### What if this person also lived with dementia?

<table>
<thead>
<tr>
<th>Time</th>
<th>Medications</th>
<th>Non-pharmacologic Therapy</th>
<th>All Day</th>
<th>Periodic</th>
</tr>
</thead>
<tbody>
<tr>
<td>7 AM</td>
<td>Ipratropium MDI, Albuterol 70mg weekly</td>
<td>Check feet: flat upright, 30 mm; Check blood sugar</td>
<td>Joint protection; Energy conservation; Exercise (non-weight bearing if severe foot disease); weight bearing (for ADL)</td>
<td>Pneumonia vaccine, Yearly influenza vaccine</td>
</tr>
<tr>
<td></td>
<td></td>
<td>2.4g Na, 10g K, Adequate Mg, L, cholecalciferol &amp; ascorbate, fat, medical nutrition therapy for diabetes, DASH</td>
<td>Exercise (non-weight bearing if severe foot disease); weight bearing (for ADL); Muscle strengthening exercises, Aerobic, Exercise ROM exercises</td>
<td>All provider visits: Evaluate foot, monitoring: blood glucose, foot exam and BD</td>
</tr>
<tr>
<td>9 AM</td>
<td>Diuretics: HCTZ 12.5 mg, Lisinopril 40mg, Glyburide 10 mg, ECAAGA 81 mg, Midodrin 80mg, Naproxen 250mg, Omeprazole 20mg</td>
<td>Diet as above; Avoid environmental exposures that might exacerbate COPD; Wear appropriate footwear</td>
<td>Avoid environmental exposures that might exacerbate COPD; Wear appropriate footwear; Avoid environmental exposures that might exacerbate COPD; Wear appropriate footwear</td>
<td>Quarterly HBA1c, brain MRI and LFTs; Yearly creatinine, electrolytes, microalbuminuria, cholestrol, Renal function, Pulmonary rehabilitation</td>
</tr>
<tr>
<td>12 PM</td>
<td>Ipratropium MDI, Calcium = VL D 500 mg</td>
<td>Diet as above; Avoid environmental exposures that might exacerbate COPD; Wear appropriate footwear</td>
<td>Avoid environmental exposures that might exacerbate COPD; Wear appropriate footwear; Avoid environmental exposures that might exacerbate COPD; Wear appropriate footwear</td>
<td>Physical Therapy; DEKA scan every 2 years; Yearly eye exam; Medical nutrition therapy; Patient Education: High-risk foot conditions, foot care, foot wear; Osteocare; COPD medication and delivery systems training; Diabetes Mellitus</td>
</tr>
<tr>
<td>5 PM</td>
<td>Ipratropium MDI, Calcium = VL D 500 mg</td>
<td>Diet as above; Avoid environmental exposures that might exacerbate COPD; Wear appropriate footwear</td>
<td>Avoid environmental exposures that might exacerbate COPD; Wear appropriate footwear; Avoid environmental exposures that might exacerbate COPD; Wear appropriate footwear</td>
<td>Physical Therapy; DEKA scan every 2 years; Yearly eye exam; Medical nutrition therapy; Patient Education: High-risk foot conditions, foot care, foot wear; Osteocare; COPD medication and delivery systems training; Diabetes Mellitus</td>
</tr>
<tr>
<td>7 PM</td>
<td>Ipratropium MDI, Calcium = VL D 500 mg</td>
<td>Diet as above; Avoid environmental exposures that might exacerbate COPD; Wear appropriate footwear</td>
<td>Avoid environmental exposures that might exacerbate COPD; Wear appropriate footwear; Avoid environmental exposures that might exacerbate COPD; Wear appropriate footwear</td>
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</tr>
</tbody>
</table>

*Boyd et al. JAMA 2005;294:716-724*
Prevalence of multiple chronic conditions (including dementia) as a function of age, stratifying on socio-economic status

On socioeconomic status scale, 1=most affluent and 10=most deprived.” From Barnett et al., Lancet 2012, 380(9836): 37-43
Promising Opportunities: Targeting Sensory Impairments and Dementia

Cognitive Load
Brain Structure, Function Networks
Depression
Social Isolation
Reduced Activity

Common Etiology (e.g., aging, vascular disease)


