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Advancing Research on Care Needs and Supportive Approaches for Persons With Dementia: Recommendations and Rationale

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Abstract

The first National Research Summit on Care, Services, and Supports for Persons with Dementia and Their Caregivers was held on October 16–17, 2017, at the National Institutes of Health. In this paper, participants from the Summit Session on Research on Care Needs and Supportive Approaches for Persons with Dementia summarize the state of the science, identify gaps in knowledge, and offer recommendations to improve science and practice in long-term care. Recommendations cover 4 areas focused on persons living with dementia: (1) symptoms (behavioral and psychological symptoms of dementia, function, cognition, and sleep); (2) dementia care settings (physical and social environments, home, and residential care); (3) living with dementia (living well with dementia, living alone with dementia, and living with dementia and intellectual and developmental disabilities); and (4) technology as a cross-cutting theme. The participants identify 10 of the most pressing research issues based on the findings from their

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collective papers. Final Summit recommendations included those presented by session participants and will be used to advise federal agencies and other organizations that fund research.

Keywords

National Dementia Care Summit; research recommendations; dementia

The first National Research Summit on Care, Services, and Supports for Persons with Dementia and Their Caregivers was held on October 16–17, 2017, at the National Institutes of Health. The Research Summit was coordinated by the Office of the Assistant Secretary for Planning and Evaluation as part of the National Alzheimer's Project Act (NAPA).

Following the passage of NAPA in 2011, 5 Research Summits have been held to identify the scientific road map that will achieve the goal of preventing, treating, and providing effective medical care for neurodegenerative diseases. These Summits focused primarily on biomedical issues. In contrast, the 2017 Research Summit sought to identify the state of the science and remaining gaps in knowledge around comprehensive care, services, and supports for persons with dementia and their caregivers. Importantly, the Summit focused on research needed to improve quality of care and quality of life across long-term care settings, and in a ground-breaking approach, was informed not only by experts within the scientific and service communities but by persons living with dementia. The final Summit report, released on April 27, 2018, will be used to advise federal agencies and other organizations that fund research (see: https://aspe.hhs.gov/national-research-summit-care-services-and-supports-persons-dementia-and-their-caregivers).

In this article, participants from Session 1, "Research on Care Needs and Supportive Approaches for Persons with Dementia," summarize the state of the science, identify knowledge gaps, and offer recommendations to improve science and practice. It is widely acknowledged that the evidence base for supporting care approaches and models where outcomes are specific to persons living with dementia is underdeveloped.[1] Moreover, the success of care models and approaches has largely been determined by outcomes specified by investigators with little or no input from persons living with dementia.[2]

Because neurodegenerative diseases are chronic and progressive, they require ongoing comprehensive services and supports that respond to the changing needs of individuals and their caregivers. Accordingly, recommendations presented in this article are especially relevant to investigators, health care professionals, and policy makers who aim to improve post-acute and long-term care. They cover 4 areas: (1) symptoms (behavioral and psychological symptoms of dementia, physical function, cognition, and sleep); (2) living with dementia (living well with dementia, living alone with dementia, and living with dementia in the context of intellectual and developmental disabilities (IDD); (3) dementia care settings (physical and social environments; home-based dementia care [HBDC], and residential long-term care); and (4) technologies as a cross-cutting theme.

Methods

Session presenters were selected by the NAPA Advisory Board and included experts who were asked to conduct an extensive literature review on their respective topic. Each presenter posed up to 6 research recommendations that were presented at the National Summit. Session 1 presenters then met in a closed session and were charged by the Advisory Board to achieve consensus on 10 of the most pressing research recommendations based on findings from their collective papers, feedback received from the Summit audience, and stakeholder groups who contributed pre-Summit reports. These 10 recommendations were shared with the Advisory Council who generated a final report of all-Session recommendations, including a process for establishing research milestones, accountability, and tracking of progress toward meeting milestones. Below is a synopsis of the 4 research areas covered by Session 1 presenters. The 10 research recommendations are listed in Table 1.

