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Staging and Treatment Frameworks for Dementia Management

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Abstract

The purpose of this article is to introduce the 2016 SIG 15 Perspectives series that will focus on issues pertinent to the different stages of dementia. This article will provide current statistics on prevalence, incidence, types, and classifications of dementia. It will also discuss various methods for staging the cognitive-communicative deficits associated with dementia progression and appropriate treatment approaches for each stage.

Dementia is a syndrome, meaning that it results in a constellation of signs and symptoms associated with a morbid process (Bayles & Tomoeda, 2007). Dementia results from acquired brain disease and is characterized by progressive deterioration in memory and other cognitive domains (American Speech-Language Hearing Association [ASHA], 2015). The deficits associated with dementia represent a decline from previous levels of functioning and are sufficient enough to interfere with activities and participation.

People with dementia-associated cognitive-communicative problems are the fastest growing clinical population in the profession of speech-language pathology (Kinsella & Phillips, 2005). The number of Americans with Alzheimer's disease and other dementias will grow each year as the size and proportion of the U.S. population age 65 and older continue to increase (ASHA, 2015). Research shows that 13.9% of those aged 71 and older (1 in 7 older adults) have some form of dementia with this number rising to 37.4% of those age 90 and older (Plassman et al., 2007). Alzheimer's disease is the most common cause of dementia as it may account up 70% of all dementia cases (Plassman et al., 2007). The Alzheimer's Association (2015) estimates that currently 5.3 million Americans of all ages have Alzheimer's disease, and almost two-thirds are women. Of these individuals, 5.1 million are over aged 65 years and older (Alzheimer's Association, 2015).

With these statistics, it is vital that speech-language pathologists (SLPs) address the cognitive-communicative and swallowing needs of adults with dementia. It is the position of ASHA that SLPs play a primary role in the screening, assessment, diagnosis, treatment, and research of cognitive-communication disorders, including those associated with dementia because SLPs are knowledgeable about normal and abnormal neurological functioning and related aspects of communication. Our academic and clinical training prepares us to serve a number of roles related to communication and dementia, including, but not limited to, the following: identification, assessment, intervention, counseling, collaboration, case management, education, advocacy, and research (ASHA, 2005). ASHA (2015) further states that "most common dementia-associated diseases are progressive in nature, and speech-language pathologists have an ethical responsibility to provide appropriate services that will benefit the individual and maximize cognitive-communication

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functioning at all stages of the disease process" (Treatment section, para. 1). The role of the SLP in dementia managements activities such as education and collaboration is vital as the Alzheimer's Association (2015) reported that less than half (45%) of older adults diagnosed with Alzheimer's disease or their caregivers report being told the dementia diagnosis by a health care provider.

It is important for health care professionals to be able to differentiate dementia from pseudo-dementias and other causes of reversible and treatable symptoms. Common causes of dementia-like symptoms that are temporary and/or treatable include infections, toxicity, depression, generalized anxiety disorder, schizophrenia, mania, and/or conversion disorder (Bourgeois & Hickey, 2009). Dementias can be classified as primary or secondary (ASHA, 2015). Primary dementias are those in which the dementia itself is the major sign of the brain disease. Primary dementias include Alzheimer's disease, vascular dementia, and dementia with Lewy bodies. Secondary dementias are those caused by, or closely related to, some other recognizable disease. Secondary dementias include HIV, head injury, multiple sclerosis, and chronic alcohol abuse.

Another diagnosis relating to dementia is Mild Cognitive Impairment (MCI). MCI is considered to be a transitory stage between the cognitive changes associated with normal aging to more clinically significant symptoms that resemble those of other dementias. Kimbarow (2016) summarized the diagnostic criteria according to the American Academy of Neurology (AAN; Petersen et al., 2001) as such:

> (a) self-report of memory problems, with corroboration from an informant or caregiver; (b) measurable memory impairment ton standardized testing, outside the range expected for healthy older adults; and (c) no impairments in reasoning, general thinking skills, or ability to perform daily activities. (p. 189)

Perhaps most importantly, MCI places an individual at high risk to develop AD. Some individuals show physiological changes congruent with early stages of AD such as neural atrophy and presence of beta-amyloid protein in the brain. Fortunately, however, this conversion may be delayed by pharmacological and nonpharmacological interventions (Alves et al., 2013).

