Health and Quality of Life in Middle-Aged and Older Autistic Adults

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Dedicated to the advancement of knowledge about human development, developmental disabilities, and neurodegenerative diseases throughout the lifespan.
Autism Spectrum Disorder

• Characterized by:
  – Challenges with social communication
  – Challenges with restricted interests and/or repetitive behaviors

• Important facts:
  – Affects 1 in 36 kids (≈2.75%)
  – Significant heterogeneity
  – Diagnostic sensitivity and practices have changed over time, leading to potential cohort effects
  – Lifelong condition yet <0.5% of research on aging
Diagnostic Boom

autism prevalence has increased 317% since 2000

1992 Birth Cohort

CDC Prevalence per ADDM*

*ADDM (Autism and Development Disabilities Monitoring Network)
Midlife and Older Adulthood in Autism

- Donald Triplett: Kanner’s Case 1
- More adults with identified autism diagnosis than ever before; many missed/misdiagnoses
- Evidence of greater morbidity and mortality
- Potential 2-3 decade decreased life expectancy
- Insufficient research on health and quality of life limits development of supports and limits advocacy efforts

*Donald Triplett, ‘Case 1’ in the Study of Autism, Dies at 89*

He was widely considered the first person to be diagnosed with autism. His happy life later became the subject of a book and documentary.

Donald Triplett, the Mississippi man known as “Case 1” in the psychology paper that first outlined the modern concept of autism. As an adult, he worked at the bank his grandfather co-founded. WLBT-TV, via Associated Press
Aging with Developmental Disabilities

- Deinstitutionalization
- Increased awareness and acceptance
- In US, access to care is usually through Medicaid/Medicare
- Increased life expectancy
What might autism look like in an older adult with a missed autism spectrum disorder diagnosis?
Quality of Life in Autistic People

- Multidimensional construct – emotional well-being, interpersonal relationships, material well-being, self-determination, social inclusion, and rights
- Increasing area of research focus
- Self-reported quality scores are lower on average in autistic adults compared to non-autistic adults
- Considerable heterogeneity across autistic people
Quality of Life: Two Types

- **Objective Quality of Life**
  - How someone would define another person’s quality of life if looking in from the outside

- **Subjective Quality of Life**
  - How an individual feels about his or her own quality of life
Our **Subjective** Quality of Life Findings

• Factors associated with a better subjective quality of life in autistic people:
  – Higher levels of independence in daily living skills
  – Higher levels of social cognition
  – More social and community support and engagement
  – Lower perceived stress
  – Lack of bullying during childhood/adolescents
  – Better sleep quality
Our **Objective** Quality of Life Findings

- Factors associated with a better objective quality of life:
  - Better daily living skills
  - Better executive function
  - Better physical and mental health
  - NOT greater independence/less interdependence
Why is Health Important?

• Health problems are a normative part of the lived experience for autistic adults, particularly as they age.
• Autistic adults who are physically and mentally healthy have the best subjective quality of life, even compared to autistic adults with traditional markers of “good” outcomes.
Disparities in Autistic People, Broadly Considered

• Does being on the autism spectrum lead to health disparities?
  – History of mistreatment in asylums
  – Social isolation
  – Poorer access to health services
  – Heightened morbidity/early mortality

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A Scoping Review of Health Disparities in Autism Spectrum Disorder

Lauren Bishop-Fitzpatrick¹,² • Amy J. H. Kind³,⁴
Early Mortality in Autism

- Median age of death in autistic Medicare beneficiaries of 72 (IQR = 68, 78; N = 4,865) vs. 74 in population controls (IQR = 69, 83; N = 46,850)
- Hazard rate of death for autistic beneficiaries was 2.63 times higher than that of population control beneficiaries
- Older age of death in autistic older adult Medicare beneficiaries than identified in mixed-age samples

Lifetime Health Problems in Decedents

RESEARCH ARTICLE

Using Machine Learning to Identify Patterns of Lifetime Health Problems in Decedents with Autism Spectrum Disorder

Lauren Bishop-Fitzpatrick, Arezoo Movaghar, Jan S. Greenberg, David Page, Leann S. DaWalt, Murray H. Brilliant, and Marsha R. Mailick
The Big Picture

• Goals
  – Identify health problems that distinguish autistic people who have died from non-autistic people who have died:
    • Data-driven approach
    • Based on information in lifetime electronic health records

