

# GERI NOTES

Academy of Geriatric Physical Therapy

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**Publication Title:** *GeriNotes*

**Statement of Frequency:** 5x/year; January, May, July, September, and November

**Authorized Organization's Name and Address:** Orthopaedic Section, APTA, Inc.

For Academy of Geriatric Physical Therapy, APTA., 2920 East Avenue South, Suite 200, La Crosse, WI 54601-7202

**Newsletter Deadlines:** March 20, May 20, July 20, September 20, November 20

**Note:** *GeriNotes* will transition from 6 editions to 5 editions in 2017. Please watch for updated deadlines for 2017 in the November 2016 issue.

**Editorial Statement:** *GeriNotes* is the official magazine of the Academy of Geriatric Physical Therapy. It is not, however, a peer-reviewed publication. Opinions expressed by the authors are their own and do not necessarily reflect the views of the Academy of Geriatric Physical Therapy, APTA. The Editor reserves the right to edit manuscripts as necessary for publication. Copyright 2016 by the Academy of Geriatric Physical Therapy, APTA.

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## IN HONOR/MEMORIAM FUND

Each of us, as we pass through life, is supported, assisted and nurtured by others. There is no better way to make a lasting tribute to these individuals than by making a memorial or honorary contribution in the individual's name. The Academy of Geriatric Physical Therapy has established such a fund which supports geriatric research. Send contributions to:

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Also, when sending a contribution, please include the individual's name and any other person you would like notified about your contribution. If you are honoring someone, a letter will be sent to that person, and if you are memorializing someone, the surviving family will be notified of your contribution.

In the field of geriatric physical therapy, we receive many rewards from our patients, associates, and our mentors. A commemorative gift to the Academy of Geriatric Physical Therapy In Honor/Memorial Fund is a wonderful expressive memorial.

# President's Message: Cognitive Issues

William H. Staples, PT, DHS, DPT, GCS, CEEAA



First, congratulations to the 197 newly certified Geriatric Clinical Specialists (see page 14), quite an impressive accomplishment!

Is it important for physical therapists to understand cognitive disorders? Of course! Being able to distinguish or understand the differences will affect how we treat our patients. This issue of *GeriNotes* on cognitive problems is a must read for all practicing therapists. Our relatively new Cognitive and Mental Health SIG is helping to shape the AGPT and individual therapist's roles with this population. Please visit their page at <http://geriatricspt.org/members/special-interest-groups/index.cfm> to see the information available to all members of the Academy.

There are differences between dementia, delirium, and depression and sometimes these are hard to diagnose. Cognitive disorders may begin subtly and progress until they significantly impede the affected individual's quality of life; or there may be a more sudden onset. Understanding the various cognitive disorders, their symptoms, and relevant treatment options can assist in therapeutic intervention on our part. We spend a great deal more time with our patients than their physician or nurse practitioner and we may be able to "catch" certain things that others do not. Cognitive disorders can be defined "as any disorder that significantly impairs the cognitive function of an individual to the point where normal functioning in society is impossible without treatment."<sup>1</sup>

Cognitive disorder signs vary according to the particular disorder. Some of the most common signs of cognitive disorder include confusion, loss of short-term or long-term memory,

and impaired judgment. Some cognitive disorders develop in stages and symptoms increase in severity the further the disease progresses. According to the Alzheimer's Association, there are over 5 million people in this country suffering from the disease.<sup>2</sup> The Alzheimer's Association also lists 10 signs and symptoms to watch for.<sup>3</sup> Alzheimer's disease usually begins with the patient showing very minor signs of forgetfulness as part of the normal aging process. Patients may forget names they know well, or they may have trouble remembering what they did recently. The initial symptoms of early-onset Alzheimer's disease are often indistinguishable from normal memory errors. However, as the disease progresses, the affected person's memory becomes persistently impaired. They may have rare moments of clarity, but life is generally lived in a state of confusion. We cannot forget the caregivers of people with dementia. The Alzheimer's Association is a great asset to refer caregivers to for vital information and services.

Additionally, cognitive disorders and depression are heavily linked and many depression-related illnesses result in at least mild cognitive dysfunction. Not being able to think clearly or remember fully can naturally lead to depression if the affected person feels like they have lost something they will never be able to get back. Lastly, the APTA Move Forward site has some good information on Alzheimer's disease for consumers.<sup>4</sup>

## REFERENCES

1. *Diagnostic and Statistical Manual of Mental Disorders (DSM-V)*. 5<sup>th</sup> ed. American Psychiatric Association; 2013.
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**Geriatric  
Physical  
Therapy**

# Editor's Message: Cognitive Issues In Aging

Meri Goebbing, PT, PhD, GCS



Physical therapists and physical therapist assistants who work with the aging adult population will encounter many patients with delirium. The

physical therapy professionals working with the patients may need to understand and be able to assist these individuals in the best manner. This continuing education module includes information for physical therapy professionals regarding delirium.

Margaret Fischer, a graduate of Columbia and Stony Brook Universities, is a board certified Geriatric Clinical Specialist with over 25 years of experience, provided the following information regarding delirium.

Delirium is an acute change in cognition brought on by a medical condition that is commonly seen in older, hospitalized patients. Prevalence rates vary—delirium is nearly ubiquitous among older patients in critical care at 70% to 87%, but postoperative rates are also high at 15% to 53%. In the Emergency Department, 14% to 24% of older patients are delirious meaning some of these patients were delirious at home or in the community. Post-acute care and rehabilitation are not immune to the disorder with prevalence rates as high as 30%. End of life and palliative care rates range from 40% to 80% especially in the days immediately preceding death. Physical therapists (PTs) and physical therapist assistants (PTAs) must be familiar with the causes and signs of delirium, not only in the acute care setting, but across the health care continuum. Physical therapists and PTAs

have an important role to play in preventing and recognizing delirium as well as intervening to reduce the severity and duration of delirium in our vulnerable patients.

I hope you enjoy this issue and will consider taking the examination for continuing professional development. The topic is timely and important. Thank you to all the wonderful authors who contributed and a special thank you to Lise McCarthy who inspired this idea and helped this focus issue of *GeriNotes* come to fruition.

## REFERENCE

1. Inouye SK, Westendorp RGJ, Saczynski JS. Delirium in elderly people. *Lancet*. 2014;383(9920):911-922.



## Academy of Geriatric Physical Therapy

### CSM 2017 Preconference Courses

#### Working with Cognitive/Mental Health Issues Across the Care Continuum - 1.6 CEUs

**Tuesday, February 14 and Wednesday, February 15, 2017**

**Presenters: Lise McCarthy, PT, DPT, Michele Stanley, PT, DPT, Laura White, PT, DScPT, Nicole Dawson, PT, Betsy Ross, DPT, Grace Knott, PT, Michelle Criss, PT, DPT, Christine Ross, PT, DPT and Lynn Steffes, PT, DPT**

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**Tuesday, February 14 and Wednesday, February 15, 2017**

**Presenter: Kristi Hallisy, PT**



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# Cognitive Issues in Aging

## A Continuing Education Module for the Academy of Geriatric Physical Therapy

### MODULE CHAPTERS

1. Cognitive-based Functional Assessment in Alzheimer's Disease: A Focus on the GDS/FAST Staging System
2. Caregivers in Crisis: Strategies to Address Caregiver Health and Wellness
3. Attending to the Science of Dual Tasking: Our Current Evidence for Testing and Treatment
4. Legal and Ethical Reasoning to Enhance Compassionate Care in Patients Experiencing Cognitive Decline
5. Dementia: Improving Function and Quality of Life with a Biopsychosocial Approach
6. Delirium Prevention, Assessment, and Treatment by the Physical Therapist
7. Application and Interpretation of Functional Outcome Measures for Testing Individuals with Cognitive Impairment

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### REFERENCE LIST

References can be found at the end of each chapter in the module.

### OBJECTIVES

1. Discuss "expert" consensus about dementia and cognitive problems specific to diagnosis and multi-component interventions that focus on quality of life factors.
2. Identify common unmet needs of people living with dementia and/or cognitive issues and their caregivers.
3. Examine cognitive-based assessment tools and cognitive-based functional assessment tools for tracking changes in people living with dementia.
4. Construct relationships between biomarkers, behaviors, or brain structures known to be affected over the course of Alzheimer's disease.
5. Appraise how physical therapy services can be guided by cognitive-based functional assessment.
6. Understand strategies to prevent cognitive decline and how to legally and ethically treat individuals with cognitive problems.

### TARGET AUDIENCE

Physical Therapists and Physical Therapist Assistants

### CONTACT HOURS/CONTINUING EDUCATION UNITS (CEUs)

Completion of the Continuing Education (CE) Module is equivalent to 4 contact hours. This converts to .4 Continuing Education Units.

### CONTINUING EDUCATION CERTIFICATE OF COMPLETION

A CE certificate will be provided to each participant after successful completion of the course requirements (post-test and module evaluation) and payment of

a processing fee. The Academy of Geriatric Physical Therapy is a recognized component of the American Physical Therapy Association. The Academy has not applied to any state licensure agency for prior approval of this course. The module has all the components (content, objectives, qualified instructors, reference lists, and post-test) that will allow participants to submit the certificate of completion to meet CE requirements in some states. Participants are urged to check with their State Licensure Board to see if this course counts towards continuing education credit.

### HOW TO OBTAIN CEUs

To obtain CEUs for this continuing education unit, participants must complete the ONLINE post-test as well as the ONLINE evaluation form. Go to <http://geriatricspt.org/exams/>

A processing fee of \$40.00 for Academy of Geriatric Physical Therapy members and \$80.00 for non-members is required. Read the module and complete the post-test and the evaluation online and provide payment online. **Test and evaluation forms must be completed online no later than March 31, 2017.** Upon submission of materials and a passing score of 80% or higher on the post-test, the Academy will email you a continuing education certificate for .4 CEUs. Those with incomplete submissions will be notified via email and given the opportunity to re-take the exam. There is only ONE correct answer for each question. NOTE: This is to be performed ONLINE ONLY at <http://geriatricspt.org/exams/>

# Cognitive-based Functional Assessment in Alzheimer's Disease: A Focus on the GDS/FAST Staging System

*Lise McCarthy, PT, DPT, GCS*

## INTRODUCTION

"What should we know about dementia in the 21<sup>st</sup> Century?"<sup>1</sup> Annear et al attempt to answer this question in their Delphi study published in 2015.<sup>1</sup> Fifteen pooled "experts in dementia" (from Australia, the United States, and the United Kingdom) participated in this consensus study. Their expertise spanned one or more areas in clinical care, education, advocacy, service delivery, neuropsychology, and research. Their occupations included a professor, a geriatrician or nurse specialist, a gerontologist, and a clinical psychologist. Six participants identified their gender as female.

There was 100% consensus among participants that "assessment of a person with dementia is important to determine whether they are suffering from treatable and co-existing medical and psychiatric conditions." There was very high consensus (87%) that "dementia affects people across 5 domains: cognitive, functional, psychiatric, behavioural, and physical." Additionally, there was very high consensus in 3 other diagnosis and treatment categories: pain in a person with dementia should be identified and treated (93% consensus), delirium should be ruled out in a person with suspected dementia (87% consensus), and depression in a person with dementia should be identified and treated (87% consensus).

However, there was poor consensus (27%) among these experts that "exercise for the person with dementia can improve symptoms" despite solid evidence reported in a 2011 global study that inactivity is the number one modifiable risk factor for dementia.<sup>2</sup> It is noteworthy that this study lacked inclusion of "experts in dementia" who were people with dementia, their caregivers, and physical therapists (PTs). In this new era of rapidly evolving person-centered and collaborative health care, some research-

ers are emphasizing inclusion of these groups to better understand quality of life measures and effective models of health care.

For example, in 2015 O'Rourke et al published "Factors that Affect Quality of Life from the Perspective of People with Dementia."<sup>3</sup> Their systematic review and metasynthesis of qualitative research from 1975 to 2012 focused on quality of life (QOL) perspectives of people with dementia. Perhaps not surprising, feelings of happiness and sadness, and personal experiences of feeling connectedness or disconnectedness, were voiced by people with dementia as key influences on outcomes of QOL.

In addition, the authors reported the following 4 potentially modifiable and influential QOL factors identified by people living with dementia:

1. Their relationships to others as characterized by respect, reciprocity, closeness, kindness, or love.
2. Their perceptions of purposefulness within one's daily existence and to others.
3. Their experiences of wellness with the context of living with disease or age-related chronic conditions.
4. Their emotional attachments to their immediate and surrounding environments.

Lending further insight into QOL factors, high-quality evidence shows that multicomponent interventions focused on caregiver education and support significantly enhances QOL and delays institutionalization by 33% after 6 to 12 months with modest cost.<sup>4</sup>

Also published in 2015 was a cross-sectional observational cohort study by Jennings et al entitled "Unmet Needs of Caregivers of Individuals Referred to a Dementia Care Program."<sup>5</sup> These authors found high internal consistency in their analysis of multiple question-

naires (eg, Patient Health Questionnaire, Modified Caregiver Strain Index, Neuropsychiatric Inventory Questionnaire). Answers to questions related to caregiver self-efficacy and perceptions of available dementia care support revealed high percentages of many unmet needs reported by the 307 caregiver participants:

- 65% did not receive advice about what dementia-related problems to expect;
- 61% did not receive advice about how to manage dementia-related problems;
- 75% were unaware of services available to help them provide care;
- 81% did not know how to access community services to help them provide care;
- 68% did not feel confident managing memory loss, wandering, or other dementia-related problems;
- 65% did not feel confident dealing with the frustrations of caregiving;
- 72% felt they did not have a health care professional who could help them work through dementia-related problems.

The authors concluded that a more comprehensive model of dementia care is needed to better meet these expressed caregiver needs for health literacy, training, and supportive and timely evaluation and care management (E&M) services. The authors suggested that these services could be provided by non-physicians in collaborative care management models of health care. Included last on their list were PTs.

With the above findings in mind, this article discusses how a cognitive-based functional assessment tool can help guide medically necessary and justifiable person-centered PTs E&M services provided to people impacted by and throughout the course of Alzheimer's disease (AD).