Symptoms

Behavioral and psychological symptoms of dementia (BPSDs)—The current real-world treatment of BPSD is often impressionistic. In contrast, a physician assessing a patient with shortness of breath recognizes it as a symptom rather than a direct medication target—for example, shortness of breath could represent pneumonia, a pulmonary embolism, or congestive heart failure. The workup for shortness of breath includes a thorough history and physical and laboratory work; treatment is rendered only after a complete assessment. In contrast, BPSDs are often treated purely as medication targets (eg, agitation = antipsychotic). This type of approach is problematic for 2 major reasons: (1) in many cases, psychotropic medications are not truly treating a particular BPSD, but rather being used for sedation, and (2) psychotropic medications are often associated with poor risk-benefit ratios, with side effects including mortality.[3–5] Although ecobiopsychosocial treatments have a growing evidence base,[6] they are not often used either first line or in a structured way in clinical settings.[7] BPSDs need to be assessed with as much precision as other medical symptoms. Similar to shortness of breath, providers need to obtain a full symptom history/ description and consider causality across person (eg, pain), caregiver (eg, problems communicating in the dyad), and environmental (eg, over- or under-stimulation) factors.[8] Systematic algorithmic approaches for assessing and responding to potential underlying causes of BPSDs help lead to heuristic treatment planning. One example is the “DICE Approach” (Describe, Investigate, Create, Evaluate).[9] Indeed, recent discourse has noted that because BPSDs are often considered “symptoms of dementia,” it is especially important to recognize that there is a cause to these symptoms.[10]

Current gaps in knowledge include the need to understand determinants of BPSDs so treatments can be tailored to modify person, caregiver, and environmental targets. Approaches like DICE could be used prerandomization to improve precision of treatment trials (eg, by removing agitation secondary to pain). In addition, such approaches could be used for trials combining pharmacologic and nonpharmacologic strategies to better target subjects who may need and respond to medication (eg, psychosis not caused by a modifiable factor).

Physical function

Older adults with dementia are among the most functionally disabled groups. Moreover, they tend to decline more rapidly than would be anticipated with normal progression of dementia.[11] Factors influencing this decline include medical comorbidities, sedation, limited opportunity to engage in physical activity, and care interactions that are custodial rather than person-centered in nature.[12–18]

For individuals with moderate to severe cognitive impairment, physical assistance with care is often perceived as a threat, and results in resistance and other behavioral symptoms.[19,20] One solution to maintaining and improving function is though implementation of a Function Focused Care approach.[12–15,21,22] Function Focused Care helps people with dementia engage in optimal function and physical activity during care interactions. Exercise interventions also help maintain function.[23–27] Home-based interventions include Care of Persons with Dementia in their Environments (which evaluates the individual's capability, optimizes the environment, and teaches caregivers to engage the person in functional tasks),[28] and the Tailored Activity Program which helps to maintain function through activity.[29]

Research needs regarding function include more uniform measures of function across studies, randomized trials to determine intervention efficacy, and theoretically based approaches to guide dissemination and implementation research. Interventions should be evaluated for treatment fidelity. Lastly, future research should consider genetic components influencing function and willingness to engage in functional activity among older adults with dementia, and also test the combined use of pharmacologic and behavioral interventions that optimize function.

Cognition

Neuronal plasticity is the brain's ability to change when networks are activated by cognitive and physical stimulation.[30] In individuals with mild cognitive impairment or dementia, 3 cognitive enhancement approaches have been employed: cognitive stimulation with a range of activities typically administered in groups; cognitive training with guided tasks to improve specific areas like attention, memory, and problem solving; and cognitive rehabilitation with an emphasis on improving everyday life and preventing further deterioration.[31,32] Meta-analyses suggested that cognitive training is not very effective, but cognitive stimulation may be useful in improving cognition as measured by the ADAS-Cog and MMSE.[33,34] In a recent meta-analysis, computerized cognitive training showed some efficacy in mild cognitive impairment but not for persons with dementia.[35] Three studies of Nintendo Wii as the intervention showed improved overall cognition and visuospatial skills compared to control groups.[35]