• Major Finding
  – Machine learning algorithm distinguished autistic people from non-autistic people with 93% accuracy
Data Source and Study

- **Marshfield Clinic**: a multi-specialty group practice
  - 97% of the population in northern, central, western WI
- Available electronic health records (EHRs) on people who have died: 91 with autism; 6,186 community members
- **Question**: Do patterns of diagnoses in EHRs distinguish autistic from non-autistic people?
Analyses

• Machine learning algorithm (Random Forest) to detect patterns in diagnostic codes that distinguish autistic decedents from non-autistic decedents

• Examine group differences in associated conditions (Elixhauser)
Characteristics of Sample

- Age of Death (Full Sample)
  - Autism: Mean = 56.1, SD = 21.8
  - Control: Mean = 75.2, SD = 15.4

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<thead>
<tr>
<th></th>
<th>Autism (N=91)</th>
<th>Control (N=6186)</th>
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<tbody>
<tr>
<td>Male, N (%)</td>
<td>53 (58.2)</td>
<td>3602 (58.2)</td>
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<tr>
<td>Intellectual Disability, N (%)</td>
<td>69 (75.8)</td>
<td>0 (0.0)</td>
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<tr>
<td>Down Syndrome, N (%)</td>
<td>10 (7.6)</td>
<td>0 (0.0)</td>
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<tr>
<td>Length of EHR, mean (SD)</td>
<td>16.8 (8.1)</td>
<td>12.4 (9.7)</td>
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<tr>
<td>Year of birth, mean (SD)</td>
<td>1940.3 (14.0)</td>
<td>1936.4 (15.3)</td>
</tr>
<tr>
<td>Age of death, mean (SD)</td>
<td>67.3 (13.5)</td>
<td>68.7 (15.1)</td>
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# Health Problems Distinguish Autistic People from Non-Autistic People

Autistic people have different patterns of health problems before they die. Including:

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<tr>
<th>In Autism, HIGHER prevalence of:</th>
<th>In Autism, LOWER prevalence of:</th>
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<td>Long-term medication use</td>
<td>Cancer diagnosis</td>
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<tr>
<td>Epilepsy</td>
<td>Cancer treatment</td>
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<td>Developmental problems</td>
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<td>Skin conditions</td>
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<td>Ear problems</td>
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<td>Non-specific lab tests &amp; encounters</td>
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<td>Urinary problems</td>
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<td>Respiratory problems</td>
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<td>Digestive problems</td>
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<td>Motor problems</td>
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<td>Cardiovascular problems</td>
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Differentiating Patterns: Elixhauser Comorbidities

- *Increased risk* for: coagulopathy, congestive heart failure, deficiency anemia, fluid and electrolyte disorders, hypothyroidism, neurological disorders, paralysis, valvular disease, unexplained weight loss

- *Decreased risk* for: alcohol abuse, uncomplicated diabetes, hypertension, metastatic cancer

- Many similarities (57% of categories)
Limitations

• EHR data may be inaccurate/incomplete
• No true estimates of all-cause mortality or life expectancy
• Cohort effects
  – Make matching difficult: stable findings across groups (randomly selected, matched for death year and sex, matched to 1:68 ratio)
  – Decedents not representative of current generation of young adults
Health of Middle Aged and Older Wisconsin Medicaid Beneficiaries

The physical and mental health of middle aged and older adults on the autism spectrum and the impact of intellectual disability

Lauren Bishop-Fitzpatrick\textsuperscript{a}, Eric Rubenstein\textsuperscript{b}

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The Big Picture

• **Medicaid** is a state-administered anti-poverty program that provides free or low-cost health coverage to people with low income and/or disabilities

• **Goals**
  – Describe the physical and mental health of a sample of middle aged and older autistic Medicaid beneficiaries
  – Test differences in health conditions between autistic adults with and without intellectual disability
Characteristics of Sample

143 Adults with autism

- 31% Women
- 69% Men

44% had an intellectual disability

Average age: 52
Oldest age: 88

- 79% White
- 4% Black
- 14% Other
Prevalence of Health Conditions in Middle Aged and Older Autistic Adults

- Dementia: 4.9%
- Depression: 28.0%
- Anxiety: 43.4%
- Sleep Disorders: 85.3%
- Gastrointestinal Disorders: 49.7%
- Neurologic Disorders: 55.9%
- Epilepsy: 25.2%
- CVD: 49.0%
- Cancer: 5.6%
- Immune Conditions: 70.6%

