The Challenges of Autism in Aging

Pennsylvania Speech-Language-Hearing Association
April 2019

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Disclosures

• Bloomsburg University – full time employee.
• SIG #15 – Coordinating Committee member
• Thank you to NESHAP for sponsoring this session

Who is here today and why?

• Perhaps you:
  • Work with or are interested in autism with pediatrics and are wondering what this is all about.
  • Work with or are interested in older people and wonder what autism could possibly have to do with that.
  • Thought you were going to hear about voice and decided this would do.
Objectives

✓ Describe three similarities and differences in older versus younger people with autism.

✓ Describe the challenges of providing appropriate care to older people with autism.

✓ State three ways to facilitate person centered care in older people with autism.

Autism defined

• Autism (autism spectrum disorder, or ASD)
• Wide range of developmental disorders
• Impairments in 3 behavioral domains
  – social interaction
  – language, communication, and imaginative play
  – range of interests and activities (Muhle, Trentacoste, & Rapin, 2004).
• Revised definitions have broadened things somewhat.

DSM-V classifications of ASD
(American Psychiatric Association, 2012; Baker, 2013)

• Persistent deficits in social communication and social interaction across contexts, not accounted for by general developmental delays, and manifest by all 3 of the following:

• 1. Deficits in social-emotional reciprocity:
  – (ranging from abnormal social approach and failure of normal back and forth conversation through reduced sharing of interests, emotions, and affect and response to total lack of initiation of social interaction)
DSM-V classifications of ASD

• 2. Deficits in nonverbal communicative behaviors used for social interaction;
  – (ranging from poorly integrated verbal and nonverbal communication, through abnormalities in eye contact and body-language, or deficits in understanding and use of nonverbal communication, to total lack of facial expression or gestures.)

• 3. Deficits in developing and maintaining relationships, appropriate to developmental level (beyond those with caregivers);
  – (ranging from difficulties adjusting behavior to suit different social contexts through difficulties in sharing imaginative play and in making friends to an apparent absence of interest in people)

DSM-V classifications of ASD

• Restricted, repetitive patterns of behavior, interests, or activities as manifested by at least two of the following:

• 1. Stereotyped or repetitive speech, motor movements, or use of objects;
  – (such as simple motor stereotypes, echolalia, repetitive use of objects, or idiosyncratic phrases).

• 2. Excessive adherence to routines, ritualized patterns of verbal or nonverbal behavior, or excessive resistance to change;
  – (such as motoric rituals, insistence on same route or food, repetitive questioning or extreme distress at small changes).

DSM-V classifications of ASD

• 3. Highly restricted, fixated interests that are abnormal in intensity or focus;
  – (such as strong attachment to or preoccupation with unusual objects, excessively circumscribed or perseverative interests).

• 4. Hyper-or hypo-reactivity to sensory input or unusual interest in sensory aspects of environment;
  – (such as apparent indifference to pain/heat/cold, adverse response to specific sounds or textures, excessive smelling or touching of objects, fascination with lights or spinning objects).
DSM-V classifications of ASD

• C. Symptoms must be present in early childhood
  – (but may not become fully manifest until social demands exceed limited capacities)

• D. Symptoms together *limit and impair everyday functioning*.

• (vs. Social Communication Disorder)

A Syndrome, not a Disease

• Estimates of the prevalence of ASD vary.

• Prevalence has increased from 5-10 per 10,000 in the 1990s [Newschaffer & Curran, 2003] to various current estimates approaching 1%, or 1 in 100... or even more.
  – Is the actual population of individuals with ASD increasing?
  – Has society become more adept at recognizing the symptoms of this disorder?

Demographic Data

• Stable percentages of ASD across the life span.
• Screening of over 7400 individuals (England) across the life span
  • 1.1% at age 16-44
  • .9% age 45-74
  • .8% above age 75 [Brugha et al., 2011]
• Few adults with ASD live alone; many live with family members.
• Lower rates of marriage and parenthood
• Cannot depend upon younger family members to care for them as they age [Pivin & Rabins, 2012].
Are all adults with ASD the same?

- Of course not, and there may be differing needs across the life span.

- Higher level ASD may be able to live independently and well

- Lower functioning individual likely to need long term support

They will age.

- Most of what is known about ASD comes from pediatrics.

- In recent years the maturational (adulthood) and aging (geriatric) aspects of ASD now considered (Harrison, 2010).

