similar efforts to use state-level public policy levers can improve and expand training and ultimately result in better care.

Conclusion

Public policy is playing an increasingly prominent role in improving dementia care and support by disseminating, promoting, and codifying the effective practices and models featured throughout this supplement and around the country. But all of these models and practices warrant more research. Like the funds that have been rightly devoted to biomedical research in pursuit of a disease-modifying therapy, policymakers should direct adequate funding to care and support research.

These practices also need greater advocacy. All types of providers from across settings should join the Alzheimer's Association and its advocates in educating Members of Congress, state legislators, and agency administrators about effective models and urge them to turn good practices into policy. The policy efforts discussed herein are not exhaustive but examples for providers and policymakers to consider, to adapt to the needs of the population and their communities, and to serve those in need of care and support today.

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