Full-Length Article
Perspectives on dementia from a speech-language pathologist: *An interdisciplinary focus*

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Abstract

Considerations of current and future aging demographics necessitate understanding of assessment approaches to ensure that projected public health needs are met accordingly. Status of medical conditions, available technologies and supports are described to underscore the critical need for planning and instituting provisions supporting assessment strategies to meet the broad global needs of developing countries. Assessment administration and considerations are presented. Greater emphasis on the details of assessing may lead toward creative expansion and a broadening of treatment options. This article describes current and future needs for assessment of dementia using a world view approach.

Keywords: *Dementia assessment, adaptations, creative approaches, global viewpoint*

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Introduction

Collaboration amongst allied professionals providing support to the vulnerable and ever-expanding population of individuals with dementia and its variants is growing. Increasingly, we find individuals with dementia being supported and sustained in community group programs, including those specialized in implementing creative arts therapies. The impact of early detection in building resilience can help to stabilize the progression of dementia. This may be of tremendous importance as engagement in creative arts therapies seemingly helps to build resilience amongst the insidious decline that accompanies this disease. Music therapy professionals have taken a leadership position in this arena and have contributed significant analyses to the assessment of dementia.

Dementia is one of the most significant causes of late-life decline in the United States and worldwide. With the explosion of the aging demographic, the incidence of this disorder stands to increase exponentially in the coming decades, with no known cure yet identified. As published by the World Health Organization, [1] the worldwide population of people over the age of 60 is exponentially increasing, and the number of individuals in this demographic will have doubled to 2 billion between 2000 and 2050. What may not be well-known, is the fact that in addition to US demographics, a large portion of this population exists in the Western Pacific Region and are identified by WHO, as one of the fastest growing regions of people 65 and over in the world. The over 200 million people already in this area will likely double by 2050. Furthermore, the World Health Organization European Region, represents another rapidly growing aging demographic, with the highest median age in the world, and people aged 65 and over are expected to increase from 14% in 2010 to 25% in 2050. These statistics are a product of a longer lifespan and better health and wellbeing in these areas. This results in the need to understand and plan for health needs of the elderly, as a worldwide imperative.

As a speech-language pathologist specializing in dementia assessment, these statistics and an expanding world view inform my practice in treating people in the US and from other countries who have emigrated to the US. However, estimates of occurrences remain elusive due to a number of constraints affecting population statistics. Most significant, is the fact that there is a lack of consensus on diagnostic terminology and staging descriptors in dementia which in turn affects the precision of subject matching, resulting in a lack of reliable population projections.

As diagnosis in the incidence and prevalence of dementia subtypes depends on analysis of communication decline, there is an urgent need to increase understanding of communication (speech, language, and cognitive functions) as these areas are primary and necessary areas for diagnosing the presence of dementia. Establishing the speech and language comorbidities of dementia subtypes provides critical information for speech-language clinicians to share with neurologists, primary practice physicians, psychologists, social workers, creative arts therapists, and all treatment team members to best inform families about the presence/absence of dementia and care planning.

Describing Dementia

Dementia is a broad diagnostic umbrella with distinct established subtypes. Considering the rapid advance of available imaging and laboratory studies that are anticipated to be developed in the near future, it seems likely that related diagnostic interventions will become increasingly essential in the future. Alzheimer's Disease is a major subtype of dementia consisting of characteristic plaques and tangles seen at the time of post-morbid brain autopsy.[2-3] It is, however, relevant to note that autopsy reports of brains with these characteristic pathologies may or may not yield consistent clinical behavioral correlations. Therefore, it is the role of professionals such as speech-language pathologists to evaluate patterns of communication decline that contribute to the projected medical diagnoses and planning. This holistic view of dementia assessment assists global healthcare communities in uncovering early onset as we work toward developing care programs that ensure best quality of life for individuals and their family partners. Furthermore, related strategies can be developed and modified for individuals both in the US and particularly where there are probable limited resources in health care and technology. This in turn is affected by disparities resulting in varying levels of diagnostic accuracy. The influence of socio-cultural attitudes, for instance, reflect major differences in health care capacity and this ultimately influences capacity for longevity and quality of life.

