CHAMP – Advancing Home Health Care Excellence for Older People



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EVIDENCE BRIEF

VNSNY CENTER FOR HOME CARE POLICY & RESEARCH

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Memory loss, impaired decision making, confusion and dementia become more common as people age. These conditions affect patients in all health care settings, including those receiving home health services. Alzheimer's disease, other dementias, and impairments contribute to high rates of depression, frustration, isolation, and profoundly affect the health and well being of older people and their families.

What are the key findings?

Family and friends provide most of the care for people with Alzheimer's disease and other dementias. Without this informal support, many older people with cognitive impairments could not remain at home. Helping cognitively impaired patients and their caregivers manage complex health needs is challenging for home health care providers.

Several studies and two recent national guidelines support: (1) screening for cognitive impairments among older people with signs of confusion, memory loss or decision-making problems; and (2) using individualized interventions to manage symptoms and support family caregivers. Although these interventions may not cure the underlying disease or stop its progression, studies show they benefit patients and their caregivers.¹

- Multiple studies identify <u>effective screening and assessment methods</u>, including interviews and standardized tests.
- Research shows that <u>behavioral and problem-focused interventions</u> can effectively manage dementia symptoms or compensate for impairments in cognitive function. Many of these interventions have been studied in nursing homes and remain to be tested in the home health care setting.
- <u>Interventions to support family caregivers</u> can delay the institutionalization of those they care for and decrease negative caregiver impacts.

More home care-specific evidence that examines what works best for individuals with different impairment levels and caregivers in different circumstances will help to advance care standards for these patients.



Older Adult Values for Home Care

This cube graphically represents CHAMP's National Framework for Geriatric Home Care Excellence. The goals of older adults comprise the foundation of the Framework. The three sides represent what home care providers must do to achieve these goals. Cross-Cutting Principles are the core characteristics of excellent care that cut across specific practice areas. Key Practice Areas are the main domains of home care. Strategies for Implementation are the actions home care providers must pursue to improve. The full set of Framework materials and recommendations is available at

http://champ-program.org/framework/.



Why is cognitive function important in home care for older people?

As individuals continue to live longer, the number of people with cognitive impairments will likely increase.

- In the United States, approximately five percent of people 71-79 years old have dementia. This increases to 24 percent of people 80 to 89 and to more than 37 percent of people 90 and older.²
- The severity of dementia increases with age. Among people 65 to 74 years old with dementia, approximately 17 percent have severe dementia. This rises to 28 percent among people 85 and older.³

Living with dementia for many years increases the probability that treatment for other conditions will be required.

- Overall, people live approximately four years after a diagnosis of dementia (the median survival), however, this varies depending on their age at diagnosis. Median survival is 10.7 years among people diagnosed at the age of 65-69, while it is 3.8 years for people over 90.⁴
- People with dementia have a higher number of other chronic conditions than people without dementia (an average of 4.2 chronic conditions in addition to dementia compared to 1.8). They are three times more likely to have more than four chronic conditions (19.7 percent compared to 6.7 percent).⁵

It is common for older home health care patients to have cognitive function impairments. Start of care assessments, conducted by home health care nurses and therapists, conservatively estimate common cognitive impairments among older patients.⁶ They indicate that:

- Thirty-six percent show some level of impairment in cognitive function.⁷
- Fifteen percent have developed a serious memory deficit.8
- Fifteen percent have demonstrated impaired decision-making affecting basic activities or risking personal safety.⁸

Cognitive impairments impede the ability of patients and families to manage chronic conditions at home. They negatively affect people's ability to participate in planning or decision-making, understand and adhere to treatment recommendations, and self-manage complex care needs.

- More than half (53 percent) of the people admitted to home health care with a cognitive impairment are incontinent, compared to 24 percent without cognitive impairment.
- People unable to manage their oral medications at admission to home health care are less likely to have improved by discharge if they also have a cognitive impairment (30 percent of people with a cognitive impairment improve compared to 48 percent of those without a cognitive impairment).