Several questions and issues remain to be resolved in cognition-related research: active therapeutic ingredients in these interventions remain unclear; few neuroimaging studies have examined brain function changes; and impacts of cognitive reserve and neuro-plasticity on therapeutic effects are inadequately understood. Optimal times to intervene, and with what frequency and intensity, require further study. How large and enduring are cognitive improvements, and at what stage of disease progression are they attenuated? Are therapeutic effects limited to mild cognitive impairment, or can they extend to dementia? How best to manage expectancy effects in the absence of a true “double-blind” intervention is not yet resolved. Further work is needed to clarify which type of intervention is most effective and in which populations. The difficulty in demonstrating transfer of cognitive improvement to functional abilities is a major limitation, and raises the question of whether direct intervention to improve function over and above cognitive training is necessary. Finally, there is limited information on the impact of diet, exercise, and other factors on the efficacy of cognitive enhancement approaches.

Sleep

Disruptions in the circadian cycle, referred to as sleep-wake cycle disturbances, are common in individuals living with dementia[36,37]; they include reduced nighttime sleep, evening agitation, fragmented sleep, and increased daytime napping.[38] These symptoms have profound effects on health and well-being in persons with dementia, including shorter survival time; increased risk for relocation to a shared residential setting; increased severity of neuropsychiatric symptoms; additional impairments to cognitive, physical, and affective functioning; and tremendous caregiver burden.[39,40]

Circadian rhythms are strongly influenced by regular physical, cognitive, and social activities that coordinate the appropriate timing of physiologic functions.[41,42] Emerging research suggests that consistent timing of these activities may program anticipatory rhythms and synchronize circadian patterns.[43,44]

Research is needed to understand underlying mechanisms by which sleep disorders interact with dementia pathogenesis in order to help provide possible targets for the treatment of dementia. Research is also needed on the combined role of light and activity to meet the human need for novelty, timed for optimal participation, and that can be scaled into routine care.

Recommendations 1, 2, 3, 9, and 10 relate to symptoms.

Living With Dementia

Living well with dementia—The experience of the person living with dementia is virtually absent in the literature because of assumptions about the validity of self-report that have led investigators to rely on informant reports or observation.[45] Most evidence for dementia care focuses on negative outcomes of neurodegenerative diseases. This focus has led to important interventions for clinical problems, but an emphasis on clinical problems to the exclusion of meaningful, positive outcomes can foster stigma and obfuscate opportunities for promoting well-being.[46]

The steering committee for the Research Summit included a group of stakeholders convened for and by persons living with dementia. In a series of pre-Summit focus groups they were asked what was important to them given their diagnosis of dementia. These stakeholders expressed their desire to remain active and involved with their communities, while reducing the stigma and financial burden associated with a dementia diagnosis. They felt that health care must extend beyond the case management approach and include individual preferences and quality of life outcomes in care planning. They stressed that it is possible to live well with dementia, but, with few exceptions,[47] little research has addressed ways to accomplish individual goals.

Recommendations put forth were as follows: methods for promoting autonomy, independent living, and the identification of preferences should be tested; psychosocial care practices and behavioral strategies should be developed to address neuropsychiatric symptoms as well as physical symptoms; more effective means to earlier diagnosis are needed; the experience of living with a cognitive disorder without an identified care partner/caregiver should be examined; and the financial burden of diagnosis, treatment, and research participation should be addressed.

Living alone with dementia—Studies indicate that 28% to 34% of people with dementia live alone.[48–51] People with dementia who live alone, in contrast to those who live with others, are less likely to be diagnosed with the condition[52] and to recognize their limitations, and are unlikely to seek the help they need.[49,53] They are at high risk for numerous adverse events and outcomes, including self-neglect,[54] malnutrition,[50,53–56] accidental injury,[56–59] medication errors,[56] financial exploitation,[60,61] social isolation,[49,55,62,63] and unattended wandering.[55,64] We know very little about how to meet the long-term care needs of people living alone with dementia.

Recommendations for research include epidemiologic studies that describe the conditions and circumstances of people living alone with dementia and the social determinants that cause some of these individuals to have little or no support. Effective approaches for identifying dementia in people living alone should be developed and evaluated. Studies should be conducted to determine how community-based services can better meet their needs. Future research should also investigate whether and which assistive technologies can meet individual needs and mitigate safety concerns.