Dementia is also detected by the absence or presence of related comorbidities, such as sensory changes, visual perceptual disorder, and dysphagia, to highlight a few. Based on these complexities, it is clear that there is an urgent need for increased data regarding differential diagnoses. Currently, there are a plethora of underlying diseases that fall under the term dementia. These include frontal temporal lobe disease, cortico-bulbar deterioration, and many others. Estimates of underlying diagnoses are on the rise and resources to meet the diagnostic demands stand to be rapidly outstripped given the projected increase in prevalence in the near future. Accordingly, The WHO has established a world dementia plan.[4] The plan marks an effort to analyze and anticipate the needs of dementia sufferers throughout the world, and includes regions such as Africa, the Americas, Southeast Asia, Europe, Eastern Mediterranean and the Western Pacific in an effort to share and expand dementia care for all.

Burden of Care

Sleeman and colleagues[5] implemented the Lancet Commission on Palliative Care and Pain Relief and WHO mortality reports (2016–60)[4] that provided compelling inforrmation projecting the social, medical, economic, and human cost that can emanate from serious life-limiting illnesses such as dementia. Their report advocates for the investigation of how this burden of care may serve to inform health system policy. Their analysis projected worldwide burden of serious health-related issues through 2060 and warned of its impact on world region, age groups, and overall health conditions.

In predicting estimates for 20 serious medical conditions typically leading to the need for palliative care they concluded that:

> *By 2060, an estimated 48 million people (47% of all deaths globally) will die with serious health-related suffering, which represents an 87% increase from 26 million people in 2016. 83% of these deaths will occur in low-income and middle-income countries. Serious health-related suffering will increase in all regions, with the largest proportional rise in low-income countries (155% increase between 2016 and 2060). Globally, serious health-related suffering will increase most rapidly among people aged 70 years or older (183% increase between 2016 and 2060). In absolute terms, it will be driven by rises in cancer deaths (16 million people, 109% increase between 2016 and 2060). The condition with the highest proportional increase in serious-related suffering will be dementia (6 million people, 264% increase between 2016 and 2060.[4]*

This analysis highlights the burden of serious illnesses on subsequent local, national, and international communities and a need for resource development. They reflect on the greatest increases occurring in low-income populations, and older people, with increasing dementia diagnoses almost doubling in numbers. The authors projected that the highest proportional increase in dementia would result in 6 million new cases, a massive 254% increase between 2016-2020, representing a near-doubling of burden of care to individuals and society at large. This is catastrophic since many countries have no system of palliative care for dementia survivors (approximately 45% are without palliative care resources according to the authors). In the US and elsewhere, long term care poses a huge financial and social burden, with in-home and institutional care both steadily becoming extremely limited. Understanding the 'big picture' of dementia-related issues, including the lack of definitive diagnosing, no medical cure, and a lack of standard-of-care combined, all serve to endanger an already weak system of resources for the most vulnerable members of society.

Challenges

It bears critical mention at this point that older definitions of dementia which were chiefly characterized by a pen and paper

assessment of impairment in memory, language, thinking, and/or daily living abilities, tended to be more generic in the recent past. However, with access to advanced medical technology, there is a growing differential diagnostic capacity to analyze many disorders earlier on in the disease process. Features of the symptoms may share the general diagnostic label of 'dementia' as a disease of progressive neuropathological decline in brain structure and function, yet can show different patterns of presentation and disease course. The neurocognitive features of dementia which comprise the most salient diagnostic characteristics are: substantial cognitive decline from a previous level of performance and cognitive deficits in complex attention, executive ability, learning, memory, language, perceptual-motor-visual perception praxis, and social cognition. These serve to interfere with independence in daily living and are not related to delirium and cannot be attributed to another mental disorder.[6]

The classification and staging of neurocognition is essential for appropriate early referral and care, especially when the cause of apparent dementia may be due to reversible features resembling dementia, such as depression, polypharmacy, and nutrition to name a few. Suspicion of dementia, also known as unspecified dementia, can be difficult to confirm through differential diagnosis. The clinical features of the major dementing illnesses can be found in Table 1.