ASD in aging is:
- Poorly understood with a changing demographic
- LESS understood in terms of its senescence
- And therefore support and care needs are not known.

Aging is a Challenge at Best

- Physical, psychological and social (Kane et al., 2008)

- Physical:
  - Decrease in Physical Strength, Endurance, and Flexibility
  - Decline in Efficiency of Body Organs
  - Loss of Bone Mass
  - Slower Reflexes
  - Sensory Decline
Aging is a Challenge at Best

• Physical, psychological and social (Kane et al., 2008)

• Psychological:
  – Secondary to changes in the brain
  – Slower processing time
  – Longer learning time
  – Mild memory reductions
  – Often improved vocabulary, general knowledge.

Aging is a Challenge at Best

• Physical, psychological and social (Kane et al., 2008)

• Social:
  – Known benefit from maintenance of social interaction
  – Greater need for social supports
  – Bereavement/grief

Aging with Autism

• Specifics of how the brain with ASD ages are not known (ongoing study)
• Sensory issues associated with ASD may become less problematic in aging.
• Socialization becomes less of an issue as adults create a life that meets their need.
• Cognitive processing changes – vary (Lever, 2016)
  – The overriding concept of CHANGE.
  – This is WITHOUT additional disability.
The number of older adults overall is increasing, so...

- ...the number of older adults with autism is increasing.
- At a 1% rate, the numbers of adults with ASD exceeds the numbers of children.
- In people diagnosed as adults, even with IQ balanced with non ASD, employment rates are low.

Why so little discussion of ASD in geriatrics?

- "Epistemology following epidemiology."

According to Wright et al., 2013, the diagnostics, the developmental stage, the disability, and the demographics all combine to create the gravitational pull by which autism is seen, focused, understood, measured, analyzed, and translated into targeted services and programs that are typically associated with early stages of the life course. This "lens" of autism is then translated in the domain of pediatrics, and with an array of school programs and services associated with the K-12 school years. The intensity, frequency, and magnitude of research and education on autism issues, therefore, has also followed the "matura-
tion of autism" as successive cohorts of youth diagnosed and identified with autism have entered into the postsecondary years or "emergent adulthood."

Appropriate Services

- Special education services mandated until the age of 21.
- Afterwards, special community programs, group home placements, etc. Not mandated through legislation.
- Funded either privately or through Medical Assistance.
- Recent focus in life planning (adulthood): How do we...
  - Meet their need for assistance and support?
  - Integrate them as much as possible while preserving their individuality and preferences?
  - Accomplish this with the expected numbers?

COST
Meet Donald

- First individuals identified with ASD were labeled in the 1940s (Kanner, 1943).
- Donald: now in his late 70s.
- Lives in the southern community where he has lived all his life (Donovan & Zucker, 2010).
- Family wealth/trust fund. Worked in the family bank.
- Socially: community accepts him as he is.
- Life skills development well into his 30s
- Supporting the need for ongoing support for individuals with ASD.

Not all individuals with ASD will be like Donald

- Financial resources
- Family support
  - Community and familiarity
  - Vocational opportunity
  - Support and acceptance

How should they be assessed?

- Adults should have a comprehensive, multidisciplinary assessment by trained professionals, to include:
  - Early development, medical and family history, behavior, education, and employment
  - Needs assessment, risks, and feedback to the individual.
  - Neurodevelopmental history should be obtained from parents/carers who have known the individual well since early childhood.
How should they be assessed?

• Validated assessment tools.
• Recommendations for adult service provisions, including care planning, risk assessment (to self and from others), challenging behavior, health passports, crisis plans, second opinions, and meeting social and educational needs.
  • Murphy et al., 2016

Meet Josh

What is a good outcome?

• Whatever constitutes a ‘good’ social outcome may not always be relevant for people with ASD. (Howlin & Magiatti, 2017)
• Higher rates of mental health issues, primarily anxiety and depression.
• Data are inconsistent due to methods of assessment and reporting.
Psychiatric and Medical Issues

- Adults with autism have greater rates of:
- All major psychiatric disorders including depression, anxiety, bipolar disorder, obsessive–compulsive disorder, schizophrenia, and suicide attempts.
- Nearly all medical conditions were significantly more common in adults with autism
- Rarer conditions, such as stroke and Parkinson’s disease, were also significantly more common among adults with autism.
  - (Croen et al., 2015)

Caring for Older ASD patients

- When people with ASD reach Medicare eligibility (via aging or through documented disability), they will need support and care.