The Stages of Primary Dementia

As summarized by Ganguli et al., (2011), the DSM-5 differentiates only two types of dementia, mild and major neurocognitive disorders (NCD; American Psychiatric Association, 2013). Mild NCD is defined as mild cognitive difficulty that may make independent activities of daily living more challenging. Major NCD requires a diagnosis or a specific cause (e.g., AD, Lewy body dementia). On the other hand, most organizations and professionals delineate three stages of dementia: mild AD, moderate AD, and severe AD. These stages conform to Alzheimer's Dementia but do include other dementia types (Rabins et al., 2007).

We must remain cognizant that, upon diagnosis, a person may experience a sense of loss and grapple with the stigma often associated with AD (Rabins et al., 2007). Perhaps as a corollary, depression is common comorbidity. People in early stage AD (mild dementia) demonstrate trouble sustaining attention, difficulty with episodic and working memory, and may lose orientation with time and space (Bayles & Tomoeda, 2007). Their language form remains intact; however, content is diminished. Ideational perseveration is common, along with difficulty in confrontation naming and generative naming (Kimbarow, 2016). Those with good orientation are able to maintain on topic conversations. Instrumental activities of daily living (IADL) such as managing finances are most likely too challenging, but these individuals can perform activities of daily living (ADLs).

Middle stage or moderate dementia commonly manifests through continued worsening memory, except long-term memory, and worse performance on all executive functioning and cognitive-communication tasks (Bayles & Tomoeda, 2007) compared to age-matched peers. People with moderate AD typically can follow two-step commands, but their verbal comprehension does decline. Relating to language, word finding difficulties increase, content is often described as

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"empty," but when presented with a tangible item, people with moderate AD can make on topic statements (Kimbarow, 2016; Mahendra, 2001). Despite being laden with errors, writing can still be used for communication. ADLs may require compensatory strategies or environmental manipulation.

At the next stage of the progression, severe dementia, a person is disoriented in person, place, and time. Incontinence of bladder and bowel movement may be present (Bayles & Tomoeda, 2007). Language ability may range from being completely mute, palilalia, echolalia, jargon, to even being able to state name and some crystallized vocabulary. On a positive note, people with severe dementia can attend to pleasant stimuli such as music (Kimbarow, 2016).

There are several tools to help stage the progression of dementia. It is important to note that the majority of these tools are based on the progression of Alzheimer's disease as it is the most prevalent form of dementia. Tools for the SLP include:

- Global Deterioration Scale (Reisberg, Ferris, de Leon, & Crook, 1982)
- Brief Cognitive Rating Scale (Reisberg & Ferris, 1988)
- Functional Assessment of Staging Alzheimer's Disease (Reisberg et al., 1984)
- Clinical Dementia Rating Scale (Hughes, Berg, Danziger, Coben, & Martin, 1982)

Tables 1-2 provide useful information regarding staging.

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Table 1. Skilled Observations Across Dementia Stages

	Normal Aging	Mild Cognitive Impairment (MCI)	Mild Dementia (Early Stage)	Moderate Dementia (Middle Stage)	Severe Dementia (Late Stage)
Following Directions	Able to follow complex directions	Able to follow complex directions, may need increased time and repetition	Able to follow multiple step simple directions, may need cues	1-2 step simple directions, may need cues	Maximum cues to follow simple directions
Memory	Variable depending on function during adulthood, working memory decreased	Decrease from earlier adulthood, working memory decreased	Working and episodic memory impairments	Working, episodic, and semantic memory impairments	Working, episodic, semantic, and procedural memory impairments
Attention/ Topic Maintenance	Able to follow conversation, can repair breakdowns	Able to follow conversation with increased breakdowns noted	Topic maintenance affected, may have increased output with decreased meaning	Difficulty maintaining topic, very vague speech	Simple utterances to muteness
Orientation	May see temporal and spatial deficits-can self-correct	Increased temporal and spatial deficits with decreased ability to self-correct	Apparent temporal and spatial deficits	Deficits with person, time, place	Oriented to self only
Pragmatics	Appropriate	Appropriate, minor changes noted	Self-centered, rigid, verbose, vague speech	Unpredictable, self-centered	Significantly affected
ADL function	Independent	Independent, minimal assistance	Minimal assistance	Moderate assistance	Maximum assistance