Living in the context of IDD—Prior to the National Research Summit, a workgroup organized by the National Task Group on Intellectual Disabilities and Dementia Practices, the Rehabilitation Research and Training Center on Developmental Disabilities and Health, and the Alzheimer's Association examined research gaps and made recommendations pertaining to older adults with IDD. Although people with IDD face many of the same age-related health issues that people without disabilities face, they may develop health issues at an earlier age. For them, the early signs of dementia are more difficult to diagnose and some have a shorter period of debilitation—especially those with Down syndrome.[65] Also, most adults with IDD, including those with dementia, live with parents, many of whom have provided lifelong caregiving.[66]

The unique challenges of adults with IDD warrant inclusion of these individuals in general studies of dementia care. The National Task Group has developed practice guidelines[67,68] and a national training curriculum[69] drawing on the dementia and IDD fields. Federal efforts can bridge the aging and disability service sectors as exemplified by the Administration on Community Living inclusion of IDD in dementia funding. There is a rich literature on career caregivers and family support models in aging and IDD that could inform dementia care practices, and also extensive research on general dementia caregiving that has the potential to inform practice in IDD.

The workgroup recommended conducting comparative effectiveness research to study different integrative support models involving aging and IDD networks; increasing research on community programming that supports people living with family caregivers, as well as those living in a variety of supported living and group settings; and including persons with IDD and dementia and their families in research on dementia care.

Recommendations 4, 5, 6, 9, and 10 relate to living with dementia.

Dementia Care Settings

Physical and Social Environments

One distinctive characteristic of the work on environments for individuals living with dementia is that it has focused on positive attributes and ways to enhance quality of life. Moving forward, a more systematic framework of the core elements of well-being and their environmental correlates should be further developed.[70,71] The majority of research to date has addressed shared residential settings. There is a need for deeper exploration of alternative residential options including co-housing, tiny houses, echo housing/granny-flats, and home sharing that help individuals live alone or with their chosen care partners. Technologies need to be more systematically evaluated to determine how they support individuals and their care partners. Product development and marketing research is not sufficient to safeguard consumers.

In nursing homes and assisted living communities, 2 central issues would benefit from deeper examination: group size and segregation. Although group sizes of households/neighborhood units have been declining over the past 25 years, there is little understanding of the differential impact of groups of 8 to 10, 12 to 15, or 18 to 20 residents living together. Longitudinal studies are needed to tease out the differential impact of group size from program design and staff training/consistency issues. As regulations are changing and people with higher acuities are staying in assisted living through end-of-life, exploration of the costs/benefits of segregated living areas for these individuals versus being able to stay in one place is needed.

Home-Based Dementia Care

Prior to the Summit, a national panel convened by the Johns Hopkins Translational Aging Services Core in the Department of Psychiatry and Behavioral Sciences and the BrightFocus Foundation developed recommendations for shifting the dementia care paradigm from the clinic to the home. The rationale for this is strong: most older adults with dementia live in the community and are cared for by unpaid family caregivers. These older adults receive services in acute and long-term care settings that are rarely delivered as a comprehensive set of services. Fragmented and poorly coordinated care is associated with negative health outcomes and high costs, including excessive health care encounters and premature long-term care placement.

Comprehensive HBDC offers advantages over a clinic-based system: increased opportunities to identify and meet needs with greater ecological validity; ability to use a growing evidence base for interventions that target the caregiving dyad; ability to bridge long-term care services with other community supports; and potential cost savings associated with reduced health care encounters using preventive and safety measures delivered in the home.