  – What supports will they need?
  – How should supports be provided?
  – Would they benefit from the same kinds of interventions provided to children with ASD? (Piven & Rabins, 2012)

Intervention and Support: It is not known:

- WHAT
- BY WHOM
- TO WHAT DEGREE
  - WHERE
  - WHEN
  - HOW

- Virtually no research yet defining what those needs might be so that these important issues can be addressed. (Happé & Charleton, 2012; Perkins & Moran, 2010; Piven & Rabins, 2012).
Is **anyone** trying to determine LT needs?

- Task forces and societies in the UK, Canada, The Netherlands
  - projections for numbers of citizens
  - estimates about costs of care within their social support systems
  - It should be noted that their social support systems differ from ours
  - US research teams now being funded but the focus is on cognitive neuroscience, not caregiving.

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Arizona State University

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University of Wisconsin - Madison
Cognitive Neuroscience of Autism Spectrum Disorders

Objective:
- The primary objective of the proposed studies is to utilize neuroimaging... and neuropsychological tools... to identify cognitive idiosyncrasies (e.g., social-cognitive deficits, visual perceptual assets, and savant skills) characteristic of individuals on the autism spectrum and their neural underpinnings across childhood and adulthood.
- A secondary aim is to... identify subtypes that may inform genetic studies.
- Ages: 5 – 89

No evidence exists but the resident is in the building.

Institutional Care
- LTC residents should ideally maintain levels of function in all domains.
- Irony:
  - Socialization is often a common goal for residents in institutions.
  - Persons with ASD may never have been able to socialize normally.
- Unrealistic to assume they can function at their optimal level in this setting.
- Few options exist, even before these people become geriatric.
Institutional Care

• Two issues:
  • 1. The higher functioning resident, who was a community dweller, needing few supports but perhaps a bit “peculiar,” who then suffers a CVA or hip fracture and requires rehabilitation or other care.
  • 2. The lower functioning resident, who, when his parents or other caregivers can no longer care for him, needs someone and somewhere else.

Institutional Care

• There are no data to examine how patients/residents with ASD respond:
  – To new onsets of disability
  – To the need for 1:1 assistance by strangers in a strange environment
  – To the intensely social approaches to rehabilitation that are commonplace in our models of care
  – To the sensory overload of medical facilities
  – To physical assistance
  – To the lack of routine
  – To inconsistency of care

Institutional Care

Many individuals with ASD prefer consistent routine, prefer to be alone and are uncomfortable with change (Happé & Charleton, 2012).
Institutional Care

Training re: ASD will be needed for people providing care

Must know how they age and respond to new disability, as well as to supportive medical and rehabilitative care.

Are we ready with EB approaches?

• NO. Emphatically.
• Our care facilities are neither prepared nor appropriately staffed to manage the issues coming with ASD.
  – language
  – communication
  – socialization
  – behavioral issues
• Resource allocation/reimbursement

But care is provided anyway.

How are SLPs providing this?

Survey targeting SLPs working with older adults; Qualtrics platform distributed via ASHA communities and social media

(Ymith, 2016)
Aims

• To determine SLP demographics of those working with possible SNF residents on the spectrum.
• To identify, to the degree possible, how these residents are evaluated.
• To identify challenges in providing care
• To identify training needs as we prepare for the future.

(Ongoing Challenges)

• SNF residents are a highly protected population.
• Current SNF environment is very cost-sensitive
• Special programs take time.
• Time is money.
• Field research is difficult

Training about ASD
Training about Aging and Autism?

(Yikes!)

How many residents?

How do SLPs conclude this?
Assessment – by experience

How are residents assessed?
\[ x^2 = 1.909, df = 3, p = 0.059 \]

Assessment/Screening

- MDS 3.0: nursing interviews are part of the tool, patient/resident’s diagnosis that affects communication and socialization
  - Not necessarily predictable communication
  - This is a complex group of residents
  - Never DID fit a social model

WHAT KINDS OF TOOLS ARE AVAILABLE FOR ASD?

