

What if this person also lived with dementia?

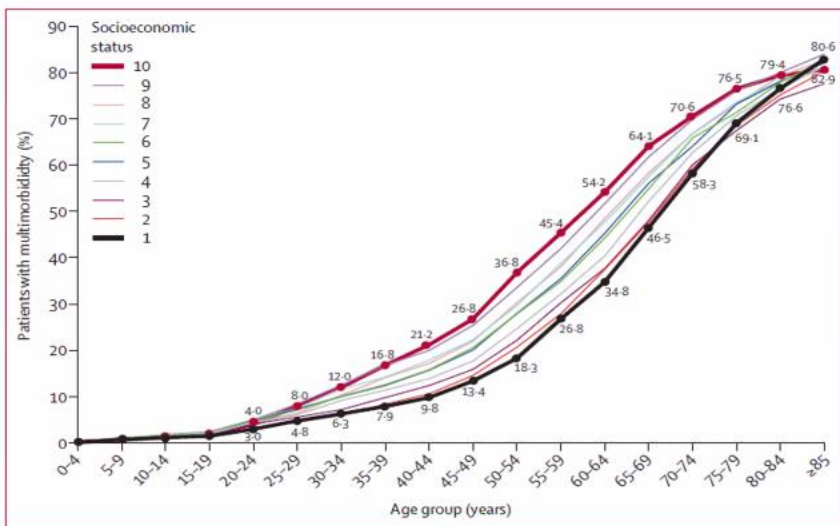
| Time | Medications | Non-pharmacologic Therapy | All Day | Periodic |
|-------|---|--|--|---|
| 7 AM | Ipratropium MDI Alendronate 70mg weekly | Check feet Sit upright 30 min. Check blood sugar | Joint protection Energy conservation | Pneumonia vaccine, Yearly influenza vaccine |
| 8 AM | Eat Breakfast HCTZ 12.5 mg Lisinopril 40mg Glyburide 10 mg ECASA 81 mg Metformin 850mg Naproxen 250mg Omeprazole 20mg Calcium + Vit D 500mg | 2.4gm Na, 90mm K, Adequate Mg, ↓ cholesterol & saturated fat, medical nutrition therapy for diabetes, DASH | Exercise (non-weight bearing if severe foot disease, weight bearing for osteoporosis) Muscle strengthening exercises, Aerobic Exercise ROM exercises | All provider visits: Evaluate Self-monitoring blood glucose, foot exam and BP Quarterly HbA1c, biannual LFTs Yearly creatinine, electrolytes, microalbuminuria, cholesterol <u>Referrals:</u> Pulmonary rehabilitation |
| 12 PM | Eat Lunch Ipratropium MDI Calcium+ Vit D 500 mg | Diet as above | Avoid environmental exposures that might exacerbate COPD Wear appropriate footwear | Physical Therapy DEXA scan every 2 years Yearly eye exam |
| 5 PM | Eat Dinner | Diet as above | Albuterol MDI prn Limit Alcohol Maintain normal body weight | Medical nutrition therapy <u>Patient Education:</u> High-risk foot conditions, foot care, foot wear Osteoarthritis COPD medication and delivery system training Diabetes Mellitus |
| 7 PM | Ipratropium MDI Metformin 850mg Naproxen 250mg Calcium 500mg Lovastatin 40mg | | | |
| 11 PM | Ipratropium MDI | | | |

Boyd et al. JAMA 2005;294:716-724



Cynthia Boyd

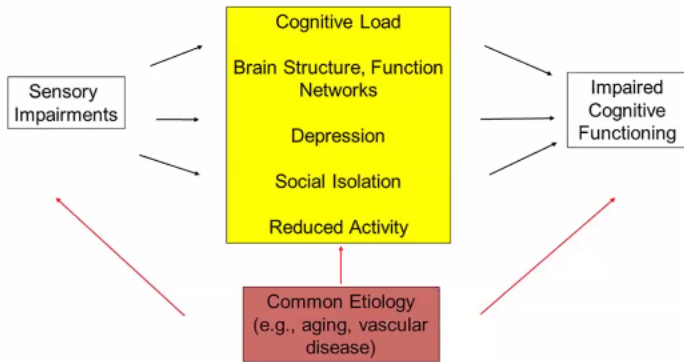
Prevalence of multiple chronic conditions (including dementia) as a function of age, stratifying on socio-economic status