Table 1: *Clinical Features of the Major Dementing Illnesses*

	Cognition	Memory	Language	Behavior	Motor
Alzheimer's	Poor safety awareness, impaired executive function, disorientation	Frequent forgetfulness, repetitive questions, impaired episodic memory	Impaired word retrieval, communication abilities decline, reading is preserved in early and middle stages	Depressions, paranoia, withdrawal, mood changes	Difficulty performing simple tasks
Fronto-temporal Dementia	Impaired executive function, decreased inhibition, impulsivity	Can be impaired, but not the primary feature	Impaired word retrieval, conversation, and comprehension deficits	Wide range of behavioral changes, especially frontal lobe variant, uninhibited behavior, including inappropriate social behavior	Tremor, rigidity, swallowing difficulty, weakness
Lewy Body	Impaired attention, concentration, executive function, difficulty completing complex tasks	May not be impaired in early stages	Intact in early stages	Depression, lethargy	Rigid and stiff muscles slowed movements
Vascular Dementia	Impaired executive function	Progressive loss of memory and attention	Dysarthria, less spontaneous communication	Various behavior changes	Slowness, poor balance, unsteady gait
Mild Cognitive Impairment	Can be generally intact	Frequent forgetfulness of recent information	Mild word retrieval, forgetfulness of train of thought	Depression, anxiety, increased irritability	
Mixed Dementia	May be variably affected with significant findings	Tends to be variably affected with significant findings	Impaired word retrieval	Increased anxiety, depression and paranoia. Changes in the individual's personality	Limited control of body movements

Communication disorder is an established characteristic in diagnosising dementia. The pathology of dementia and specific particular sub-types center on the loss of purposeful communication as well as a loss of lexical activation networks.[7] In fact, a change in word-finding ability is one of the main complaints that brings a family into a provider's office for assessment.

Other prominent changes include inevitable physical and cognitive declines. The World Health Organization acknowledges that this encompasses deterioration of cognitively related abstract language functions, such as comprehension and the use of metaphoric language, humor, sarcasm, and double-entendres which comprise mature day-to-day interpersonal communication. There is also the inevitable decline and ultimately loss of secondary language representation (i.e., reading, writing, math.) Word finding and problem-solving pragmatic domains are most notably diminished in the early stages, while structural elements such as basic grammar rules and rote language (i.e., counting, familiar songs) will generally be preserved until later disease progression. However, an inevitable decline of motor speech and vegetative function including articulation precision, prosodic tone, and coarticulation in rapid speech will follow. Ultimately, patients who survive to late stage may become mute and have central nervous system damage to feeding and swallowing skills. This downward deterioration is a hallmark of the disease and directly related to the central nervous system deterioration of the disease which contributes to final morbidity.[7] The majority of patients will lose propositional meaningful novel language first, then may have preserved rote language functions for a period. Only highly rote social greetings and occasional music recall may remain but, unless integrated within a therapeutic plan, may not be useful for directive interaction-such as meaningful question and answer dialogue.

The speech, language, communication, and motor speech changes associated with the most prominent dementia subtypes are summarized in the Table 2. There may be prominent changes in oral motor control and coordination that follow as the disease progresses, with dysphagia being a common characteristic particularly as the disease advances and leads to an inability to chew and swallow. This may lead to decision-making about alternative methods for feeding and medicine administration such as intravenous apparatus; and/or other medical decision-making involving withdrawal of nutrition and end of life care. As speech and language are necessary diagnostic factors of dementia, a breakdown of speech-language changes by dementia subtype is provided in Table 2.

Table 2: *Speech and Language Changes by Dementia Subtype*

Dementia Subtype	Speech and Language Changes
Alzheimer's	Significant decline in semantics, word-finding difficulties, as signaled by long latencies, paraphasias, word substitutions, difficulty with topic maintenance, echolalia, lack of meaningful speech, gradual progression to mutism
Vascular Dementia	Word retrieval difficulties, difficulty following instructions, slurred speech, dysarthria, less spontaneous communication
Lewy Body Dementia	Motor speech disorder with hypophonia, disorganized speech
Frontotemporal Dementia	Progressive decrease in expressive vocabulary, word-finding problems, reduced spontaneous conversation, echolalia and meaningless repetition of phrases

American Speech-Language-Hearing Association. (n.d.) *Dementia* (Practice Portal) https://www.asha.org/practice-portal/clinical-topics/dementia/

The ensuing propositional communication loss in dementia relates directly to quality-of-life decline and the difficulties a patient can have in sustaining any form of independent living. Confabulations, decline/distortion of problem-solving abilities, hallucinations, and incoherence can render an affected individual unable to sustain even a supervised independent lifestyle. Such pathological declines co-occur with other changes in function such as distortion in reality orientation and even a lack of recognition of one's familiar surroundings. Therefore, many patients require supervision for their safety and well-being.