Assessment/Screening

- Cognitive screenings are widely used in the SNF
  - SLUMS – Saint Louis University Mental Status exam
  - MOCA – Montreal Cognitive Assessment
  - MMSE – Mini Mental Status Exam

- Not normed for disorders seen in ASD.
Possible Tools

- **Autism Diagnostic Interview-Revised** (Lecouteur, Lord & Rutter, 2003)
- **Social Responsiveness Scale** (Constantino, 2005)
- **Autism Spectrum Quotient** (Baron-Cohen, Wheelwright, Skinner, Martin, & Chivers, 2001) *(available online)*
- **Friendship Questionnaire** (Baron-Cohen & Wheelwright, 2003) *(form online)*
- **Empathy Quotient** (Baron-Cohen & Wheelwright, 2004) *(available online)*
- More here: [https://www.autismresearchcentre.com/arc_tests/](https://www.autismresearchcentre.com/arc_tests/)

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**Autism Diagnostic Interview - R**

- Audiotaped interview with parent/caregiver.
- Tool relates responses to DSM-IV categories
  - (91% of samples still identified with DSM-V; Huerta, 2012)
- Sample question from the form:
  - “Can you tell me about ___’s family? Was there anyone in the family with problems with development?”
  - “Tell me about his early childhood. When was their first concern?”

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**Social Responsiveness Scale**  
*Constantino, 2005*

- Parent/teacher/family member/caregiver rating scale.
- A sixty-five item scale where behaviors are rated on a 0-3 scale (3 = always true).
- Higher scores indicate greater social impairment. Initial edition normed 4-18.
- SRS-2 normed through adulthood.
  - Social Awareness
  - Social Cognition
  - Social Communication
  - Social Motivation
  - Restricted Interests and Repetitive Behavior
Autism Spectrum Quotient

• Self-report, 50 items.

You can take it online!


Pam's score: 27

0 - 10 = low
11 - 22 = average (most women score about 15 and most men score about 17)
23 - 34 = above average
32 - 50 = very high (most people with Asperger Syndrome or high-functioning autism score about 35)
50 is maximum

Friendship Questionnaire

• Self-report, 35 items.

Friendship is an important part of normal social functioning, yet there are precious few instruments for measuring individual differences in this domain. In this article, we report on a new self-report questionnaire, the Friendship Questionnaire (FQ), for use with adults of normal intelligence. A high score on the FQ is achieved by the respondent reporting that they enjoy close, empathetic, supportive, caring friendships that are important to them, that they like and are interested in people, and that they enjoy interacting with others for its own sake. The FQ has a maximum score of 35 and a minimum of zero.
Friendship Questionnaire
http://docs.autismresearchcentre.com/papers/2003_BGandSW_FQ.pdf

- Higher scores by respondents who report enjoying close, supportive friendships, who like and are interested in people; who enjoy interaction with others
- Women scored significantly higher than men
- ASD scored significantly lower on the FQ than unaffected males

Empathy Quotient

- Self report, 60 items
- Assess the ability to understand the feelings other people.
- https://psychology-tools.com/test/empathy-quotient
- Correlates negatively with the Autism Quotient and positively with the Friendship Questionnaire.
- ASD score lower on the Empathy Quotient than controls.
- (scores above 30 not usually ASD)

Links to tools

- https://www.autismresearchcentre.com/arc_tests/
In addition to Questionnaires

• Thorough case history
• Corroborated by a relative who has known the resident for at least 10 years (van Niekerk, Groen, Vissers, van Driel-de Jong, Kan, & Oude Voshaar, 2011).

• Must include reports about childhood
• (problematic)

Differentiating ASD from Dementing Conditions

• ASD is a lifelong condition
• NO insidious OR sudden onset

• Most difficult: Dx ASD from psychiatric conditions
• Need early development info
• Need info re: psychosocial functioning prior to adolescence (van Niekerk et al., 2011).

• Need a psychiatrist or PCP who has the knowledge and expertise for the task.

Differentiating ASD from Dementing Conditions

• Disorders of mood, anxiety and depression occur more frequently in patients with ASD (Happe & Charlton, 2012).

• IMPORTANT! Characteristics seen in ASD – inappropriate behavior, impairments in socialization, etc.
  – Often trigger a psychiatric referral
  – Often leads to medications if medical staff does not consider ASD as a potential diagnosis (van Niekerk et al., 2011).
There is a large need for information to support policy and funding.

And training for care providers.

Perceived SLP training needs

Perceived Staff Training Needs
SLPs working with older people

- We MUST:
  - Become aware of the behaviors associated with ASD
  - Advocate for these individuals in work settings and our communities
  - Help meet their socialization and communication needs.
  - Provide person centered care.
  - Educate, document, educate, document, etc.
  - *Practice based evidence will precede evidence based practice.*

How do WE start?

