

Autistic Burnout: Exploring Autistic Perspectives on Treatment Availability and Effectiveness

Heather Mason

Outline

- Background
 - Defining Autistic Burnout
 - Impact
- Participants
- Method
- Preliminary Findings
- Discussion

Defining Autistic Burnout

- Cause
 - chronic life stress
 - a mismatch of expectations and abilities without adequate supports



Dr. Raymaker

Preliminary Criteria

- The following criteria must be met:
 1. significant mental and physical exhaustion
 2. interpersonal withdrawal.

- With one or more of the following:
 1. Significant reduction in social, occupational, educational, academic, behavioural, or other important areas of functioning
 2. Confusion, difficulties with executive function, and/or dissociative states
 3. Increased intensity of autistic traits and/or reduced capacity to camouflage/mask

Differential Diagnoses

- Depressive episode
- Mainstream (non-autistic) burnout
- Autistic “meltdown”

Impact

- Increased presence of autistic traits
- Difficulty processing emotions
- Decreased functioning
- Cognitive disruption – confusion & dissociation
- Exhaustion
- Loss of skills
- Social isolation
- Suicidal ideation & suicide

No Treatments Specifically for Autistic Burnout

- Behavioural Activation & Cognitive Behavioural Therapy contra-indicated Arnold et al., 2021
- Mainstream burnout treatments ineffective Hale and Sanders 2023

Research on Autistic Burnout is lacking

- Only 6 studies on Autistic Burnout to date
 - The first was only done in 2020

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Person-Oriented Research

- Designed by an autistic researcher with the autistic participant in mind
- Multiple and alternative avenues of communication
- Interview participants may have a support person present
- Participants may review the transcript and make edits

Research Questions

- What are the experiences of autistic adults seeking professional mental health support for autistic burnout?
 - How do the participants describe autistic burnout?
 - How was autistic burnout defined by the treatment provider?
 - What was their experience accessing treatment?
 - What treatments were provided?
 - What are the perceptions of the effectiveness of treatments?

Participants – Inclusion Criteria

- 18+
- Able to give voluntary informed consent
- Identifies as autistic
- Has personal experience with autistic burnout
- Has sought help for autistic burnout from a professional in the mental health field

Participants – Demographic Information

- Gender

- Man (n=2)
- Woman (n=6)
- Non-Binary (n=1)
- Gray Gender (n=1)
- Not disclosed (n=1)

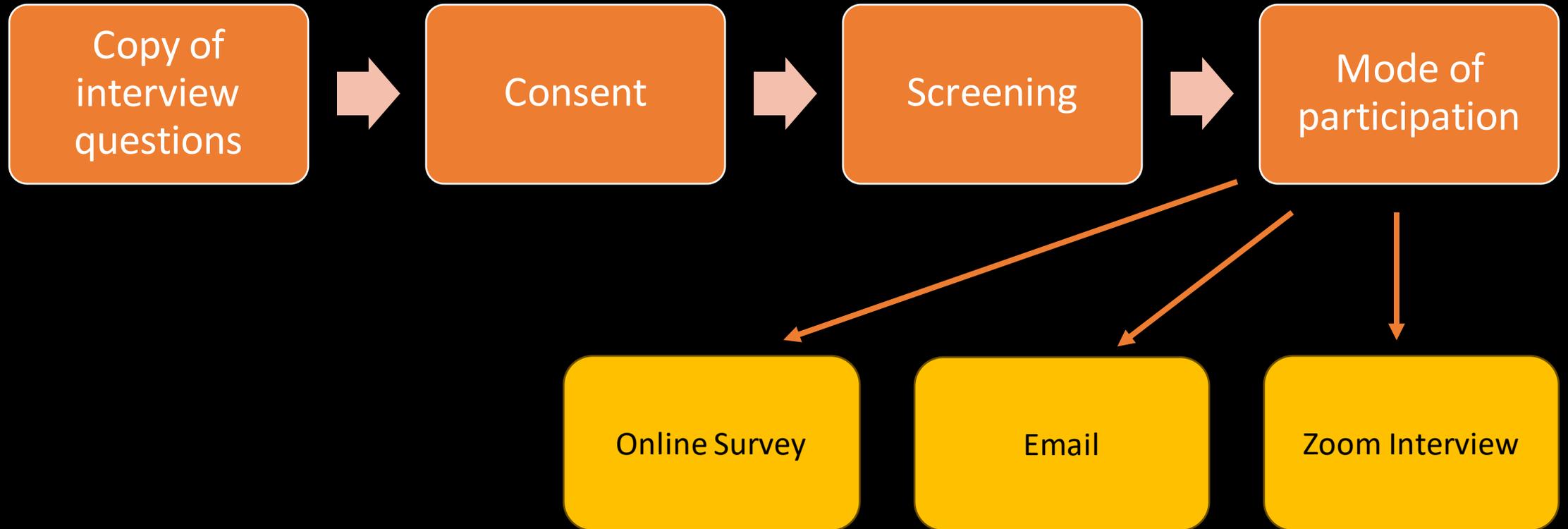
- Location:

- Canada (n=5)
- USA (n=5)
- Vietnam/South Africa (n=1)

Methods

- Self-selected
 - Online Advertisement – social media

Methods



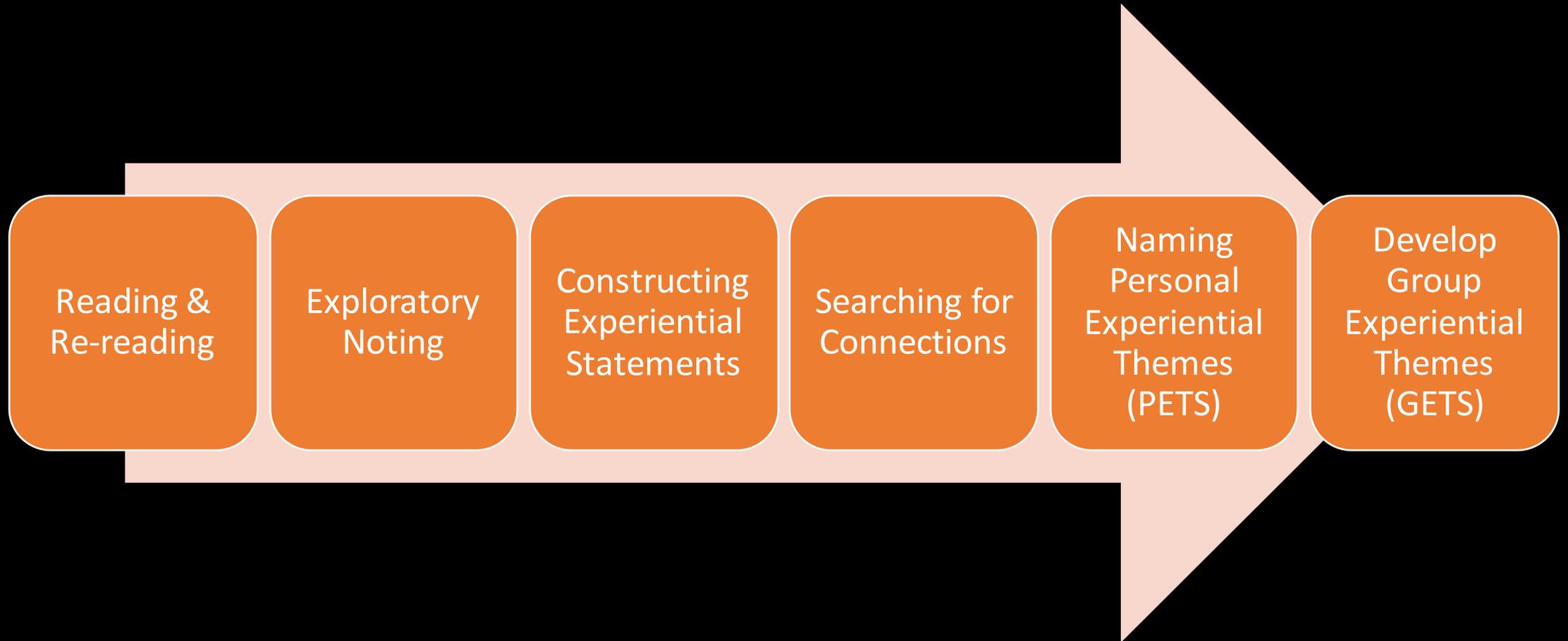
Methods - General



Qualitative Analysis

- Thematic analysis
- Inductive-deductive approach
- Coding

Interpretive Phenomenological Analysis



Preliminary Findings

Provider Definition

- NO provider definition
 - *“I have not had explanations from a professional - only fellow autistic people”*