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



Journal of the American Geriatrics Society, Volume: 66, Issue: 11, Pages: 2052-2058, First published: 24 September 2018, DOI: (10.1111/jgs.15506)

American Geriatrics Society and National Institute on Aging Bench-to-Bedside Conference: Sensory Impairment and Cognitive Decline in Older Adults



Cynthia Boyd

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



Kimberly Van Haitsma

Promising Evidence-based approaches for family care partners & staff care providers

APPROACHES

- 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>

OUTCOMES

- Well-being, self-efficacy, confidence, health behaviors, better communication, knowledge, attitude toward dementia
- Depression, burden, and distress



[Gitlin & Hodgson (2020); Gitlin, Jutkowski, & Gaugler (2020)]

#DementiaCareSummit



Kimberly Van Haitsma

Document Recovery

PowerPoint has recovered the following files. Save the ones you wish to keep.

- concludingcider_... Version created from 6/26/2020 21:07
- ppt54EA.pptm [A... Version created from 7/9/2020 22:00
- pptA500.pptm [A... Version created from 7/16/2020 11:43

Step 1: What Outcomes Matter to a PLWD & their care partners?

| | |
|---|---|
| Outcomes related TO IMPACT | How do we think about <u>what a successful impact of an evidence-based approach would look like</u> from the perspective of the PLWD and care partners? |
| Outcomes related TO CARE DELIVERY & PROCESSES | How do we think about <u>what elements of care delivery</u> are important from the perspective of the PLWD and care partners? |

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

RESEARCH SUMMIT ON DEMENTIA CARE Building Evidence for Services and Support

DementiaCareSummit¹²

Zoom Webinar: You are viewing Kim Williamson - RLA's screen

Recording

Speaker View Exit Full Screen

Matthew Jani... Helen Lamont Katie Brandt Lisa McGuire Sheritta Co... Carrie Molke Maria Ordon... alicia Deborah Ois...

Kimberly Van Haitsma

Chat Q&A Closed Caption

Leave

File Home Insert Design Transitions Animations Slide Show Review View Help Acrobat

Cut Copy Paste Format Painter Clipboard

New Slide Reset Section Slides

B I U S AV Aa Font

Text Direction Align Text Convert to SmartArt Paragraph

Shape Fill Shape Outline Shape Effects Drawing

Find Replace Select Editing

Dictate Voice Designer

Document Recovery

PowerPoint has recovered the following files. Save the ones you wish to keep.

- concludingcider_... Version created from 6/26/2020 21:07
- ppt54EA.pptm [A] Version created from 7/9/2020 22:00
- pptA500.pptm [A] Version created from 7/16/2020 11:43

Zoom Webinar You are viewing Kim Williamson - RLA's screen View Options

Recording

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

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

PERCEIVED VALUATION OF LIFE
i.e., Sense of purpose, Personal growth, dignity

*[Gitlin & Hodgson (2018); Lawton (1983)]
[Desai et al. (2016); Oksnebjerg et al. (2018); O'Rourke et al. (2015); Wolverson, Clarke, & Moniz-Cook (2016)]

#DementiaCareSummit

RESEARCH SUMMIT ON DEMENTIA CARE
Building Evidence for Services and Support

Kimberly Van Haitsma

Chat Q&A Closed Caption

Leave

Speaker View Exit Full Screen

Matthew Jani...

Helen Lamont

Katie Brandt

Lisa McGuire

Sheritta Co...

Carrie Molke

Maria Ordon...

alicea

Deborah Ois...

Leave

File Home Insert Design Transitions Animations Slide Show Review View Help Acrobat

Cut Copy Paste Format Painter Clipboard

Layout Reset Section Slides

Font Paragraph

Text Direction Align Text Convert to SmartArt

Drawing

Shape Fill Shape Outline Shape Effects

Find Replace Select

Dictate Design Ideas

Zoom Webinar You are viewing Kim Williamson - RLA's screen View Options

Document Recovery PowerPoint has recovered the files. Save the ones you wish to keep.

- concludingcider_... Version created from 6/26/2020 21:07
- ppt54EA.pptm [A] Version created from 7/9/2020 22:00
- pptA500.pptm [A] Version created from 7/16/2020 11:43

Step 2: Frameworks to guide alignment of care processes with care impact: How do we define optimal dementia care?

2018 DEMENTIA CARE PRACTICE RECOMMENDATIONS



alzheimer's association



Figure 1. Dementia Care Practice Recommendations.

