



19th May 2026

Early-onset Dementia and Autism

Presentation for Young Dementia Network Webinar

- Background:

- What is autism?
- The 'under-diagnosis' problem

- Research overview:

- 1) Rates of early-onset dementia
- 2) Potential sources of risk and potential false positives
- 3) Clinical limitations

- Opportunities for the future and conclusions

- **Background:**

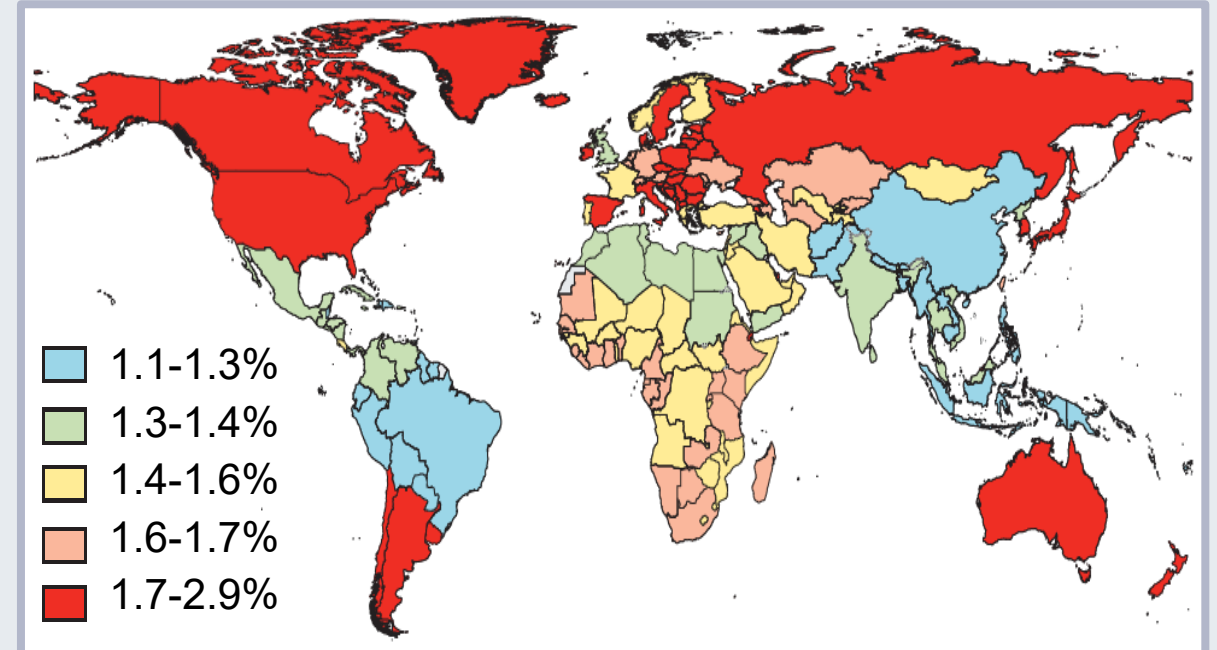
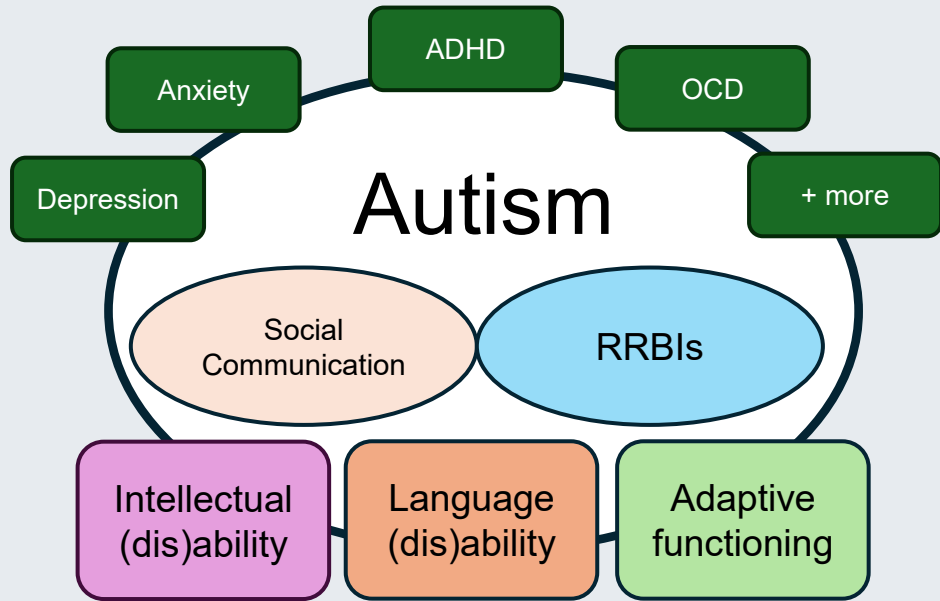
- **What is autism?**
- **The 'under-diagnosis' problem**

