2021

Strengthening Capacities to Respond to Dementia with Lifelong Disabilities: Using the Project ECHO Model

Edward F. Ansello
Virginia Commonwealth University, eansello@vcu.edu

Volume 36 Number 2 Spring 2021

age in action

Activities in geriatrics and gerontology education and research
Virginia Center on Aging
and
Virginia Department for Aging and Rehabilitative Services

Case Study

Strengthening Capacities to Respond to Dementia with Lifelong Disabilities: Using the Project ECHO Model

By Edward F. Ansello, PhD

Educational Objectives

1. To discuss the need for interprofessional training about aging with lifelong disabilities and dementia.
2. To demonstrate the continuing heterogeneity among adults growing older with these conditions.
3. To report the relevance of the Project ECHO model as a means of collaborative training and practice improvement.

Background

More adults are growing into later life (ages 55+) with lifelong disabilities such as Down syndrome, other intellectual disabilities, and cerebral palsy. They are beneficiaries of the gift of time because of a number of circumstances, including better management of midlife conditions through medications and the extended survival of their family caregivers. However, upon reaching later life, these individuals tend to encounter healthcare providers who are underprepared or great gaps in related expertise and resources across support and services sectors. If dementia accompanies these lifelong disabilities, odds are even worse.

Interventive care for persons with intellectual and developmental disabilities (I/DD) has been pediatrically driven, in the understandable position that early intervention can improve the course of life. There's been remarkable success, e.g., a doubling of life expectancy within the last decades of the 20th century for those with Down syndrome (Yang et al., 2002). However, healthcare providers have little clinical experience with older adults with lifelong I/DD. Parental care has often limited interactions with health systems that themselves have few providers with combined expertise in healthcare, geriatrics, and I/DD; so providers are undertrained to differentially diagnose dementia from multiple conditions that can create similar behaviors and typically have little or no baseline data on the individual with lifelong disabilities.

Project ECHO, an innovation in distance education that emerged to address healthcare shortfalls in rural and isolated areas, has proven to be especially effective in building interprofessional geriatrics training on dementia with lifelong disabilities.

Project ECHO (Extension for Community Healthcare Outcomes)

Project ECHO employs a technique called

Inside This Issue

guided-practice credited with reducing health disparities in underserved areas around the world (see https://hsc.unm.edu/echo/ for details). Created by the University of New Mexico School of Medicine, ECHO features "telementoring," with virtual interactions, that is not only well-suited to a COVID-19 reality of restricted in-person meetings but is also fully adaptable to an interprofessional focus on under-recognized issues like aging with lifelong disabilities.

Project ECHO uses a Hub-and-Spoke model where subject matter expertise is gathered at the Hub site and providers seeking guidance on that subject matter are at practice or clinical sites elsewhere. In the strict medical model, knowledge-sharing experts at the Hub site constitute a team that leads virtual clinics, "amplifying the capacity for providers to deliver best-in-practice care to the underserved in their own communities." However, the model, as noted, is fully adaptable to non-clinical sites and matters. The Hub-and-Spoke model relies upon an "all-in, all-share, all-learn" approach. After the Hub team shares a brief didactic lesson on a given topic, the Spoke sites share a de-identified case or cases that relate to the topic at hand. Everyone, both Hub and Spokes, is encouraged to offer insights on any given case, possible alternative diagnoses, potential remedies, interventions, related resources, etc.

Growing Older with Intellectual and Developmental Disabilities: When Dementia Is Suspected or Diagnosed

Our Project ECHO on I/DD for healthcare and other service providers addresses an underserved but growing population, offering these providers an interactive, five-part, case-based series to enhance their knowledge, competence, and performance.

Development

The Virginia Geriatric Education Center (VGEC) conducts the Geriatrics Workforce Enhancement Program (GWEP), funded by the Health Resources and Services Administration of the USDHHS for the period 2019-2024. The VGEC partnered with the University of Rhode Island Geriatric Education Center (RIGEC) GWEP to conceive and implement an interprofessional geriatrics training program on helping older adults with lifelong disabilities who have signs of dementia. Both GWEPs recognized this population as a growing segment within their states and saw, as well, a dearth of extant training for professionals. These two GWEPs reached out to colleagues with known expertise in this content area to build a responsive team.