## COGNITIVE-BASED ASSESSMENT TOOLS WITH AND WITHOUT FUNCTION-BASED ASSESSMENT

There is no one gold standard for cognitive-based assessment. The Mini-Mental State Examination (MMSE), Montreal Cognitive Assessment (MoCA) and Abbreviated-MoCA (A-MoCA) are widely used to cognitively screen people for mild cognitive impairment (MCI) and early dementia characteristics. In 2015, a crosswalk of the scores from these 3 cognitive assessment tools was published, and this crosswalk allows clinicians and clinical researchers to better track cognitive changes when different tools are used.<sup>6</sup> Yet, despite their wide use, the clinical benefits for using these cognitive assessment tools are limited by floor effects, especially when complex and basic activities of daily living (ADLs) and function become significantly impaired in the moderate and advanced stages of dementia.<sup>7</sup>

The Global Deterioration Scale (GDS) and the Functional Assessment Staging Tool (FAST) are well-researched tools that have existed since the 1980s and complement each other.<sup>8</sup> When used together, the GDS/FAST staging system is reliable and valid for staging people with Alzheimer's dementia who live in a variety of settings, and is not influenced by educational achievements and socioeconomic status, unlike the MMSE.<sup>7-10</sup> Further, the GDS/FAST staging system shows variances in temporal changes in the course of AD nearly 3 times that of the MMSE.<sup>7</sup> Hence, there are clinical benefits for PTs, who are the functional movement experts, to use the GDS/FAST staging system to track the cognitive-based functional course of Alzheimer's dementia over time, especially in the moderate and advanced stages of dementia when the MMSE, MoCA, and A-MoCA cease to be informative.

On its own, the GDS is clinically simple to use, identifies cognitive-based functional changes across 7 global and distinctly recognizable stages of AD, and considers 20 person-centered domains.<sup>8,11</sup> Each global stage is defined by impaired and preserved cognitive skills and abilities that affect, first complex ADLs and then basic ADLs. The Brief Cognitive Rating Scale is a 5-axis measure that guides the scoring of a person's abilities and deficits in concentration,

recent memory, past memory, orientation, and functioning and self-care in order to determine the GDS Stage.<sup>8</sup>

The FAST further enhances the GDS by providing another multi-axial, hierarchical sub-staging system that identifies nuanced progressive functional changes during the last two stages of the GDS, making it the gold standard for hospice admission under Medicare.<sup>7</sup> Specifically, the FAST can be used to help differentiate AD-related dementia from other dementias, and can identify AD-related and non-AD-related (eg, infection, medication side effects) functional changes over time.<sup>7</sup>

### GDS/FAST STAGES 1, 2

The course of AD starts in myelinated (white matter) structures in the brain (eg, hippocampus, corpus callosum and olfactory bulb) and slowly (over years) progresses into the unmyelinated (grey matter) lobes of the cerebral cortex (eg, frontal, temporal, parietal, occipital). The resulting neuropathological structural damage to white and grey matter causes dramatic shrinkage in brain cell volume over time that can be determined by magnetic resonance imaging (MRI).<sup>12</sup>

New imaging tools and AD-related biomarkers have recently shown neuropathological damage begins to accumulate upwards of a decade or more before clinical manifestation of AD.<sup>12</sup> However, it is important to note that other conditions (eg, hydrocephalus, stroke, fall-related head injury) and diseases (eg, white matter, Parkinson's, hippocampal sclerosis) may complicate/skew a person's clinical presentation.

People in GDS/FAST Stage 1 are considered to have normal cognitive health, but they may have other conditions (eg, diabetes, obesity, hypertension, depression) that put them at higher risk for developing cognitive and brain health impairments.<sup>2</sup> People in GDS/FAST Stage 2 have mild forgetfulness, but this type of memory loss may be age-related and not necessarily related to disease.

Person-centered PTs E&M services may include but are not limited to:

1. Screening for impairments in common health domains (eg, cognitive, mental, behavioral, functional, physical).

2. Screening for common health risks (eg, fall risk, polypharmacy, abnormal weight, smoking).
3. Screening for vision and hearing deficits for possible referral and/or need for specific aids/equipment as deficits in these areas are known to accelerate cognitive decline.<sup>13-15</sup>
4. Screening for signs of dementia/delirium (eg, Mini-Cog test) and making a diagnostic referral when indicated.
5. Screening for signs of depression, and providing interventions for mild depression if indicated or diagnostic referral when major depression is suspected and of concern.
6. Providing health literacy instruction and designing/progressing programs that help reduce health domain impairments and modifiable health risks for dementia.
7. Monitoring and treating abnormal trends in vital signs (eg, blood pressure, heart/pulse rate, oxygen saturation, pain) and making a referral when indicated.

### GDS/FAST STAGE 3

The effects of AD only become clinically apparent in GDS/FAST Stage 3. People in this stage are now within the dementia spectrum. They may or may not have a diagnosis of MCI, described as the state of being when "cognition is no longer normal relative to age expectations, however, daily functions are not sufficiently disrupted to correlate with the diagnosis of dementia."<sup>16</sup>

In this stage, AD has destroyed parts of the limbic system called the hippocampus and has caused significant atrophy in specific areas of the corpus callosum and olfactory bulb.<sup>17-19</sup> The primary function of the hippocampus is to help make and recall long-term memories, navigate through space, and recognize familiar environments.<sup>19</sup> The corpus callosum is the largest white matter structure in the brain; it is the sensorimotor highway that connects the cerebral hemispheres.<sup>20</sup> Four functional activation foci areas of the corpus callosum have been identified through topographical functional MRI (fMRI): anterior (taste stimuli), central (motor tasks), central and posterior (tactile stimuli) and splenium (auditory and visual stimuli).<sup>17</sup> Current research indicates people in this stage of AD have a pattern of damage involving the anterior portion of the corpus callosum.<sup>20</sup>



Generally, cognitive-based functional deficits in this stage include faulty declarative memory (ie, recall of words, names, and facts), impaired spatial memory (ie, ability to recall how to navigate in large or unfamiliar environments), and diminished sense of smell and taste.<sup>17-22</sup> However, people in this stage and their family/caregivers/friends may lack awareness of these deficits, especially if a diagnosis of MCI has not yet been made. Additionally, fall risk is higher and pain is more prevalent in people on the dementia spectrum, and other health care professionals may not be as focused on these areas as PTs and PT assistants (PTAs).<sup>23,24</sup>

Early screening for cognitive changes and biomarkers is a needed skilled service that can be provided by PTs and PTAs. For example, declines in cognitive assessment scores or accelerated weight loss are biomarkers that can help identify the progression of MCI to early dementia or GDS/FAST Stage 4.<sup>25</sup>

A referral for diagnosis can result in timely short-term treatment and planning long-term options. Cognitive-based functional screening can also help identify subtle changes related to transient conditions (eg, infection, medication toxicity, dehydration) that PTs and PTAs may notice in their patients.

People with AD can appear to have a more advanced dementia presentation when they also have impaired vision and/or hearing. Screening for visual and auditory impairments is an important service because poor vision or hearing can diminish one's sense of space, decrease cognitive function, negatively impact ADLs, contribute to hallucinations, and distort high and low frequency sounds adding to miscommunication and impaired comprehension.<sup>13-15</sup>

Person-centered PTs E&M services may include but are not limited to:

1. Incorporating the 4 QOL factors expressed by people living with dementia.
2. Identifying and meeting, as able, the expressed unmet needs of caregivers of people with dementia.
3. Continuing/targeting/intensifying frequency of services provided in GDS/FAST Stages 1-2.
4. Tracking dementia-related changes in biomarkers (eg, accelerated weight changes, declines in cognitive scores).

5. Incorporating visual, auditory, declarative memory cues and spatial navigation cues into structured programs and the environment to enhance meaning and familiarity while defining spatial boundaries.

6. Using pain assessment tools appropriate for people within the dementia spectrum.

#### GDS/FAST STAGE 4

For people in GDS/FAST Stage 4, the AD has further damaged already affected structures so deficits in declarative memory and spatial memory are much more pronounced. Because the AD has spread outside the hippocampus and to other areas of the cortex involved in thinking and planning, significant deficits in procedural types of memories, markedly impaired attention spans, and decreased awareness of these deficits are now present. Functional MRI shows damage to the posterior portion of the corpus callosum, and corroborates findings from other studies that have noted markedly impaired sensory processing of smell, taste, and tactile stimuli when a diagnosis of AD exists.<sup>17,21,22</sup>

People in this early dementia stage are poor historians, and because they have decreased awareness of their deficits, they often deny having these deficits. They often fill in their memory gaps with incongruent information that makes sense to them and others who may not know them and their history.

Because their procedural memories are impaired, they often forget to perform all the necessary sequential steps involved to successfully complete complex ADLs, and they do not realize they may have missed a step or two in following a well-practiced procedure. For example, when a person pays a bill with a check, she needs to be attentive and maintain her attention to make sure the bill is accurate, to make sure to completely write and record the check, to make sure the check and the bill are placed in a stamped envelope, and then mailed. A person in GDS/FAST Stage 4 will often, but not always, forget any one or more of these steps.

Despite having diminished awareness of their cognitive deficits, people in this stage can still travel by themselves to familiar locations. They can live alone because they can still perform basic ADLs (eg, eating, dressing, and bath-

ing). However, they need some support to help them manage complex ADLs (eg, paying bills, preparing meals), are prone to refuse help, may become upset when others try to correct their story, become angry when help is repeatedly offered, and retreat from challenging people and situations.

Person-centered PTs E&M services may include but are not limited to:

1. Continuing/targeting/intensifying frequency of services provided in GDS/FAST Stage 3.
2. Identify and tracking dementia-related changes in cognitive and functional biomarkers (eg, declines in complex ADLs such as meal preparation and financial management).
3. Incorporating procedural memory cues into structured programs, especially when providing caregiver health literacy instruction and self-care management training.
4. Monitoring for signs of self-neglect, environmental neglect, or financial abuse and reporting serious concerns as mandated reporters.

#### GDS/FAST STAGE 5

People in GDS/FAST Stage 5 are still able to recognize faces and people with whom they have close relationships or frequent interactions. However, disorientation to time (eg, recalling the time of day and the season), increased procedural memory deficits about dressing (eg, dressing/undressing, choosing what clothes are appropriate to wear for the day and for the season) and difficulty performing infrequent sequential tasks (eg, serial subtractions) are hallmark experiences of people in this stage.

Person-centered PTs E&M services may include but are not limited to:

1. Continuing/modifying services provided in GDS/FAST Stage 4.
2. Identifying and tracking dementia-related changes in cognitive and functional biomarkers (eg, disorientation to time, difficulty with the ADL of dressing).
3. Incorporating the use of orienting cues, especially when providing caregiver health literacy instruction and self-care management training.

#### GDS/FAST STAGE 6

In this stage, the AD has now spread to more of the sensory processing



centers of the brain. Visual and auditory sensory information is quickly forgotten or easily misconstrued that can contribute to delusions, hallucinations, and obsessive/repetitive behaviors.<sup>13-15</sup>

People in GDS/FAST Stage 6 can usually remember their first name, but not the names of close family and friends, or facts about major events in their life. They cannot live alone because they are severely disoriented and spatially confused so they need a variety of cues from others and the environment, as well as more sensory processing time in order to become optimally oriented and motivated to initiate, perform and complete the basic ADLs needed for survival.

Person-centered PTs E&M services may include but are not limited to:

1. Continuing/modifying services provided in GDS/FAST Stage 5.
2. Incorporating the use of GDS/FAST substages, especially when providing caregiver health literacy instruction (eg, need for others to use slower and simpler speech, minimizing environmental distractions to allow for increased time to process information/requests) and self-care management training (eg, use of good body mechanics when assisting another person with basic ADLs).

### GDS/FAST STAGE 7

For people in GDS/FAST Stage 7, the AD has now spread into the autonomic centers of the brain and cortical dysfunction is profound. People in this stage eventually become wheelchair/bed bound. Their participation in basic ADLs generally requires progressive and significant physical assistance. People in this stage become increasingly passive until they are totally dependent as they experience global autonomic and cortical dysfunction affecting:

- breathing, swallowing and throat control for speaking;
- reflexive stepping for walking;
- postural sitting control responses; and
- facial expressions that convey information about their internal experience.

Person-centered PTs E&M services may include but are not limited to:

1. Continuing/modifying services provided in GDS/FAST Stage 6.
2. Providing health literacy and caregiver training in the use of specialized equipment and programs that promote comfort and safety, and help minimize health risks as able.
3. Making a referral to hospice care when needed.

### CONCLUSION

Alzheimer's disease-related dementia is the most common form of dementia (80% consensus).<sup>1</sup> Although much has been published about AD, recent research findings indicate people impacted by AD do not yet feel adequately supported by their healthcare professionals. Physical Therapists and PTAs are functional movement experts, and the body of knowledge and practice of physical therapy continues to evolve. Incorporating cognitive-based functional assessment tools, such as the GDS/FAST staging system, into physical therapy practice can help guide person-centered care, especially of those people impacted throughout the course of AD.

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**Note:** Corrected on Feb 4, 2017. An earlier version of this article had a misspelling in the title which has now been corrected.

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## Caregivers in Crisis: Strategies to Address Caregiver Health and Wellness

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### INTRODUCTION

Aging-in-place often necessitates caregiver assistance for help with instrumental and basic activities of daily living. Caregiving involves a substantial commitment through emotional, financial, mental, and physical mechanisms often contributing to high levels of stress, burden, depression, and anxiety. As physical therapists (PTs) regularly interact with caregivers during an interval of care for an older adult, PTs are in a prime position to address caregiver health to promote optimal outcomes for both the caregiver and older adult. This paper will present information on the burden of caregiving, caregiver screening tools, and strategies to improve caregiver health and wellness.

### EPIDEMIOLOGY AND IMPACT OF INFORMAL CAREGIVING

Informal caregivers are family, friends, or neighbors who provide unpaid care out of love, respect, obligation, or friendship.<sup>1</sup> There are currently 43.5 million informal caregivers nationwide, of whom 34.2 million provide care to someone older than 50 years of age. Of these informal caregivers, 85% provide care for a relative. Females are more likely to be caregivers than males and the average amount of time spent providing care is 24 hours a week.<sup>2</sup> Importantly, approximately 34% of caregivers provide assistance to someone with Alzheimer's disease or dementia and 10% of caregivers are currently 75 years of age or older, highlighting unique challenges

of providing caregiving within a rapidly aging society.