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Table 2. Comparisons of Test Scores Across Dementia Stages

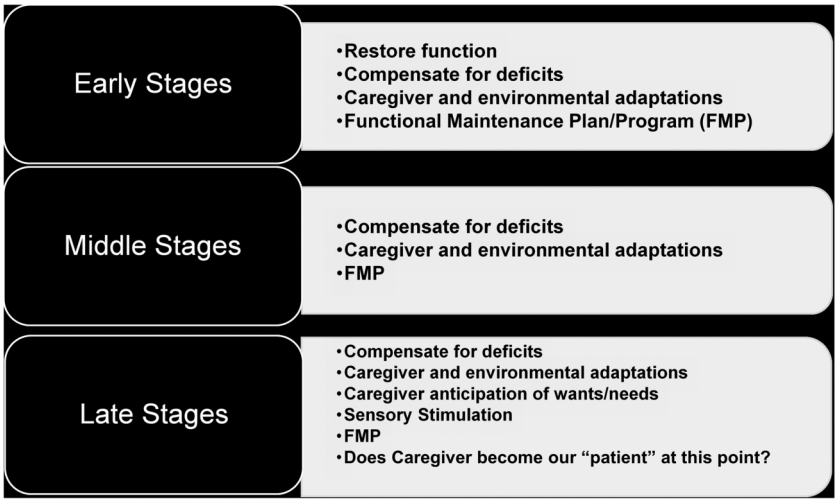
	Normal Aging	Mild Cognitive Impairment (MCI)	Mild Dementia (Early Stage)	Moderate Dementia (Middle Stage)	Severe Dementia (Late Stage)
ABCD Overall (Bayles & Tomoeda, 1993)	23.58+	NA	16–22	7–15	NA
ABCD Story Retelling: Immediate	14+	11	8	3	0–1
ABCD Story Retelling: Delayed	12.4+	2–11	1	0	0
ABCD Mental Status	12.8+	NA	7.3–12.5	8–15	0–4
FLCI (Bayles & Tomoeda, 1994)	NA	NA	72–82	46–71	0–45
GDS (Reisberg, Ferris, de Leon, & Crook, 1982)	1	2	3	4–6	7+
RBANS (Total Scaled Score and Index Scores; Randolph, 1998)	110+	90–109	80–89	70–79	<70
FAST (Reisberg et al., 1984)	1	2	3–4	5	6-7
BCRS (Reisberg & Ferris, 1988)	1	2	3	4–5	6–7
MMSE (Folstein, Folstein, & McHugh, 1975)	27–30	25–26	16–24	8–15	0–7
SLUMS with High School Education (Tariq, Tumosa, Chibnall, Perry III, & Morley, 2006)	27–30	24–26	21–24	10–23	0–9
SLUMS less than High School Education	25–30	20–24		10–19	0–9
CLQT Composite Severity Rating (Helm-Estabrooks, 2001)	3.5–4.0	NA	2.5–3.4	1.5–2.4	1.4–1.0
Allen Cognitive Scale (Allen, 1996)	6	5	4	3	< 3
MOCA (Nasreddine, n.d.)	26–30	18–25		10–17	<10
CDR Scale (Morris, 1993)	0	0.5	1	2	3
CDR Scale: Memory	0	0.5	1	2	3
CDR Scale: Orientation	0	0.5	1	2	3
CDR Scale: Judgment & Problem Solving	0	0.5	1	2	3