The VGEC and RIGEC partners created an interprofessional Hub team to complement their own expertise by recruiting clinical experts from the National Task Group on Intellectual Disabilities and Dementia Practices (NTG), YAI, Inc. (a New York–based I/DD services provider), and several other organizations.

The overall team included: Edward Ansello, PhD, (Co-Facilitator) Virginia Center on Aging (VCoA) and Virginia Geriatric Education Center (VGEC), Virginia Commonwealth University; Kathleen M. Bishop, PhD, National Task Group on Intellectual Disabilities and Dementia Practices (NTG); Phillip Clark, ScD, (Co-Facilitator) Rhode Island Geriatric Education Center (RIGEC), University of Rhode Island; Catherine Conway, MS, RDN, CDN, CDCES, YAI, Inc.; Samantha Cotton, PhD, MSW, University of Louisville School of Medicine; Ashara Edwards, MS, YAI, Inc.; Faith Helm, MS, RIGEC; Seth Keller, MD, NTG; Matthew Janicki, PhD, NTG; Kathy Service, RN, MS, CFNP-BC, CDDN, NTG; Jennifer Mathews, BS, VCoA and VGEC; Catherine Taylor, BA, RIGEC; and Leland (Bert) Waters, PhD, VCoA and VGEC.

This team tested the waters, so to speak, by conducting in spring 2020 a three-part webinar series to introduce issues of dementia with lifelong disabilities. This series drew over 1,000 participants in total. The webinar series proved our collaborative capabilities and served as advance promotion of the forthcoming ECHO series.

The full team, in turn, worked to develop a virtual, interactive, case-based Project ECHO experience entitled ***Growing Older with Lifelong Intellectual Disabilities: When Dementia Is Suspected or Diagnosed.*** ECHO emphasizes brief, focused interactions, with a session typically lasting only 60-75 minutes.

As noted, ECHO employs a Hub-and-Spoke model

whereby Hub members share their content expertise didactically, that is, in a brief lecture, and through analyses of a case study submitted by one of the Spoke sites. However, the format is not unidirectional, from experts to learners. Once discussion of the submitted case study begins, all participants at the Hub and Spoke sites may offer their perspectives. Because Spoke sites can include representatives from day programs, residential facilities, healthcare practices, and more, and because the case under consideration may relate to a medication regimen, diet and nutrition, clinical care, social supports or other factors, a true interprofessional geriatrics mentality is required in order to address each case effectively. Using the Zoom platform allows everyone to see each other. The discussion produces recommended interventions and resources.

Implementation

Through extensive collaboration over the months that followed the webinar series, this team identified core content areas and related competencies for four 75-minute ECHO sessions during October through December 2020. Each session began with a brief (15-20 minutes) didactic presented by one of our Hub team: 1) Assessment and Diagnosis of Dementia by Seth Keller; 2) Behavior = Communication by Kathy Service; 3) The Difference Physical and Social Environments Can Make through Understanding Sensory Processing and Sensory Impairment by Kathleen Bishop; and 4) Nutritional Concerns by Catherine Conway.

The ECHO series was promoted this way: "This Project ECHO series is a free, practical, case-based education series for health care and other providers who want to enhance their knowledge, competence, and performance related to improving care for people with intellectual and developmental disabilities affected by dementia. Each virtual meeting will include a short presentation by a content expert followed by a case study (submitted in advance by participants), and open discussion to teach and learn from one another."

Each session listed in advance the session's synopsis, objectives, and didactic speaker's qualifications. Typical is the description for the first session:

Assessment and Diagnosis of Dementia
Presented October 19, 2020:
This session includes a discussion of the challenge of assessing a decline in function and making an accurate and appropriate diagnosis of Alzheimer's disease/dementia.