Cognitive impairments increase use of home health care and other resources.

- Patients with chronic conditions who also had any level of cognitive impairment stay longer in home health care than patients without cognitive impairments.⁷
- Home health care patients with a cognitive impairment at admission have a 29 percent higher risk of being hospitalized while receiving home care than people without a cognitive impairment.⁸

INITIATIVE DESCRIPTION

This Evidence Brief is part of CHAMP, a national program to advance excellent home health care for older people. The Brief was produced during development of a National Framework for Geriatric Home Care Excellence to inform improvement efforts in the field. A National Advisory Council of experts in geriatrics and home care guided development of the Framework. The Center for Home Care Policy & Research, Visiting Nurse Service of New York, spearheaded the effort with funding from the John A. Hartford Foundation. The National Advisory Council reviewed evidence from literature reviews, commissioned papers and three regional focus groups. Informed by these sources, it developed a consensus on cross-cutting principles and overarching strategies for advancing home care excellence. It amplified these with specific practice, policy and research recommendations in six key practice areas for home care of older adults:

- Care Coordination, Management and Transitions
- Medication Management
- Cognitive Function
- Physical Function
- Chronic Pain Management
- Palliative Care and Advanced Illness Management

This Brief summarizes the literature review conducted by project staff in the area of **Cognitive Function**. The full set of Framework materials and recommendations, including short biographies of the members of the National Advisory Council and the proceedings from a National Conference convened in July 2008, are available at: http://champ-program.org/framework/.



What does the research tell us about managing cognitive impairment?

General management

Research and evidence-based guidelines outline actions needed to provide and monitor a plan of care for managing cognitive impairments. These underscore the importance of: (1) <u>assessing people with symptoms</u> of a cognitive impairment, and (2) <u>intervening to address problems</u> resulting from impairment. Most available evidence pertains to dementia care,¹ with evidence gaps in other areas such as care of post-stroke patients with memory deficits.⁹

Based on publications and statements by the American Psychiatric Association, the American Academy of Neurology, the Alzheimer's Association, the Agency for Health Care Policy and Research (now AHRQ), and previously by the American Association for Geriatric Psychiatry (AAGP), the AAGP developed and updated a guideline for dementia patients.¹ The guideline provides these general principles for physicians and other licensed clinicians:

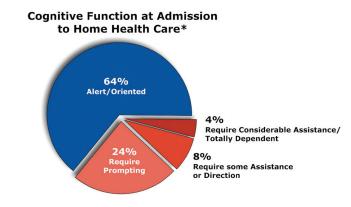
- Be able to identify neuropsychiatric syndromes and consider all possible contributing causes.
- Implement non-drug interventions or refer patients to others who can.
- If drug therapies are used, a specialist should be involved given the risks and current lack of standards.
- Provide supportive care to patients and caregivers.

Assessment

Assessment involves screening to determine whether cognitive impairment exists and, in some cases, estimating or measuring the extent of impairment. People without symptoms should not be screened.¹⁰

Research supports several different assessment methods. This allows clinicians to choose what best fits a particular situation.

- Based on 74 studies, the Quality Standards Subcommittee of the American Academy of Neurology cites evidence supporting use of the <u>Mini-Mental</u> <u>State Exam (MMSE) and other generally available tests</u> that measure neurological and psychological function. Other acceptable ways to evaluate a person with symptoms include the <u>Clock Drawing Test and</u> informant interviews.¹⁰
- A meta-analysis of 10 studies compared screening tests such as the MMSE to interviews with a person who knows the patient. Researchers concluded that the interviews were as effective as the tests and could be especially useful in cases where a test might be problematic because of issues such as low literacy or cultural considerations.¹¹



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METHODS

Staff searched four databases (Medline, CINAL, AgeLine and GreyLit) between January and May 2008 to locate meta-analyses and systematic reviews in the six key practice areas. The searches included evidence-based guidelines and individual studies where systematic reviews or meta-analyses were not available. Two project investigators reviewed titles and abstracts to identify articles for full review. Tables with information abstracted from the reviewed articles were prepared for the National Advisory Council and are available at http://champ-program. org/framework/.