Note. ABCD= Arizona Battery for Communication Disorders of Dementia; FLCI= Functional Linguistic Communication Inventory; GDS= Global Deterioration Scale; RBANS= Repeatable Battery for the Assessment of Neurophysiological Status; FAST= Functional Assessment Stages; BCRS= Brief Cognitive Rating Scale; MMSE= Mini Mental State Examination; SLUMS= St. Louis University Mental Examination; CLQT= Cognitive Linguistic Quick Test; MoCA= Montreal Cognitive Assessment; CDR= Clinical Dementia Rating.

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Treatment to address the cognitive-communication deficits associated with dementia should be patient-centered and account for the stage of dementia. Some restorative approaches may be successful in mild and moderate dementia. These approaches should be paired with compensatory strategy training and environmental adaptations to ensure functionality throughout the progression of dementia. Figure 1 illustrates approaches for each stage of dementia.

Figure 1. Treatment Approaches Across Dementia Stages



Treatment Approaches for Mild/Early-Stage Dementia

Restorative treatment can encompass direct cognitive treatment strategies to address areas of cognitive-communicative function including working memory, semantic knowledge, safety, reasoning, and naming. Treatment also can focus on training the adult with dementia to independently utilize compensatory strategies to compensate for deficit areas. Environmental adaptations should be utilized to increase safety and independence within the structure environment. Montessori-based methods use personally meaningful activities to allow an adult with dementia to participate at the most appropriate level. Tasks are broken down and taught from simple to complex, concrete to abstract, and rely on the use of external cues and implicit memory (Camp, 2010). The focus on remaining abilities instead of deficits fosters self-esteem and also provides opportunities for participation in meaningful social roles. In early stages of dementia, Montessori programming and tasks that utilize intact procedure memory are useful. Family and caregiver training should be an integral part of the treatment plan. Suggested ADL adaptations include providing minimal supervision during ADL tasks to ensure task initiation and completion. Patient-specific strengths and weaknesses should be established to determine the appropriate amount of supervision required by an individual.

Treatment Approaches for Moderate/Middle-Stage Dementia

Adults with moderate dementia will need cues and support to successfully utilize compensatory strategies so family and caregiver training will be vital for ensuring functionality in the adult's familiar environment. Spaced retrieval may be a successful approach for compensatory strategy training. Environmental adaptations and modifications can be utilized to increase safety and independence in familiar structured environments. Progression through the health care continuum during the middle-stage would likely necessitate skilled speech-language pathology

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services to help transition the adult with dementia to a new environment and ensure cognitive-communicative functionality in that environment. Montessori activities are appropriate and emphasis should be placed on increasing/maintaining participation and socialization. Suggested ADL adaptations include providing moderate supervision/assistance during ADL tasks to ensure safety and comprehension and establishing patient-specific strengths and weaknesses to determine appropriate adaptations.

Treatment Approaches for Severe/Late-Stage Dementia

Family and caregiver training and education is key for adults with severe dementia. Training and education can focus on anticipation of wants/needs, sensory stimulation, and passive reminiscing. Environmental adaptations and modifications are needed to increase sensory stimulation and safety. Montessori activities are appropriate for adults in this stage with meaningful participation in activities emphasized. Suggested ADL adaptations include providing maximum assistance during ADL tasks to ensure safety and establishing patient-specific strengths and weaknesses to determine appropriate adaptations.

An Overview of Other Direct Interventions

Spaced-Retrieval Training

Spaced-retrieval training (SRT) is a treatment that attempts to pair new associations (e.g., room number, meal schedule, compensatory strategy) through repeated stimulus response trials (Helm-Estabrooks, Albert, & Marjorie, 2014). Interval length doubles following correct recall responses and is shortened following an incorrect response (Kimbarow, 2016). SRT aims to teach successful recall over extended periods of time.