- **Research overview:**

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- **Opportunities for the future and conclusions**

What is autism?



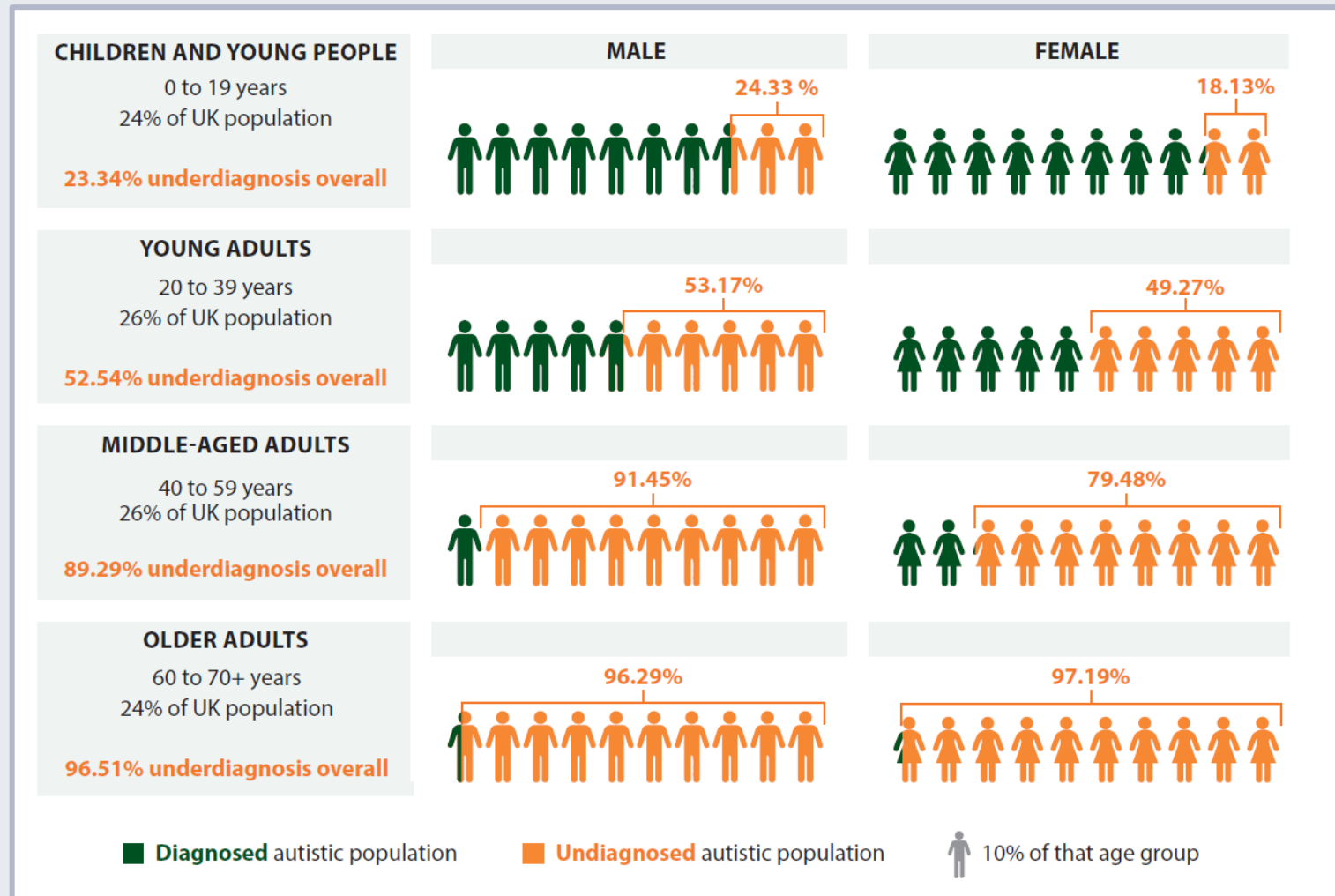
Autism
1-3% prevalence
680,000 to 2,100,000 people

