AUTISTIC BURNOUT: “MY PHYSICAL BODY AND MIND STARTED SHUTTING DOWN”

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Introduction: Dora Raymaker

- Research Assistant Professor, PSU Regional Research Institute for Human Services, School of Social Work
- Transition-age and adult populations (autism, mental health, developmental disability)
- Social services intervention research (systems scientist, not a clinician—though clinicians are on our team!)
- Community based participatory research approach
- Co-director Academic Autism Spectrum Partnership in Research and Education (aaspire.org)
- Autistic and disability rights (self-)advocate
- Science for social change!
Academic Autism Spectrum Partnership in Research and Education

- Research group founded in 2006 by Christina Nicolaidis, MD, MPH and me
- Christina used “Autism Journal Club” to lure me into a social interaction
- Lots of complaints about autism research:
  - Not relevant / useful to autistic people
  - Issues with research design
  - Stigmatizing questions, language, dissemination
  - Potential harm to autistic people
- ...just like other marginalized populations
- Stop complaining and do something!
Community Based Participatory Research

- Emancipatory approach to research developed in public health
- Community members are co-researchers in every phase of the research
- Lived experience and community knowledge is respected on the same level as academic expertise
- AASPIRE community partners involved at all stages of this project
Academic Autism Spectrum Partnership in Research and Education

- 12 years later...
- Team made up of academic researchers, autistic individuals, family members, healthcare providers, and disability services professionals.
- In partnership with PSU, OHSU, Autistic Self Advocacy Network, Autism Society of Oregon, Syracuse University, Indiana University, and members of the Autistic community at large.

aaspire.org
Currently Active AASPIRE Areas of Study

**Autistic burnout (this talk)**
- Exploratory study to understand and define experience of autistic burnout
- Begin creating a measure of autistic burnout

**Autism and professional employment**
- Exploratory study to understand facilitators of success
- Intervention to facilitate employer autism-friendly culture change
- Intervention development to improve professional employment outcomes

**Healthcare**
- Healthcare disparities study / understanding hc experiences
- AASPIRE Healthcare Toolkit and Autism Healthcare Accommodations Tool
- Adaptation of Toolkit for emergency / hospital [autismandhealth.org](http://autismandhealth.org)
Agenda

1. “Autistic burnout” and why it needs research
2. AASPIRE autistic burnout study
3. What we’ve learned so far about autistic burnout
4. Implications/recommendations for people on the spectrum, families, clinicians
5. Wrap-up and questions
1. “AUTISTIC BURNOUT” AND WHY IT NEEDS RESEARCH

Background
What Is “Autistic Burnout”?

- Term used in the autistic community, typically for a feeling similar to professional burnout?—only applied to all areas of life
- Sometimes called “autistic regression?”
- Autistic adults report times when they can no longer cope, lose skills / function, start acting or feeling “more autistic,” lose jobs / school / relationships / mental and physical health; sometimes leads to permanent disability or suicidal behavior
- Something is happening but many questions, like
  - Is there an unambiguous definition of “autistic burnout?”
  - Is it different from professional or other well-explored kinds of burnout?
  - Is it different from depression?
  - Why does it happen and how can it be relieved or prevented?
Autistic Experience vs. Current State of the Science

- Much discussion on blogs, social media, community spaces about autistic burnout
  - Source of distress
  - Factor in poor life outcomes
  - Factor in suicidal behavior
  - Connected to stress, masking (having to “pass” as non-autistic)

- High priority for autistic adults
Autistic Experience vs. Current State of the Science

- Published research for autism and burnout is on family, teacher, caregiver burnout
  - *Little is empirically known about burnout in autistic people themselves*

- Burnout, in part driven by masking, may mediate suicidal behavior in physicians and medical students whose suicide rates are 1.5-2x higher than general population
  - *Could similar mechanisms contribute to the 35% rate of suicide plans or attempts by autistic adults?*

- What’s the answer to the question of “what helps?”
  - *We have to start somewhere*
2. AASPIRE AUTISTIC BURNOUT STUDY

Aims and Methods
Study Aims

1. To characterize autistic burnout, and qualitatively understand people’s experience of it and strategies for preventing or recovering from it

2. To develop and conduct initial psychometric testing (content, construct, and congruent validity, internal reliability, and acceptability) of a measure of autistic burnout based on what we learn in aim 1
Study Design

- 9 employment interviews that spontaneously mentioned autistic burnout
- 10 new interviews specifically about autistic burnout
- 19 public media posts about burnout

Qualitative analysis

Create and pilot test (N=50) autistic burnout measure

Study findings and recommendations

Future Research

Study findings and recommendations
Qualitative Data Sources

- 9 employment interviews that discussed autistic burnout spontaneously (from interviews with 45 autistic adults with professional training) national sample; community-based recruitment.

