

Beyond Memory: The Behavioral and Neuropsychiatric Symptoms of Dementia

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When it comes to Alzheimer's disease and the other dementias, memory loss gets top billing. That's why UCI MIND and its community partners, the Alzheimer's Association of Orange County and Alzheimer's Family Services Center, turned attention to the less understood yet highly prevalent behavioral and neuropsychiatric symptoms of dementia at the 20th Annual Southern California Alzheimer's Disease Conference, held on World Alzheimer's Day, September 21st, 2012.

An audience of 560-plus professionals in health care and aging services, caregivers, and community members at large spent the day learning about the non-cognitive symptoms of Alzheimer's disease and other dementias from nationally known researchers and clinicians as well as a panel of individuals with MCI and their care partners. Through 42 exhibitors who generously sponsored the event, attendees also gained access to Orange County's rich array of dementia-related community services.

Across the day, six key points, as summarized here, emerged about the management of behavioral and neuropsychiatric symptoms in the dementias.

I. Use Medications with Caution

Antipsychotics and other psychotropic medications are commonly used to treat behavioral and neuropsychiatric symptoms in dementia, but these drugs have limited benefit and may even cause harm, as emphasized by Dr. Lon Schneider of the University of Southern California. In a series of studies, Dr. Schneider and his colleagues clearly demonstrated that atypical antipsychotics (e.g., Seroquel, Risperdal, and Zyprexa) have little benefit over placebo in treating symptoms such as agitation, aggression, and psychosis, come with significant side effects, and increase risk for death. In 2005, the FDA issued a "black box" warning against the use of atypical antipsychotics for dementia-related psychosis due to a heightened risk for death from stroke.

In his discussion of frontotemporal dementia (FTD), Dr. Adam Boxer of the University of California, San Francisco (UCSF), noted that no medications – psychotropics like the atypical antipsychotics and anti-depressants as well as cognitive enhancers used in Alzheimer's disease (e.g., acetylcholinesterase inhibitors, memantine) – are approved for FTD. Only anti-depressants (e.g., selective serotonin reuptake inhibitors/SSRIs, and Trazadone) have proven effective in helping alleviate the neuropsychiatric symptoms of FTD. When used in this atypical dementia, acetylcholinesterase inhibitors (i.e., Aricept, Razadine, and Exelon) have worsened behavioral symptoms while memantine has further impaired cognition and the ability to perform activities of daily living skills.

Given the limitations of medications in the treatment of non-cognitive symptoms, speakers throughout the day cautioned professionals and family caregivers alike to (1) carefully weigh potential benefits of medications against their risks prior to initiating use, and (2) always try non-pharmacological approaches first to reduce behavioral symptoms. As Judy Cooper, who participated with her husband Jay, in a panel discussion involving individuals with Mild Cognitive Impairment (MCI) and their care partners, explained,

she's decided not to treat Jay's hallucinations with medications for the time being. "When it is more bad than good, we will take the next step, but now it is more good than bad."

II. Rule out Unrecognized Medical Illnesses

Unrecognized medical illnesses, use of inappropriate medications (e.g., anticholinergics), suboptimal prescribing, and polypharmacy, can all be the source of new behavioral symptoms or worsen existing ones, as described by Dr. Daniel Sewell of the University of California, San Diego. Upon reviewing the charts of 79 older adults who had been admitted to a psychiatric unit for a behavioral disturbance, Dr. Sewell and his colleagues found 34% had an unrecognized medical illness (e.g., constipation, urinary tract infection and pneumonia). To illustrate the impact of medical illnesses on behavior, Dr. Sewell gave the example of a person with both dementia and diabetes who refuses to eat, thus driving blood sugar levels down and precipitating confused, agitated behavior.

Whenever a new behavior emerges or existing one worsens, clinicians and family caregivers ought to first rule out possible medical causes, including an acute medical condition, exacerbation of a chronic illness, or use of medications known to cause adverse events in older adults as detailed in the 2012 American Geriatrics Society Beers Criteria.

III. Recognize Differences in Behavioral and Psychiatric Symptoms Among the Dementias

Like cognitive symptoms, behavioral and psychiatric ones do not look the same across Alzheimer's disease and the other dementias. Both Dr. Mario Mendez of the University of California, Los Angeles and Dr. Maria Luisa Gorno-Tempini of USCF highlighted differences between the frontotemporal dementias, which include both a behavioral and language variants. As described by Dr. Mendez, the behavioral variant is characterized by early and predominant changes in behavior and personality (e.g., social inappropriate conduct, apathy, compulsiveness). Dr. Mendez noted that affected individuals may have difficulty taking another's point of view, recognizing facial expressions, and stopping themselves from actions they know are wrong (e.g., stealing). In comparison, the language variants, as described by Dr. Gorno-Tempini, feature, for example, slow, halting, and effortful speech (i.e., progressive non-fluent aphasia) and the inability to understand the meaning of words (i.e., semantic dementia). As noted by Dr. Gorno-Tempini, tailoring one's communication style to the specific speech and language impairments of the individual is essential for preventing misunderstandings and behavioral reactions.