BUT:

We see age disparities in rates of diagnosis across the lifespan

The 'under-diagnosis' problem

- Most autistic people are adults, and most are undiagnosed.
- UK health records indicate:
 - ~89% of autistic people in midlife are undiagnosed.
 - ~96% of autistic people in old age are undiagnosed.



Note: Estimate accounts for male/female ratio.

ANNUAL
REVIEWS

Annual Review of Developmental Psychology
Aging Across the Autism
Spectrum

Gavin R. Stewart and Francesca Happé

Social, Genetic, and Developmental Psychiatry Centre, Institute of Psychiatry, Psychology, and Neuroscience, King's College London, United Kingdom; email: gavin.stewart@kcl.ac.uk

- Background:

- What is autism?
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- **Research overview:**





- 1) **Rates of early-onset dementia**
- 2) Potential sources of risk and potential false positives
- 3) Clinical limitations

- Opportunities for the future and conclusions

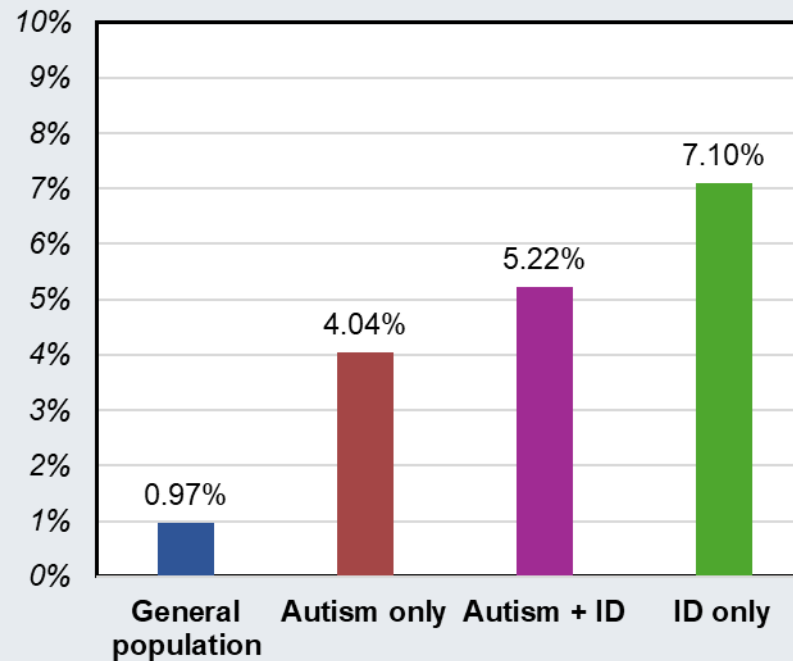
Rates of Early-onset Dementia

- Middle-aged and older autistic people have been found to have higher rates of dementia (early onset and old age onset) compared to non-autistic people.
- Analysis of USA Medicaid data totalling ~1.2million, ~37,000 with an autism diagnosis.
- Prevalence of early onset dementia in autistic people aged 30-64 was ~4% (or 4x), compared to <1% in general population.

The prevalence and incidence of early-onset dementia among adults with autism spectrum disorder

Giacomo Vivanti  | Sha Tao | Kristen Lyall  | Diana L. Robins  | Lindsay L. Shea 

Prevalence of 'early-onset dementia'