On varying scales, the burden to families is largely unsustainable, especially in households where adults are required to go out to work to support a family. The cost of in-home care is prohibitive to most families, and the availability of supervised day programs is relatively scarce as well. Taken on a national and international level, with elderly populations tending to live longer, there is an intolerable burden on most families' resources, economic and otherwise.

World-wide, the best available strategies include the earliest detection, careful differential diagnosis, and access to the latest medical interventions including potential experimental trials.

Assessment Overview

Early detection is one of the most important ways to alleviate the humane and societal costs of dementia care. The following is a brief overview of some of the best practices recommended in the current literature, though this review is not exhaustive. The assessment of patients via cognitive screenings versus providing full formal batteries can be an expeditious way to evaluate who may be at risk for dementia, and may serve to differentiate those who may have other conditions. The careful identification of dementia and its variants by means of clinical and instrumental efforts is a worldwide research endeavor that stands to increase the quality of life of millions of people and their loved ones currently and in the future.

In line with this, commonly used cognition screening tests include the Mini-Mental States Examination (MMSE),[8] the Mini-Cog Test,[9] the Montreal Cognitive Assessment Test for Dementia (MoCA),[10] The Addenbrooke's Cognitive Examination Revised (ACE-R),[11] and the General Practitioner Assessment of Cognition (GPCOG).[12] Each of

these tests is brief, typically under 30 minutes, and can assist in establishing cutoffs leading toward further assessment.

Assessments of overall dementia severity include the Clinical Dementia Rating Scale (CDR),[15] the Global Deterioration Scale (GDS),[14] and the Clinician's Global Impression of Change Scale (CGI).[15] The GDS, developed by Dr. Barry Reisberg,[15] divides primary degenerative dementia into 7 stages. The contribution of staging is especially critical in dementia since strategies for patients and caregivers are specific to patient care needs at each level of decline. The first 3 stages range from no cognitive decline to mild cognitive decline. Stages 4 and 5 describe moderate and moderately severe decline. The final two stages, 6 and 7, describe severe cognitive decline and very severe cognitive decline, respectively. Stage 7 includes the loss of all verbal abilities, basic psychomotor skills, toileting, and feeding abilities. References from ASHA provide the material for the following information, including prognostic information. As indicated in Table 3.

Table 3: *Assessments for Dementia*

Assessment Tool	Description	Probability of accurate diagnosis
Montreal Cognitive Assessment (MoCA; Nasreddine, 1996)	The MoCA evaluates cognitive abilities, including orientation, short-term memory, executive function, language abilities, attention, and visual-spatial abilities.	Sensitivity of 100% in detecting mild Alzheimer's and 90% for detecting MCI (Nasreddine et al., 2005)
Mini-Mental State Exam (MMSE; Folstein et al., 1975)	The MMSE is a widely used test of cognitive function among the elderly. It includes tests of orientation, attention, memory, language, and visual-spatial skills.	Sensitivity of 85% in detecting dementia (Creavin et al., 2016)
Addenbrooke's Cognitive Examination Revised (ACE-R; Mioshi et al., 2006)	The ACE-R is a dementia screening test that incorporates five sub-domain scores: orientation/attention, memory, verbal fluency, language and visuospatial.	Reliability of the ACE-R is considered very good, alpha coefficient = 0.8 (Mioshi et al., 2006)
General Practitioner Assessment of Cognition (GPCOG; Brodaty et al., 2002)	The GPCOG is a screening tool for cognitive impairment consisting of seven stages.	Sensitivity and specificity of the GPCOG range from 0.81 to 0.98 and 0.72 and 0.95, respectively (Seeher & Brodaty, 2017)
Repeatable Battery for the Assessment of Neuropsychological Status (RBANS; Randolph, Tierney, Mohr & Chase, 1998)	The purpose of the RBANS is to determine the neuropsychological status of adults ages 20-89 with neurologic injury or disease, such as dementia.	Standardized on 540 adults selected to represent the U.S. population demographics