- 10 new interviews focused on autistic burnout; national sample; community-based recruitment; purposively sampled to fit demographics not covered in the employment interviews;
  - *Tell me the story of your experiences with autistic burnout*
  - *Definitions / characteristics of autistic burnout*
  - *Strategies / advice / resources to prevent or relieve autistic burnout*

- 19 key public online media sources (blogs, videos, twitter, Instagram) compiled by the AASPIRE Autistic community partners and recommended by study participants; threads followed from the initial list.
Qualitative Analysis

- Thematic analysis – look for recurrent, strong, and pervasive ideas across interviews
- Semantic and latent levels – both taking words at face-value, and inferring underlying meanings from narrative and broader context
- Critical paradigm – “reality” as represented by qualitative data is a product of an interaction between participant and researcher, positioned within a broader context
- Verification
  - Multiple coders, double-coding, meetings to discuss and converge codes
  - Member checking with our CBPR team
  - Triangulation with other data sources
Current Status

9 employment interviews that spontaneously mentioned autistic burnout

10 new interviews specifically about autistic burnout

19 public media posts about burnout

Qualitative analysis

Create and pilot test (N=50) autistic burnout measure

Study findings and recommendations

Future Research
3. WHAT WE’VE LEARNED SO FAR

Results
### Demographics and Data Characteristics

#### Burnout (N=10)

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#### Employment (N=9)

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#### Disability Service Use

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#### Age

- **Mean**: 41.2
- **Std.dev.**: 12.2
- **Range**: 24-65
“So this combination [of stress, masking, social isolation, loss of an important support person], along with the overwhelming confusion of what was 'wrong' with me, why I couldn't really connect with anyone, why people singled me out or played tricks or used me, of what the hell was wrong with me and why i [sic] just kept hitting this wall over and over again, was what led me to crash and burn out - my physical body and mind started shutting down. I could feel each system in my body closing off as gravity got heavier than it had ever been. I didn't know what to do - did not understand what was happening to me - I had no way to communicate this. It was like a switch had gone off, my verbal ability to convey what was going on in my mind and body was gone. I did not want to die, I've never wanted to die. I needed to step out. I needed to remove myself from the environment and take myself elsewhere; I needed to escape. But the only way I knew how to do that was to die. So I tried.”

Components or Features

- Loss of skills: cognition, executive function, memory, speech/communication, ability to cope, ability to do things once could do
- Increased sensitivity: to sensory stimulus, to sensory overload, to change, to social stimulus
- Increased autistic behavior (e.g., stimming, speech difficulties)
- More frequent meltdowns / shutdowns
- Chronic exhaustion
Causes

- External expectations chronically outweigh abilities to meet them
- Chronic masking, struggle to “pass” as non-autistic and/or repress autistic behavior
- Change, stress from change, stress
- Inability to recover quickly enough from the strain of pushing to meet external expectations / mask / cope
Possible Dynamics?

- Leads to a “growth and collapse” type behavior
- System grows faster than available resources can keep up
Impacts on Life

- Loss of job, social standing, sense of belonging
- Lack of understanding from others
- Reduced self-esteem and self-efficacy
- Increased depression, anxiety
- Self-injury and suicidality
Onset and Course

■ Timing throughout life
  – Puberty, post-puberty
  – Points of increased independence (e.g., starting high school or college)
  – (then a period of stability?)
  – Points of increased stress
  – Aging

■ Collapse and retreat to recover

■ Often (especially later in life) incomplete recovery
“Types” of Autistic Burnout?

- Low-level and constant
- Intense / acute
- Social burnout (only coping with / tolerance for social interactions is exhausted)
Autistic Burnout vs. Professional Burnout

- Professional burnout is characterized by
  - *Exhaustion*
  - *Depersonalization*
  - *Reduced self-efficacy*

- Much evidence in data for exhaustion and reduced self-efficacy
- Little evidence for depersonalization
Autistic Burnout vs. Depression

- Some overlap; for example, feelings of worthlessness, exhaustion
- Likely insufficient overlap to be the same
- Autistic burnout did NOT include, for example, slowed or speeded movement, hypersomnia/insomnia, etc.
- Notably did not include anhedonia (not caring/feeling); if anything there was a pervasive frustration because people continued to care and feel but felt incapable of taking action on their feelings
- Some participants who had a diagnosis of depression took care to differentiate it from their burnout
Working Toward a Definition

■ “Autistic burnout is a state of physical and mental fatigue, heightened stress, and diminished capacity to manage life skills, sensory input, and/or social interactions, which comes from years of being severely overtaxed by the strain of trying to live up to demands that are out of sync with our needs.”

■ “It’s like promoting a [neuro-typical] person beyond their own skill level...until they flop...only times 100...and sometimes far more.”

■ “Having all of your internal resources exhausted beyond measure and being left with no clean up crew.”
4. WHAT DOES IT MEAN AND WHAT CAN BE DONE ABOUT IT

Implications and Recommendations
"WHAT HELPS? HELP ME."
Fitting in... Autistic Burnout

What is it? .
1. Late onset loss of functionality due to sustained monumental efforts.
2. Happens to MANY young ASD adults and many more all the way up into 50-60 years.
3. Often directly related to failing at “fitting in” with NT social skills despite faking it all the time to make it.