Caregiving requires a tremendous amount of commitment on the part of the caregiver through emotional, physical, mental, and financial mechanisms. This commitment can contribute to high levels of stress leading to depression and anxiety,<sup>3</sup> impaired cardiovascular function,<sup>4</sup> immune dysregulation,<sup>5</sup> sleep disturbances,<sup>6</sup> and lower quality of life.<sup>7,8</sup> As such, caregivers are subject to burden; a broad term referring to the psychological, physical, social, and economic impact on the caregiver.<sup>9</sup>

### THEORIES OF CAREGIVER STRESS AND BURDEN

A number of theories explain factors that contribute or mitigate the degree of

burden faced by caregivers. The Stress Process Model<sup>10</sup> hypothesizes that caregivers have poorer health outcomes than non-caregivers because the chronic stress involved in caregiving impacts physical and cognitive health. Primary stressors such as the needs of care recipients and the caregiver's perception of stress influence the caregivers' roles increasing strain and contributing to changes in the caregiver's sense of control, identity, and self-esteem. These changes then impact physical, mental, and emotional health, often contributing to burnout and cessation of caregiving.

Despite the stressors that caregivers face, not all caregivers suffer from burden. In fact, some caregivers show improved health outcomes compared to age-matched, non-caregivers.<sup>11</sup> The Healthy Caregiver Hypothesis suggests that factors inherent in caregiving actually preserve a caregiver's physical and cognitive health. As a caregiver, one must complete functional tasks, increasing overall levels of physical activity and manage instrumental activities of daily living, placing a higher cognitive demand on the person. These factors, physical activity and continued cognitive challenges, are independently related with decreased rates of functional and cognitive decline.

Despite the inherent stressors in caregiving, burnout occurs when the demands become overwhelming. Caregiver burnout is a state of physical, emotional, and mental exhaustion that may be accompanied by a change in attitude from positive and caring to negative and unconcerned.<sup>12</sup> Factors such as care recipient's cognitive deficits, physical stress, lack of support, length of caregiving, caregiving intensity, and financial challenges contribute to burnout.<sup>13</sup> Symptoms of burnout are highlighted in Table 1.

## ROLE OF PHYSICAL THERAPISTS IN PROMOTING CAREGIVER HEALTH

In the health care team, PTs are well positioned to provide caregiver

education. Given the close relationship and amount of time that PTs spend with patients and caregivers, PTs can lead caregiver training to enhance skills and improve caregiver performance with tasks to decrease burden. In the domain of health and wellness, PTs play an important role in monitoring caregivers for signs of burnout.

## CAREGIVER BURDEN SCALES

To assess the degree of caregiver burden, a number of outcome measures quantify various aspects of caregiving, including the psychological, physical, social, and economic impact. Physical therapists can utilize these scales to identify sources of burden, screen caregivers at risk for burnout to help make appropriate referrals, and evaluate the effectiveness of interventions and rehabilitation services. The most commonly used caregiver burden scales are found in Table 2.

## INTERVENTION TO IMPROVE CAREGIVER HEALTH

### Support Groups

Support groups are an important resource for patients, caregivers, and their families and are commonly offered through health care systems, professional organizations such as the Family Caregiving Alliance, Alzheimer's Association, online support resources like caring.com, or Area Agencies on Aging. Support groups have been shown useful in providing peer support and an opportunity to vent feelings and gain help to prepare for the future.<sup>20</sup>

### Respite Care

Respite care is a temporary relief in care offered through a variety of different mechanisms. In-home services provide companionship, personal care, or homemaker services for supervision, allowing the caregiver to leave the home for short periods of time. Adult day centers are locations that offer activities

such as music, exercise, and art programs for 4 to 12 hours per day. Transportation is often provided and costs range from \$25 to \$100 per day. Some nursing home or other residential facilities offer respite care options for an individual to stay overnight or for a very short-term stay. Caregivers can use residential facilities for an extended respite; however, these services are not usually covered by insurance or Medicare. Archrespite.org provides detailed descriptions of the various respite programs offered in different states.

## CAREGIVER TRAINING

A critical element of caregiver training is the development of self-efficacy; the task specific confidence that one can successfully perform a task and accomplish a goal.<sup>21</sup> The 4 sources of self-efficacy and specific strategies to develop these areas are found in Table 3.

One framework by which to structure caregiver training is the Four E's Approach,<sup>22</sup> a framework consisting of exposure, expertise, experience, and embedding. To incorporate these elements, a PT can provide exposure through handouts or videos providing demonstration of tasks. It may also be helpful for caregivers to experience the patient role by the PT first demonstrating the skill using the caregiver as the patient. To facilitate expertise, challenging or unanticipated situations that the caregiver may encounter should be incorporated into training. Finally, PTs should embed their contact information and follow-up resources for communication after discharge.

Components of caregiver training include design, implementation, and evaluation of patient and caregiver education programs. The initial stage of design includes a determination of the caregivers needs taking into account the setup of the home and

**Table 1.** Symptoms of Burnout

Feeling overwhelmed Gaining or losing weight Feeling tired most of the time Losing interest in activities previously enjoyed Headaches or body aches	Feeling alone, isolated, or deserted by others Sleeping too much or too little Becoming easily irritated or angered Feeling worried or sad often Withdrawing from friends and family
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**Table 2.** Caregiver Burden Scales

Scale	Concepts/Domains Measured	Number of Items	Scoring
<b>Caregiver Burden Inventory<sup>14</sup></b>	Burden in aspects of time, emotional & physical health, social relationships, & development.	24 – 5 subscales	5-point Likert Scale
<b>Caregiver Burden Scale<sup>15</sup></b>	Caregiving consequences and quality of relationship with care recipient.	13 – 2 subscales	5-point Likert Scale
<b>Caregiver Well-being Scale<sup>16</sup></b>	Identifies areas of basic needs and activities of living. Needs are defined in three areas of love, physical needs, and self-esteem. Activities of living are non-basic needs required for a healthy life, such as exercise, relaxation, skill development, personal growth, and social support.	43	7-point Likert Scale
<b>Modified Caregiver Strain Index<sup>17</sup></b>	Strain relative to care provision.	13	Answers are yes, sometimes, and no
<b>Zarit Burden Scale<sup>18</sup></b>	Appraisal of impact of caregiving on life.	22	5-point Likert Scale Scoring: 0-21: little or no burden 21-40: mild to moderate burden 41-60: moderate to severe burden 61-88: severe burden
<b>Caregiver Self-assessment Questionnaire<sup>19</sup></b>	Assesses caregiver stress.	18 items	Questions 1-16 with yes/no response, 17-18 with scored from 1-10; caregiver has high distress with yes response to 4 or 11, total score of 10 or more, or 6 or more on 17 or 18

the tasks the caregiver will need to complete. Typically, the training session should include hands-on training, with the caregiver completing transfers or handling techniques. Evaluation may include completion of a mobility technique, or a knowledge checklist for the caregiver. Physical therapists can benefit from reflection on the caregiver training process, using this to identify improved methods in order to better support caregivers.

Incorporation of adult education principles<sup>23</sup> can also help to improve caregiver training effectiveness. To best engage caregivers in the education process, it is important to recognize that caregivers bring their own perspectives and needs to the caregiver training process. Making ties to previous learning experiences and making the training as collaborative as possible are other strategies.<sup>24</sup> Acknowledging that caregivers are adult learners and choosing teaching methods to meet their needs can also lead to better training outcomes

## CONCLUSION

Caregiving has a significant impact on mental, physical, and emotional health outcomes. The use of theoretical grounded intervention and education should help promote active caregiving and needed social support for caregivers. Physical therapists should use appropriate caregiver burden scales to screen burnout in caregivers and after screening, use referrals to other health providers, supportive resources, and social services to assist caregivers. Finally, effective training programs for caregivers should address self-efficacy and utilize a structured framework to optimize learning.

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**Table 3.** Sources and Strategies to Develop Self-efficacy

Source of Self-efficacy	Definition	Strategy to Incorporate within Caregiver Training
Performance Outcomes	Past results influence confidence with future performance	Begin caregiver training in tasks that are readily accomplished. Progress training so there is a larger bank of successful attempts to draw upon.
Vicarious Experience	Observing someone similar successfully performing a task	Have other caregivers demonstrate a task. Videos of successful caregiver tasks can be shown.
Verbal Persuasion	Use of constructive positive feedback by which encouragement is provided	Communication should focus on acknowledging the skills the caregiver has performed successfully and not solely focusing on tasks the caregiver needs to improve.
Positive Appraisals	Positive mood enhances perceived self-efficacy; negative emotions and anxiety reduces self-efficacy	Use apps like Headspace, relaxation training, and guided imagery prior to caregiver training to reduce stressors.

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# Attending to the Science of Dual-tasking: Our Current Evidence for Testing and Treatment

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## INTRODUCTION

Regaining or even retaining functional mobility involves a complex set of skills and resources. Health care consumers, referral sources, and payers alike may readily recognize physical therapy (PT) as the go-to profession for many of these resources (strength, balance, endurance, etc). Yet many of these same groups (and some physical therapists) would be inclined to overlook the underlying attention demands of functional mobility in the community and much of our mobility-related activities of daily living. The multi- and dual-task (DT) body of knowledge is growing in the literature and clinic alike, yet many gaps remain, limiting our capacity to both apply valid tests and effective training in the wellness and rehabilitative efforts alike. This article will provide an overview of what is known about DT from physiology, testing, and training, as well as a commentary on what the near-term future of dual tasking holds.

### The Ubiquity of Dual and Multi-tasking

McIsaac and colleagues defined dual task as, "...the concurrent performance of two tasks with distinct and separate goals."<sup>1</sup> How often are your patients "dual tasking"? As an example, your patient is *merely* walking to the bathroom from his bed in the skilled nursing facility. While this may sound like a single-task, there are variables of task complexity and dual-task that are likely inherent when we consider corollary demands of manipulating a walker around the leg rests of a nearby wheelchair, thinking about how much time he has to make it to the bathroom to prevent incontinence; listening to his roommate snore; or during ambulation-wiggling his foot the rest of the way into his shoe...then it is clearly more than

a single-task. The scenario described above, based in reality, includes examples within each of the 4 different modalities of distractions: visual, cognitive, auditory, and manual—a paradigm that is only recently receiving attention in the literature.<sup>2-8</sup> Distractions are all-around us, and sometimes inside of us as well (cognitive operations, paranoias, and perseverations). The ability to be skilled, if not just safe, in the presence of dual and multi-task demands is a requirement in nearly every living setting.

While DT demands are everywhere, no two people should be affected by the same environmental and task demands, in the same manner, due to: (1) their past experiences with the proposed task or related tasks; (2) their relative automaticity in a primary motor task (gait, or otherwise) will influence the amount of cognitive reserve they have to offer; and (3) each person's tolerance for a specific type of secondary task, is an individual skill with both biological and experiential (nature and nurture) influence.

### The Neurophysiology of Attention and Dual-tasking

While it is beyond the scope of this article to comprehensively cover the vast network of attention in the brain, it is important to understand the diverse connectivity required to pay selective or divided attention. Suffice to say that attention is allocated in a diverse network throughout the brain, including extensive connections between the frontal lobe and various sensory-specialty zones (occipital for vision, parietal for perception and tactile, etc.) as well as deep structures including the thalamus and cingulate gyrus. These centers are largely regulated by the dorso-lateral prefrontal cortex (DLPFC) and the nearby ventro-lateral prefrontal cortex.<sup>9-13</sup> The DLPFC

receives dopaminergic input directly from the substantia nigra and to serve the functions as described, connects both directly and indirectly connected to the occipital, parietal and remaining motor cortices of the frontal lobe.<sup>11</sup> The non-dominant parietal lobe serves as a center for body image, and attention to the spatial relationships of body and environment – leading to well-cited neglect syndromes when lesioned.<sup>14</sup> As noted, attention is organized with separate networks – be that visual, temporal, or otherwise. Similarly, the four discrete functions of attention as described by McDowd<sup>15</sup> as: switching, divided, sustained, selective (Table 1), have overlapping and dedicated networks as well. While these aspects of attention are important to recognize for a more complete understanding of attention, this discussion is beyond the scope of this article.

### The Role of Cognition and Experience in Establishing and Allocating Resources for Procedural Memories

Our tolerance for secondary-tasks and distractions is partially dependent

**Table 1.** Parameters of Attention<sup>15</sup>

<b>Sustained:</b> The ability to endure and maintain a consistent behavioral response.
<b>Selective:</b> The capacity to maintain a behavioral response or cognitive set in a complex environment of distractions or competing stimuli.
<b>Alternating:</b> The capacity to shift cognitive set or re-prioritize between two or more tasks having different cognitive requirements.
<b>Divided:</b> The capacity to both process (receive) and respond simultaneously to two or more task demands.

on the extent to which the primary task is automatic, or formed as a procedural memory. In other words, the more skilled a person is, the harder it is to distract them. Take a high-pressure, fan-filled, away-game free throw, with a 90% shooter, and a 48% shooter. Which player should be more influenced by the fans behind the backboard? Similarly, if an elderly patient is not used to their footwear, is ambulating with a new assistive device, is experiencing ankle pain, or is 5 days postsurgical from total knee replacement, they are not operating under full automaticity and can be more easily distracted.

In a related consideration, patients with mild cognitive impairment (MCI), may have fewer cognitive resources to devote to the “equation” of dual task tolerance.<sup>1</sup> As such, redundancy or reserve in intelligence and cognition can afford enough shared resources to divide (simultaneous), or decide (allocate appropriate resources through filtering) when faced with dual task demands.