- Document cases of suspected ASD in facilities
- Work with medical staff toward proper identification
- Work with nursing and other staff toward appropriate care planning for these individuals.
- Educate staff about ASD.

What is Person Centered Care?

- Disability is way of being, not a defect
- Any disability has multiple dimensions – for autism: sensory – communicative –social/pragmatic
- What do people with autism say?  *(Nicolaidis et al. 2016)*

Participants offered hundreds of practical ideas for how to improve care. They almost uniformly asked for increased provider training on autism. They had many recommendations for providers, ranging from general recommendations (e.g., “respect the way I need to communicate with you”) to specific ideas for strategies and accommodations to facilitate care (e.g., “dim your lights in the exam room you take me into” or “avoid open-ended or vague questions as these are often difficult to answer”). Recognizing the great heterogeneity of patients on the autism spectrum (e.g., “Each of us is in the spectrum are different”), they also wanted to have a way to give providers personalized information about their accommodation needs. They urged other autistic patients and supporters to advocate for
What is Person Centered Care?

Fostering healing relationships
Exchanging information
Responding to emotions
Managing uncertainty
Making decisions
Enabling patient self-management (Ianuzzi et al., 2015)

INTERNATIONAL JOURNAL OF GERIATRIC PSYCHIATRY

Diagnosing Asperger’s syndrome in the elderly: a series of case presentations

James et al., 2006

SUMMARY

There are many older adults who may have met the criteria for AS as children, but never received such a diagnosis due to the fact it had yet to be established. What happened to these people as they aged?

Conclusion: Older patients with undiagnosed AS may currently be receiving inappropriate treatments.

Greater awareness of AS in the older population would enable better management of such patients.
Case Presentations

- Caveat: None of these residents were ever officially diagnosed with ASD. (two are deceased).
- No way to obtain permission to review records.
- Interview with SLPs who participated in their care.
- Changed names, other potentially identifying information.
- Retrospective in nature.

"Adam," "Ronald," and "Stan."

Commonalities
(*similar to James et al. 2006)

- Male*
- Admitted for falls plus generally other comorbidities.
- Lived alone with varying types of community assistance*
- Poor relationships with family*
- Disconnections with children, either no marriage or multiple marriages/divorces (unlike several of James et al. 2006)
- Lack of insight into needs*
- Inflexibility*
- 2 of 3 well above average intelligence.
- One unable to interact in society on any level.
- Others considered "peculiar" by family for many years.
VERY LIMITED “N,” but...

• ...staff seriously questioned in all cases whether this type of facility (SNF) could meet the needs of this (type of) patient.

• Never diagnosed with AD.

• (Would having had the diagnose help them?)

Survey Clinician Comments

“I have helped adults who arrived non communicative achieve alternative means of communication to share their wants/needs, communicate pain, etc. - I had to be creative to receive reimbursement for services and keep this individual on caseload, as "prior level" was non communicative. I believe we have much work to do in this area. Individuals are not having their needs met.”

Comments

“How do you differentiate autism from other disorders in the elderly population? People may have silent infarcts, especially R CVAs that have similar behavioral consequences.”

“It can be confused with early dementia as some of the behavioral changes can be similar.”
Comments

“Society as well as medical staff need more training and understanding of this population. Not only do we have patients, but also staff. Training is needed for helping both succeed.”

“We would treat the same as any language impaired individual; I’m not sure I see how this particular resident would gain from any other services. Her basic needs are met. As others in this facility, she doesn’t seem to have a need for anything further, based on her current cognitive level”

Comments (end)

“It is a developmental problem and Medicare wouldn’t cover.”

“The characteristics are often masked by CVA.”

“They were not dx’d as children and we were unsure if they could be dx’d as adults. We tx under a different dx.”

Conclusions

• We have a duty to these residents to prepare for them. It is a clinical, ethical as well as a human obligation.

• Our colleagues in pediatrics have done so, admirably, in those settings.

• We look forward to collaboration and continued learning about aging with autism.
Special Thanks

• ...to the clinicians who granted interviews about their residents and who participated in the survey....
• ...to all caregivers who work so tirelessly meeting the needs of our older citizens...
• ...to the researchers who are working toward finding answers...
• ...to you, for your attention today.

Questions, comments, thoughts?

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References


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