Learning Objectives:
After completing this webinar, participants will be able to:
1. Describe the possible reasons why decline may occur in someone aging with an I/DD
2. Describe what tools may be helpful in determining if dementia is occurring
3. Explain how a family member/caregiver is helpful in providing input to a healthcare provider with dementia care

Presenter(s)/Panelist(s):
Seth M. Keller, MD, Neurologist, Neurology Associates of South Jersey and National Task Group on ID and Dementia Practices.

Dr. Keller in his brief didactic shared observations on how to determine if behavior is attributable to dementia and not to some other condition. The expectation that Down syndrome leads to dementia can lead to "diagnostic overshadowing," that is, the tendency to see what one expects to see. He asked participants to ask, when changes occur: Is the change normative or a sign of disease? Are there co-morbidities that might cause the changes? Could depression be an issue? Further, he recommended assessing functional decline by categories: cognitive, sensory, neuromotor, etc. He cited the NTG's EDSD (Early Detection Screen for Dementia) as an especially helpful first step tool, and, as a neurologist, discussed the benefits of testing for Alzheimer's disease biomarkers like amyloid imaging and cerebral spinal fluid.

This series presented five, real life, de-identified cases in the Project ECHO format of individuals with lifelong disabilities who were diagnosed with or suspected of having dementia. The cases ranged in impairment from mild to severe; not all individuals were ultimately deemed to have dementia, as Down syndrome regression can mimic dementia. The group process helped to create a person-centered, 4Ms

(What Matters to the person, Medications, Mobility, Mentation), interprofessional approach to healthcare and produced practice change recommendations.

After launching the four-part ECHO series, the team added a fifth session to focus on the case of misdiagnosed "dementia" in a young man with I/DD and to revisit cases and group recommendations presented earlier. The overall team partnered with the Special Interest Group on Lifelong Disabilities within the national Geriatrics Workforce Enhancement Program, the Virginia Center on Aging, NTG, the Academy for Gerontology in Higher Education, and others to promote this ECHO series, recruiting for each session 30 or more participants at 13 or more Spoke sites, including those in CA, CO, MA, NJ, NY, OH, OR, RI, and VA.

Follow up in the fifth session revealed that implementation of group recommendations regarding two of the earlier presented cases had already resulted in some improvements within the individuals in the intervening period. While focus was on practice change, participant evaluations, although limited, were very positive and the interprofessional team is implementing another five-session series in spring 2021 based on participants' feedback. Evaluation questions common to the first four sessions included 5-point Likert scales (5 most positive) on the featured didactic, the case study presentation, and the case study discussion by Hub and by Spokes; scores in the four sessions ranged from 3.94 to 4.13; 4.40 to 4.62; 4.57 to 4.86; and 4.81 to 4.94. Intention to train their staffs on session content ranged from 62% to 81% overall. Knowledge gain questions showed consistent positive directionality.

Case Study #1

Ronald is a 48-year old man with Down syndrome who has been diagnosed with early onset Alzheimer's disease. Ronald has been living for the past three years in a mid-size residential facility in the memory care unit. His behavior changed dramatically over a short period of time. He has been having seizures and reports episodes of intense pain. He had transferred here from a small group home when he could no longer keep up with the day program tasks. He began spitting on the floor and running out of the house. This behavior changed, and there is no aggressive behavior or wandering but his irritability, confusion, and disorientation have increased. Ronald's medications include clonazepam (Klonopin), an anti-anxiety tranquilizer, levetiracetam (Keppra) for seizures, and Haldol (2 mg/twice a day) for mood disorders. His history incudes seizures, frequent infections, suspected depression, and myoclonic jerks (involuntary muscle contractions), mostly in the morning.

The Hub and Spokes participants determined that the goal was to promote a better quality of life for Ronald at this stage of his dementia. Participants asked about the composition of his healthcare team (there had not been a neurologist or a pharmacist consultation); if the staff had been creating a behavior log tracking his behaviors (when and where did the seizures and the upsetting behaviors occur, time of day, environmental conditions, presence of people, stimuli, etc.).