American Geriatrics Society and National Institute on Aging Bench-to-Bedside Conference: Sensory Impairment and Cognitive Decline in Older Adults
Promising Evidence-based approaches for PLWD

**APPROACHES**
- **Cognitive Decline**: i.e., Cognitive Stimulation; Reality orientation; Exercise
- **Functional Decline**: i.e., Occupation-based; In-home modifications
- **Behavioral Expressions**: i.e., Tailored activities; Massage and touch, Music, Animal or CBT therapy

**OUTCOMES**
- Cognition and memory, Quality of life and mood
- Cognitive decline, Functional decline, Aggression and agitated behaviors, Depressive symptoms

[Gaugler, Jutkowski, & Gitlin (2020)]
#DementiaCareSummit
Promising Evidence-based approaches for family care partners & staff care providers

- Programs: i.e., Psychoeducation; Counseling; Problem-solving; Skill building; Social support; Respite

- Elements of Effectiveness: Multicomponent; Tailored; Assess needs and risks; Skill building and education; In-home; Experiential training

- Resources:
  - https://bpc.caregiver.org/
  - https://nursinghometoolkit.com

- Well-being, self-efficacy, confidence, health behaviors, better communication, knowledge, attitude toward dementia

- Depression, burden, and distress

[Gitlin & Hodgson (2020); Gitlin, Justkowski, & Gaugler (2020)]  #DementiaCareSummit
Step 1: What Outcomes Matter to a PLWD & their care partners?

Outcomes related TO IMPACT

How do we think about what a successful impact of an evidence-based approach would look like from the perspective of the PLWD and care partners?

Outcomes related TO CARE DELIVERY & PROCESSES

How do we think about what elements of care delivery are important from the perspective of the PLWD and care partners?

[Desai et al. (2016); Okonkwo et al. (2018); O'Rourke et al. (2015); Wolverson, Clarke, & Moniz-Cook (2016)]

@DementiaCareSummit
Step 2: Models to Guide Outcome Impact Development: How do we define success?

THE GOOD LIFE MODEL*
A multi-dimensional framework for assessing, intervening, supporting, and evaluating

PSYCHOLOGICAL WELLBEING
i.e., Positive affect, hope, joy

BEHAVIORAL COMPETENCE
i.e., Physical function, cognitive status

QUALITY OF LIFE; PERSONHOOD; SELF
i.e., Sense of purpose, Personal growth, dignity

OBJECTIVE ENVIRONMENT
i.e., Social support, Sense of place

PERCEIVED VALUATION OF LIFE

*Griff & Hodgson (2018); Lawton (1983); Desai et al. (2016); O'Connel et al. (2018); O'Rourke et al. (2015); Wolverson, Clarke, & Moriz-Cook (2016)

#DementiaCareSummit
Step 2: Frameworks to guide alignment of care processes with care impact: How do we define optimal dementia care?
Who provides care for people living with dementia?

**Employment (in thousands)**

- Personal care aides
- Nursing assistants
- Counselors
- Registered nurses
- Social workers
- Lic practical nurses
- Home health aides
- Physicians
- EMTs & paramedics
- Physical therapists
- CHWs
- Occ therapists

Most employment is in occupations that do not require a college degree.

Source: U.S. Bureau of Labor Statistics, industry-occupation matrix, 2018

#DementiaCareSummit
Dually eligible beneficiaries

The dually eligible population
- Higher incidence of chronic conditions, disability:
  - 41% have at least one mental health dx
  - 41% eligible for Medicare due to disability (vs. 8% for non-dual Medicare beneficiaries)
  - About half use long term services and supports
  - 19% have Alzheimer’s or related dementia

How it works
- Dually eligible beneficiaries navigate two separate programs:
  - Medicare for the coverage of most preventive, primary, and acute health care services and drugs
  - Medicaid for the coverage of long-term care supports and services, certain behavioral health services, and for help with Medicare premiums and cost-sharing
  - Where benefits overlap, Medicare is primary payer

12 million individuals are simultaneously enrolled in Medicare and Medicaid
Age at evaluation

![Age distribution chart]

- Proportion of respondents (%)
- 0-19
- 20-29
- 30-39
- 40-49
- 50-59
- 60 and older