Themes: Barriers To Support

- Lack of Autism Awareness & Education
- Misdiagnosing Autistic Burnout as Other Mental Health Condition
- Stereotypes as a Barrier to Support
- Concerns Dismissed
- Lack of Empathy
- Lack of Support
- Lack of Support is Life-Threatening

Treatments Tried

- CBT
- DBT
- Behavioural Activation
- Medication
 - Anti-Anxiety
 - Anti-depression

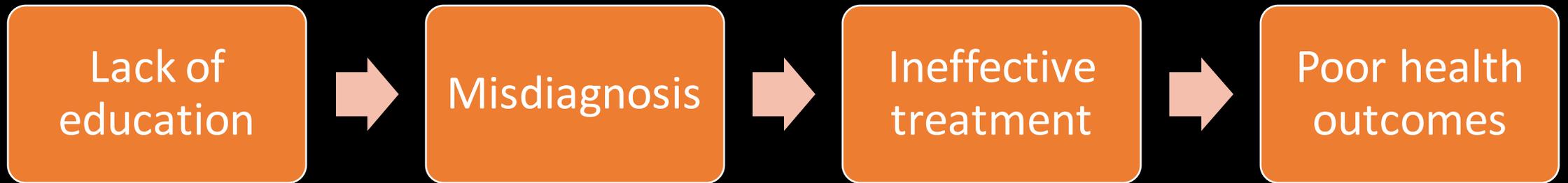
Themes: Perceived Effectiveness of Treatments

- CBT is Invalidating
- Behavioural Activation Worsens Autistic Burnout
- Medications are Ineffective
 - Anti-anxiety
 - Anti-Depressants
- DBT
 - Self-Soothing
 - Interpersonal Effectiveness

Themes: Self-Management

- Time
- Rest
- Solitude
- Control of Sensory Environment
- Pacing Activities

Discussion



Discussion

- Healthcare providers are unable to differentiate between autistic burnout and depression
- Standard treatments for depression are ineffective and/or harmful
- Effective supports focus on rest and building interpersonal skills to be able to communicate boundaries

Implications for Change

- Increase Autism education among clinicians
 - Prevent misdiagnosis & increase early detection
- We need more support for autistic adults

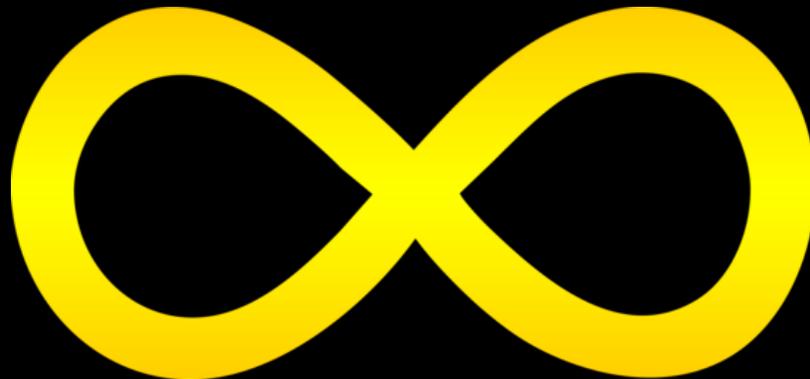
Future Research

- Explore treatment providers understanding of autistic burnout
- Clinician training – identifying autistic burnout
- Develop screening / measurement tool
- Treatment guidelines

NOTHING ABOUT US WITHOUT US

This research contributes to the growing number of autistic researchers researching autism.

This research was designed with autistic priorities in mind and was conducted in collaboration with autistic participants.



Thank You For Your Time!