### Testing Dual-task Performance

There appears to be as much controversy as there is evidence in the world of dual-task testing. Most typically, the primary task in physical therapy literature is ambulation. This is where the agreement across methodologies stops. The variables to be considered include (1) type of secondary task distracter, or “mode” of distraction: cognitive, visual, auditory, or manual; (2) methodology (testing each task as a single-task prior to combining); (3) considerations of task complexity/novelty and reality (meaning how contrived or reality-based the task should or can be). In all, the most common investigations in dual task literature are dual-task cost (DTC) or dual-task effect, being the statistical reflection of change in performance in the primary task in single and DT.<sup>1</sup>

Emerging DT testing strategies include during sensory-organization testing, clinical test of sensory integration in balance, and word-recall items carried over an activities of daily living or during gait, such as the Walking and Remembering Test.<sup>15</sup> Still, the most common applications of DT testing in the clinic include the CTUG and TUG-M, or an application that includes an overlay of common psychological tests such as the Auditory Stroop or

Trails B tests.<sup>17,18</sup> The future of dual tasking is likely to soon include wireless gait analysis, as this is presently being explored on a clinical basis.

### Training Dual-task Performance

Clinical applications of DT training are only as sophisticated as the evidence to date. As it is functionally relevant to focus on ambulation, the task specific nature of DT practice in the clinic often stops there. Asking patients to perform mathematical calculations, spell words backwards, name state capitals...may be tasks that most of us as clinicians have applied. While these paradigms can be effective in *testing* DT, they fall-short of task specificity and should not be expected to translate from training to *function*. As we mature in DT applications, clinicians can be seen incorporating cell phones; pulling items from a purse, wallet, or pocket; recalling information delivered prior-to and after a primary task (requiring cognitive rehearsal during); using obstacles for visual distraction; and overlaying relevant auditory distractions during the motor task. In all, the best DT training takes into consideration the following:

- (1) Patient's relative experience with the task or level of automaticity with the primary task (will distractions interfere with motor learning?).
- (2) Transfer of training (what are the environmental constraints for this person).
- (3) Underlying diagnosis (what strengths and limitations are superimposed). See below.
- (4) Patient tolerance of error (will the patient improve or become more frustrated by the DT loading).
- (5) Exposure to one modality of DT condition should not transfer to skill (tolerance) in another.

### Effects of Age and Diagnosis on Dual-tasking

It should not be assumed that a stroke, a concussion, or even Parkinson's disease affects two different people in the same way. However, clinicians must be aware of phenotypes and tendencies, investigating dual task cost with cognitive stimuli in mild cognitive impairment (MCI), multiple sclerosis, and concussion; dysfunctional preference to visual stimuli presented

on the right after right-hemisphere stroke; and intolerance to most any dual task condition after brain injury. While some persons with Parkinson's disease (PD) have been shown to benefit from visual cues, they can have the highest dual-task cost in the face of visual distractions. Some of the most common situations for persons with PD to experience freezing of gait (FoG) include a change in floor surface, and visible stimuli such as a destination for sitting (bed, chair, toilet) or a doorway. While these trends are routinely evident in the conditions listed, it is important to test each individual for their specific capacities. As McIsaac and colleagues<sup>1</sup> write, “*In aging and disease states, declines in sensorimotor and cognitive functions may lead to reduced postural reserve and cognitive reserve creating overall greater demands for attention to the task.*”

Additionally, both rehabilitative “loading” and expectations within DT should include a consideration for diagnosis and age.<sup>16-23</sup> While all dual-tasking must be proportionate to capabilities, success rates, and personal tolerance (see previous section), we must recognize additional trends by diagnosis. Therapists must watch for signs of DT overload, including agitation (MCI, brain injury), headaches, dizziness, nausea (concussion, vestibular), FoG (PD), apraxia (MCI), and increased contraversive lateropulsion in post-stroke pusher syndrome. Clinicians should *not* assume that all groups possess the capacity to overcome their DT intolerance. For example, some persons with later-stage PD, could be physiologically incapable of resolving DT impairments<sup>11</sup> due to the aforementioned loss in dopaminergic pathways to the frontal lobe.<sup>12</sup>

### CONCLUSION

The science of dual-tasking continues to advance, as does the clinical application of both testing and training. Fortunately, more research is underway, with a focus to resolve some of the most pressing issues of transfer of training, specificity in regard to modality of dual-task distraction, and timing of application so as to not interfere with motor learning. In all, our patients are better when they can regain a measure of automaticity in primary motor tasks, allocating attentional reserves to secondary tasks and more



capable of filtering distracting stimuli. Do your part, become well-versed in the application of dual-tasking for the benefit of your patients and your profession.

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# Legal and Ethical Reasoning to Enhance Compassionate Care in Patients Experiencing Cognitive Decline

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Legal and ethical concerns regarding decision making and treatments have surfaced with the prevalence of cognitive impairment increasing as one ages.<sup>1,2</sup> This article will focus on legal and ethical issues concerning Alzheimer's disease (AD) and dementia and how these might affect that person's care. The influence of cognitive decline is far-reaching, with effects on cognitive and physical function, quality of life, and related medical cost/utilization impacting not just the person living with dementia but also all who come in contact with that individual.

## LEGAL ISSUES WITH COMPETENCY

To discuss legal and ethical issues, one must first understand the difference. A legal right is an action that health care providers/society has an obligation to fulfill. Failure to provide this obligation leaves one vulnerable to litigation. Ethics involves conflicts between right and wrong and is based on individual ideals, preferences, and beliefs that may vary within a diverse population. However, ethical issues are also rules of conduct established by society or organizations, such as professional organizations.<sup>3,4</sup> The American Physical Therapy Association has an established Code of Ethics and Standards of Ethical Conduct that physical therapists and physical therapist assistants are expected to heed. Failure to adhere to these rules of conduct can impact an individual's professional practice.<sup>5</sup>

Legal issues may vary from state to state, however, there are some issues that have been mandated by the Federal Government. The Health Information Protection and Accessibility Act (HIPAA) of 1996 (with additions in 2000, 2002, and 2003)<sup>6</sup> guarantees the Right to Privacy/Confidentiality. Along with privacy, informed consent is mandated by HIPAA. Informed consent is a legal requirement in all 50 states

and is a process for communication between the patient and provider to discuss diagnosis, treatment, risk/benefits, and alternatives. Patients have the right to self-determine bodily integrity and volunteerism in decision-making.<sup>6</sup> An important question is how to determine if the person with cognitive decline can properly consent to treatment?

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**While most people look at who makes everyday decisions as an issue of competence, one must not forget the complexity of informed consent as it applies to research in this population.**

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Family members, health care providers (HCPs) and society as a whole often immediately assume the person with dementia is not able to make decisions and they are not aware of what is happening.<sup>7</sup> Autonomy and decision-making ability are often at the center of ethical and legal issues in patients with cognitive decline.<sup>8</sup> Health care providers need to remember that competence is a legal definition, and very few patients are legally declared incompetent. Medical professionals often determine mental capacity during bedside exams with tools (ie, Mini-Mental Status Exam, clock drawing) that measure cognitive capacity. Providers often base capacity decisions on past experience and reports of performance of activities of daily living.<sup>9,10</sup> Many of the items on screening tools are biased towards certain ethnic groups and gender roles.<sup>11</sup> A HCPs' own biases about how a decision should be made can also impact bedside capacity assessments. Ironically, HCPs let people who do not have the label of "dementia" make irrational decisions without deeming them incompetent.<sup>9</sup> Capacity

however, is only part of legal competence. There currently is no universally accepted definition of competence and a growing realization that context and risk must be included in assessment.<sup>11</sup> All too often, those with dementia are thought of as "nonpersons owing to the prevalent equation of personhood with the capacity for rationality and self reflections; elements lost in Alzheimer disease."<sup>11(p560)</sup>

Unfortunately, this stigma is now being associated with mild cognitive impairment (MCI) and "pre-AD" as well.

When looking at informed consent, there is variability in decision-making based on the stages of AD, personal ethical background, as well as differences between what the patient and their caregivers want and value.<sup>12</sup> These differing opinions can impact decisions regarding driving,<sup>9,13</sup> living at home,<sup>1</sup> as well as treatment including pharmaceuticals, therapy, and even research participation.<sup>14</sup> Optimizing the patient's involvement in decision-making contributes to his/her identity, quality of life, and dignity. Smebye and colleagues<sup>10</sup> emphasized "decision-specific competence" being more feasible than absolute capacity to make decisions because behavior and awareness vary daily and as dementia progresses. Providing patients decision-making control can lead to positive behaviors such as reducing the need for medications. Most patients, even with severe dementia, are still able to express (even nonverbally) their preferences fairly consistently.<sup>15,16</sup> These decisions may include choice of foods, activities, where they would like to sit, and more.

While most people look at who makes everyday decisions as an issue of competence, one must not forget the complexity of informed consent as it applies to research in this population. There is controversy over risks versus benefits of research in those with cognitive decline. Research guidelines put forth by the Alzheimer Association include 4 components<sup>17,18</sup>:

1. In studies with minimal risk, proxy consent is acceptable in absence of an advanced directive.
2. For studies with greater than minimal risk and reasonable benefit potential, proxy consent is acceptable in absence of an advanced directive.
3. In studies with greater than minimal risk and no reasonable potential benefit for the patient, patients must be able to make their own informed consent or have an advance directive.
4. ALL patients and surrogates MUST understand that they may be randomly assigned to a control group and not have the benefit of the experimental treatment.

In summary, therapists need to remember that most patients do not have competence legally determined, to follow advanced directives but that patients should be involved in decision-making as much as possible, and that the ability to consent may depend on the context/situation.

## ETHICAL ISSUES IN DEMENTIA CARE

Ethical concerns are part of everyday clinical practice, but often are unrecognized or ignored by therapists. However, working with older adults with dementia poses multiple ethical dilemmas and demands that therapists provide compassionate care at the highest level of professional competence. Challenges are encountered as the disease progresses and the person experiences difficult behaviors, changes in personality, loss of language skills, and social withdrawal from friends and family. Optimal care should aim for respecting the individual and his/her autonomy, preserving decision-making abilities, upholding confidentiality with the person and designated health care proxy, and offering meaningful participation in everyday activities of daily living.<sup>19</sup> In short, therapists should focus on current strengths and abilities and not solely the person's cognitive pathology.<sup>20</sup>

While much of the ethics literature focuses on "big or extraordinary" ethical issues (Table 1), it is the everyday experience of incorporating ethical practice into treatment that affects the ongoing quality of life and protects the vulnerable from abusive practices. Reflecting on ethics in everyday living enhances

**Table 1.** Commonly Identified Ethical Issues in Dementia Practice\*

- Decision-making capacity and competency
- Informed consent
- Patient autonomy
- Patient's right to refuse
- Conflicts in moral and legal rights of patients and families/caregivers
- Disclosure
- Truth-telling
- Challenging behaviors
- Discharge decisions
- Safety
- Risk-taking
- Elder abuse
- Palliative and end of life care
- Research

\*Adapted from Daly and Fahey-McCarthy.<sup>20</sup>

dignity and fosters an approach to dementia care that is both strength-based and abilities-focused—concepts that are advocated as best practice in contemporary dementia care.<sup>20</sup>

Traditionally, therapists rely on APTA's Codes of Ethics<sup>5</sup> and Standards of Ethical Conduct for the Physical Therapist Assistant<sup>21</sup> to provide guidance in dealing with ethical concerns. While reference to these documents may provide general guidance for interactions with others, they will not provide an answer for an ethical dilemma. Primarily, the guidance provided is limited to principles of respect, trust worthiness, compassion/caring, and autonomy, and does not account for the complex issues associated with providing care for patients with dementia. Only when the Codes/Standards are viewed in the context of real cases can they take on meaning and allow the reflective process that underlies moral judgments.<sup>22</sup>

Similarly, traditional bioethical theories and principles (Table 2) often fail to provide an answer to a particular clinical dilemma involving patients with dementia. Rather, they provide common understandings for enhancing awareness and insight into challenging situations. One example is the need to balance patient autonomy with the ethical duties of beneficence/nonmaleficence, which obligate therapists to do well and avoid harm. Autonomy gives patients the right to actively negotiate health care decisions and have those decisions respected.

This is fundamental to bioethics and is an important aspect of patient-centered care. However, conflicts may exist between maintaining the autonomy of a person with dementia while also not compromising their health and well-being.<sup>23</sup> The issue of autonomy must take into account individual capacity and competency to make decisions. Therapists must respect the decision-making capacity of individuals with dementia as long as possible. Tension between autonomy and beneficence/nonmaleficence may occur when the therapist's desire to promote good/avoid harm comes into conflict with the patient's wishes. In cases of diminished capacity, therapists may conclude that beneficence/nonmaleficence may overrule the patient's autonomy or they may err on the side of over-adherence to patient autonomy giving insufficient attention to principles that protect and benefit the patient. The goal should be to strike a balance between autonomy and beneficence/nonmaleficence to make the best possible choice. Related to autonomy is the issue of paternalism, which is coercion or interference with another person's freedom of action. When working with patients with dementia, therapists need to respect patient autonomy while providing competent care in a way that is not forced or coerced, but is collaborative.<sup>22</sup>

Contemporary ethical approaches that focus on the value of life narratives and experiences rather than cognitive abilities provide a more meaningful approach to dilemmas faced during patient care. The approaches advocate consideration of the decision-making context and inter-relations with others as important aspects of ethical decision-making. These approaches use stories, narrative, and biographies to emphasize the importance of the values and virtues of everyone involved, the inter-relations among people, and a belief that multiple perspectives may arise. They are especially applicable to guide therapists to meet ethical obligations and act in the patient's best interest, even in advanced dementia where additional challenges are realized.<sup>20</sup>

These contemporary ethical theories are rooted in ethical mindfulness and employ a phenomenological approach to clinical reasoning. Mindful practice is a way for clinicians to attend in a nonjudgmental way to their own

**Table 2.** Traditional Ethical Theories and Principles\*

Theories & Principles	Key Features
Deontology	<ul style="list-style-type: none"> <li>• Patient First</li> <li>• Based on rules and universal principles of duties and rights</li> <li>• Focuses on doing the “right” thing</li> <li>• Consequences are denied importance</li> <li>• Includes duties of beneficence, nonmaleficence, justice, fidelity, and veracity</li> <li>• Includes right of autonomy</li> <li>• Emmanuel Kant</li> </ul>
Utilitarianism	<ul style="list-style-type: none"> <li>• Focuses on consequences – goals, outcomes</li> <li>• Action is based on predicted outcomes</li> <li>• Actions aim to achieve the greatest good for as many as possible – ie, society more than individual</li> <li>• Requires identification of values</li> <li>• The intrinsic good is promotion of “happiness”</li> <li>• John Stuart Mills</li> </ul>

\*Adapted from Daly and Fahey-McCarthy.<sup>20</sup>

physical and mental processes during ordinary, everyday tasks with clarity and insight.<sup>24</sup> Mindfulness is a logical extension of the concept of reflective practice, leading clinicians away from theories to the experience itself. Inherent in mindfulness is the ability to listen more attentively, recognize bias/judgment, and act with compassion based on insight.<sup>24</sup> Ethical mindfulness requires integration of phenomenological inquiry skills into clinical reasoning and decision-making frameworks. A phenomenological approach is based on probing, interpreting, and understanding the experiences of how a person lives with dementia from that individual’s viewpoint and also

considers the needs of all stakeholders. Trigger questions provide an analytical and interpretive view to promote clinicians to think more deeply and facilitate ethical engagement (Table 3). The intent is to uncover moral concerns and the meanings of a patient’s illness experience from the perspectives of the patient and all relevant stakeholders.<sup>25</sup>

### SELECT TREATMENT CONSIDERATIONS FOR ADHERING TO ETHICAL CARE

#### Communication Strategies to Maximize Participation and Decision-Making

Best practice in dementia care involves continuing to treat the person with dementia as an individual, which adheres to ethical care. Kitwood and Bredin<sup>26</sup> championed person-centered dementia care, reminding us that those with dementia need comfort, attachment, inclusion, identity, and purpose to exist in a state of relative well-being. Their assertions about the need for socialization, involvement in decision-making, and purpose are supported by the viewpoints of those actually living with dementia.<sup>10,23</sup> Protective instincts may result in the desire to “care” for the loved one by making decisions for that person. However, paternalism flourishes when others take charge simply because the person has dementia and not based on the person’s current ability.