ASD Adult NEEDS:
1. Know basic polite skills
2. Acceptance.
3. Protection.
5. Education on awareness and advocacy.
7. Vocational training in a strength area.

NEVER:
1. Assume social skills learned in a classroom will work outside of the classroom.
2. Under estimate how hard it is to be someone you are not neurologically meant to be.
3. Assume that NT social skills are the only way to success and/or integration in society.
4. Under estimate the importance of “like” people/friends for social interactions and practicing of ASD social skills.
5. Believe the books have all the answers. Ask about Autistic Burnout on forums where there are autistic adults.

No ASD book or NT professional references Autistic Burnout. Only ASD adults talk of it. Please treat this as a real and serious threat until it can be disproven as a threat.

Visit Karla’s ASD Page for more information

Karla Fischer  https://www.facebook.com/Karlas-ASD-Page-155369821204141/
Rapidly Evolving Topic in the Community

- For example, see the list of strategies for avoiding or coping with autistic burnout at: https://queenofthedrowned.com/2019/05/26/resources-for-burnout-recovery-featuring-the-autistic-social-network/

Strategies and Recommendations for Autistic People

- Time off from school, job, life
- Reduced self-expectations
- Stimming, time with special interests
- Sensory and/or social withdrawal
- In general, time spent without the “mask”
- Passage of time; time to recover
Strategies and Recommendations for Families and Friends

- Reduced expectations
- Acceptance of the person even when they don’t “pass” for non-autistic / acceptance of autistic behavior
- Emotional support, empathic connections
- Direct support for instrumental activities of daily living
- Accommodations at work / school / community
Broader Systems-Level Considerations

- Discrimination and stigma around autistic behavior and disability encourage people to mask – anti-discrimination / anti-stigma work may have long-term, indirect impact?
- Therapy with normalization goals may need to be reconsidered?
- System-level changes that normalize disability may be beneficial in reducing overall risk of autistic burnout?
- Professional, clinical, family, and self-advocate communities all could benefit from further understanding and discussion around autistic burnout
Considerations Around Transition Age

- Many adults report their first autistic burnout around transition age.
- May be a particularly vulnerable time due to increase in expectations, number and scope of life-changes, and general stress of that developmental time.
- Young people may not understand what is happening to them if it is their first experience of autistic burnout.
“I was intellectually gifted, but emotionally and socially way behind my age. I burned out completely at age 14 from stress, socializing issues, and the start of an erratic puberty...Only now do I see it as burnout...”

“It actually started in middle school, my sensory issues got a lot worse, then I started socially withdrawing...like hanging out in my room and going into shutdown and...then my parents were really concerned because...they thought I was depressed, and for that [instance of burnout] afterwards...I never got to the point where I was before, like, I couldn’t deal with sensory issues the same way I went from having no diagnosis of autism to have a diagnosis of autism so it was a significant point in my life....I think that [instance of burnout] was caused by the social differences and interaction of a teenager versus pre-adolescent years.”
A Caution About “Reduced Expectations”

- **NOT MEANING** reducing expectations about a person’s ability to achieve their goals in life!!! They should have the same opportunities as anyone!

- ONLY talking about expectations of how close to a non-autistic person’s path theirs should look

- In other words:
  - **DO EXPECT US** to be able to achieve our dreams!
  - ...Just don’t expect us to always achieve them in the same way a non-autistic person would 😊
Key Points from the AASPIRE Research Team for Family and Professionals

■ The more people need to mask the more likely they are to experience burnout
■ Educate yourself about disability rights, and cultivate positive autistic or disability identity in young people
■ Teach young people to pace themselves and set flexible boundaries for themselves
■ Focus on autistic strengths and preservations to reduce the risk of burnout; for example, choose activities or employment in alignment with special interests
■ Be sensitive to the possibility that decreases in function (when someone can do something at one time but is unable to do the same thing at another time) may be a sign of autistic burnout
Limitations

- Small, qualitative study, convenience sample, burnout-specific interviews missing important demographics
- Designed to get an in-depth understanding from experts, not to generalize to a population
- Preliminary, exploratory work
- Analysis and interpretation presented here is still developing and has not been finalized
Next Steps

■ More research is needed
  – Measure development
  – Increased understanding of underlying causes and associations
  – Understanding of role in suicidality
  – Programs to relieve or prevent

■ More conversation is needed
  – Autistic people have been talking about this experience amongst ourselves for a long time
  – It’s time to broaden the discussion outside of the community so it can gain more potential for action
5. WRAPUP AND QUESTIONS
Thanks & Questions

- Thank you to the AASPIRE team, and to all of our research participants who shared their wisdom and experience with us

- Autism in Adulthood journal

- Contact me! draymake@pdx.edu | http://doraraymaker.com

- Happy to answer questions on: autistic burnout, community-engaged approaches to research, AASPIRE’s employment or healthcare studies

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