LIMITATIONS

Geriatric research is plentiful, but some topic areas lack a robust body of research evidence, even though expert guidelines may be available. Much research is descriptive, many intervention studies include small sample sizes, and evaluations often cannot isolate the effectiveness of individual intervention components due to reliance on multifaceted interventions and/or research design. In addition, relatively few rigorous research studies have focused on older adults in the home care setting. Thus generalizations about "what works best for whom" are necessarily limited, and it is possible that evidence about both the effectiveness of specific strategies and the relative value of different strategies will change as more research is done and more data become available.

Research tells us...

Targeted Interventions to Manage Impairments and Symptoms

Many studies evaluated interventions for different impairments and dementia-related symptoms – including anxiety, withdrawal, agitation, wandering, and aggression, as well as caregiver stress (research related to caregivers is addressed after symptoms below). Study findings occasionally contradict each other in part because of differences in design. However, they support <u>behavioral and problem-focused</u> interventions that match a patient's and caregiver's needs.

A summary of evidence supporting the effectiveness of varied interventions appears below. Some studies compare interventions to each other, while others compare interventions to "usual care."

- <u>Behavioral interventions</u> that train family or staff to observe problem behaviors, <u>identify causes</u> or triggers, and then <u>modify the environment, schedules</u>, <u>or interactions</u> improve quality of life or reduce problem behaviors for individuals with mild to moderate memory problems.¹²
- <u>Redirection</u> (switching focus or attention to a different object or activity), <u>reinforcement</u> (rewards for good behavior) and similar interventions based on principles of behavioral psychology tailored to an individual's needs have produced promising, if not statistically significant, improvements in symptoms such as aggression and wandering. More research will determine if these are effective.¹³
- <u>Reality orientation</u> presents information on date, time, location and names/roles of the people patients interact with either in classroom training sessions or as an ongoing part of care. Reality orientation has improved scores on cognitive function tests such as the MMSE for people with milder dementia.^{14, 15} A systematic review of classroom reality training in congregate living situations found that scores on tests of cognitive function or orientation improved and behavior problems were reduced.¹⁶
- <u>Physical activity</u> resulted in moderate improvements in cognitive function and behavior when 30 randomized controlled trials were combined in a meta-analysis.¹⁷ Another review of 27 studies found a positive effect on mood and sleep.¹⁸
- <u>Reminiscence therapy</u> (individual or group discussions of the past aided with music, pictures, or other prompts) may have potential benefits in improving relations with caregivers, decreasing problem behaviors, improving autobiographical memory, and reducing depression.¹⁵ However, reminiscence interventions did not improve communication and

behavior in five studies included in a meta-analysis.¹⁹

• <u>Social contact, music therapy, and multiple sensory</u> <u>activities</u> produced better results than other interventions in the few studies that directly compared different activities to each other rather than to a control or usual care group. For example, music therapy was more effective than reading aloud, and activities that involved multiple senses were more effective than traditional activities such as Bingo.²⁰

Research has found other interventions to be relatively ineffective.

- Cognitive training, including guided practice on a set of tasks, did not improve cognitive performance in people with early stages of dementia in nine randomized controlled studies.²¹
- Memory skills training (use of reminders, diaries, etc.) proved less effective in improving cognitive performance than comprehensive cognitive remediation, an integrated approach that combines work on memory, problem solving and communication.¹⁵
- A review of non-pharmacologic interventions designed to reduce wandering (electronic tracking, caregiver interventions, exercise, music and sensory therapy, and environmental design) concluded that the available, high-quality evidence (results from randomized controlled studies) does not support any of these interventions.²²

Insufficient research has been conducted in the home health care setting.