The easiest way to support the person with dementia and validate his/her worth is to continue to offer choice

and facilitate decision-making ability through person-centered communication strategies.<sup>27</sup> Recognizing the person as an individual, negotiating by using personal preferences, facilitating performance, and validating the person’s reality/feelings are all ways to support personhood in dementia care.<sup>27</sup> Table 4 presents suggestions for person-centered communication in this positive manner.

There are several decision-making techniques that caregivers use with people with dementia: autonomous, shared, and pseudo-autonomous decision-making.<sup>10</sup> People living with dementia appreciate the ability to retain control in daily life. As decision-making ability declines, supporting autonomy through fewer choices or cues to make available choices more obvious can keep patients actively engaged in decisions.<sup>10,23</sup> People with dementia appreciate information about options, not being rushed to make choices, being heard, allowed to express opinion,<sup>28</sup> and using various methods to remember their decisions (eg, diaries, lists).<sup>23</sup> Shared decision-making in dementia care involves a back-and-forth negotiation that enables self-worth and lets a person remain central to decision-making.<sup>10,23</sup> An example might be developing a grocery list together: having the person with dementia look into the refrigerator, comment on what is there, while the caregiver asks questions like “is the milk still good?” or “don’t you like yogurt?” to guide decisions. Another example is negotiating a shower: have the person agree to a day, write it down, and then refer to the person’s decision if they

**Table 3.** Questions for Facilitating Ethical Engagement\*

- What are the relevant ethical principles?
- How do they relate to one another?
- How has the story been cast or framed?
- What are the ethically important moments?
- Who is telling the story?
- What has been left out?
- Whose voice is not being heard?
- What is ethically at stake?
- What does the story tell us that would otherwise not be visible or heard?
- How does this story lead to ethical mindfulness?

\*Adapted from Guillemin and Gillam as reported in Jensen, Randall, and Wharton.<sup>22</sup>



are reluctant to take the shower on the appointed day.<sup>10</sup> Pseudo-autonomy occurs when caregivers assume to know the person's preferences: such as keeping the person at home when other options for care are not discussed. While the intent is good, the result could be a prioritization of the caregiver's preferences over those of the person with dementia.<sup>10</sup>

### Validating a Person's Reality

Validating a person's reality is an important part of acknowledging personhood. As facts or people are forgotten, the world of those with dementia changes. There may be awareness that something is not right even if details are not remembered; anxiety or agitation may be the result. How should one respond to difficult situations like a person searching frantically for a deceased spouse? There is literature to suggest that many providers resort to deception in order to ease the distress experienced in these circumstances.<sup>29-31</sup>

Fundamentally, however, lying violates ethical principles. Truth-telling is a virtue often instilled through religious/authority-based ethics and is congruent with many traditional and contemporary ethical theories. Arguments for telling the truth include preserving autonomy, generating trust, encouraging compliance with treatment, enhancing

decision-making ability, and having a duty to tell the truth.<sup>32,33</sup> Most of the reasons for deception or "therapeutic lying" involve minimizing harm or maximizing happiness through the reduction of anxiety or agitation.<sup>32,33</sup> This intent to reduce harm causes some to comment that although lying is *prima facie* wrong, it is not absolutely wrong in all instances.<sup>32,34</sup>

An ethically mindful response to a dementia-altered reality involves validating this reality by acknowledging the truth of another's experience.<sup>30</sup> To refrain from speaking actual truth, however, is not deception; there is no obligation to tell the truth if one has not asked specifically about the falsehoods in their world. "Where is my mother?" can be honestly answered, "I do not know." The purpose of validation, to comfort rather than to purposefully mislead or to gain cooperation for someone else's benefit, is the crux of the issue with deception for many clinicians.<sup>34</sup> When seeking to better the patient's experience by accepting their reality, conversations about the deceased spouse, encouraging remembrances of happy events, and validating feelings felt for that person can be used. When a person's need cannot be met directly ("Where is my husband?"), substitutions like offering comfort with a blanket/hug and distraction ("Let's go

set the table for dinner so we are ready") should be used before deception.<sup>30</sup>

By using communication strategies to enhance decision-making and validate the person with cognitive decline's reality, therapists will maximize the well-being and honor the personhood of patients/clients. This, in turn, creates ethical, benevolent practitioners who focus on client abilities and strengths in line with best practice in dementia care.

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**Table 4.** Suggestions for Person-centered Communication\*

Communication Strategy	Examples and Techniques
Recognizing	Greet by name; affirm/state preferences ("you like cream in your coffee, right?"); use yes/no to discover unknown preferences; acknowledge life history with open-ended questions useful to start conversation ("tell me about your wife")
Negotiating	Consult about preferences/needs and use them in later care; yes/no questions are useful ("do you want something warm on?" "yes", "then let's put on socks"); rephrase when needed ("do you want to shave? No answer; "do you want me to shave you?" and resident answers, "no"). Open-ended questions may also be useful to negotiate ("I want to go to bed." Answer: "How about after you eat?" Resident: "I suppose.")
Facilitating	Assist to do what person could not do alone; suggest steps to complete; offer missing words to ease communication; affirm choices ("I want coffee." Answer: "Well, let's go get some."); soften requests to allay fear (resident fears going to bathroom: "will it hurt?" Answer: "It's not suppose to hurt to use the bathroom."); initiate meaningful conversation with routine care; encouraging comments during activity (during hand washing: "you're doing a great job; rub your hands together a little more") Note: open-ended questions facilitate initiation of a task or conversation; closed-ended questions facilitate task completion
Validating	Respond to feelings more than the person's reality (patient is fretting about family member not there: "What do you like to do with your wife?"); acknowledge emotions; affirm intention to fulfill requests; nonverbal communication is also useful (comfort via a hug or rubbing a person's back)

\*Adapted from Savundranayagam & Moore-Nielsen, 2015.<sup>27</sup>

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# Dementia: Improving Function and Quality of Life With a Biopsychosocial Approach

*Julie Hardy, PT, MS, COS-C; Nicole A. Morgan, OTR, CAPS, CSA, CHAMP*

In 1967, Dame Cicely Saunders, founder of the first modern hospice, made a promise to her patients: “You matter to the very last moment of your life, and we will do all we can, not only to help you die peacefully, but to live until you die.” In this discussion, we examine how a biopsychosocial care model for dementia may advance this objective and help lower overall costs in caring for this population.

A biopsychosocial care model is a holistic approach that focuses on rehabilitation, or maximizing functional independence and morale. This approach requires a greater understanding of the person with dementia and a paradigm shift to non-pharmacological therapeutic approaches that modify behaviors and/or the physical and social environment. Emphasis shifts away from management and containment to active engagement by the person with dementia as well as education and support of caregivers.

The objectives of this article:

1. Identify communication and therapeutic approaches that can be implemented to facilitate achievement of functional goals for patients with cognitive impairment.
2. Recognize the impact that modification of the physical and social environment can have on both quality of life and on financial resources.
3. Understand Centers for Medicare & Medicaid Services (CMS) regulations that involve documentation and payment for care of this population.

## COMMUNICATION AND THERAPEUTIC APPROACHES

Awareness of techniques that embed engagement and cognitively appropriate learning strategies to strength, balance, and movement principles may facilitate achievement of goals. Delay of decline of function and improvement of quality

of life and safety for the person with ADRD (Alzheimer’s disease and related dementias) as well as their caregiver is achievable when readily applicable strategies including errorless learning, spaced retrieval, and Montessori Method are incorporated into the rehab plan of care. A very brief overview of each technique follows.

### Errorless Learning

Recent evidence suggests that learning in individuals with ADRD can be facilitated with errorless learning (EL). In EL, new skills are taught by reducing or preventing errors made during the process.<sup>1</sup> Trial and error (errorful) learning is dependent upon explicit, or conscious, learning and memory, which is impacted early on in ADRD. Errorless learning maximizes exposure to the correct response and uses implicit (unconscious) memory to facilitate learning. For example, when an incorrect response is given, rather than correcting with “No, that is not how you do that” (scolding) or encouraging guessing (can be frustrating and confusing), EL promotes a response of, “Actually, let’s try this” (positive, encouraging). Error reduction can also be achieved by breaking the task down into small steps, immediate error correction in a positive manner, modeling the task, and fading prompts as able. The De Werd review of 26 studies applying principles of EL found that people with mild to moderate dementias can (re)learn meaningful life skills or relevant knowledge using an error-reducing teaching approach.<sup>2</sup>

### Spaced Retrieval

Spaced retrieval (SR) is a structured teaching method that has been shown to promote the ability to recall information for increasing periods of time and facilitate (re)learning a skill. Spaced retrieval requires active recall attempts of specific information over increasing

time intervals. The goal is to remember information or demonstrate skill for clinically meaningful time periods (days, weeks, months) and consolidate it into long-term memory.<sup>3</sup> Spaced retrieval has been shown to be effective in relearning swallowing strategies as well as in walker training and active daily living (ADL) performance in persons with dementia.<sup>3-6</sup> For example, a consistent spaced retrieval cue of “What do you do before you sit down” and a response of “I reach back for my chair” may be used strategically with increasing time intervals to improve safety. An incorrect response can be corrected positively with “actually....” from errorless learning.

### Montessori Method

Principles developed by Dr. Maria Montessori to enhance the education of young children by encouraging engagement have been shown to be effective when applied to persons with ADRD. Some of the key principles of the Montessori Method, almost all of which apply to best care practices for dementia, include<sup>7</sup>:

- providing freedom and choice within an ordered structure,
- providing contexts and activities that interest the individual,
- reliance on procedural/ implicit memory,
- need for movement and motor learning in activities,
- guided repetition,
- task progression from simple to complex and concrete to abstract, and/or
- a structured environment that facilitates individual success.

Consider a long time golfer who develops dementia and is no longer able to get out on the golf course. He has become sedentary as a result of this and depressed due to lack of meaningful engagement. His fall risk increases as his



activity decreases. The person is referred to physical therapy to decrease fall risk. However, performing a traditional balance and strengthening program (eg, Otago) may prove difficult due to his cognitive issues and an overwhelmed caregiver, which likely will result in lack of carryover and may be ineffective. Now try handing him a putter and an indoor golf ball and give him a target to shoot for. The goal is to elicit components of balance: weight shift as he settles into his stance, movement out of the base of support as he stretches the putter out to draw the ball back to him, endurance training as he performs this activity for longer periods of time. Bonus: he is enjoying himself, which may translate into motivation for carryover. An interested son, grandson, or friend is more likely to be engaged to continue this activity after discharge from therapy rather than a traditional home exercise program, thereby increasing the potential for preserving the gains achieved.

### IMPORTANCE OF SOCIAL AND PHYSICAL ENVIRONMENTAL MODIFICATIONS

“Whereas medicine has historically focused on the effects of disease on the patient, dementia care requires a broader focus extending to family members, caregivers, and support networks.”<sup>8</sup>

Recognition of environmental impact has been a health care tenet since introduction by the World Health Organization in 2002. Particularly for the person with ADRD, consideration of societal attitudes, caregiver knowledge, and structural constraints are critical for success. Research demonstrates the impact of modification of the physical and social environment on both quality of life and financial resources.

The MIND (Maximizing Independence at Home) was an 18-month pilot study developed by Johns Hopkins University demonstrating that individual care planning (person centered approach), referral to appropriate community services, as well as caregiver education and skill-building can have a positive impact. It was designed to provide a model that could be used by community service agencies throughout the country. Results showed that patients who received in-home care that focused on meeting needs, behavior problems, and chronic disease management were able to safely stay in their homes a me-

dian of 288 days, or around 9.5 months, longer over a median follow-up period of 2 years. Intervention participants also showed a significant improvement in self-reported quality of life measures.<sup>9</sup>

The NYU Caregiver Intervention provides enhanced support and education for family caregivers. Over a 10-year period, from 1987-1997, 406 spouse caregivers of persons with dementia received services and were followed to determine effectiveness of the program. The results were a 28.3% decrease in nursing home (NH) placement, and a difference in model-predicted median time to NH placement of 557 days. With the implementation of the NYU model in Minnesota, researchers are estimating the potential savings of \$996 million in direct care costs from 2010-2025.<sup>10</sup>

North Dakota's state-funded Dementia Care Services Program provides individualized assistance to caregivers of persons with dementia. In survey responses and other self-reported data from the program's first 42 months of operation (January 2010 to June 2013), unpaid caregivers credited the assistance program with helping them feel more empowered. They also considered their charges less likely to be placed in long-term care, and used less potentially avoidable medical services such as hospitalizations and 911 calls. The program's estimated potential savings were \$39.2 million from delayed long-term care placement and \$0.8 million from reduced use of medical services, and its 2-year costs were \$1.2 million.<sup>11</sup>

Nearly 10% of Medicare beneficiaries have dementia, and this is costing Medicare 3 times more per beneficiary than those without dementia. The already high cost of expensive chronic conditions like coronary heart disease, congestive heart failure, diabetes, and chronic obstructive pulmonary disease more than double when Alzheimer's disease is also present.<sup>12</sup> These studies suggest that a focus on the social environment may help decrease Medicare costs in this population.