Higher prevalence of epilepsy and lower prevalence of depression and anxiety in autistic adults with ID

Bishop-Fitzpatrick & Rubenstein (2019)
Limitations

• Cohort differences
• Claims data (many benefits but a few limitations)
  – No clinical validation of diagnoses
  – More accurately captures chronic conditions (e.g., cardiovascular disease) and less accurately captures less serious medical conditions (e.g., rashes)
  – Represent only identified autism and identified health conditions
• All adults qualified for Medicaid and thus met asset requirements
Summary: Morbidity in Older Adulthood

• What we know:
  – Poor health outcomes across the board
  – Health may differ by IDD type/subphenotype

• What we don’t know:
  – Predictors of positive health outcomes OR mortality
  – Effects of social policy, benefits, and environment
  – Effects of poverty and racial disparities

  – **The big gap:** Why is this happening, and what do we do about it?
Experiences with Health and Healthcare Among Autistic Adults
The Big Picture

• Autistic autistic adults experience their health and access healthcare differently, which may help explain poor health outcomes among middle aged and older autistic adults

• Goal
  – To understand how middle aged and older autistic adults experience health and make decisions about how and if to interface with the healthcare system
Methods

• Inclusion criteria for autistic adults
  – Age 35+
  – Have an administrative or professional diagnosis of autism spectrum disorder
  – Able to communicate in English
  – Included autistic adults with and without intellectual disability

• One-on-one interviews with autistic adults (N=15) and their emergency contacts (N=7)
Methods, continued

• Semi-structured interviews probed experiences with health and healthcare across four domains:
  – health habits
  – health problems
  – health services
  – autism and aging impact

• Conventional content analysis
• Transcribed and analyzed consecutively
• Emerging themes continually tested against data
Conceptualization of Health

- Absence of pain, illness, and injury
- Lack of sensory changes within the body
- “Health” and “being healthy” are inclusive of both physical and mental health
“being able to get through the day and not having anything that really gets in the way of your daily functions or daily life or causes any major pain or hardship”
“[Pain] can feel like on the 1 to 10 scale it can feel like a six or seven to me but as far as [experiences of neurotypical people] go it's really only a two”
Decisions about Care Utilization

• Adults and emergency contacts report utilizing regular preventive care
• Decisions about when to utilize care for acute pain, illness, or injury are more difficult
• When things do no go according to plan
“when my body changes the way it's working, then to me, that feels like a medical emergency”
“When the paramedics arrived, [PN] was non-responsive. And no one had any idea what was wrong with him, right. There was no clear sign that anything in particular was wrong. [PN] hadn't been complaining about any pain or anything. But he was literally, I mean, he had gone into shock. Right. And and could have died. So as they were disrobing in him at the emergency room, they notice the bruising on his shoulder, which turned out to be from the broken shoulder, which he now has a partially replaced shoulder joint. But he also had aspiration pneumonia because he also had a big hole in his tongue. And then they did a bunch of blood screenings and things to kind of look at what else was going on in his system and he had extremely low sodium.”
“He manages all his own medication. He orders and refills all his meds and picks it up and everything. I never have to think about that except if something goes awry. You know like some expected renewal doesn't get done or in one case he takes Ritalin and there was some law change that prevented him from getting the quantity of Ritalin that he was used to getting. And that just absolutely threw him for a loop and somebody else had to get involved because there was a lot of detailed communication about what do you do next that was not the typical day-to-day stuff. And so we got involved and it got taken care of and now everything's fine again. But life is full of unexpected stuff and unexpected stuff just throws [PN] for a loop all the time.”
Communication

• Care providers often do not understand how to talk to autistic people clearly and with sensitivity to the autistic experience

• Preparing to communicate with a provider takes a lot of preparation and energy
“I would say that their approach is not person-centered and not tailored to me, and it's not effective based on the evidence that I see.”
“It's practically impossible [to find a provider who is flexible]. I finally have found one, who’s a chiropractic neurologist who has enough of a framework and has a way to work directly with the body that he doesn't require us matching our words in order to find the right treatment.”
Independence

• Autistic adults strive to be independent in accessing and utilizing health services

• Emergency contacts highlighted the importance for all adults—including autistic adults—of receiving support from loved ones while managing health and healthcare

• Lack of social support among autistic people may mean that they do not have anyone to help them; less than half of autistic adults had an emergency contact
“If they need certain types of supports, it's a sign of strength to ask for those supports”
“In an ideal world the health care providers would recognize, based on his autism diagnosis and interaction with him that they will not have productive meetings with him and they will require support and help him make sure it gets set up. And also in this ideal world, [PN] would realize how important it is for these situations to have someone there to support him not because he is weak but because he is strong and knows that this is what he needs to be successful and take control of his life by making sure that he has the support he needs in situations that are potentially problematic”
Executive Functioning

• Challenges with time management, planning, organization, attention, and self-inhibiting make maintaining health habits and accessing healthcare difficult for autistic adults.