- A review of non-drug interventions for wandering by people with dementia in non-institutional settings was unable to identify any studies that met established scientific criteria for reviews of evidence for clinical practice.²³
- More research is needed on using psychosocial interventions, such as behavior therapy to remediate depression in people living at home with Alzheimer's disease. This led a recent systematic review to call for more high quality studies.²⁴

Supporting Caregivers

Numerous studies evaluated caregiver support interventions.²⁵⁻³² Researchers and healthcare providers have designed interventions to reduce caregivers' burden, depression, anger, or anxiety and improve their knowledge, quality of life and social support. These interventions include counseling, behavioral and cognitive therapy, respite care providing the caregiver with a break for a few hours or a few days, education and training, support groups, and multifaceted programs containing a mix of services.

Evaluating these services has often posed methodological



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challenges. Individual studies vary widely, making generalizations across studies difficult. Two recent reviews of caregiver interventions have led to positive conclusions.^{30,31} However, many prior reviews concluded that available evidence was insufficient or that intervention effects were small.

Research also tells us...

Reducing Institutionalization

A systematic review and meta-analysis of 13 studies (including 10 randomized studies) conducted in several countries examined a variety of interventions designed to reduce or delay institutionalization. <u>People with dementia were significantly less likely to be institutionalized if they and their caregivers were involved in any type of caregiver intervention. Caregiver interventions were different in each study and included counseling/therapy, respite care, education/training, and case management. The four studies that examined delay in institutionalization did not find a strong effect.²⁵</u>

Reducing Caregiver Stress

A review of interventions to reduce caregiver stress concluded that <u>skill building</u>, <u>counseling and multifaceted</u> <u>interventions all reduced distress and increased self-efficacy</u> <u>and coping</u>.³⁰ The largest effects were from individual or group counseling.

Some reviews have sought to identify characteristics of <u>effective caregiver interventions</u>.

- <u>Individualized and intensive interventions</u> are most effective, especially when they focus on caregiver choice and involvement,²⁵ and/or some combination of problem solving, behavior management and social support.^{26, 27}
- Interventions that <u>involved both the caregiver and</u> <u>the person with dementia</u> can successfully reduce psychological morbidity, improve mood, and increase knowledge among caregivers of people with dementia, although no improvement was shown in caregiver burden.²⁸

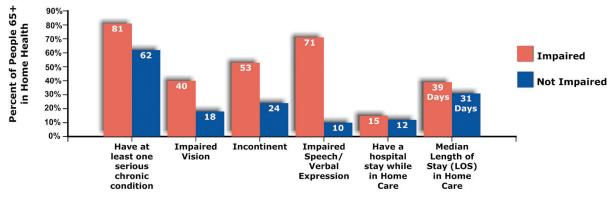
• <u>Psychoeducational interventions</u> (a structured combination of information about resources and training in coping skills) and <u>psychotherapy</u> for caregivers produced improvements in all major outcomes in a meta-analysis of 78 studies, while other types of interventions produced less consistent results.²⁹

Reviews have highlighted important areas where evidence is not yet available or more research is needed. Additional evidence could determine:

- The most effective interventions for caregivers of people with different levels of impairment.³⁰
- How intervention effects vary across different subgroups of caregivers (e.g., caregivers that are women, Hispanic, not-spouses, or have lower education levels, etc.).³¹
- What combinations of services for the caregiver and the person with dementia that hold the most promise for specific subgroups of caregivers.³²

New models of care

- The Medicare Alzheimer's Disease Demonstration was a randomized controlled study conducted in eight sites and designed to test an approach to the general management of care for people living in the community with dementia. The model used a professional case manager and provided funding for community care, including family caregiver support. In the treatment group, family caregivers had better access to services, and the persons with dementia had significantly lower regular Medicare expenses than those receiving usual services. However, the program cost more than the savings it produced and rates of nursing home entry or time to institutionalization did not change.³³
- The Alzheimer's Association is developing recommendations for home care staff working with people who have dementia. This will be available in summer 2009 at http://www.alz.org.