- Family survey
- Clinician survey

7/30/2020
Anke Hüls, PhD
Clinical outcome of COVID-19 in hospitalized patients

- Males die more often than females, as in the general population
- The overall proportion of deaths seems to be similar to the general population
- However, we do not know whether those with Down syndrome are sent to the hospital at the same rate or for the same signs/symptoms

Proportion of COVID-19 deaths in hospital

- General population UK: 3269/8799
- General population NYC: 1896/6169
- General population Spain: 337/1499
- General population Spain: 216/1135
- General population Spain: 286/1019
- General population Spain: 174/1152
- Individuals with DS: 44/136
- Individuals with DS: 22/105

7/30/2020
Anke Huels, PhD
Medical complications increase risk of mortality

- 59% of the cases reported by a clinician experienced medical complications
- The most common medical complications were pneumonia and acute respiratory distress syndrome
- Medical complications increase the risk for mortality
Potential risk factors for mortality among COVID-19 patients with Down syndrome

Risk factors:
- Age (older than 40 years)
- Obesity
- Alzheimer disease/dementia
- Male

Potential risk factors:
- Gastroesophageal reflux
- Seizures/epilepsy
- Obstructive sleep apnea

No evidence for increased risk:
- Living condition (residential care facility)
- Level of intellectual disability
- Thyroid disorder
- Congenital heart defect
- Behavioral/psychiatric condition

7/30/2020
Anke Huis, PhD
Further understanding the connection between Alzheimer’s disease and Down syndrome

Heather M. Snyder1,2 | Lisa J. Bane3 | Adam M. Brislawn2 | Marie C. Carrillo1
Anna J. Edelson4 | Joaquin M. Espinosa5 | Fabian Fernandez6 | Juan Forteza2
Siobhan Hartley7 | Elizabeth Head8 | James Hendrix9 | Priya S. Kishnani2
Florence Li10 | Patrício Liao10 | Cynthia Lemora10 | William Molter10
Elke J. Mufson11 | Huntington Potter10 | Shahid Hussain10 | Anne-Charlotte Grahovac10,12 | H. Diana Ross12 | Andre Strydom13
Michelle Sie Whitten14 | Michael E. Rafi15

1Department of Laboratory Medicine and Pathology, Mayo Clinic, Rochester, Minnesota, USA
2Department of Neurology, Massachusetts General Hospital, Harvard Medical School, Boston, Massachusetts, USA
3Division of Genomics and Personalized Medicine, Mayo Clinic Florida, Jacksonville, Florida, USA
4Department of Neurology, Columbia University Irving Medical Center, New York, New York, USA
5Department of Neurology, University of Pennsylvania School of Medicine, Philadelphia, Pennsylvania, USA
6Department of Neurology, University of California, Irvine, California, USA
7Department of Neurology, Duke University Medical Center, Durham, North Carolina, USA
8Department of Neurology, University of California, San Francisco, California, USA
9Division of Genomics and Personalized Medicine, Mayo Clinic Florida, Jacksonville, Florida, USA
10Department of Neurology, Mayo Clinic, Rochester, Minnesota, USA
11Department of Neurology, University of California, San Francisco, California, USA
12Department of Neurology, University of California, San Francisco, California, USA
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Abstract
Improved medical care of individuals with Down syndrome (DS) has led to an increase in life expectancy over the age of 60 years. In this review, there has been an increase in the prevalence of Alzheimer’s disease (AD) in DS. This review examines evidence supporting the hypothesis that DS and AD share common biological hallmarks and suggests that further understanding of this overlap may help to identify potential therapies to treat AD.

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Effectively training professional caregivers to screen and refer persons with dementia and intellectual disability

Art Walszczak, MD1, Molly Schroeder, CSW2, Jody Krainer, MSW, LCSW, MBA3, Gregory Prickett, PsyD1, Nickell Wilczanski, MS, CTRS4, Sarah Endicot, DNP, APNP, GNP-BC5, Tammi Albrecht, DNP2, Cynthia M. Carlson, MS, MD1, Jane Mahoney, MD1

1University of Wisconsin School of Medicine & Public Health, 2Wisconsin Alzheimer’s Institute, 3Gundersen Health System, 4Aptiv, Inc., 5University of Wisconsin School of Nursing

BACKGROUND

By age 40, almost all people with Down syndrome, the most common cause of intellectual disability (ID), have neuropathological changes consistent with Alzheimer’s disease. By age 50, about half have dementia. Detecting dementia in persons with ID can be challenging because baseline cognitive impairment can be severe and because persons with ID may have difficulty reporting symptoms.