Assessment Tool	Description	Sensitivity & Specificity	Time to administer (minutes)	Cost
Addenbrooke's Cognitive Examination Revised (ACE-R; Mioshi et al., 2006)	The ACE-R is a dementia screening test that incorporates five sub-domain scores: orientation/attention, memory, verbal fluency, language and visuospatial.	Sensitivity of 0.90 and specificity of 0.93 (Mioshi et al., 2006)	15-20	No cost
General Practitioner Assessment of Cognition (GPCOG; Brodaty et al., 2002)	The GPCOG is a screening tool for cognitive impairment consisting of seven stages.	Sensitivity of 0.82 and specificity of 0.83 (Seeher & Brodaty, 2017)	6	No cost
Mini-Cog: Screening for Cognitive Impairment in Older Adults (Borson et al., 2003)	The Mini-Cog was constructed from 3-word recall, a common element in many cognitive screening tests and the earliest to decline impairment in common dementias such as Alzheimer's disease, and a clock drawing task included as an executive/cognitive composite.	Sensitivity of 0.76 and specificity of 0.89 (Borson et al., 2003)	3	No cost
Mini-Mental State Exam (MMSE; Folstein et al., 1975)	The MMSE is a widely used test of cognitive function among the elderly. It includes tests of orientation, attention, memory, language, and visual-spatial skills.	Sensitivity of 0.79 and specificity of 0.95 (Hancock and Larner, 2011)	5-10	MMSE-2: Expanded Version Kit (User's Manual, Blue and Red Forms, Scoring Templates, Pocket Norms Guide): $259.00
Montreal Cognitive Assessment (MoCA; Nasreddine, 1996)	The MoCA evaluates cognitive abilities, including orientation, short-term memory, executive function, language abilities, attention, and visual-spatial abilities.	Sensitivity of 1.00 and specificity of 0.87 (Nasreddine et al., 2005)	10	MoCA test training and certification: $125.00
Repeatable Battery for the Assessment of Neuropsychological Status (RBANS; Randolph, Tierney, Mohr & Chase, 1998)	The purpose of the RBANS is to determine the neuropsychological status of adults ages 20-89 with neurologic injury or disease, such as dementia.	Sensitivity of 0.98 and specificity of 0.82 (LaPointe & Homer, 1998)	20-30	RBANS Updated Combo Kit (Includes Stimulus Books, Coding Templates, and Manual): $752.80
Six-item Cognitive Impairment Test (6CIT; Brooke & Bullock, 1999)	The 6CIT is a brief cognitive screening test containing three orientation items that is widely used in primary care settings.	Sensitivity of 0.90 and specificity of 1.00	3-4	No cost

Ongoing assessment through therapeutic interventions – An Overview

Contributions from the music therapy literature
An early important music therapy study by Lipe et al.[21] included 50 subjects, and compared the Mini-Mental State Examination (MMSE), the Residual Music Skills Test (RMST) and the Music-Based Evaluation of Cognitive Function (MBECF). Significant correlations were noted as well as additional information regarding the unique contributions of music cognition to general cognition.

The MMSE can predict MBECF performance and thus has predictive validity, which is important in the collaboration of inter-professional communities serving the dementia population. Proposed specialized neural networks may underlie performance that is maintained in certain test populations, which can be useful in diagnosis as well as in the development of treatment strategies. The authors pointed out that the patterns of the relationships between these instruments should be further examined for correlation properties particularly in verbal and rhythm performance, which can assess the contribution of task-dependent findings. The predictive abilities of music-based cognitive assessment is a valuable contribution in the arsenal of dementia assessment especially in considering that early detection is essential for appropriate referral and management.

In 2015, a Music in Dementia Assessment Scale (MIDAS)[24] was developed. A unique aspect of this measurement tool is its incorporation of information gathered from a focus group which contributed to its content validity. Field testing supported by qualitative metrics yielded consensus and experimental results that can be reliably used to assess individuals with dementia using music therapy-based protocols, as supported by valid measures of interest, response, initiation, involvement and enjoyment as meaningful outcome measures. The MIDAS is therefore an additional valid assessment instrument in dementia using music therapy as a diagnostic platform. It can be implemented by staff and music therapy professionals alike. These in-field reports are important in bringing as much diagnostic and planning information into the hands of the treating professionals as possible.

