

Examining the presentation of depression in autistic adults

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Persistent feelings of sadness



Loss of interests in activities



Trouble sleeping or oversleeping



Appetite or weight changes



Fatigue or decreased energy



Difficulty thinking clearly or quickly



Irritability, frustration, or pessimism



Physical aches and pains



Recurrent thoughts of death or suicide

Depression in Autistic People

- Depression is a **significant** public health problem in Canada, USA, and worldwide
- Autistic youth and adults are **3-4x more likely** to experience depression than their peers
- Often, depression is **missed** in autistic people...
 - Diagnostic overshadowing
 - Few assessment tools
 - Limited research
 - Lack of clinical training

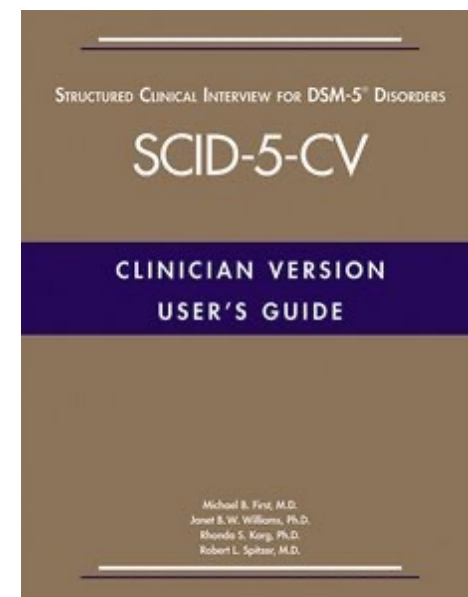
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Common Assessments for Depression

- Self-report questionnaires
- Caregiver/parent-report questionnaires
- Clinical interviews
- History
- Clinical Judgment

PATIENT HEALTH QUESTIONNAIRE-9 (PHQ-9)				
Over the <u>last 2 weeks</u> , how often have you been bothered by any of the following problems? (Use "✓" to indicate your answer)	Not at all	Several days	More than half the days	Nearly every day
1. Little interest or pleasure in doing things	0	1	2	3
2. Feeling down, depressed, or hopeless	0	1	2	3
3. Trouble falling or staying asleep, or sleeping too much	0	1	2	3
4. Feeling tired or having little energy	0	1	2	3
5. Poor appetite or overeating	0	1	2	3
6. Feeling bad about yourself — or that you are a failure or have let yourself or your family down	0	1	2	3
7. Trouble concentrating on things, such as reading the newspaper or watching television	0	1	2	3
8. Moving or speaking so slowly that other people could have noticed? Or the opposite — being so fidgety or restless that you have been moving around a lot more than usual	0	1	2	3
9. Thoughts that you would be better off dead or of hurting yourself in some way	0	1	2	3



Practical challenges:
Common assessments for depression were developed for, and tested on, non-autistic people

How do autistic adults experience depression?

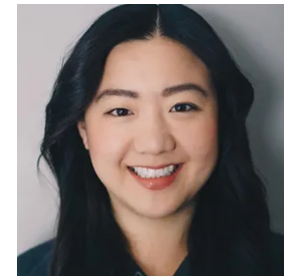
Interviews with **21 autistic adults** experiencing current and lifetime depression

Objectives

- 1) How do autistic adults **describe** depression symptoms?
- 2) Which depression symptoms are **most common** among autistic adults?
- 3) What may be **unique** about the presentation of depression in autistic adults?



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How do autistic adults describe depression?

Common Descriptions of Common Symptoms

Anhedonia: “Yeah I don’t care about the things that used to matter to me”
“You just don’t feel like doing anything, even things you like”

Mood: “I know I feel sad when I want to cry all the time, like I can’t help it”
“There are times when I can’t feel happy, just like blah and empty”

Fatigue: “I have like no energy when I’m sad, can barely do anything because I’m just so tired”
“Even though I sleep at night, I wake up feeling so tired”

Unique Descriptions of Common Symptoms

Anhedonia: “I get bored, like **boredom** takes over me and it’s all I can do or think about”
“My **battery is zapped**, like I just can’t do it anymore even if I want to”

Mood: “I feel like a **hermit crab**...I don’t feel like me”
“Over time, I become like a **hollowed out tree stump**, there’s just nothing there”

Fatigue: “Some days my energy is a like a ghost...an **apathetic ghost**”

How do autistic adults describe depression?