The National Task Group Early Detection Screen for Dementia (NTG-EDSD) was developed to aid detection of cognitive impairment in adults with ID. We implemented an educational curriculum using the NTG-EDSD to increase the ability of professional caregivers to identify and support persons with ID and dementia.

METHODS

From November 2018 to April 2019, we held three in-person training sessions for professional caregivers of persons with intellectual disability, partnering with various managed care organizations and social services agencies across the State of Wisconsin. We assessed knowledge and attitudes at baseline, immediately after training, and one week, one month and six months after training.

RESULTS

104 direct care workers, case managers, healthcare providers, and other social services staff participated in the training (demographics in Table 1). Through 98 participants indicated that their organizations already used NTG-EDSD, only 20% indicated that they were ‘very’ or ‘quite confident’ using the tool. Other screening tools they reported using to detect cognitive impairment included animal naming (11.0%) and the Mini-Cog (11.0%).

Satisfaction with the NTG-EDSD training was very high (Figure 1), and 94.0% of participants agreed or strongly agreed that they could use the NTG-EDSD tool with their clients. Participants reported a marked increase in confidence in their ability to track various health circumstances and detect functional decline in their clients (post-training immediately after the training (Table 2). At one-month follow-up (compared with pre-training), participants found the NTG-EDSD questionnaire to be feasible and usable on a wide variety of measures (Table 3). Participants’ gains in confidence were generally not sustained at six-month follow-up. Some feasibility gains were lost after six months, but few measures reached statistical significance due to a small portion of the sample completing both baseline and 6-month follow-ups.

Following the training, one managed care organization, serving 62 of 72 counties in Wisconsin, made the NTG-EDSD a standard part of its assessment of adults with Down syndrome starting at age 40.

CONCLUSIONS

A wide variety of social services and healthcare professionals can be effectively trained to detect dementia in persons with intellectual disability (ID) using a standardized screening tool, the NTG-EDSD. Participants were highly satisfied with the training, experienced an increase in confidence in their care of person with ID, and found the NTG-EDSD feasible to use. This educational intervention can lead to changes in practice at a systems level. Some gains were not sustained over time, suggesting that repeated interventions may be necessary.

We plan on disseminating our training materials throughout the Wisconsin Alzheimer’s Institute website. Other next steps could include (1) assessing the impact of this training on healthcare outcomes in persons with ID, and (2) ensuring that the tool is applicable to persons from a wide range of ethnic, racial and socioeconomic backgrounds.

REFERENCES


Figures

Table 1. Demographics of participants

<table>
<thead>
<tr>
<th>Characteristic</th>
<th>N (%) / M (SD)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Professional role</td>
<td></td>
</tr>
<tr>
<td>- Case manager or care coordinator</td>
<td>92 (39.7)</td>
</tr>
<tr>
<td>- Direct care worker</td>
<td>11 (7.1%)</td>
</tr>
<tr>
<td>- Health educator</td>
<td>20 (13.6%)</td>
</tr>
<tr>
<td>- ADL</td>
<td>10 (5.3%)</td>
</tr>
<tr>
<td>- Other</td>
<td>21 (13.7%)</td>
</tr>
<tr>
<td>Age</td>
<td></td>
</tr>
<tr>
<td>- Years in Res of aging or dementia</td>
<td>7.6 (3.2)</td>
</tr>
<tr>
<td>- Years in Res of ID</td>
<td>11.3 (3.5)</td>
</tr>
<tr>
<td>Gender</td>
<td></td>
</tr>
<tr>
<td>- Female</td>
<td>164 (93.5%)</td>
</tr>
<tr>
<td>- Male</td>
<td>11 (6.5%)</td>
</tr>
<tr>
<td>Ethnicity</td>
<td></td>
</tr>
<tr>
<td>- Not Hispanic/Latino</td>
<td>167 (95.0%)</td>
</tr>
<tr>
<td>- Hispanic/Latino</td>
<td>7 (4.5%)</td>
</tr>
<tr>
<td>Race</td>
<td></td>
</tr>
<tr>
<td>- American/Indian Origin</td>
<td>12 (6.5%)</td>
</tr>
<tr>
<td>- Asian/Pacific Island</td>
<td>10 (5.3%)</td>
</tr>
<tr>
<td>- Other</td>
<td>138 (76.3%)</td>
</tr>
<tr>
<td>Age</td>
<td></td>
</tr>
<tr>
<td>- 5-12 years</td>
<td>9 (19.2%)</td>
</tr>
<tr>
<td>- 13-15 years</td>
<td>68 (12.4%)</td>
</tr>
<tr>
<td>- 16-18 years</td>
<td>46 (22.5%)</td>
</tr>
</tbody>
</table>