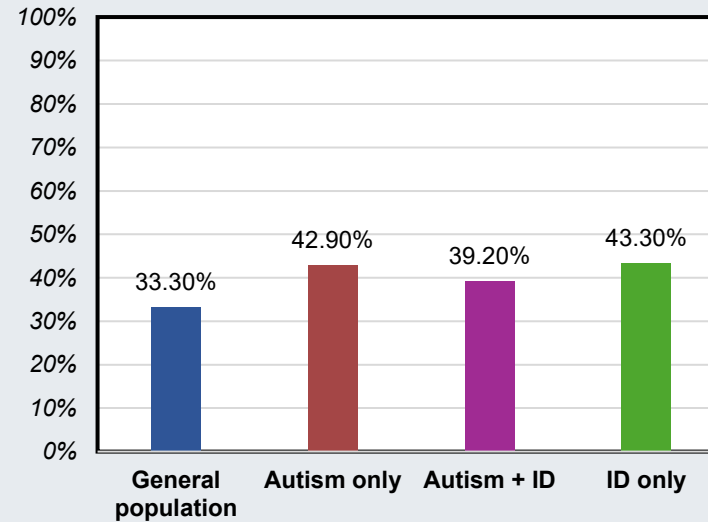


Dr Giacomo Vivanti
(Drexel)

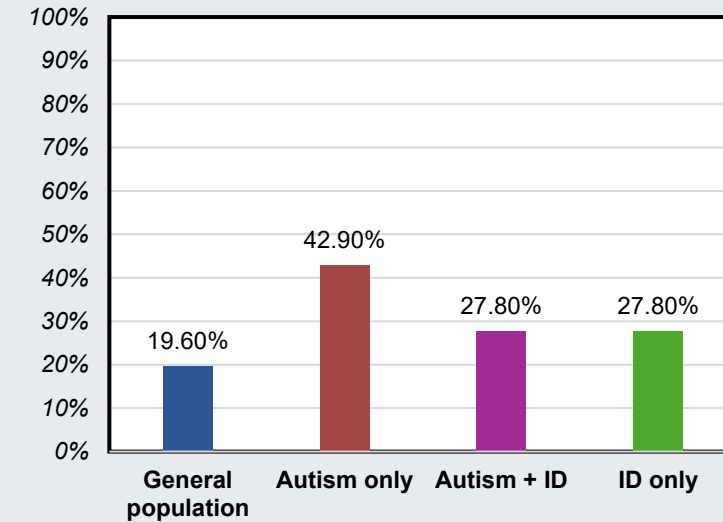
Rates of Early-onset Dementia

- What might be driving this...
 - Being autistic and/or other factors?
- Higher rates of many risk factors.
 - When accounting for these, risk in the autism group reduces to 2x (from 4x).

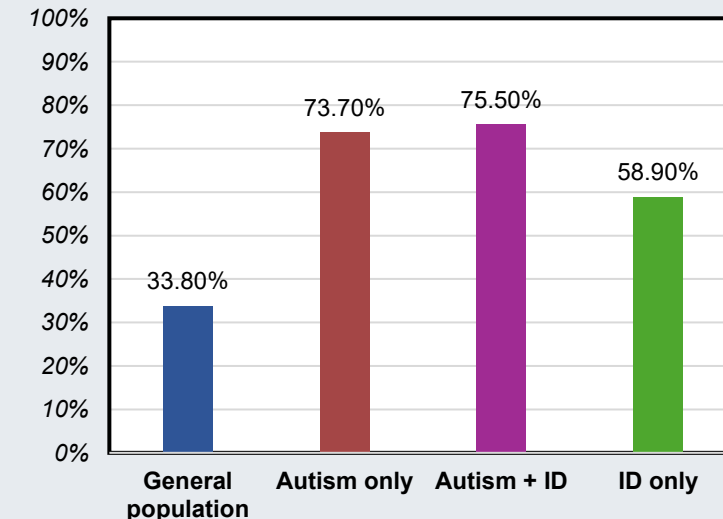
Has high cardiovascular risk factors



Has depression



Has other psychiatric condition



Dr Giacomo Vivanti (Drexel)



The prevalence and incidence of early-onset dementia among adults with autism spectrum disorder

Giacomo Vivanti ^{ORCID} | Sha Tao | Kristen Lyall ^{ORCID} | Diana L. Robins ^{ORCID} | Lindsay L. Shea ^{ORCID}

Rates of Early-onset Dementia

- My thoughts on interpretation:
 - Data is from Medicaid records.
 - While published in 2021, data was extracted from 2008-2012.
 - Doesn't account for under-diagnosis of autism in adulthood.
 - “4x” and “2x” risk are quite scary sounding – risk is 2% (vs. 1%).

The prevalence and incidence of early-onset dementia among adults with autism spectrum disorder

Giacomo Vivanti  | Sha Tao | Kristen Lyall  | Diana L. Robins  |
Lindsay L. Shea 

We need more
contemporary
and
representative
research!