Q & A

Interview Questions

- What made you decide to seek help for autistic burnout? Was there a specific moment or realization that prompted you to do so?
- How many times have you sought professional help for autistic burnout?
- How did your treatment provider explain autistic burnout?
- How have healthcare professionals or therapists responded to your concerns about autistic burnout?
- How knowledgeable did your treatment provider seem about autistic burnout?
- What types of support or interventions have you tried so far?
 - What has been helpful, and what hasn't?
- Have the treatment plans suggested by professionals been effective for you?
 - Why?
 - Why not?
- Are there any specific accommodations or strategies that you've found helpful in managing/preventing burnout?
- What challenges have you encountered when trying to access support for autistic burnout?
 - Is there anything you wish service providers understood better about your experiences/needs?
- What do you think healthcare professionals, educators, employers, and society need to understand about autistic burnout?
- Have you ever been turned away from healthcare providers? What was their reason?
- Did you feel understood by your healthcare provider?
- Did your healthcare provider accommodate your unique needs?
 - E.g., sensory needs, processing time
- Are there any questions that you think I should have asked? What are they?
- Is there anything else you'd like to share that you believe is relevant to this research?

Lack of Autism Awareness & Education

- Lack of Autism Awareness & Education Among Healthcare Providers
 - *“The VAST majority of mental health professionals have no idea what it means to be Autistic, and they know even less how to help an Autistic person in crisis”*

Misdiagnosis

- Borderline Personality Disorder
 - *“I was horribly misdiagnosed with borderline personality disorder”*
- Depression
 - *“They thought everything was rooting from depression, low self-esteem...”*
- Anxiety
 - *“PCP...notes how “anxious” I am (noting lack of eye contact and the stimming behaviour)”*
- Early-Onset Schizophrenia

Unable to Differentiate from Depression

- “One thing that’s been an issue for us is the difference between depression and autistic burnout”
- “It was always viewed it as “this is just your depression””

Stereotypes as a Barrier to Support

- Gender Bias
 - *“If I woman like me seems social and successful, they can’t comprehend that they could be autistic”*
- Too Empathetic
 - *“How can you be extremely empathetic if you’re autistic?”*
- Too Smart
 - *“If you’re someone who didn’t have any intellectual issues...autism is not really the route that they go”*
- Too Functional
 - *“Being at the functional level I am is the hardest...if I was less functional, I would have more support”*

Concerns Dismissed

- *“I was completely dismissed”*
- *“Dismissed by most health professionals”*
- *“They have dismissed me in clinics, their offices, and in hospital”*

Lack of Empathy

- *“I have always been treated as a liar, or exaggerator and always wrong”*
- *“Their answer was...just push yourself to do it”*

Lack of Support

- “There does not appear to be any help”
- *“So much of what I’ve seen is focused on behaviourism and children, neither of which is very helpful for my situation.”*

Lack of Support is Life-Threatening

- *“If you’re not getting support as an autistic person, honestly, I feel like your life is in danger”*
- *“Not having a diagnosis can lead to that suicidality”*

Ineffective Support

- *Invalidating CBT*
 - *“trying and failing to just change my behaviour and feelings”*
 - *“Reframing my thoughts...is tone deaf to my reality”*
- Behavioural Activation Further Drains Energy
 - *“Going out more puts me into a more severe burnout”*
 - *“Behavioural activation...worsens burnout because rest is required”*

Ineffective Support

- Medications are Ineffective
 - *“The meds led me to become suicidal”*
 - *“Throwing anti-depressants at the problem just gave me side effects with no relief of other issues”*

Effective Treatments

- DBT

- Self-Soothing

- *“Helped me to make myself feel better when I was burnt out”*

- *Interpersonal Effectiveness*

- *“It did help me prevent burnout...by being able to communicate my needs and my limits”*

Recovery Needs

- Rest
 - *“I need time to just do nothing”*
- Time
 - *“It’s kind of a waiting game”*
- Solitude
 - *“I’m just going to need to wait and rest and spend time on my own”*

Managing Autistic Burnout

- Control of Sensory Environment

- *“I’m more in control of my settings now and I can manipulate them to accommodate myself”*
- *“We had to change the environment”*

- Pacing

- *“I’m very intentional about what I plan, and I like planning in advance so I know what’s coming and I can brace myself for it and pace it”*
- *“It’s about spacing things”*