Recommendations were as follows: HBDC should be considered the nexus of new long-term care models; new payment models that stimulate, reward, and support home care practices are needed; a skilled workforce spanning long-term care should be developed and equipped; new technologies to promote best practices must be tested, integrated, and deployed; and more effective development of value, understanding of competing local priorities and adaption, and improved communication about HBDC are needed. The full report of the consensus panel has been published elsewhere.[72]

Residential Long-term Care

Broadly speaking, long-term care includes the 15,640 nursing homes that care for 1.4 million individuals—65% of whom have dementia—and the 30,200 assisted living (AL) residences that care for more than 835,000 individuals, 42% of who have dementia.[73–75] Within these settings, special dementia care grew over the last decades, now being offered in 15% of nursing homes and 22% of AL residences[75]; however, research indicates that because specialization is variable and outcomes inconsistent, it is advisable to examine more discrete structures and processes to promote quality.[76,77]

Optimal dementia care in residential long-term care must recognize that residential care is a *system* of care. Consequently, it must recognize that structures (eg, type of residence) and processes (eg, roles assigned to staff) affect the provision of care, which then affects the experiences and outcomes of people with dementia and their family.[73] In addition, optimal dementia care in long-term care must address the progressive nature of dementia, and be responsive to the fact that people living with dementia in residential settings typically have numerous comorbid conditions.

Evidence suggests 7 key areas in which there is need for research: because there is scant research that addresses optimal approaches to treat comorbid conditions in persons with dementia, it is necessary to develop and evaluate practices that integrate dementia care with care of other conditions; integrated medical models of care in AL merit research to determine the optimal manner in which to provide care; there are no available measures to determine optimal staffing ratios across diverse AL residences; transitions in care are common, and development and widespread adoption of dementia-related protocols for transitions in care are needed; few technological care aids were developed specifically for persons with dementia and so assistive technologies should be developed and evaluated with/for persons with dementia; although there are numerous evidence-based practices to attenuate BPSDs, few have been developed into protocols that can be readily used by providers; and it is necessary to develop and evaluate person-centered measures responsive to the complexity of the long-term care system.

Recommendations 7, 8, 9, and 10 relate to dementia care settings.

Technologies as a Cross-Cutting Theme

We live in a world full of technologies. The challenge is to identify the most promising use cases and build strong evidence of what works. Based on reviews of the literature,[78–84] experience in the Oregon Center for Aging & Technology, and the recently formed NIH initiative, Collaborative Aging Research Using Technology, several themes have emerged to guide the successful use of technology for dementia. Technologies of greatest assistance and value are those that bring assessments out of the clinic into the community, reflecting everyday life. These technologies work optimally when they are unobtrusive. Conceptually, technologies provide assessment or intervention capabilities in major domains of function as well as caregiving itself.

Although there are a growing number of studies of the development and deployment of technologies for dementia care, the evidence base remains small relative to other dementia research areas. In general, the technologies are wide-ranging (eg, passive sensors, wearables, apps, integrated multidomain systems) and have been used in many types of assessments and interventions. Within a specific technology domain, there is variability in the devices or technologies used (hardware/software) and poor specification of the systems used and the analytic algorithms applied. This makes comparisons and replication of research challenging. There is little research on the usability of these technologies for persons with dementia, their caregivers, or researchers. Various benefits are mainly based on low-quality studies. Finally, a number of barriers to deployment of technologies in dementia care are prevalent, such as ease of use, research expertise, and costs.

This state of the science leads to these recommendations: feasibility research is still important—investigators should involve persons with dementia and their caregivers in the earliest stages of research and include iterative development designs as the norm; technology research needs to include more diverse populations with respect to ethnicity/culture and technical savvy/naïveté, and encompass the heterogeneity of dementia; different outcome measures are used in efficacy and effectiveness studies, making developing consensus on the use of device/sensor ontologies, data specifications, and outcome measures a priority; research into the effectiveness of technologies must move beyond explorative studies with more and adequately powered RCTs, as well as innovative designs (eg, adaptive, n-of-1); technologies should be embedded in "conventional" studies whenever possible.

Recommendation 10 relates to technologies as a cross-cutting theme.

Recommendations: Implications for Research, Practice, and Policy

The 10 most pressing research issues that emerged were the need for the following: more precise and valid measures of outcomes, including those meaningful to people living with dementia and at various stages of the disease (recommendations 1 and 2); improved methodological approaches in intervention research that consider the heterogeneity in diagnoses and stage of dementia, as well as the optimal timing of interventions, including use of multicomponent interventions for maximal effect (recommendation 3); greater understanding of the diversity of people living in diverse contexts throughout the trajectory of dementia (recommendations 4, 5, 6, and 8); more precise determination of optimal staff mix for resident outcomes (recommendation 7); better integration of technological solutions into conventional studies (recommendation 9); and greater emphasis on implementation and dissemination science in areas where evidence exists (recommendation 10).