• Using the executive functioning skills needed to make it through a regular day is exhausting and makes maintaining “robust health” difficult.
“If I had more capabilities with executive functioning, I would not have the inertia that kind of prevents me from playing a more active part in addressing my health”
“It’s not necessarily that I don't have enough time. It's that having both the time and the energy and focus at the same time, the same period is difficult. And things like repeated task switching, it takes longer for me, so that's eating up time. So I in principle, have the time in many cases to do something else. But the ability to then engage in what I'm doing doesn't feel like it's there. I kind of have this sense of being perpetually behind on at least personal goals, occasionally more important things too. And so to be able to have all of that on my plate and to then try to make time for other kinds of exercise, other sorts of general activities, that kind of stuff, feels very difficult on top of not having a lot of energy left over for that kind of thing. I know that doing more exercise would likely help me upregulate my ability to have energy and things along those lines. That's part of why I’m keeping interests in doing so. While in practice that has been very difficult.”
Conclusions and Implications

• Autistic adults have sensory, communication, and executive functioning differences that impact health and engagement with healthcare

• Accessing healthcare is an area in which autistic adults want to be fully independent, yet full independence in accessing healthcare is not feasible for most adults, including autistic adults

• Providers can encourage autistic adults identify ways to partner with loved ones to access healthcare while maintaining independence in their choices about their bodies and health
Policy Implications

• High human and monetary costs to individuals, families, and government programs
• Providing adequate care will be more complicated, intensive, and costly as growing cohorts age into older adulthood
• Autistic adults experience marginalization within society and within the healthcare system
• Should independence be the goal of services?
Services & Supports Can Help Encourage Healthy Aging

- **Social**: Inclusion in social, recreation, and leisure activities
- **Family**: Supporting families in care transitions as parents age
- **Housing**: Independent living, family living, and nursing home care
- **Health**: Preventive and routine health care
- **Activity**: Aging autistic adults need to be active like all adults
- **Special Care**: Disability-specific risks and accelerated aging may necessitate early screening
Establish Correct Permissions/Legal Documents

- Medical power of attorney
- Mental health power of attorney (if applicable)
- Advanced directive/living will
- Permissions on file with doctor to allow trusted people to access medical records
Advocate…while we work on changing physician behavior and the system

- Know what preventive care you should receive and ask for it
- Request sensory and communicative accommodations
- Be aware that autistic people may experience pain/illness differently
- Insist that providers see more than the autism diagnosis
  - “Behavioritis” (Sara Luterman) – inappropriately placing importance on a person’s behavior and not their health or medical problems
  - Changes in behavior or mood may indicate a medical problem

Thanks to #ActuallyAutistic advocates @slooterman, @autismage, @A4AOntario, @TuffRings, @RoaDemille, & @AutisticDoctor for advice on tips based on autistic lived experience
“You have to learn about thousands of diseases, but I only have to focus on fixing what’s wrong with ME! Now which one of us do you think is the expert?”
What’s Next?
Toward Healthy Aging in Adults with Autism: A Longitudinal and Clinical Multimodal Brain Imaging Study

- AIM 2: Measure and evaluate age-related decline between autistic and non-autistic adults.
- AIM 3: Investigate the relationships between clinical, health, and brain imaging measures in autistic adults.
- AIM 4: Collect whole blood specimens from all consenting autistic and non-autistic for the NIMH Repository and Genomics Resource (NRGR) for future genetic studies.
AIM 1: Identify comorbidities that differentially influence time-to-mortality for autistic vs. non-autistic older adults.

AIM 2: Develop an autism-specific index for predicting autistic older adults’ risk of mortality and compare to existing mortality risk indices.

EXPLORATORY AIM 3: Quantify the number of autistic older adults at low, medium, and high risk of mortality within two large academic medical center.

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