#DementiaCareSummit

EIGHT TIMES OF CARE



Speaker View Exit Full Screen

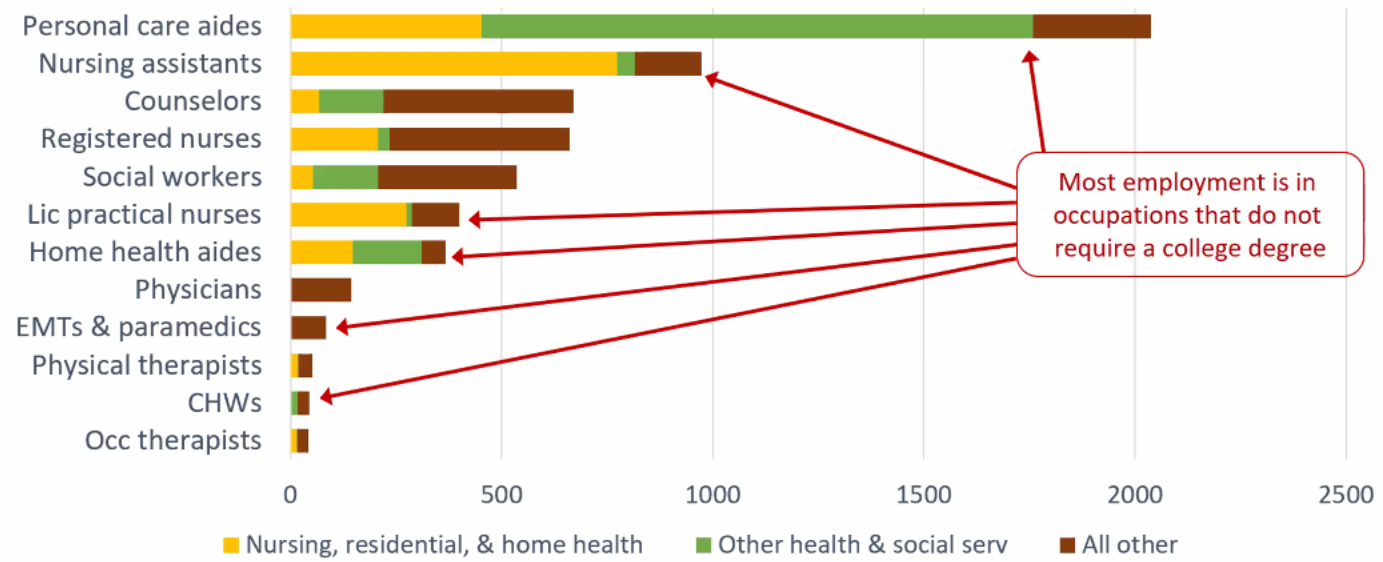
- Matthew Jan...
- Helen Lamont
- Katie Brandt
- Lisa McGuire
- Sheritta Coo...
- Carrie Molke
- Maria Ordon...
- alicea
- Deborah Ois...

Leave

Who provides care for people living with dementia?



Employment (in thousands)