- Background:

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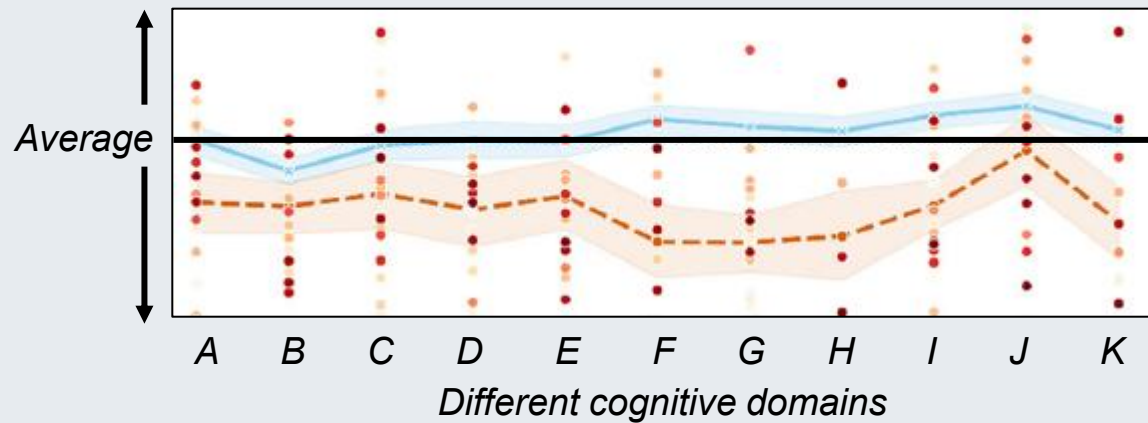
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- Opportunities for the future and conclusions

Earlier natural decline?

- Some autistic people may be at risk for earlier cognitive decline.



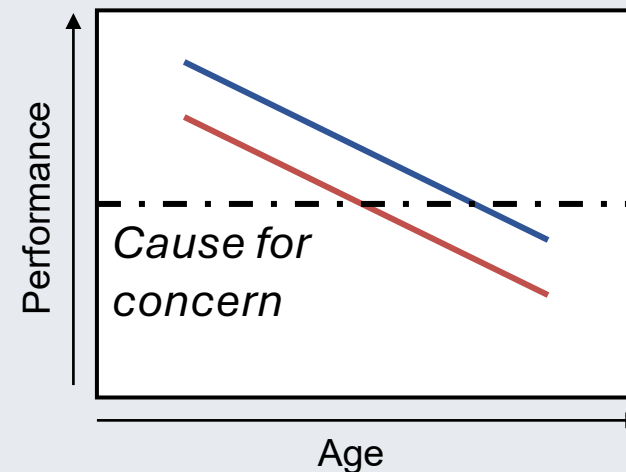
- Why is this important? May result in an 'old age' cognitive profile at a younger age, so red flags for dementia may appear earlier.
- More work needed in this area.

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RESEARCH ARTICLE

One size does not fit all: An individualized approach to understand heterogeneous cognitive performance in autistic adults

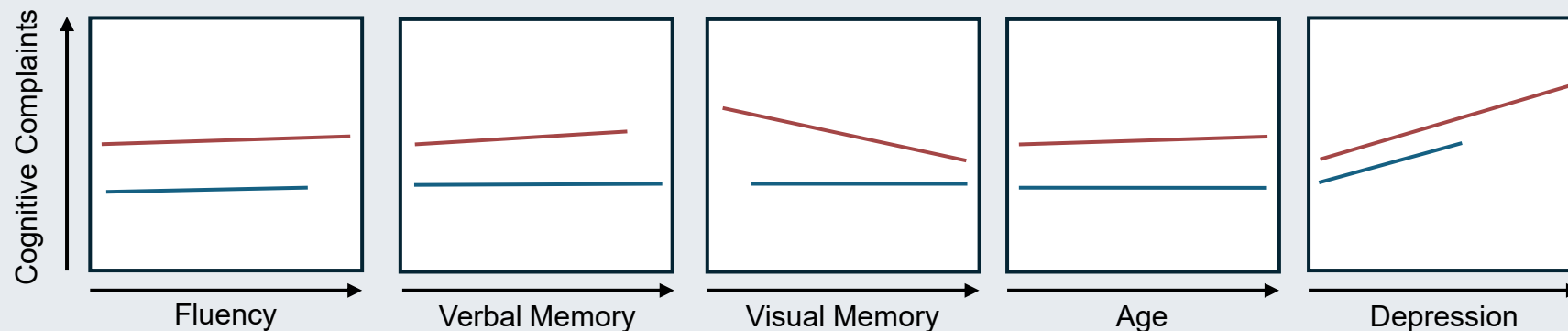
Carolien Torenvliet¹ | Annabeth P. Groenman^{1,2} | Tulsi A. Radhoe¹ |
Joost A. Agelink van Rentergem¹ | Hilde M. Geurts^{1,3}