### EVIDENCE-BASED ENVIRONMENTAL DESIGN

Environmental design is emerging as an effective tool in allowing the person with dementia (PWD) to age in place, decreasing agitation and anxiety (factors that often hasten institutional

placement), and preserving well-being. Hwang et al found a positive relationship between home modification and aging in place.<sup>13</sup> Some of the design elements that promote the PWD safely aging in place and decrease the incidence of unwanted behaviors include but are not limited to small scale environment, sensory enhancements (eg, lighting), noise level control, and personalization.

An evidence-based review by Marquardt revealed that there is strong evidence that small scale care environments (10-15 residents) lead to positive outcomes for people with dementia and they should be implemented whenever possible. Some of the findings included a reduction in aggression and more active and engaged behavior in residents in double versus multiple occupancy bedrooms. Two of the studies reviewed found more violent behavior in units with higher numbers of residents. Small scale environments facilitate more individualized care and attention to residents' needs. Two of the studies indicated that residents in small scale units had lower drug use than residents in traditional nursing homes. In addition, caregivers in small scale environments tend to show increased job satisfaction because it allows for more opportunities for individualized care and attention to resident needs.<sup>14</sup>

People with dementia face particular visual deficits, including difficulty with color discrimination, depth perception, and sensitivity to contrast.<sup>15</sup> Visual perceptual impairments in this population involve not only the sensory decline associated with age-related changes, such as cataracts, but a sensory processing impairment due to dementia-related pathology in the cortical areas involved in visual processing. Design guides for dementia environments recommend strategies to reduce glare, increase contrast where appropriate, and minimize confusion due to depth perception. Studies on exposure to bright light patterns has been shown to regulate circadian rhythms and improve sleep patterns among PWD.<sup>16</sup> Providing consistent, even light levels can reduce glare and shadows that can be frightening in certain levels of dementia causing increased agitation, anxiety, and confusion. Lighting design should consider the changes in function of the eyes that accompany aging as well as visual-perceptual changes involved with cognitive pathology.<sup>17</sup>

Other factors to consider in environmental design for the person with dementia include noise level and personalization. Background noise can cause agitation and restlessness, and can hinder communication, limiting ability to hear clearly, and to focus on tasks. The World Health Organization suggests that background noise should be limited to 35dB–45dB.<sup>18</sup> The Center for Health Design (CHD) conducted a study on how different aspects of sound affect patient outcomes. The study revealed that poor acoustical environments impeded effective communication.<sup>19</sup> Creating an environment that can absorb background noise is recommended.

Personalization is a design element that is focused on deinstitutionalizing the care environment. When transferring from a home environment to a group setting, rather than purchasing all new home décor, it is recommended to use familiar items to trim the new environment, which promotes routine and comfort.<sup>17</sup> As dementia impairs memory and judgment, the PWD falls back on prior learned knowledge from long term memory which is relatively spared until late in the dementia. An established routine and familiar environment are crucial to the comfort level of the PWD.

The primary focus of an evidence-based dementia environment is to facilitate routine, maximize current abilities, and minimize confusion and anxiety.

## MEDICARE AND DEMENTIA

The questions arise, “What does Medicare allow?” and “How will caring for persons with dementia, with the inherent progressive functional decline, impact an agency’s STAR ratings?” In 2001, CMS reversed a long-standing practice in home health. For years, some Medicare contractors pre-programmed their reimbursement systems to automatically deny therapy services for Alzheimer’s disease solely because the claim was submitted on the behalf of a beneficiary with a diagnosis of Alzheimer’s disease or other dementia.<sup>20</sup> CMS Transmittal AB-01-135, dated Sept. 25, 2011, reversed this policy stating, “Medicare can no longer deny a claim based solely upon dementia coding.” Regarding therapy specifically, “Throughout the course of their disease, patients with dementia may benefit from pharmacologic, physical, occupational, and speech therapies.” The CMS continues to show support for

home care in this population with the current Star Rating system. It provides for patients with “constant disorientation” or “problematic behaviors that could jeopardize the safety and well-being of the patient or caregiver” to be excluded from the outcome measures of (1) improvement in ambulation, (2) improvement in transfers, (3) improvement in bathing, and (4) improvement in pain interfering with activity.<sup>14</sup> Acute care hospitalization can be greatly reduced in this population with environmental caregiver support and education, as well as other environmental supports, such as safety assessments with a better understanding of this population.<sup>16</sup>

It is becoming increasingly clear that the aims of an effective dementia care program are to delay functional decline, improve quality of life, support dignity, control symptoms, and provide comfort at all stages of AD and that national policies and payer systems are supporting this.

## CONCLUSION

Adoption of a holistic, biopsychosocial approach that goes beyond physical impairments to consider cognitive impairment and environmental factors may facilitate achievement of the APTA vision statement, “Transforming society by optimizing movement to improve the human experience” as well as fulfilling Dame Saunderson’s worthy promise to her patients. The coming dementia “epidemic” threatens to bankrupt Medicare and significantly impact the quality of life of a huge segment of the population. Alternative methods for learning/relearning, as well as comprehensive caregiver education, and promoting an environment that facilitates a person’s best ability to function can be incorporated into the therapist’s plan of care. This article has provided a brief overview of principles and methods that reflect a shifting paradigm toward a biopsychosocial approach that can delay decline in function and improve quality of life for this population, and may help lower overall costs with better health outcomes for persons with dementia.

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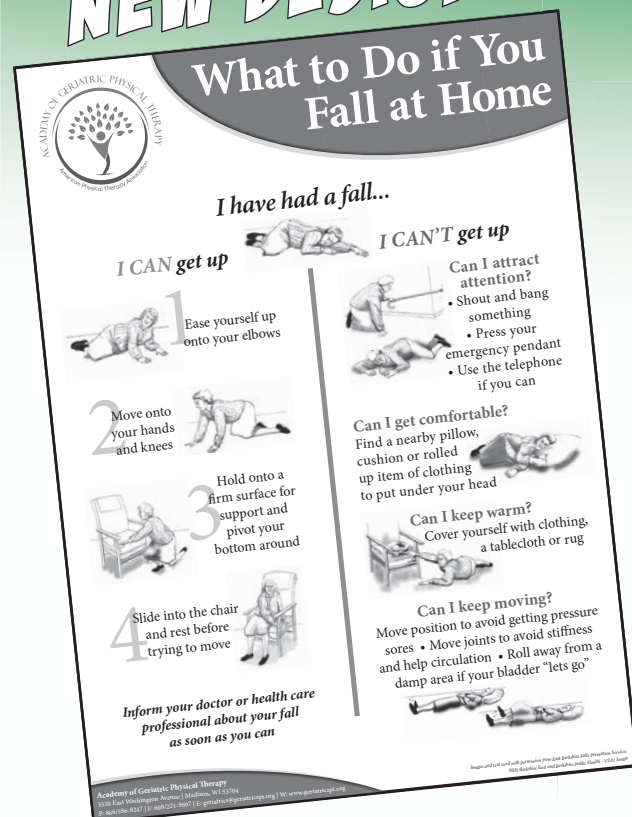
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# Delirium Prevention, Assessment and Treatment by the Physical Therapist

Mary G. Fischer, PT, DPT, GCS; Jena Harb, PT, DPT, GCS; Kristine L. Josef, PT, DPT

## INTRODUCTION AND DEFINITION

Delirium is an acute change in mental status characterized by confusion and inattention that occurs over hours to days. A multifactorial syndrome, delirium results from the interaction of a vulnerable patient and health care related insults. Previously thought to be an innocuous and inevitable consequence of illness in the elderly, delirium is receiving renewed attention due to its association with short- and long-term negative outcomes.<sup>1</sup> Physical therapists (PTs) are well-poised to detect delirium across health care settings and are well-suited to intervene in the prevention and treatment of delirium since mobility and exercise are its two most effective, non-pharmacologic interventions.<sup>2</sup>

According to the Diagnostic and Statistical Manual of Mental Disorders (DSM-V), delirium is a “disturbance in attention and awareness, developing over a short period of time, representing a change from baseline and tending to fluctuate in severity over the course of a day.” There can be additional “cognitive disturbances in memory, orientation, language and perception, not better explained by a pre-existing cognitive or evolving neurocognitive disorder.” By reviewing a patient’s history, physical exam, or lab results, delirium can be traced to “another medical condition, substance intoxication or withdrawal, exposure to a toxin, or is due to multiple etiologies.”<sup>3</sup>

## RISK FACTORS

Delirium is associated with numerous risk factors, namely, advanced age, pre-existing cognitive impairment, critical illness, sensory impairment (especially of vision or hearing), infection, metabolic imbalance, sleep disturbance, certain medications such as narcotics and benzodiazepines, alcohol misuse, depression, and most important to the

PTs: immobility. A highly vulnerable person with multiple risk factors may require only a mild insult to become delirious, while a healthy older person would require multiple noxious events.<sup>4</sup>

A good example of the vulnerable patient would be the 90-year-old who develops a urinary tract infection and is found to be lethargic and disoriented by her home attendant and is brought to the emergency department. The less vulnerable patient example is the otherwise healthy 65-year-old admitted for cardiac valve replacement who develops respiratory distress requiring re-intubation, post-op ileus requiring nasogastric tube placement and is transferred to the intensive care unit.

## CLINICAL PRESENTATION: HYPOACTIVE AND HYPERACTIVE SUBTYPES

Delirium may conjure up images of agitated patients, “acting crazy” and perhaps “seeing things.” While 30% of delirious patients do experience hallucinations, this is not the presentation that occurs in the majority of cases. The more typical presentation, especially among older patients, is lethargy with reduced awareness of the environment and inability to focus attention. This hypoactive subtype is often the reason delirium is missed; patients are quiet, not disturbing others, and staff assumes they are “tired” or “out of it” because they are old. The hyperactive subtype can also occur among older patients; they may present as restless, hyper-vigilant, irritable or even aggressive. Other patients present with the “mixed” subtype-their level of consciousness varies from drowsy to vigilant and their mood is labile, changing from euphoria to anxiety or paranoia.

## PATHOPHYSIOLOGY

Multiple theories on delirium pathophysiology exist and are comple-

mentary rather than competing.<sup>5</sup> In patients with sepsis, it is hypothesized that peripheral immune signals change the blood brain barrier’s permeability, leading to neurobehavioral and cognitive changes. Another theory hypothesizes that the physiologic stress of illness requires increased oxygen consumption, which decreases oxygen availability for cerebral metabolism and contributes to cerebral dysfunction. Neurotransmitter and neuroendocrine imbalances have been associated with altered brain activity, while dysregulation of the sleep-wake cycle may also have implications for our patients’ hypoactive versus hyperactive states of delirium. The lower “cognitive reserve” associated with aging increases the risk of developing delirium by 2% per year after the age of 65. The onset of delirium in our patients can result from any combination of these theories.

## DIFFERENTIAL DIAGNOSIS

Because delirium is so common, especially in older, hospitalized adults, an effort must be made to differentiate its signs from other geriatric diagnoses such as depression and dementia (Table 1). Key characteristics of delirium include its acute onset and fluctuating course typically associated with one or more medical causes. Early symptoms include inattention, altered consciousness (hypo versus hyperactive), and disorganized thought process. Dementia is a chronic condition with a slow, uncertain starting point, short-term memory loss, and a progressive and currently irreversible course. Depression is primarily characterized by anhedonia and often has a clear onset typically associated with a life crisis. Depression can last months to years, but can resolve with treatment.<sup>6</sup> Awareness of diagnoses commonly associated with delirium can also guide the provider who may suspect delirium in their older patient – in fact, delirium may be the first symptom of an infec-



**Table 1.** Differential Diagnosis of Delirium, Dementia, and Depression

Feature	Delirium	Dementia	Depression
Development	Sudden onset, often definite beginning point	Slow with uncertain starting point	Clear onset, often associated with life crisis
Cause	Medical: infection, dehydration, meds, etc.	Alzheimer's, Lewy Body or Vascular Dementia	Recent or cumulative loss, drug toxicity
Early Symptoms	Inattention, fluctuating mental status	Memory loss	Anhedonia
Effect at night	Almost always worse	Often worse	Disturbed sleep, daytime hypersomnia
Level of Consciousness	Variable depending on type (hypo or hyperactive or mixed)	Normal until late stages	Normal, may be selective
Effect on Speech/ Language	Tangential, perseverative, disorganized thought process	Anomia, slow processing, reduced initiation of speech	Reduced output versus belligerent/ attacking; however language skills remain intact
Memory	Varies	Significant short term memory loss	May be impaired (slow recall)
Progression	Fluctuating mental status	Slow but progressive	Lasts months to years
Need for Treatment	Immediate	Needed, not urgent	Needed, urgency dependent on severity (suicidal ideation)
Effect of Treatment	Typically reverses symptoms but effects can linger	May slow progression but cannot reverse or cure the disorder	Can resolve with treatment

tion, such as pneumonia or urinary tract infection.<sup>4</sup> Other groups the therapist should consider high risk are older patients undergoing hip fracture repair and cardiac surgery.<sup>7</sup>