Dementia with Lewy bodies (DLB) is still different in cognitive and behavioral presentation. Characterized by three core features – cognitive fluctuations, early hallucinations, and slowed parkinsonian-like movements – DLB may, as described by Dr. Aimee Pierce, also present with rapid eye movement (REM) sleep disorder, in which the individual acts out dreams. In fact, care partner Judy Cooper noted that her husband, Jay, developed REM sleep disorder a couple of years prior to being diagnosed with MCI due to Dementia with Lewy bodies.

IV. Partner for Effective Problem-Solving

Effectively evaluating and addressing dementia-related behavioral and psychiatric symptoms entails partnerships that involve the affected individual, the family, and entire healthcare team. Urging

physicians and other health care professionals to take a collaborative approach to dementia care, UCI's own Dr. Laura Mosqueda emphasized involving the person with dementia, family, and physician in a shared-decision-making process when addressing medication use and other issues. Most importantly, if partnerships are to work, they must, as Dr. Mosqueda noted, involve listening, communication, clear expectations, negotiation, empathy, and compassion.

V. Listen to People with MCI and their Care Partners

Committed to including the voices of people with MCI and early Alzheimer's disease or another dementia, the Southern California Alzheimer's Research Conference features a panel of affected individuals and their care partners each year. Participants in this year's panel shared their experience of living with challenging behavioral and psychiatric symptoms such as depression and hallucinations while reminding the audience that there is life beyond the diagnosis of MCI or a dementia. Using a range of strategies to cope – such as focusing on the positive, drawing on spiritual resources, exercising regularly, engaging in activities that draw on remaining strengths, and participating in support groups – panelists demonstrated an ability to “rise above” daily challenges. As Steve Heins, who has MCI and struggled with depression, noted, “You have to learn your limitations so you can expand your horizons.” For example, while reading and writing are difficult for Steve now, he's discovered acting as an activity he can excel in despite his limitations.

While these couples demonstrated a remarkable resilience, or ability to “rebound,” their journey hasn't been easy. In fact, at times, it was made more difficult by the health care professionals who didn't take time to listen to them or explain conditions such as DLB or symptoms such as depression. In her “take home” message to the audience, Judy noted her frustration with professionals assuming DLB is the same as Alzheimer's disease. “It's often misdiagnosed; medical professionals need to learn about Lewy body; what it is and how it works; it's not the same as Alzheimer's. Steve's wife, Gincy, in turn directed her final comment to physicians in the audience, noting, “If you have a patient at risk for depression, spend a couple of minutes telling family members what to look for. Don't just say, ‘Is he experiencing depression?’ Say, ‘Look for A, B, C, D, or E – if you see A and B, don't wait for the next visit to follow up.’”

VI. Attend to Caregiver Stress

Behavioral and psychiatric symptoms of dementia are widely recognized as a significant contributor to caregiver stress. As summarized by Dr. Richard Schulz from the University of Pennsylvania, the prolonged stress of caregiving has been associated with depression, poor health and premature death. Caregiver stress may evidence itself through a variety of physical (e.g., disturbed sleep, headaches, gastrointestinal problems, pain, high blood pressure, and susceptibility to colds) and psychological (e.g., moodiness, depression, anxiety, irritability, and substance use) symptoms. In a series of collaborative studies investigating the effectiveness of “Resources for Enhancing Alzheimer's Caregiver Health” or REACH, researchers, including Dr. Schulz, learned that effectively reducing difficult behaviors involves teaching caregivers possible causes for and options to alleviate specific symptoms. For example, through REACH, the caregiver whose loved one becomes combative is taught how to calm the individual, look for a trigger, reduce danger and develop an emergency plan, and when to contact the doctor.

Alternatively, a caregiver with a loved one who is having difficulty dressing is taught to buy practical clothes and lay them out daily in the order to be put on as well as to give step-by-step instructions and praise. Looking to the future, Dr. Schulz noted that families will increasingly be able to find support for decision-making and care through online sources, such as www.lotsahelpinghands.com, which offers a free social network and allows users to sign up for the purpose of helping each other.

A Final Thought - Focusing on the Person

With biomedical solutions such as medications not readily available to ease the behavioral and psychiatric symptoms of dementia, the conference reminded attendees to focus on the humanity of the affected **person**. While often thought of in terms of brain impairment, behavioral and psychiatric symptoms are, more often than not, expressions of need made when language escapes the person. Needs such as hunger, thirst, pain, fear, and loneliness expressed in behaviors demand a personal intervention grounded in knowledge of the person and the nuances of how dementia has affected the individual. Most importantly, such behavioral expressions require our empathy and compassion.

While we strive to find effective treatments and prevention strategies for Alzheimer's disease and other dementias, all of us at UCI MIND stand in solidarity with the families affected today. Through research, education, and service to our community, we continuously seek to empower families to face their daily challenges with dignity, strength, and hope.