Implications for practice follow from these recommendations. Because dementia is progressive, assessments should be conducted on a regular basis to capture changes in cognition, symptoms, and function that impact individualized care planning and delivery. The person living with dementia and caregivers should be included as members of the health care team in assessment and care planning so that meaningful goals of care can be established (recommendation 1). Health care providers should be prepared to meet the needs of diverse populations living with dementia (recommendations 4, 5, and 6) and to ensure that options for long-term care provide the best fit for quality of life (recommendation 8). Finally, optimal staff mix and ratios in communal living sites should be determined based on desired resident outcomes for health and well-being (recommendation 7).

There are implications for policy as well. Policy should be informed by research data, but to date there is no strong evidence that the National Partnership has increased the use of effective nonpharmacologic strategies for BPSDs (recommendation 2). There is a need for community programing and education that will support the independence of individuals living with dementia as long as possible (recommendations 5 and 9). Across the trajectory of dementia, fundamental changes will need to be made in Medicare and Medicaid covered benefits to achieve cost-effective outcomes that promote quality of life (recommendations 4, 5, 7, and 8). Considering the rapid growth of Medicare Advantage plans and their entry into the dually eligible population market, it will be critical for those administering these plans to work closely with providers at the local level to ensure that these recommendations are implemented. Finally, at the state level, Medicaid and state-funded home and community-based waiver programs should heed these recommendations and work with providers to implement them to the benefit of persons and families facing the daily challenges of dementia.

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Table 1

Recommendations for Advancing Research on Care Needs and Supportive Approaches for Persons With Dementia

Symptoms

1. Develop/identify measures that capture intervention outcomes that are meaningful to people living with dementia.
    a. refine current measures of function, pain, and quality-of-life (QoL) so they can be used in these populations.
    b. develop measures of cognition and function that are sensitive to stage of dementia.
    c. develop measures that adequately assess specific BPSD (aggression, apathy, etc).
    d. develop methods to improve the validity of self-report of outcomes.
2. Identify specific determinants of behavioral and psychological symptoms and function so that interventions can be tailored with greater precision (eg, determine the impact of circadian rhythms, caregiver, and environmental factors on BPSD and function).
3. Improve methodological approaches used in studies of dementia care, services, and supports.
    a. for interventions: determine stage of dementia, timing of intervention, duration and dose when the intervention is most effective; determine mechanisms of intervention action and identify for what outcomes interventions are effective.
    b. select appropriate control conditions that avoid outcome expectancy.
    c. conduct studies that test combinations of treatments using adaptive designs.
    d. use mixed methods with special attention to capturing outcomes meaningful to people living with dementia.

Living with Dementia

4. Determine the impact of, and ways to overcome, financial burden on access to care and services, and improve research participation and QoL for diverse populations living with dementia.
5. Conduct epidemiologic studies using new or existing data sets that describe and explain the needs and care circumstances of people living with dementia in diverse contexts, including those living alone with dementia.
6. Build capacity to conduct care research through existing or new centers on diverse populations with dementia (eg, individuals with intellectual disabilities, LGBT individuals)

Dementia Care Settings

7. Determine optimal staff mix, ratios, and models of care in assisted living, to promote health and well-being.
8. Determine desired housing/living options for persons with dementia throughout the trajectory of the disease, and the related outcomes for persons living with dementia (eg, engagement, mood/affect), their family members (eg, satisfaction, participation), and the staff who serve as care partners (eg, satisfaction, turnover).

Technologies as a Cross-cutting Theme

9. Conduct developmental research on technology solutions that are responsive to the needs of different stakeholders in dementia care across settings and that build on existing technologies.

Across All Topics

10. Conduct dissemination and implementation trials of effective approaches/models of care.

BPSD, behavioral and psychological symptoms of dementia; LGBT, lesbian, gay, bisexual, transgender; QoL, quality of life.