A Hub team member noted that myoclonic jerks are common with Down syndrome with Alzheimer's disease, that a frequent side effect of levetiracetam (Keppra) is headaches, that the combination of Haldol and clonazepam could trigger a stroke, and that Keppra could cause irritability; he added that Haldol is a very strong medicine and recommended a consultation with a neurologist to assess his regimen's dosages and appropriateness.

Participants asked if Ronald could be easily distracted when upset; staff answered yes and noted that giving him a mirror calmed things. A Hub team member inquired about sensory processing, as persons with Alzheimer's disease are lost in space and time and are "meaning deaf," unable to understand their surroundings as before; and about sensory impairments, noting the frequency of ear infections among persons with Down syndrome because of their narrowed ear canals; infected ear passages could cause hearing difficulties that trigger inappropriate responses and could also be painful. As well, a heightened sensory sensitivity might mean that Ronald's clothing is irritating him and staff might explore offering more loose fitting clothing. Participants agreed that we need to help Ronald find his place in space; they suggested, among other things, strong contrasting colors along halls and walkways to help guide him.

A participant recommended Music & Memory as an alternative to medications to calm Ronald. As Ronald frequently visits with his family, this music is something that they can enjoy together. A Hub member noted that beating a drum quietly at a pace desired for Ronald might achieve a calm slow down, and reported anecdotes from individuals taking Haldol that they were just as agitated inside, even as externally they were slowed down. One of this session's concluding remarks was that diagnosis is a continuous process.

Case Study #2

Theresa is a 61-year old woman with moderate intellectual disability and severe arthritis who lives with her unmarried sister is an apartment complex. There is very little regular involvement by other members of her family. She loved participating in a supervised day program. She has always been social and warm with peers and staff. A few years ago, the program staff noted changes in her behavior: she stopped one of her favorite activities, writing in her notebooks, and had a period of crying, pouting, and yelling. She became disoriented when walking in familiar places. Her sister took her on vacation to family out of state but she didn't recognize her brother and each night stood in a corner of the room and would not go to bed without coaxing. She had six eye surgeries in 2017 and gall bladder surgery in 2018. In 2018, there were rapid changes in her behavior that included confusion regarding bathroom routine and onset of incontinence (no UTI) that resulted in her leaving the day program. She is now completely bedridden, sleeps during the day, and sleeps little at night, sometimes screaming. She is currently non-verbal.

Theresa has an extensive drug regimen that includes Omeprazole DR (Prilosec) for acid reflux; thyroxine for digestion, etc.; levetiracetam (Keppra) 100mg, twice a day; Tramadol for pain, four times/day; simethicone, an anti-gas, three times/day; diphenhydramine (children's Benadryl) as needed for sleep; quetiapine (Seroquel), anti-psychotic, three times/day; and Tylenol, PRN (as needed). Theresa had been taking lorazepam (Ativan), a sedative, 1 mg, three times/day and again in the evening, 2 mg, for sleep. However, her primary care physician has just discontinued these and has prescribed Haldol, 0.5 mg, three times/day.

The Hub team first addressed Theresa's heavy medication list, saying that some medications don't make sense, particularly taking two different antipsychotics (Haldol and Seroquel). A Hub member stated that Theresa's Keppra dosage was "super low, a pediatric dosage" and she may be having seizures; she should have an EEG to make sure that she isn't. Hub and Spoke participants discussed Theresa's inability to sleep at night and suggested that the timing of the administration of some medications could be affecting sleep. They also questioned whether Theresa may be in more pain at night because of lack of movement all day; obtaining a hospital bed might help with repositioning and prevent pain and bedsores; they noted that giving medications PRN for pain does not work well with someone who is non-communicative. The Hub team asked if anyone was keeping a behavior log to determine when and under what conditions Theresa was evidencing pain.