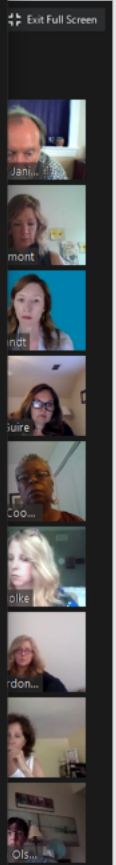


Most employment is in occupations that do not require a college degree



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

WITHIN THIS WORKFORCE, MOST OF



Dually eligible beneficiaries

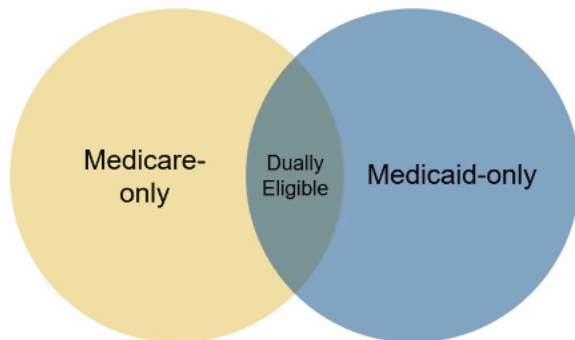
The dually eligible population

- 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



Leave Meeting

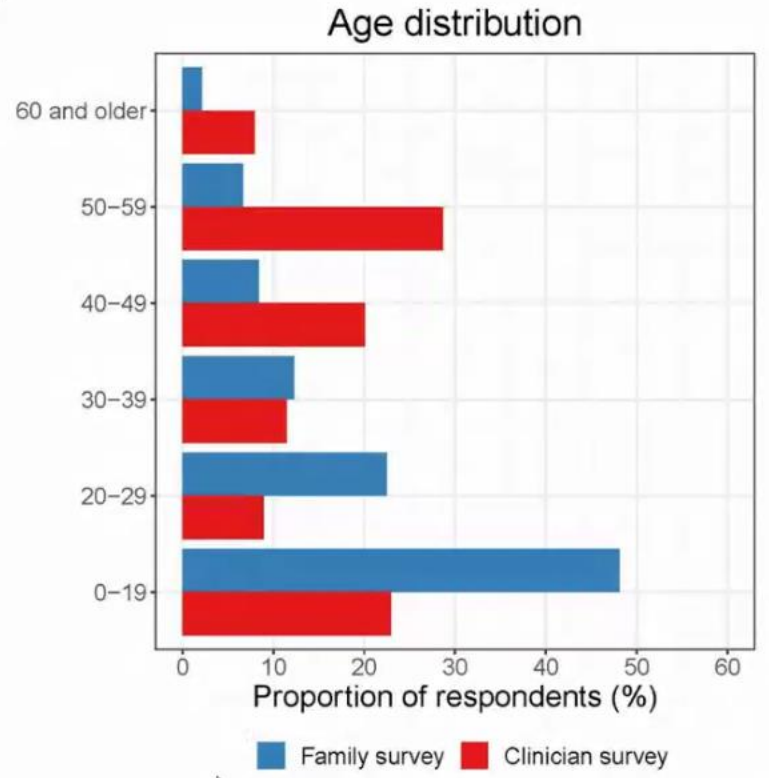
Cancel

MEETING REMINDER: Monday, July 27th at 5:30 and Request - Good Morning! I wanted to remind everyone that our res... 11:58 AM

Your Single Transaction Alert from Chase - This is an Alert to help you manage your credit card account ending in 8502. ... 11:50 AM

Anke Hüls is presenting

Age at evaluation



7/30/2020

Anke Huels, PhD

3

Participant grid showing video feeds and names of attendees:

- Gabriele Bazzocchi
- Anke Hüls (Presenting)
- Elizabeth Corcoran
- Andre Strydom
- +44 771* ****46
- Shiela Puri
- Bryn Gelaro
- David Tolleson
- Helen Powell
- Julian Hallett
- London Jacqueline
- T21 Research Soci...
- National Down Syn...
- Unknown
- Hampus Hillerstrom
- Jim Hendrix

Anke Hüls is presenting

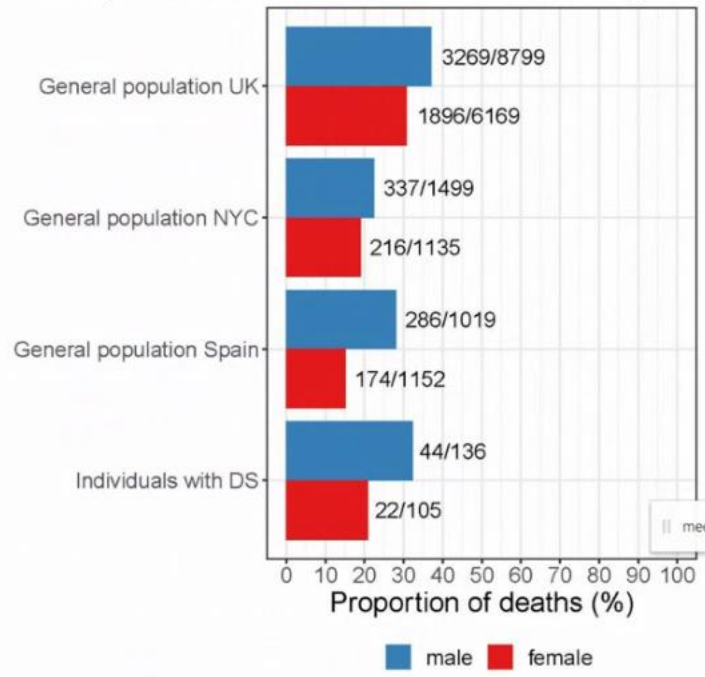
Vicky Ho is also here 10:47 AM You M

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



7/30/2020

Anke Huels, PhD

4

Grid of participant video thumbnails:

- Gabriele Bazzocchi
- Anke Hüls (presenting)
- Elizabeth Corcoran
- Andre Strydom
- +44 771* ****46
- Shiela Puri
- Bryn Gelaro
- David Tolleson
- Helen Powell
- Julian Hallett
- London Jacqueline
- T21 Research Soci...
- National Down Syn...
- Unknown
- Hampus Hillerstrom
- Jim Hendrix

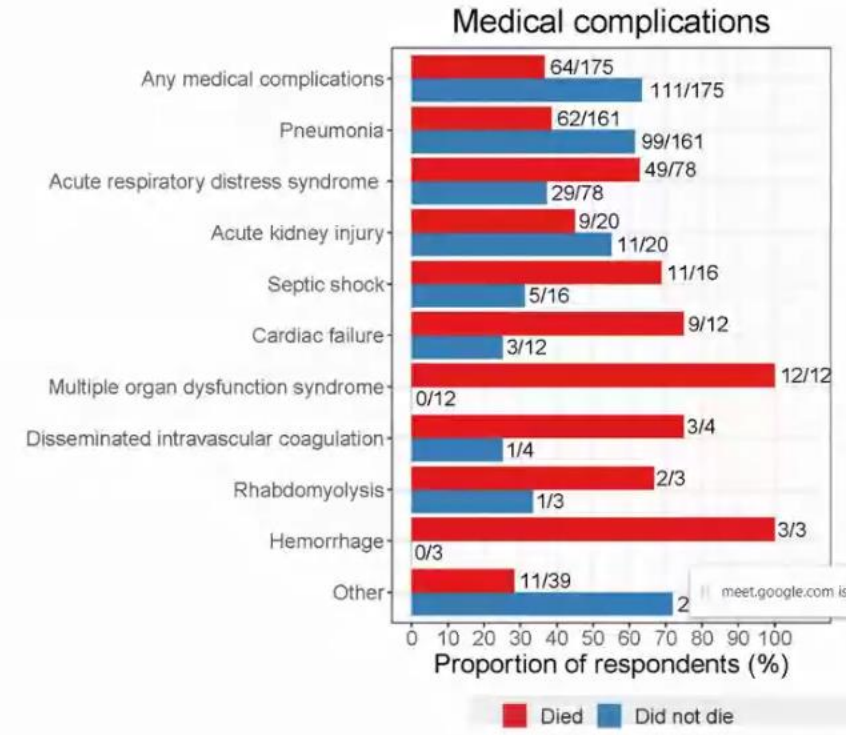
Anke Hüls is presenting

Jim Hendrix and 2 more 11:01 AM You M

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



7/30/2020

Anke Hüls, PhD

6

Grid of video thumbnails for meeting participants:

- Gabriele Bazzocchi
- Anke Hüls (Presenting)
- Elizabeth Corcoran
- Andre Strydom
- +44 771* ****46
- Shiela Puri
- Bryn Gelaro
- David Tolleson
- Helen Powell
- Julian Hallett
- London Jacqueline
- Vicky Ho
- National Down Syn...
- Unknown
- Hampus Hillerstrom
- Sue Buckley

Meeting details ^

Meeting controls: Mute, End call, Screen share

Meeting options: Turn on captions, Anke Hüls is presenting

Anke Hüls is presenting

T21 Research So... and 2 more | 21 | 11:09 AM | You M



Potential risk factors for mortality among COVID-19 patients with Down syndrome

| Risk factors | Potential risk factors | No evidence for increased risk |
|----------------------------|-------------------------|--|
| Age (older than 40 years) | Gastroesophageal reflux | Living condition (residential care facility) |
| Obesity | Seizures/epilepsy | Level of intellectual disability |
| Alzheimer disease/dementia | Obstructive sleep apnea | Thyroid disorder |
| Male | | Congenital heart defect |
| | | Behavioral/psychiatric condition |

meet.google.com is sharing your screen. Stop sharing Hide

7/30/2020

Anke Huels, PhD

7


Meeting details ^

Microphone, End call, Screen share icons

Turn on captions | Anke Hüls is presenting

REVIEW ARTICLE

Further understanding the connection between Alzheimer's disease and Down syndrome