Table 2. Confidence in ability to track health circumstances & functional decline

<table>
<thead>
<tr>
<th>Domain</th>
<th>Pre</th>
<th>Post</th>
<th>p-value</th>
</tr>
</thead>
<tbody>
<tr>
<td>Interpersonal disability</td>
<td>2.01</td>
<td>2.33</td>
<td>&lt;0.001</td>
</tr>
<tr>
<td>Changes in mood or behavior</td>
<td>2.69</td>
<td>2.95</td>
<td>&lt;0.001</td>
</tr>
<tr>
<td>Significant life events</td>
<td>2.00</td>
<td>2.54</td>
<td>&lt;0.001</td>
</tr>
<tr>
<td>Diagnosis of new cognitive impairment</td>
<td>2.07</td>
<td>2.32</td>
<td>&lt;0.001</td>
</tr>
<tr>
<td>Decline in ADL</td>
<td>2.55</td>
<td>2.86</td>
<td>&lt;0.001</td>
</tr>
<tr>
<td>Changes in memory</td>
<td>2.11</td>
<td>2.49</td>
<td>&lt;0.001</td>
</tr>
<tr>
<td>Changes in behavior &amp; affect</td>
<td>2.20</td>
<td>2.48</td>
<td>&lt;0.001</td>
</tr>
</tbody>
</table>

Table 3. Feasibility of using NTG-EDSD questionnaire

<table>
<thead>
<tr>
<th>Domain</th>
<th>Pre</th>
<th>Post</th>
<th>p-value</th>
</tr>
</thead>
<tbody>
<tr>
<td>Demographics</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Age of first diagnosis</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Years in ID</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Years of aging or dementia</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Education</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>- Overall education</td>
<td>80 (18%)</td>
<td>80 (18%)</td>
<td>1.00</td>
</tr>
<tr>
<td>- Technical college</td>
<td>58 (19%)</td>
<td>58 (19%)</td>
<td>1.00</td>
</tr>
<tr>
<td>- Graduate school</td>
<td>46 (20%)</td>
<td>46 (20%)</td>
<td>1.00</td>
</tr>
</tbody>
</table>

A few statistically significant changes at six-month follow-up
Effectively training professional caregivers to screen and refer persons with dementia and intellectual disability

Art Walaszek, MD,1,2, Molly Schroeder, CSW, Jody Kraynen, MSW, LCSW, MBA, Gregory Prickett, PsyD, Nichell Wilonski, MS, CTR54, Sarah Endicott, DNP, APNP, GNP, BC5, Tammi Albrecht, DNP,2, Cynthia M. Carlsson, MD, MS,1,2, Jane Mahoney, MD1

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RESULTS

154 direct care workers, case managers, healthcare providers, and social services staff participated in the training (demographics in Table 1). Through 98 participants indicated that their organizations already used NTG-EDSS, only 20.1% indicated they were “very” or “quite confident” using the tool. Other screening tools they reported using to detect cognitive impairment included animal naming (11.0%) and the Mini-Cog (11.0%).