Participants suggested exploring non-pharmacological interventions for Theresa's sleep and pain. Because Theresa is in bed all day staring at the ceiling, they recommended purchasing a small projector that would project stars or movement on the ceiling. Noting the relative stimulus deprivation she is experiencing, they suggested playing soft Christmas music at bedtime (she loves this music year round), adding a gurgling fountain, and soothing sounds in her room. A participant occupational therapist asked if Theresa has been visited by an OT (she has not) for help with moving and observed that the less one moves, the harder it is to move; others suggested that she might also be moved into other rooms periodically for stimulation but they cautioned that one has to pay attention to her reactions to these added stimuli in case they are too much for her to handle. Because of her taking medications for acid reflux, they asked if Theresa was sitting up when eating and if she lay back down immediately afterward, conditions that could exacerbate reflux and cause pain.

Conclusion

Older adults grow less like each other with increasing age, a process we have long called *individuation* (Janicki & Ansello, 2000). This growing heterogeneity has begun to be recognized formally in healthcare (Ferrucci & Kuchel, 2021). It is critical to understand

that this growing heterogeneity pertains to older adults with I/DD and to care appropriately with interprofessinal responses. The Project ECHO model proved to be an effective means of building interprofessional knowledge and skills about individuals who will increasingly be seen in clinical practices and various supportive services. Participants in this Project ECHO series discussed real-life cases presented by the Hub and Spokes and contributed to diagnoses and treatment recommendations. Cases always engendered more than originally anticipated, so Hub and Spoke participants learned of interventions related to pain management, family caregiving, program eligibility, sensory impairments, drug regimen reviews, screening tools, content resources online and in the community, and more.

The Project ECHO model was productive for interprofessional geriatrics communication. The overall team has developed Series 2 on *Growing Older with Lifelong Intellectual Disabilities: When Dementia Is Suspected or Diagnosed.* It began March 29, 2021 and contains four parts on: Nurturing Brain Health across the Lifespan; Family Dynamics and Communication; Families and Planning for the Future; Medications and ID and ADRD; and may contain a fifth session to introduce a new case and assess the effectiveness of earlier suggested interventions.

Study Questions

1. Why should healthcare providers and supportive services staff receive interprofessional geriatrics training about older adults with lifelong disabilities and dementia?
2. What are some examples of heterogeneity among these older adults?
3. What are the principal features of the Project ECHO model?

Suggested Resources

Down syndrome regression

Ferrucci, L. & Kuchel, G. A. (2021). Editorial: Heterogeneity of aging: Individual risk factors, mechanisms, patient priorities, and outcomes. *Journal of the American Geriatrics Society, 69*, 610-612.

Graham, M.E. (2017). From wandering to wayfaring: Reconsidering movement in people with dementia in long-term care. *Dementia, 16*(6), 732-749.

Janicki, M.P. & Ansello, E.F. (2000). *Community supports for aging adults with lifelong disabilities.* Baltimore, MD: Paul H. Brookes Publishing Co.

National Task Group on Intellectual Disabilities and Dementia Practices

Project ECHO

Virginia Geriatric Education Center

YAI, Inc.

Yang, Q., Rasmussen, S. A., & Friedman, J. M. (2002). Mortality associated with Down's syndrome in the USA from 1983 to 1997: A population-based study. *Lancet, 59,* 1019–1025

About the Author

Dr. Ed Ansello is the Director of the Virginia Center on Aging and the Virginia Geriatric Education Center at Virginia Commonwealth University. He has worked in the field of aging with lifelong disabilities on intersystem collaboration and development since 1986. Currently, he chairs the Area Planning and Services Committee on Aging with Lifelong Disabilities in metropolitan Richmond. You may contact him at eansello@vcu.edu.

This project is supported by the Health Resources and Services Administration (HRSA) of the U.S. Department of Health and Human Services (HHS) under grant numbers U1QHP28737 (URI) and U1QHP28744 (VCU), Geriatrics Workforce Enhancement Program. Information, content, and conclusions are those of the author and should not be construed as the official position or policy of, nor should any endorsements be inferred by, HRSA, HHS, or the U.S. Government.