Heather M. Snyder¹  | Lisa J. Bain² | Adam M. Brickman³ | Maria C. Carrillo¹ | Anna J. Esbensen⁴ | Joaquín M. Espinosa⁵ | Fabian Fernandez⁶ | Juan Fortea^{7,8} | Sigan L. Hartley⁹ | Elizabeth Head¹⁰ | James Hendrix¹¹ | Priya S. Kishnani¹² | Florence La¹³ | Patrick Lao¹⁴ | Cynthia Lemere¹⁵ | William Mobley¹⁶ | Elliott J. Mufson¹⁷ | Huntington Potter¹⁸ | Shahid H. Zaman¹⁹ | Ann-Charlotte Granholm^{20,21} | H. Diana Rosas²² | Andre Strydom²³ | Michelle Sie Whitten²⁴ | Michael S. Rafii²⁵

¹Alzheimer's Association, Medical & Scientific Relations, Chicago, Illinois, USA

²Independent Science Writer, Elverson, Pennsylvania, USA

³Department of Neurology, College of Physicians and Surgeons, Taub Institute for Research on Alzheimer's Disease and the Aging Brain, Columbia University, New York, New York, USA

⁴Division of Developmental and Behavioral Pediatrics, Cincinnati Children's Hospital Medical Center & University of Cincinnati College of Medicine, Cincinnati, Ohio, USA

⁵Department of Pharmacology, Linda Crnic Institute for Down Syndrome, University of Colorado School of Medicine, Aurora, Colorado, USA

⁶Departments of Psychology and Neurology, BIOS Institute, and the Evelyn F. McKnight Brain Institute, University of Arizona, Tucson, AZ, USA

⁷Department of Neurology, Hospital de la Santa Creu i Sant Pau, Biomedical Research Institute Sant Pau, Universitat Autònoma de Barcelona, CIBERNED, Barcelona, Spain

⁸Down Medical Center, Catalan Down Syndrome Foundation, Barcelona, Spain

⁹Department of Human Development and Family Studies, University of Wisconsin-Madison, Madison, Wisconsin, USA

¹⁰Department of Pathology & Laboratory Medicine, University of California, Irvine, Irvine, California, USA

¹¹LuMind IDSC Foundation, Burlington, Massachusetts, USA

¹²Division of Medical Genetics, Department of Pediatrics, Duke University Medical Center, Durham, North Carolina, USA

¹³Department of Neurology, Harvard University/Massachusetts General Hospital, Boston, Massachusetts, USA

¹⁴Department of Neurology, Columbia University Irving Medical Center, New York, New York, USA

¹⁵Department of Neurology, Brigham & Women's Hospital and Harvard University, Boston, Massachusetts, USA

¹⁶Department of Neurosciences, University of California, San Diego, San Diego, California, USA

¹⁷Barrow Neurological Institute, Phoenix, Arizona, USA

¹⁸Rocky Mountain Alzheimer's Disease Center and Linda Crnic Institute for Down Syndrome, University of Colorado School of Medicine, Denver, Colorado, USA

¹⁹Cambridge Intellectual & Developmental Disability Research Group, Department of Psychiatry University of Cambridge, Cambridgehire & Peterborough NHS Foundation Trust, Cambridge, UK

²⁰Knoebel Institute for Healthy Aging, University of Denver, Denver, Colorado, USA

²¹Department of Neurobiology, Care Sciences and Society (NVS), Karolinska Institutet, Stockholm, Sweden

²²Department of Neurology and Radiology, Massachusetts General Hospital, Boston, Massachusetts, USA

²³Department of Forensic and Neurodevelopmental Sciences, Psychology and Neuroscience, King's College London, South London and the Maudsley NHS Foundation Trust, London Consortium, Institute of Psychiatry, London, UK

²⁴Global Down Syndrome Foundation, Denver, Colorado, USA

²⁵Alzheimer's Therapeutic Research Institute and Department of Neurology, University of Southern California, Los Angeles, California, USA

Correspondence

Heather M. Snyder, PhD, Alzheimer's Association, Chicago, IL, USA.
Email: hsnyder@alz.org

Abstract

Improved medical care of individuals with Down syndrome (DS) has led to an increase in life expectancy to over the age of 60 years. In conjunction, there has been an increase in

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



Art Walaszek, MD^{1,2}, Molly Schroeder, CSW², Jody Krainer, MSW, LCSW, MBA², Gregory Prichett, PsyD³, Mickell Wilcenski, MS, CTRS⁴, Sarah Endicott, DNP, APNP, GNP-BC⁵, Tammi Albrecht, DNP², Cynthia M. Carlsson, MS, MD^{1,2}, 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 60, 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 five 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

154 direct care workers, case managers, healthcare providers, and other social services staff participated in the training (demographics in **Table 1**). Though 98 participants indicated that their organizations already used NTG-EDSD, 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-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 (pre-training vs immediately after the training) (**Table 2**). At one-month follow-up (compared with prior to training), participants found the NTG-EDSD 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-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 through 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

Esralev, L., Janicki, M.P., DiSpio, M., Jokinen, N., Keller, S.M. and Members of the National Task Group Section on Early Detection and Screening. (2013). National Task Group Early Detection Screen for Dementia: Manual. Available from www.aadmd.org/ntg/screening.