Unique Symptoms / Experiences

Identity: “Being on the spectrum, I have a lot of feelings of just not fitting in, and for me, I feel like a lot of the times isolation is the best”

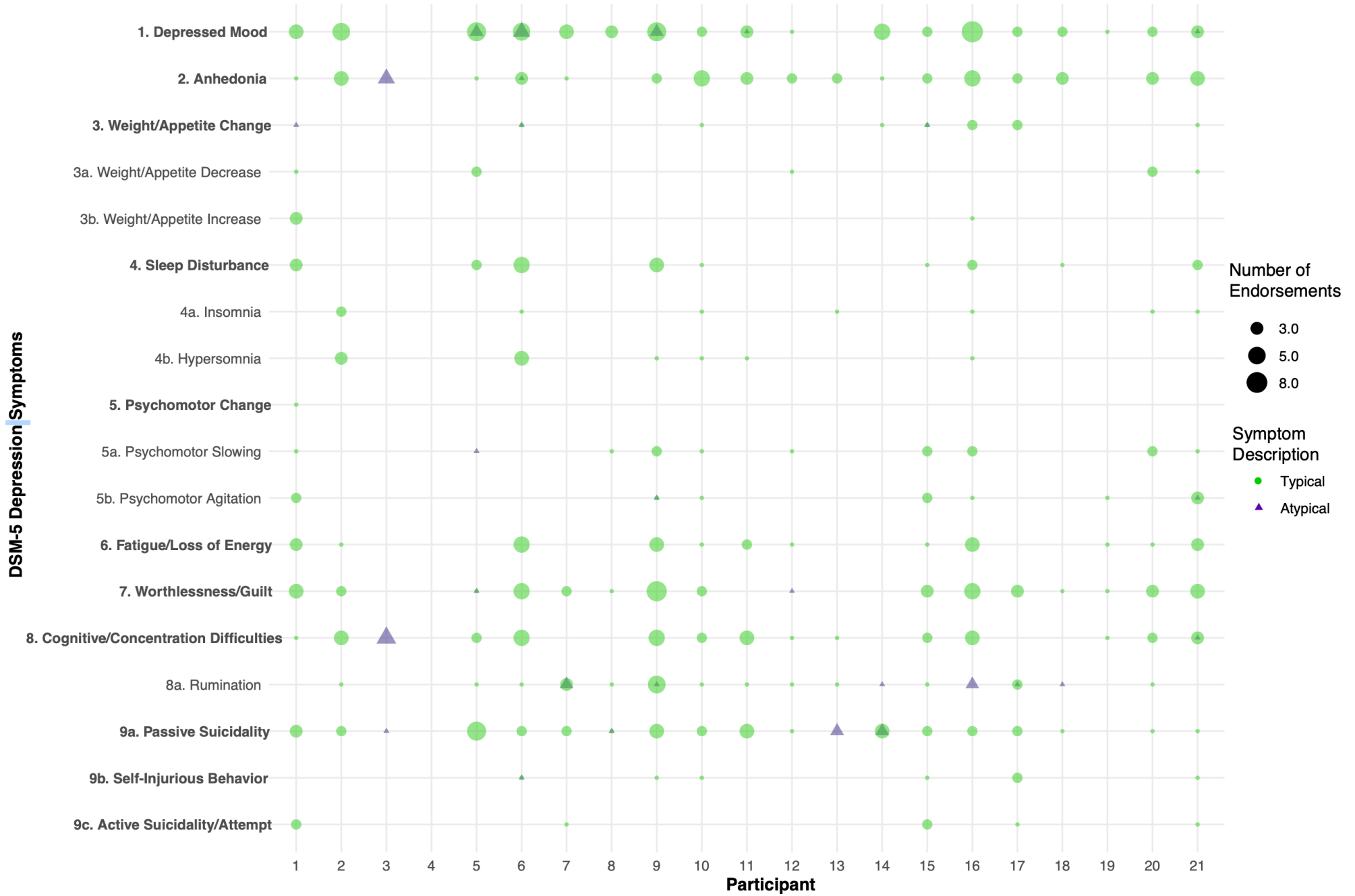
“I think a lot of times my autism makes it difficult for me to know if I need help...like if it's [depression] getting really bad like what do I do about it?”

Sensory: “All systems are a go...like my body can't handle it all and I spiral”