Satisfaction with the NTG-EDSS training was very high (Figure 1), and 94.0% of participants agreed or strongly agreed that they could use the NTG-EDSS tool with their clients. Participants reported a marked increase in confidence in their ability to track various health circumstances and detect functional decline in their clients (pre-training vs immediately after the training) (Table 2). At one-month follow-up (compared with prior to training), participants found the NTG-EDSS questionnaire to be feasible to use on a wide variety of measures (Table 3). Participants’ gains in confidence were generally not sustained at 6-month follow-up. Some feasibility gains were sustained at 6 months, but few measures reached statistical significance due to only a small portion of the sample completing both baseline and 6-months follow-ups.

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FIGURES & TABLES

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<tr>
<th>Characteristic</th>
<th>% (SD)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Gender</td>
<td></td>
</tr>
<tr>
<td>Female</td>
<td>144 (0.35)</td>
</tr>
<tr>
<td>Race</td>
<td></td>
</tr>
<tr>
<td>Asian/Asian-American</td>
<td>0.6%</td>
</tr>
<tr>
<td>Caucasian</td>
<td>21.3%</td>
</tr>
<tr>
<td>Black/African-American</td>
<td>7.4%</td>
</tr>
<tr>
<td>Hawaiian/NativePacific Islander</td>
<td>1.6%</td>
</tr>
<tr>
<td>White</td>
<td>130 (69.9%)</td>
</tr>
<tr>
<td>Educational level</td>
<td></td>
</tr>
<tr>
<td>0-12 years</td>
<td>83 (63.0%)</td>
</tr>
<tr>
<td>13-17 years</td>
<td>98 (73.0%)</td>
</tr>
<tr>
<td>Special education</td>
<td></td>
</tr>
<tr>
<td>Graduate</td>
<td>45 (35.3%)</td>
</tr>
</tbody>
</table>

Table 2. Feasibility of using NTG-EDSS questionnaire

<table>
<thead>
<tr>
<th>Question</th>
<th>Pre</th>
<th>Post</th>
<th>p-value</th>
</tr>
</thead>
<tbody>
<tr>
<td>Questions allow for an accurate representation of the person</td>
<td>2.69</td>
<td>3.15</td>
<td>0.06</td>
</tr>
<tr>
<td>I have sufficient experience with ID to complete questionnaires</td>
<td>2.77</td>
<td>3.23</td>
<td>0.07</td>
</tr>
<tr>
<td>Questions are not coherent</td>
<td>2.58</td>
<td>2.92</td>
<td>0.012</td>
</tr>
<tr>
<td>Instructions for using the tool are comprehensible</td>
<td>3.16</td>
<td>3.60</td>
<td>0.005</td>
</tr>
<tr>
<td>The tool is completed</td>
<td>1.77</td>
<td>1.16</td>
<td>1.0</td>
</tr>
<tr>
<td>The purpose of the questionnaires is clear</td>
<td>2.83</td>
<td>3.23</td>
<td>0.031</td>
</tr>
<tr>
<td>Using the questionnaire for periodic assessments would be meaningful</td>
<td>2.68</td>
<td>3.39</td>
<td>0.001</td>
</tr>
</tbody>
</table>

Table 3. Feasibility of using NTG-EDSS questionnaire

<table>
<thead>
<tr>
<th>Measure</th>
<th>Pre</th>
<th>Post</th>
<th>p-value</th>
</tr>
</thead>
<tbody>
<tr>
<td>Intellectual disability</td>
<td>2.10</td>
<td>2.33</td>
<td>0.003</td>
</tr>
<tr>
<td>Changes in mental health</td>
<td>2.24</td>
<td>2.39</td>
<td>0.032</td>
</tr>
<tr>
<td>Significant life events</td>
<td>2.50</td>
<td>2.54</td>
<td>0.001</td>
</tr>
<tr>
<td>Diagnosis of mild cognitive impairment or dementia</td>
<td>2.32</td>
<td>0.001</td>
<td></td>
</tr>
<tr>
<td>Dementia in ADLs</td>
<td>2.50</td>
<td>2.00</td>
<td>0.002</td>
</tr>
<tr>
<td>Changes in memory</td>
<td>2.11</td>
<td>2.48</td>
<td>0.001</td>
</tr>
<tr>
<td>Changes in behavior and affect</td>
<td>2.22</td>
<td>2.46</td>
<td>0.001</td>
</tr>
</tbody>
</table>

REFERENCES


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