Moran JA, Rafii MS, Keller SM, et al., The National Task Group on Intellectual Disabilities and Dementia Practices consensus recommendations for the evaluation and management of dementia in adults with intellectual disabilities. *Mayo Clin Proc* 2013;88:831-840.

FIGURES & TABLES

Table 1. Demographics of participants

| Characteristic | N(%) / M±SD |
|-------------------------------------|-------------|
| Professional role | |
| - case manager or care coordinator | 92 (59.7%) |
| - direct care worker | 11 (7.1%) |
| - healthcare provider | 20 (13.0%) |
| - health educator | 10 (6.5%) |
| - other | 21 (13.7%) |
| Years in role | 7.8 ± 8.2 |
| Years in field of aging or dementia | 11.7 ± 8.0 |
| Years in field of ID | 11.3 ± 8.6 |
| Gender | |
| - female | 144 (93.5%) |
| Ethnicity | |
| - Not Hispanic/Latino | 147 (95.5%) |
| - Hispanic/Latino | 7 (4.5%) |
| Race | |
| - American Indian/Alaskan Native | 1 (0.6%) |
| - Asian/Asian-American | 3 (1.9%) |
| - Black/African-American | 7 (4.5%) |
| - Hawaiian Native/Pacific Islander | 1 (0.6%) |
| - White | 138 (89.6%) |
| - 2 or more races | 2 (1.3%) |
| Educational level | |
| - 6-12 years | 8 (5.25%) |
| - technical/4-yr college | 98 (63.6%) |
| - graduate school | 45 (29.2%) |

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

| (0=not at all, 3=very confident) | pre | post | p-value |
|--|------|------|---------|
| Intellectual disability | 2.10 | 2.33 | 0.003 |
| Changes in mental health | 2.24 | 2.39 | 0.032 |
| Significant life events | 2.30 | 2.54 | <0.001 |
| Diagnosis of mild cognitive impairment or dementia | 2.03 | 2.32 | <0.001 |
| Declines in ADLs | 2.39 | 2.56 | 0.002 |
| Changes in memory | 2.11 | 2.48 | <0.001 |
| Changes in behavior & affect | 2.20 | 2.48 | <0.001 |

Figure 1. Satisfaction with training

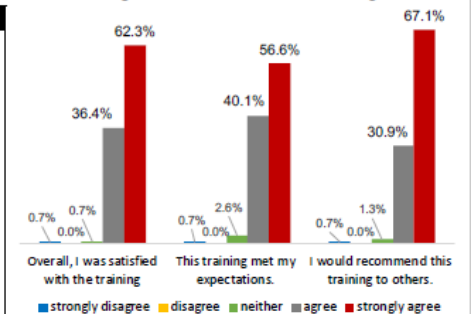


Table 3. Feasibility of using NTG-EDSD questionnaire

| (0=strongly disagree, 4=strongly agree) | pre | 1-mo post | p-value |
|--|------|-----------|---------|
| Questions allow for an accurate representation of the person | 2.69 | 3.15 | 0.08 |
| I have sufficient experience w/ person with ID to complete questionnaire | 2.77 | 3.23 | 0.027 |
| Questions are comprehensible | 2.38 | 2.92 | 0.012 |
| Instructions for using the tool are comprehensible* | 2.46 | 3.08 | 0.005 |
| Tool is complicated | 1.77 | 1.15 | 0.04 |
| The purpose of the questionnaire is clear* | 2.38 | 3.23 | 0.01 |
| Using the questionnaire for periodic reassessments would be meaningful | 2.69 | 3.38 | <0.001 |

* also statistically significant change at 6-month follow-up

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



Art Walaszek, MD^{1,2}, Molly Schroeder, CSW², Jody Krainer, MSW, LCSW, MBA², Gregory Prichett, PsyD³, Mickell Wilcenski, MS, CTRS⁴, Sarah Endicott, DNP, APNP, GNP-BC⁵, Tammi Albrecht, DNP², Cynthia M. Carlsson, MS, MD^{1,2}, 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 60, 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 five 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