Understanding People with Cognitive Impairments*



What are the implications for home health care practice?

Dementia is rarely the primary reason for home health care. However, dementia should not be a reason to deny coverage so long as a person can live safely at home. Skilled nursing care for Medicare beneficiaries can include teaching and training activities for the family caregiver to help the caregiver better manage behavioral disturbances.[†] Moreover, a significant number of older people have some degree of cognitive impairment when they are admitted to home health care for care of another disease or condition. Others may experience worsening cognitive function during the time they receive care because of disease progression or adverse medication effects. Ineffective teaching, unimplemented care plans, and poor outcomes may occur if home health nurses do not understand and adapt care to a patient's cognitive abilities.

Research on managing cognitive impairments in home health care is limited. However, available evidence from other settings and clinical guidelines developed for all licensed clinicians are relevant to home health care providers. This body of work suggests that to maximize cognitive function, help older people with cognitive impairments and support caregivers with necessary health care management and personal care tasks, home health care providers should:

- Address cognitive impairment as an essential factor in establishing and implementing individualized care plans for older adults with signs of confusion, memory loss, decision-making problems or presence of dementia.
- Incorporate evidence-based interventions into the care plans of people with cognitive impairments, or refer patients to other clinicians who can recommend and help implement interventions designed to ameliorate or support function.

- Educate everyone involved in the person's care, particularly family caregivers, about the stages of dementia and stage-specific interventions.
- Train direct care workers and family to use individualized management techniques and monitor their effect.

Many interventions have been developed for people with dementia in institutional settings. Adapting these to home health care will not be easy. The formal supports available to institutional residents are technically available 24 hours a day, while home health care is currently a part-time and intermittent benefit. Lack of evidence-based interventions specifically tailored to patients with varying levels of cognitive function and varied health care needs further hinders management of cognitive impairment in home health care. Yet, overlooking cognitive impairments may put both patients and caregivers at risk and lead to avoidable problems that result in costly and unnecessary expenditure of scarce clinical resources.

To move beyond ad hoc approaches to care and support of cognitively impaired home health care patients, home health care-specific research is necessary in two key areas:

- Testing and evaluating interventions and referral strategies to assist clinicians, patients, and families in managing cognitive impairments affecting older patients with chronic conditions and complex care needs.
- Assessing the impact of cognitive impairment, dementia and related interventions on:
 - ~ Management, use and cost of home health services.
 - ~ Management of other health conditions and geriatric syndromes in the home care setting.
 - ~ Hospitalization, rehospitalization, and nursing home admissions.

† See the Local Coverage Decision for Home Health Skilled Nursing Care-Teaching and Training: Alzheimer's Disease and Behavioral Disturbances (L19817) available at: http://www.cms.hhs.gov/mcd/viewlcd.asp?lcd_id=19817&lcd_version=11&show=all. Home Healthcare agencies should contact their Regional Home Health Intermediary if they have questions about coverage

For More Information

To learn more about CHAMP, the ongoing program to advance excellence in geriatric home health care, go to http://champ-program.org/ or contact the Center at 212-609-6329, champ@vnsny.org.

Project Staff

Penny Hollander Feldman, PhD, Vice President for Research and Evaluation Director, Center for Home Care Policy and Research

Annette M. Totten, PhD, Director, Establishing a National Framework for Geriatric Home Care Excellence

Janice Foust, PhD, RN, Nurse Research Associate Dhara Naik, MPH, Research Analyst Beth Costello, MA, Research Analyst Margaret McDonald, MSW, Senior Project Manager Ellen Kurtzman, RN, MPH, Project Consultant

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