The effectiveness of music interventions for people living with dementia was tested during a cluster randomized controlled in Australian residential aged care facilities (RACF).[20] The study emphasized the detriment of delays in beginning the baseline assessments and intervention delivery due to the COVID-19 pandemic on the efficacy of music interventions. The study underscored the importance of focusing on building relationships with RACF staff and resident families and reducing the time between initial assessments and intervention. Furthermore, the study revealed the difficult work conditions due to staff shortages, heavy work schedules, time constraints, and demands of the 'caring' role.

Concetta Tomaino, who currently serves as executive director and co-founder of the Institute for Music and Neurologic Function (IMNF), explains that for people with neurodegenerative diseases, such as Alzeimer's dementia, music can be "a window to their memories."[20] The auditory system has networks throughout the brain that are aroused and stimulated by patterns of sound. Those patterns of sound can stimulate motor function and attention. Music interventions, including listening and responding to familiar songs, writing music, and other expressive and creative music-related activities, can be used to enhance quality of life by strengthening cognitive abilities, such as short-term memory and information pairing ability, as well as physical abilities (queuing of gait, balance, coordination, and confident movement).

It can be concluded that incorporating music in varying contexts of dementia care is widely practiced and its implementation is relevant and advantageous. In accommodating this area of practice in assessment protocols and looking toward integrative mechanisms of treatment, speech-language pathology, and music therapy collaborations may yield stronger diagnostic interprofessional practice guidelines and resources. Co-delivered programs in speech and language therapy along with music therapy has an established potential in acquired neurogenic populations with positive outcomes reported in collaborative studies.[25] Continued research and development in this area should be valued as a promising, highly viable and cost-effective assessment pathway.

While the primary emphasis of this article is the description, comparison and understanding of assessing dementia, prominent reported treatment paradigms in the current literature are critical to mention. This is especially important since public health factors call upon integrative communal strategic planning as the increase in cases requiring diagnoses has risen in need, which neccesitates the value of accurate assessment.

It follows therefore that since there is no known cure for dementia, the goal of alleviation of symptoms and prolonging quality of life is of critical importance world-wide. An abundant array of literature is aimed at patient and family care with varying degrees of scientific support. As a prominent example, in speech-language pathology, methodologies that might help a patient retain and recall salient information and important routines for daily functions have been increasingly identified with related research support. While at present, the evidence-based interventions remain scant, clinicians currently report a level of success with specific methodologies, namely spaced

retrieval strategies.[26] A further functional strategy has been in the area of environmental supports for this client population, such as 'memory' gardens, horticulture activities, the use of iPads to greet a loved one in the morning, therapeutic companions such as animal-assisted therapy, robotic pets for interaction, and other stimulating and creative individualized care. However, these interventions for both assessment and continued quality of care are out of reach of most families, who may be older themselves with no financial or travel access to centers providing innovative care.

Nevertheless, skilled clinicians can capitalize on the knowledge of personal routines for both assessment and quality of life in providing "low-tech" strategies. Some of these important techniques include assurances that patients feel secure through basic physical companionship. Meaningful eye contact, well-modulated vocal tones, familiar routines and reassurance are examples of simple strategies. These are in addition to monitoring changes in function and accommodating, understanding the role of medications on arousal states, capitalizing on sustained procedural memory for routines, and addressing the client's social-emotional and cultural comfort levels through familiar activities routine activities that encourage patients' sense of safety and control. In all endeavors, person-centered approaches and related social daycare programs customized to familiar environments and personnel will yield the most reliable results for ongoing monitoring and care planning. These and other salient reports of quality of life, non-pharmacologic assessment and therapeutic considerations are outlined by Carozza.[7] In maximizing our understanding of published data and adapting clinical environments for individualized consideration, integral aspects of care, such as maintaining non-threatening environments, adhering to low arousal situations, and in imbuing person-centeredness, clinicians will find the greatest success in meaningful assessment and planning.

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Biographical Statements

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