154 direct care workers, case managers, healthcare providers, and other social services staff participated in the training (demographics in **Table 1**). Though 98 participants indicated that their organizations already used NTG-EDSD, 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-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 (pre-training vs immediately after the training) (**Table 2**). At one-month follow-up (compared with prior to training), participants found the NTG-EDSD 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-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 through 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

Esrilew, L., Janicki, M.P., DiSipio, M., Jokinen, N., Keller, S.M. and Members of the National Task Group Section on Early Detection and Screening. (2013). National Task Group Early Detection Screen for Dementia: Manual. Available from www.aadmd.org/intg/screening.

Moran JA, Rafii MS, Keller SM, et al., The National Task Group on Intellectual Disabilities and Dementia Practices consensus recommendations for the evaluation and management of dementia in adults with intellectual disabilities. *Mayo Clin Proc* 2013;88:831-840.

FIGURES & TABLES

Table 1. Demographics of participants

| Characteristic | N(%) / M±SD |
|-------------------------------------|-------------|
| Professional role | |
| - case manager or care coordinator | 92 (59.7%) |
| - direct care worker | 11 (7.1%) |
| - healthcare provider | 20 (13.0%) |
| - health educator | 10 (6.5%) |
| - other | 21 (13.7%) |
| Years in role | 7.8 ± 8.2 |
| Years in field of aging or dementia | 11.7 ± 8.0 |
| Years in field of ID | 11.3 ± 8.6 |
| Gender | |
| - female | 144 (93.5%) |
| Ethnicity | |
| - Not Hispanic/Latino | 147 (95.5%) |
| - Hispanic/Latino | 7 (4.5%) |
| Race | |
| - American Indian/Alaskan Native | 1 (0.6%) |
| - Asian/Asian-American | 3 (1.9%) |
| - Black/African-American | 7 (4.5%) |
| - Hawaiian Native/Pacific Islander | 1 (0.6%) |
| - White | 138 (89.6%) |
| - 2 or more races | 2 (1.3%) |
| Educational level | |
| - 6-12 years | 8 (5.25%) |
| - technical/4-yr college | 98 (63.6%) |
| - graduate school | 45 (29.2%) |

Figure 1. Satisfaction with training

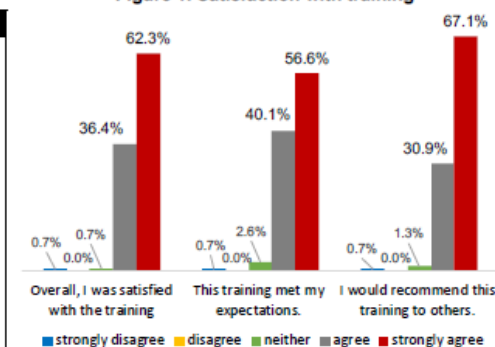


Table 3. Feasibility of using NTG-EDSD questionnaire

| (0=strongly disagree, 4=strongly agree) | pre | 1-mo post | p-value |
|--|------|-----------|---------|
| Questions allow for an accurate representation of the person | 2.69 | 3.15 | 0.08 |
| I have sufficient experience w/ person with ID to complete questionnaire | 2.77 | 3.23 | 0.027 |
| Questions are comprehensible | 2.38 | 2.92 | 0.012 |
| Instructions for using the tool are comprehensible* | 2.46 | 3.08 | 0.005 |
| Tool is complicated | 1.77 | 1.15 | 0.04 |
| The purpose of the questionnaire is clear* | 2.38 | 3.23 | 0.01 |
| Using the questionnaire for periodic reassessments would be meaningful | 2.69 | 3.38 | <0.001 |

* also statistically significant change at 6-month follow-up

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

| (0=not at all, 3=very confident) | pre | post | p-value |
|--|------|------|---------|
| Intellectual disability | 2.10 | 2.33 | 0.003 |
| Changes in mental health | 2.24 | 2.39 | 0.032 |
| Significant life events | 2.30 | 2.54 | <0.001 |
| Diagnosis of mild cognitive impairment or dementia | 2.03 | 2.32 | <0.001 |
| Declines in ADLs | 2.39 | 2.56 | 0.002 |
| Changes in memory | 2.11 | 2.48 | <0.001 |
| Changes in behavior & affect | 2.20 | 2.48 | <0.001 |