## CONSEQUENCES

The main consequences of delirium fall into two realms—quality of life and cost. Patients experience decreased quality of life through functional decline, cognitive impairment, and increased rates of morbidity and even early death. Hospital mortality rates in older patients with delirium are 25% to 33% higher than age and disease burden-matched controls. Delirium and dementia, though different entities, share a strong affinity with one another. A study that followed 77 patients who had been delirious in the hospital found that 70% of them had persistent cognitive impairment at 12 months post-discharge.<sup>8</sup> Hospitalized patients with delirium superimposed on dementia had more than twice the risk of mortality in the year following their discharge as compared to those with dementia alone, delirium alone, or neither dementia nor delirium.<sup>9</sup>

Patients, families, and health care systems deal with the cost of increased length of stay, burden of care, and ad-

mission to post-acute care settings due to delirium.<sup>10-21</sup> Total hospital costs are higher in those with delirium and not surprisingly, the worse the severity and the longer the duration of delirium the higher the overall cost. Delirium alone has been associated with 39% higher intensive care unit costs and 31% higher hospital costs.<sup>10</sup> Overall Medicare costs for delirium are estimated at \$164 billion per year.<sup>22</sup> The diagnosis of delirium strongly and independently increases the chances of being discharged to a post-acute facility due to functional decline.<sup>12-14</sup>

## ASSESSMENT TOOLS

Prevention is the ultimate antidote for the rise in delirium incidence in the acute and post-acute care settings; however, we cannot prevent what we do not recognize. There are several assessment tools available to diagnose delirium. The Confusion Assessment Method (CAM), shown in Table 2, is a standardized, valid, and reliable tool that enables providers to identify delirium quickly and accurately. Developed in 1990, the CAM is a bedside assessment for use by non-psychiatrists to assess for delirium. The CAM includes 4 features found to have the greatest ability to distinguish

delirium from other types of cognitive impairment: (1) acute onset or fluctuating course, (2) inattention, (3) disorganized thinking, and (4) altered level of consciousness. To be identified as delirious, the patient must exhibit both features 1 and 2 as well as either 3 or 4.<sup>23</sup>

The Confusion Assessment Method-Intensive Care Unit (CAM-ICU), shown in Table 3, is used for those patients who are non-verbal (ie, intubated or aphasic). It has the same 4 realms and is scored similarly to the CAM, though the line of questioning is more detailed.<sup>24</sup> The Richmond Agitation Sedation Scale (RASS), shown in Table 4, is used as part of the CAM-ICU to determine level of consciousness. Any score other than “alert and calm” yields a positive score for the realm of altered consciousness.<sup>25,26</sup> A fundamental prerequisite of both tools is the assessor's ability to determine the patient's baseline cognitive status so that a change can be detected when present. Not only is this an important part of the assessment, it is sometimes the most challenging component. It is helpful to use all resources available to establish the patient's baseline, including but not limited to, patient report, family or caregiver report, and the medical record. This baseline

**Table 2.** When Using the Confusion Assessment Method, A Diagnosis of Delirium Requires Features of 1 and 2 and Either 3 or 4

Confusion Assessment Method	
The diagnosis of delirium requires the presence of both 1 AND 2	
<b>1</b>	<b>Acute Change or Fluctuating Course of Mental Status:</b> <ul style="list-style-type: none"> <li>Is there an acute change from mental status baseline?</li> <li>Has the patient's mental status fluctuated during the past 24 hours?</li> </ul>
<b>2</b>	<b>Inattention</b> <ul style="list-style-type: none"> <li>Does the patient have difficulty focusing attention (ie, easily distractible or having difficulty keeping track of what is said)?</li> <li>Does this behavior fluctuate (ie, tend to come and go, increase or decrease in severity)?</li> </ul>
plus EITHER 3 OR 4	
<b>3</b>	<b>Disorganized Thinking</b> <ul style="list-style-type: none"> <li>Is the patient's thinking incoherent (ie, rambling or irrelevant conversation, illogical flow of ideas, unpredictable)</li> </ul>
<b>4</b>	<b>Altered Level of Consciousness</b> <ul style="list-style-type: none"> <li>Is the patient vigilant (hyper, alert, overly sensitive to environment stimuli) OR lethargic (drowsy, stuporous)</li> </ul>

**Table 3.** Despite the Name, the CAM-ICU can be Used for Any Non-verbal Patients

Confusion Assessment Method for the ICU (CAM-ICU) Flowsheet			
The diagnosis of delirium requires the presence of both 1 AND 2 plus EITHER 3 OR 4			
<b>1</b>	Acute Change or Fluctuating Course of Mental Status: <ul style="list-style-type: none"> <li>Is there an acute change from mental status baseline?</li> <li>Has the patient's mental status fluctuated during the past 24 hours?</li> </ul>	No <input type="checkbox"/>	CAM-ICU negative NO DELIRIUM
	Yes ↓		
<b>2</b>	Inattention: <ul style="list-style-type: none"> <li>"Squeeze my hand when I say the letter 'A'"</li> <li>Read the following sequence of letters: S A V E A H A A R T</li> <li>ERRORS: No squeeze with 'A' &amp; Squeeze on letter other than 'A'</li> <li>If unable to complete letters → Use Pictures</li> </ul>	0-2 Errors <input type="checkbox"/>	CAM-ICU negative NO DELIRIUM
	>0-2 Errors ↓		
<b>3</b>	Altered Level of Consciousness <ul style="list-style-type: none"> <li>Current RASS level</li> </ul>	RASS other than zero <input type="checkbox"/>	DELIRIUM PRESENT
	RASS = 0 (alert and calm) ↓		
<b>4</b>	Disorganized Thinking: <ul style="list-style-type: none"> <li>Will a stone float on water?</li> <li>Are there fish in the sea?</li> <li>Does one pound weigh more than two?</li> <li>Can you use a hammer to pound a nail?</li> </ul> <u>Command:</u> "Hold up this many fingers" (Hold up 2 fingers) "Now do the same thing with the other hand" (Do not demonstrate) OR "Add one more finger" (If patient unable to move both arms)	>1 Error <input type="checkbox"/>	DELIRIUM PRESENT
		0-1 Error <input type="checkbox"/>	CAM-ICU negative NO DELIRIUM

**Table 4.** The Richmond Agitation Sedation Scale is Used with the CAM-ICU to Determine Level of Consciousness\*

Richmond Agitation Sedation Scale (RASS)			
Score	Term	Description	
<b>+4</b>	Combative	Overtly combative, violent, immediate danger to staff	
<b>+3</b>	Very agitated	Pulls or removes tubes(s) or catheter(s); aggressive	
<b>+2</b>	Agitated	Frequent non-purposeful movement, fights ventilator	
<b>+1</b>	Restless	Anxious but movements not aggressive; vigorous	
<b>0</b>	Alert and calm		
<b>-1</b>	Drowsy	Not fully alert, but has sustained awakening (eye-opening/eye contact) to <i>voice</i> ( <b>≥ 10 seconds</b> )	Verbal Stimulation
<b>-2</b>	Light sedation	Briefly awakens with eye contact to <i>voice</i> ( <b>&lt;10 seconds</b> )	
<b>-3</b>	Moderate sedation	Movement or eye opening to <i>voice</i> ( <b>but no eye contact</b> )	
<b>-4</b>	Deep sedation	No response to voice, but movement or eye opening to <i>physical</i> stimulation	Physical Stimulation
<b>-5</b>	Unarousable	No response to voice or <i>physical</i> stimulation	
<b>Procedure for RASS Assessment</b> 1. Observe patient a. Patient is alert, restless, or agitated. 2. If not alert, state patient's name and <i>say</i> to open eyes and look at speaker. a. Patient awakens with sustained eye opening and eye contact. b. Patient awakens with eye opening and eye contact, but not sustained c. Patient has any movement in response to voice but no eye contact. 3. When no response to verbal stimulation, physically stimulate patient by shaking shoulder and/or rubbing sternum. a. Patient has any movement to physical stimulation. b. Patient has no response to any stimulation.			<b>(score 0 to +4)</b>  <b>(score -1)</b> <b>(score -2)</b> <b>(score -3)</b>  <b>(score -4)</b> <b>(score -5)</b>

\*Reprinted with permission from Dr Curtis Sessler.<sup>25</sup>

will then serve as the baseline for all future comparisons and assessments for delirium.

## PREVENTION OF DELIRIUM

Delirium is preventable in 30% to 40% of cases<sup>27,28</sup> and prevention methods are an instrumental treatment approach for at risk patients. Embracing a strategy of providing 'pre-' care and anticipating patients' needs includes performing pre-operative screening for risk factors, providing pre-habilitation when feasible, planning for family/caregiver involvement, managing pain and agitation, promoting early mobility, involvement in self-care, and promoting a normal sleep-wake cycle.

## TREATMENT

Unfortunately, delirium is not preventable in all cases. Once the diagnosis

of delirium has been established, this should trigger a work-up by the medical team to locate and treat the underlying medical condition or conditions that may be the culprit(s). Foundations in critical care practice include the management of PAD (Pain, Agitation, Delirium)<sup>2</sup> and the ABCDEF bundle (Assess, prevent and manage pain, Both SAT (Spontaneous Awakening Trial) and SBT (Spontaneous Breathing Trial), Choice of analgesia and sedation, Delirium: assess, prevent, and manage, Early mobility and Exercise, Family engagement and empowerment).<sup>17,18,29-31</sup>

Originally conceived in critical care, these guidelines were created to summarize evidence-based practice and to direct, synchronize, and coordinate best practice with a specific focus on delirium. Today they are used across the continuum of care. Of note, early mobil-

ity was found to be the only intervention in the ABCDEF bundle resulting in a decrease in duration of delirium. The recommendation for early mobility is classified as "1B research," revealing a strong endorsement for the intervention and indicative of a moderate quality of evidence to support the recommendation. Interestingly, there were no pharmacologic or non-pharmacologic recommendations graded higher than early mobility. Early mobility is a broad term that can include a variety of activities such as bed-level exercises, mobility in bed, edge of bed, out of bed, and ambulation. The key feature of early mobility is to initiate an appropriate mobility intervention as soon as is medically safe and feasible. For a hypoactive patient, this may include sitting out of bed to allow for safe hydration and nutrition, engaging in stimulating activities such

as music during bed or chair exercise. Hyperactive patients may feel the need to move but are unsafe and at risk for falling. Physical therapists can take cues from the patient's behavior and promote safe mobility (rather than restraints, whether physical or chemical) around the nursing unit with assistance and or appropriate assistive device.

Additional delirium treatment interventions include screening for any missed risk factors, addressing sensory deficits by providing patients with eyeglasses and hearing aids, arranging for an interpreter as appropriate, promoting self-care activities and a daily routine, removing unnecessary attachments and hiding necessary ones to minimize self-harm, providing environmental modification to increase exposure to natural light during daytime and minimize near bedtime, reviewing medications, and promoting hydration in accordance with the medical treatment plan. Perhaps one of the more under-utilized treatment strategies involves family members and caregivers. It is vital to provide them with education on delirium, reassure them on what is happening [and why], and encourage them to remain involved in the care of their loved one. Patients may benefit from cognitive stimulation, including orientation review, use of puzzles, crosswords, access to news/current events, and participation in a daily routine. Lastly, it is important to consider sleep quality and optimize sleep at the appropriate times. This may be achieved non-pharmacologically by providing a warm drink, soothing music, a gentle massage, and adherence to a noise reduction program especially at night.

## FUTURE

Because of its serious consequences and high rate of missed diagnosis, the future of delirium prevention and treatment is the education and training of all providers on delirium and its risk factors. Physical therapists should be seen as key players in detecting, preventing, and treating delirium. "The Essential Competencies in the Care of Older Adults at the Completion of the Entry-level Physical Therapist Professional Program of Study"<sup>32</sup> created in 2011 by the Academy of Geriatric Physical Therapy and the Partnership for Health in Aging includes delirium

assessment under Domain 2: Evaluation and Assessment: "Demonstrate knowledge of the signs and symptoms of delirium and whom to notify if an older adult exhibits these signs and symptoms. Differentiate between depression, delirium, and dementia based on presentation and related conditions; and refer as appropriate." We must now take our role further than merely alerting the provider to a change in a patient's behavior or thinking. Physical Therapists, Occupational Therapists (OTs), Speech Language Pathologists (SLPs), Nurses and Physicians can work together to screen for risk factors, educate patients and families and implement delirium prevention programs. Physical therapists (and OTs and SLPs) are uniquely positioned to detect changes in attention and behavior since we spend extended time with patients, asking them to complete tasks requiring environmental awareness, focus, and comprehension. If a patient becomes delirious, PTs, as the movement experts, can develop an appropriate and safe mobilization plan. Working together to educate our colleagues, our patients, and their families, we can help lessen the severity and duration of delirium, thereby reducing its numerous negative consequences.

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# Application and Interpretation of Functional Outcome Measures for Testing Individuals with Cognitive Impairment

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Physical therapists (PTs) are a valuable component of the comprehensive medical care team that treats an individual with neurodegenerative disease. The prevalence of individuals living with dementia worldwide is expected to increase exponentially to a projected 115.4 million people by 2050, due to higher rates of diagnosis and changing demography.<sup>1</sup> On average, individuals with cognitive impairment (IWCI) receive the recommended quality of care about 35% of the time.<sup>2</sup> Utilization of evidence-based outcome measures to determine optimal care is critical with the rise of this global health crisis. Improving the effectiveness of care for IWCI includes a standardized use of assessment tools. Standardization and implementation of appropriate outcome measures for this population will decrease the considerable variability in the evaluation of IWCI. Using an integrated approach that relies on creativity, flexibility, and clinical knowledge, physical therapists (PTs) can effectively evaluate and treat IWCI throughout the spectrum of the disease process.

## SUBJECTIVE EXAMINATION

A proper skilled physical therapist evaluation for an IWCI must involve a thorough history intake, cognitive screening with staging, evaluation of functional status, as well as an understanding of the individual's and caregiver's goals. Interviewing the IWCI and the caregiver separately enables the therapist to assess the individual's cooperation and language skills without them being masked by interruptions or assistance from the caregiver. However, when evaluating an individual who may have moderate to severe cognitive impairment, having a caregiver present during the exam may be important for corroboration and assisting in capturing the full history. Perhaps a combination of the two situations is optimal, particularly during the subjective examination.