Errorless Learning

Errorless learning is a training approach that minimizes error to avoid establishing an engram of an incorrect response (Bayles & Tomoeda, 2007). Complex processes are broken down into single steps. Training takes place one step at a time, through repetitive practice, and with the necessary supports to avoid error. Therapists build on each step until the client sequentially performs the task correctly (Kimbarow, 2016, p. 235).

Reminiscence Therapy

Typically performed in a group setting, reminiscence therapy facilitates interaction with others through the discussion of past experiences. Props (e.g., music, newspaper articles, pictures, food) are presented to stimulate all five senses and further enhance the clients' recall. Outcomes include increased communication and social interaction, improved mood, and better quality of life (Mizuko, Lloyd, Dierkhising, & Grantham, 2009; Woods, Spector, Jones, Orrell, & Davies, 2009).

Validation Therapy

Validation therapy is a person-centered approach that acknowledges and validates the beliefs and feelings of a client, even when a statement seems inaccurate. Techniques include finding an underlying meaning, mirroring emotions, using a calm tone, maintaining eye contact, and never correcting an individual (Feil, 1992). Goals of therapy include improving mood, behavior, and overall quality of life; however, research provides mixed support (articles finding validation therapy effective: O'Neil et al., 2011; ineffective: Vernooij-Dassen, Vasse, Zuidema, Cohen-Mansfield, & Myle, 2010; mixed: Hulme, Wright, Crocker, Oluboyede, & House, 2010; Neal & Barton Wright, 2009).

Reality Orientation (RO)

Reality orientation is a therapy technique that involves presenting the client with orienting information (e.g., time, place) related to environmental and personal information (Metitieri et al., 2001; Spector, Davies, Woods, & Orrell, 2000). This information can be presented continuously or during therapy (e.g., discussing daily routines, recent events). Although this is a long-

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standing technique, research presents mixed results (articles finding RO effective: Burgener et al., 2007; O'Connell et al., 2007; ineffective: Rabins et al., 2007; mixed results: Hulme et al., 2010; Vasse et al., 2012).

This treatment list is not to discount the importance of indirect treatment (e.g., caregiver education). The goal of intervention is also to assist in maintaining the quality of life for both people with dementia and their caregivers (LaPointe, Murdoch, & Stierwalt, 2010).

In conclusion, it is vital for SLPs working with older adults to stay current with dementia management issues. There are several tools that SLPs can use to appropriately stage the cognitive-communicative function of adults with dementia. Staging is important in developing an appropriate treatment plan and setting realistic and functional goals.

Screening Tools and Assessments

- ABCD
    - Bayles, K., & Tomoeda, C. (1993). *The Arizona Battery for Communication Disorders of Dementia (ABCD)*. Tucson, AZ: Canyonlands Publishing.
- FLCI
    - Bayles, K. A., & Tomoeda, C. K. (1994). *The functional linguistic communication inventory*. Austin, TX: Pro-ed.
- Global Deterioration Scale
    - Reisberg, B., Ferris, S. H., de Leon, M. J., & Crook, T. (1982). The global deterioration scale for assessment of primary degenerative dementia. *American Journal of Psychiatry, 139,* 1136–1139.
- Mini Mental State Examination
    - Folstein, M., Folstein, S., & McHugh, P. (1975). "Mini-Mental State": A practical method for grading the cognitive state of patients for the clinician. *Journal of Psychiatric Research, 12,* 189–198.
- RBANS
    - Randolph, C. R. (1998). *Repeatable battery for the assessment of neuropsychological status*. San Antonio, TX: NCS Pearson Inc.
- Saint Louis University Mental Status Examination
    - Tariq, S. H., Tumosa, N., Chibnall, J. T., Perry III, H. M., & Morley, J. E. (2006). The Saint Louis University Mental Status (SLUMS) examination for detecting Mild Cognitive Impairment and Dementia is more sensitive than the Mini-Mental Status Examination (MMSE) - A pilot study. *American Journal of Geriatric Psychology*.

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