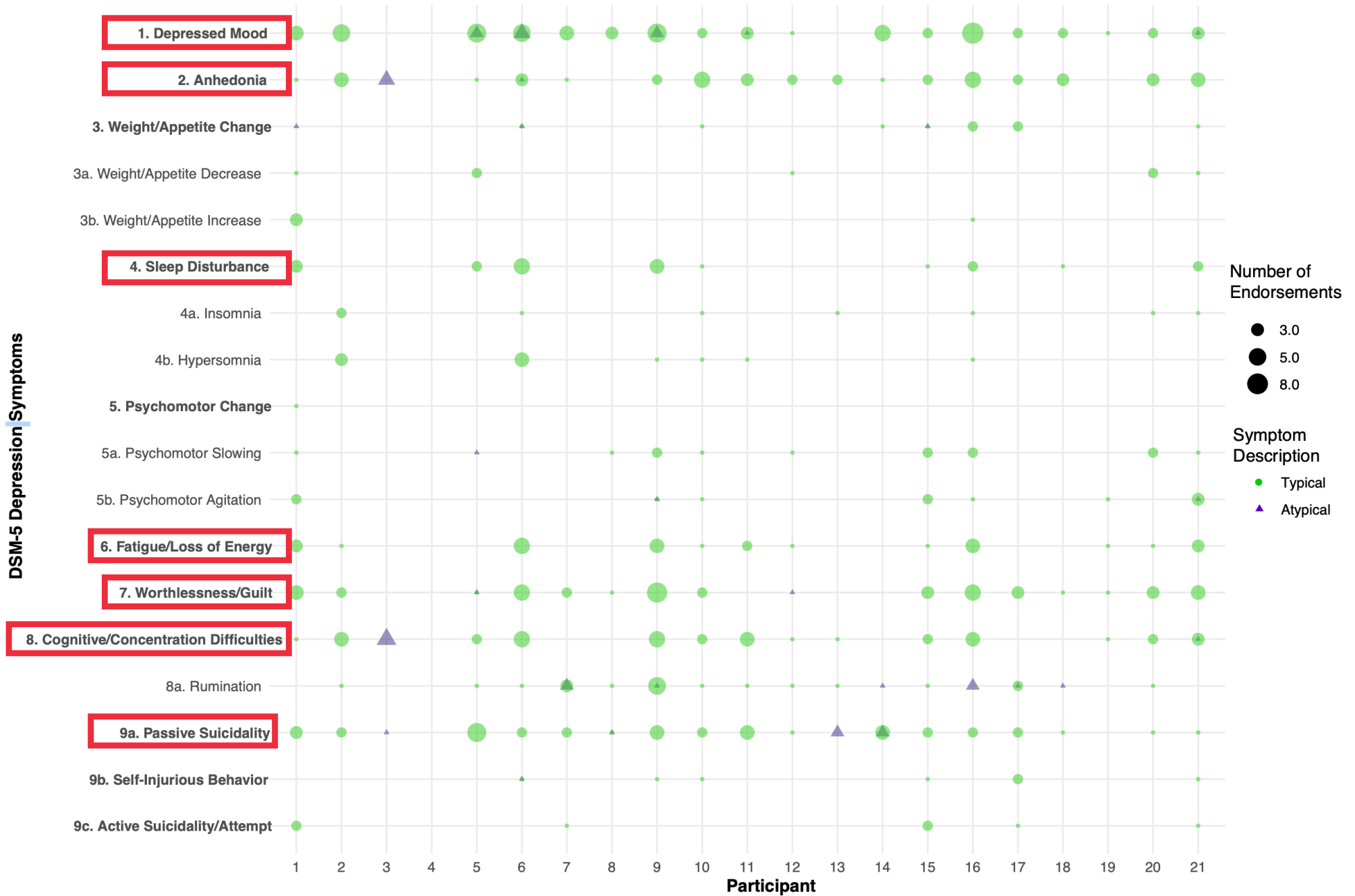
“It [sensory experiences] becomes so intense and so powerful that it's like all you can think about or feel, like it's painful and hard to get over”

Camouflaging: “I do what people expect of me, but it's not like I feel like it, in fact it makes it worse for me...like my mood tanks”

“It's so hard, like so hard, to really know my true self anymore because I've spent so much time worried about what people think or what they need me to be...so you ask about self-esteem or how I view myself and I'm honestly still trying to figure out the real me”



Which depression symptoms are most common among autistic adults'



Which depression symptoms are most common among autistic adults?

What may be unique about the presentation of depression in autistic adults?

- Autistic identity, minority stress, and internalized experiences appears **intertwined** with depression for many (but not all) autistic adults
- In most adults, outward presentation **does not match** internal experiences
- **Flexible interviewing** - in-person, virtual, texting, emailing, etc. – is optimal for most adults
- Normative questionnaires may work for some, but not all, autistic adults...**mixed approaches** may be best

Takeaways

- Examine our biases – are we **assuming** autistic traits and missing signs of depression?
- Depression symptoms can be **universally** and **uniquely** experienced by autistic adults
- Mixed methods – standard interviews/surveys **and** open-ended questions about symptoms may be best
- **Flexible assessments** - in-person, virtual, texting, emailing, etc. – in isolation and/or combination
- Internalization of **autistic identity and minority stress experiences** are critical to understanding depression in autistic people

Acknowledgements



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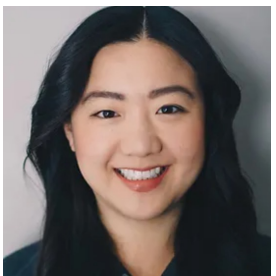
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