Careful history taking is paramount and should be completed in a quiet environment with minimal distractions. It is important to capture the following in the subjective examination: duration of cognitive impairment, past medical history, chief complaint, prior level of function, current level of function, history of falls, pain, behavior changes, daily routine, physical activity, community activity participation, social engagements, living environment, and caregiver assistance.<sup>3</sup> Smith et al<sup>4</sup> recommends asking questions about daily life, memory, health, relationships, life satisfaction, and autonomy. Learning details of the individual's life story can help the PTs develop a rapport, creating a connection useful during the plan of care. This time spent may be valuable to complete prior to initiating the evaluation process. Furthermore, a medication review, discussing literacy and adherence, annual hearing and vision exams, and identification of any other contributors to fall risk factors, such as peripheral neuropathy or the presence of dysautonomia, should be investigated.<sup>5</sup> Most importantly, approaching the IWCI with care, patience, and respect in an unhurried manner will go a long way.

Communicating with an IWCI requires use of conversational strategies to promote successful comprehension, creating an environment of ease and safety,<sup>6</sup> while the individual's level of communication skills will vary depending on severity, poor communication can compromise care. Thus, being a skilled communicator enables the PTs to engage with the IWCI on a therapeutic level.<sup>6</sup> Communication strategies include: being sure to identify yourself; maintaining good eye contact; increasing the use of friendly nonverbal communication; using multi-sensory cues and reassuring touch; allowing time for processing with a slowed rate of speech in simple phrases; minimizing environmental distractions;

minimizing instructions to 3 steps or less, demonstrating the test again if necessary; and listening to the emotions behind what the individual is saying.<sup>7</sup> Encouragement and neutral feedback may be given to assist in decreasing the individual's anxiety. Allowing for rest breaks and monitoring for fatigue, especially between challenging tasks, will assist with the individual's participation.

## Cognitive Screening and Staging

Dementia is the process of gradual cognitive decline with progressive limitations in one or more cognitive domains including memory, executive function, language, judgment, and spatial abilities, and may be accompanied by aphasia and apraxia.<sup>8</sup> Cognitive screening as part of the objective examination will assist the clinician in establishing the individual's baseline orientation, communication, spatial awareness, and ability to follow instructions. It provides objective documentation on cognition and communication abilities that will assist in successful delivery of PTs interventions. Payers look for justification into why each IWCI in your care needs skilled PTs services. As the incidence of falls in IWCI is more than twice that of individuals that are cognitively intact, it is clear that cognition and attentiveness are factors contributing to falls.<sup>5</sup> Data collected during cognitive screening may give the PTs guidance to what outcome measures would be most appropriate to test. Performing cognitive screening necessary for the development of a skilled PTs plan of care is considered billable time.

The Mini-Cog™ recommended by the Cognitive and Mental Health Special Interest Group of the Academy of Geriatric Physical Therapy, is a simple 3-minute screening tool that includes a 3-item recall and a clock drawing test. The Mini-Cog™ has strong predictive value and sensitivity used to identify individuals in need of more thorough

cognitive evaluation.<sup>9</sup> With a total potential score of 5, a cut-off point of less than 3 out of 5 has been validated for dementia screening.<sup>9</sup>

The Montreal Cognitive Assessment (MOCA) is a brief cognitive screening tool with excellent sensitivity and specificity, which can be used to detect individuals with mild cognitive impairment (MCI) and mild Alzheimer's disease (AD).<sup>10</sup> Physical therapists use the MOCA to assess 5 cognitive domains within 10 minutes of skilled time, thus making it feasible to use in a clinical setting where assessment time is often limited. Individuals screened and found to have a MOCA score lower than 26/30 would be more likely to meet clinical and neuropsychological criteria for extensive evaluation, lending quick guidance to refer for further investigation with a neurologist.<sup>10</sup> In contrast, the Mini-Mental Status Examination used extensively in clinical and research settings is superior for more-advanced stages of AD, screening for dementia, rather than MCI.<sup>10,11</sup> Results from the cognitive screening would assist the clinician in documenting the IWCI's current cognitive status, selecting the most appropriate delivery method for interventions, and assist in identifying their disease stage severity.

Staging systems are helpful tools that allow clinicians to categorize disease severity in progressive cognitive illness. Dementia severity can be assessed using a number of valid and reliable instruments, which include: the Global Deterioration Scale (GDS), the Functional Assessment Staging Tool (FAST), the Clinical Dementia Rating, and the Dementia Severity Rating Scale.<sup>12</sup> The GDS Staging System, which includes the FAST and the Brief Cognitive Rating Scale (BCRS), was developed by Dr. Barry Reisberg. It is one of the most widely used and extensively studied systems proven to be reliable and valid for staging dementia in AD. The GDS spans the entire course of normal aging and progressive AD, enhancing the ability to track the longitudinal course, while providing differential diagnostic and prognostic information.<sup>13,14</sup> In an effort to expand the 7 level staging system of the GDS, Dr. Reisberg developed the 16 level FAST, providing more clinicopathologic observations, sub-stages at the final levels of the disease process,

and enhanced diagnostic and prognostic information.<sup>15</sup> In order to identify the appropriate stage, the BCRS is used to evaluate functional and cognitive abilities within 5 questions to assess a variety of domains. There are 5 axes in which the examiner identifies the appropriate level of ability using one of the objective ratings given. After all 5 axes are completed, the total is added up and divided by 5 to get the stage on the GDS, with the decimal point indicating the sub-stage within the level.<sup>16</sup> Staging using the GDS helps the health care team, families, and caregivers understand the cognitive deficits and set realistic goals for living situations and therapy care.

### PHYSICAL PERFORMANCE TESTING

As with any individual in the care of a physical therapist, outcome measures serve as the basis for assessing functional performance and fall risk, identifying treatment goals, developing plans of care, recommending other discipline referrals, and selecting proper treatment interventions. Variability of impairments and the progressive nature of the disease can make selection and administration of the physical performance test challenging.

The *Dementia Performance Measure Set* developed within the Physician Consortium for Performance Improvement states that an assessment of functional status should include, at minimum, an evaluation of the individual's ability to perform instrumental activities of daily living (IADLs) and activities of daily living (ADLs).<sup>12</sup> Most falls occur when performing ADLs or walking, and functional limitations during daily activities increase the fall risk of IWCI.<sup>17</sup> Functional status can be assessed using a valid and reliable tool including, but not limited to: Barthel ADL Index, Katz Index of Independence in ADLs, or Lawton IADL Scale.<sup>12</sup>

In addition to identifying limitations in functional and community participation, impairments such as strength, balance, and gait speed should also be evaluated to track changes over time. Poor balance, postural instability, decreased reaction time, and inability to complete sit-to-stand chair transfer are associated with falls in IWCI.<sup>5</sup> Literature review found several tools used to cover the domains of endurance ca-

capacity, strength, balance, and mobility when testing individuals with cognitive impairment. However, only a few have been proven reliable or valid for testing in individuals with dementia. These tools include Timed Up and Go Test (TUG), Six Meter Walk, The Groningen Meander Walking Test (TGMWT), and Six Minute Walk Test (6MWT).<sup>18</sup>

The TUG is a valid and reliable fall risk measure for testing IWCI. Recent studies indicate slower TUG time is linked to poor cognitive function performance.<sup>19</sup> Mirelman et al<sup>20</sup> found that individuals with MCI may have a normal TUG, yet noted increased time required for completion, less axial rotation during turn. This may suggest the importance of consideration in the use of an instrumented walking mat for assessing gait parameters.<sup>21</sup> Minimal Detectable Change (MDC) data is available for the TUG for this population.<sup>21,22</sup> Within later stages of dementia, modifications such as using a cone at the end line and one to two step commands may be beneficial, as the TUG is actually a sequence of multiple complex tasks. The TUG Cognitive and TUG Manual Tests serve as additional opportunities to assess the IWCI's dual task performance, documenting any cues required, or spilling of water or errors in counting, respectively.

The MiniBESTest (MBT), though not proven to be valid and reliable when testing IWCI, measures anticipatory postural adjustments, reactive postural control, sensory orientation, and dynamic gait.<sup>23,24</sup> The MBT may only be appropriate for individuals with MCI and early-middle stages of AD, due to the level of complexity of the test tasks.

To further assess dynamic balance, TGMWT was created by Bossers et al<sup>25</sup> was found to be valid and reliable for testing IWCI. On a 20 foot curvilinear track, starting 1m prior to the course, the PTs ask the individual to walk over the path as fast and accurately as possible without stepping out of the line, recording the time and oversteps. An assistive device can be used yet this may negatively affect the assessment of change over time. Minimal detectable changes both with and without an assistive device are available (Figure 1).

Due to the level of complexity of the MBT and TGMWT, the Berg Balance Scale (BBS)<sup>26,27</sup> or the Tinetti – Performance Oriented Mobility Assessment



(POMA)<sup>18,28</sup> may be more appropriate for individuals with mild-moderate levels of cognitive impairment, as the items can be completed predominantly with one-step instructions. With the appropriate cuing and creativity of a skilled clinician, an individual with more severe memory impairment may be able to successfully complete the test items, thus the clinician would document such cues accordingly.<sup>28</sup> However, Sterke et al<sup>28</sup> found that there are several feasibility problems when completing the POMA on individuals with moderate-severe stages of cognitive impairment, therefore, it could not be recommended as a balance and gait assessment in this population. Every attempt should be made to promote participation of the IWCI in their outcome measure testing. The need for two clinicians present during the assessments may be beneficial when testing individuals with severe physical and/or cognitive impairments.<sup>25</sup> Thus, other outcome measures such as the Functional Reach Test, the Four Stage Balance Test, or a timed Sit to Supine Transfer Test may be appropriate. Physical performance tests completed on individuals with moderate to severe cognitive impairment have been understudied.

Gait disturbances at the onset or very early in the course of the neurocognitive illness make the diagnosis of AD uncertain.<sup>29</sup> However, changes in spatiotemporal gait parameters early in the pre-clinical and MCI stages, including increased stance time, decreased gait velocity, and decreased step length were found in individuals with MCI when using the GaitRite.<sup>20,22,28</sup> The 6 Meter Walk is a reliable and valid test to measure gait speed for IWCI.<sup>18</sup> Alterations in walking may be detected early in

the course of dementia and even in the prodromal stage of MCI. Mild cognitive impairment and slow gait speed ( $< 1.00$  m/s) are twice as likely to develop dementia. Fast gait speed is a more sensitive measure and was more predictive of significant cognitive decline over a 3-year follow-up. Minimal detectable changes are available for self-selected and fast gait speeds, as well as temporal and spatial gait parameters.<sup>21,22</sup>

Muscle weakness and self-reported musculoskeletal problems limiting physical function have been associated with falls and fall-related fractures in older people with AD.<sup>17,30</sup> Five Time Sit to Stand test is a good functional measure that may be successfully completed even in the later stages of the disease. In healthy adults, it assesses leg power and fall risk associated with norms and MDC of 4.2 seconds in healthy elderly.<sup>31</sup> It is the best lower extremity measure for those who are not able to understand instructions of manual muscle testing.

The 6MWT was found to be reliable, valid, and sensitive to change in IWCI.<sup>18</sup> Reis et al<sup>22</sup> identified a MDC for the 6MWT of 110 feet for this population. In MCI, poor performance on the 6MWT correlated with decreased hippocampal and cerebral gray matter volume. Modifications to the test procedure may be necessary to facilitate successful participation. Providing verbal cuing when appropriate and positioning other targets such as a table at each end point, giving instruction to move cups from one table to the other may assist in maintaining attention to task completion.

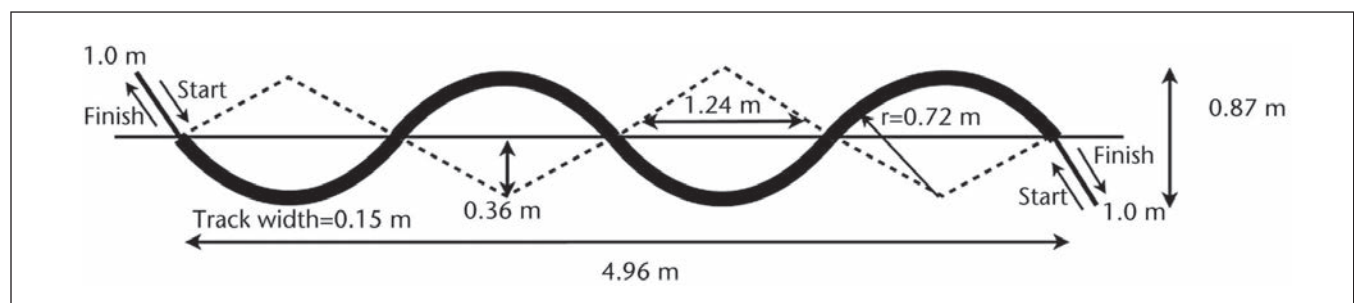
## SUMMARY

Translating assessment into action when effectively evaluating IWCI takes

a knowledgeable and skilled PTs with insight, observation skills, creativity, and flexibility using an integrated approach. In addition, the ability to adapt the communication process to engage with the IWCI will facilitate improved outcomes and quality of life. Given progressive impairment and function over time for IWCI, performing cognitive and physical performance testing plays a pivotal role in their care management plans. Performance outcome assessment, including staging, completed at the initiation of skilled physical therapist care helps to determine a baseline of functional status, assists with documentation of skilled and necessary care, and guides the plan of care. Thus, standardized outcome measure testing remains an important component of the plan of care and ongoing assessments are fundamental for proper management of an individual's functional status and fall risk. Currently, there is no one outcome measure that is useful for every patient in every setting. Therapists must search for and carefully select the correct measure or set of measures appropriate for the individual in their care. There is a strong need for consensus in the use of assessment tools for IWCI. It is imperative that we continue to improve our skills in working effectively with the rapidly growing population of IWCI's requiring our services so that we may utilize interventions of best practice as we serve these individuals and their care partners.

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**Figure 1.** Dimensions of the Gromingen Meander Walking Test.<sup>25</sup> Reprinted from *Phys Ther.* 2014;91(7):262-272, with permission of the American Physical Therapy Association. © 2014 American Physical Therapy Association.

r = radius to draw the curved TGMWT path.



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