Dr Carolien Torenvliet
(Amsterdam)

Harsher self-appraisals?

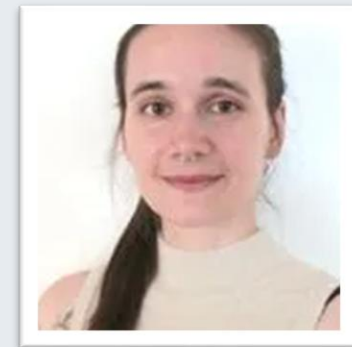
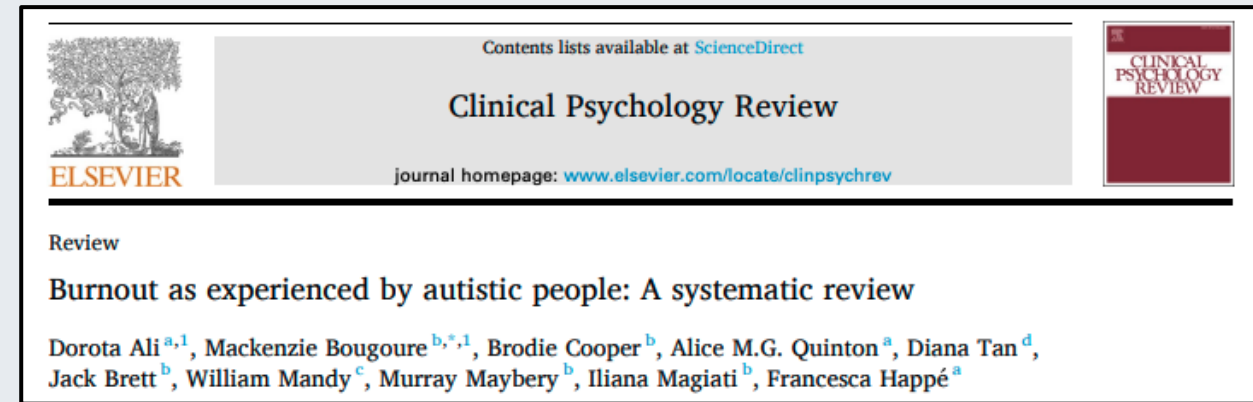
- Autistic people often self-appraise their cognitive abilities to be worse than they actually are.
- No associations between age and objective cognitive performance with subjective cognitive complaints
- But depression is associated with subjective cognitive complaints.



Dr Carolien Torenvliet
(Amsterdam)

Burnout mistaken for cognitive decline?

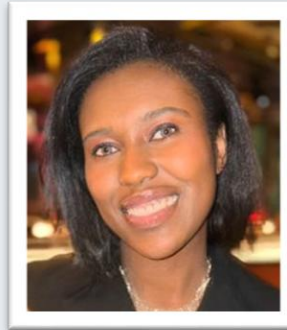
- Autistic people often experience 'burnout'.
- WHO definition, within a workplace context:
 - "Burnout is a syndrome conceptualized as resulting from chronic workplace stress that has not been successfully managed.
- Burnout is characterised by three dimensions:
 - feelings of energy depletion or exhaustion
 - increased mental distance from one's job, or feelings of negativism or cynicism related to one's job,
 - reduced professional efficacy.
- Manifests in autistic people as (temporary):
 - Extreme long-term exhaustion
 - Loss of function [cognitive, physical, emotional]
 - Reduced tolerance to stimulus
- Could burnout be mistaken for early-onset dementia?



Dr Dorota Ali
(King's College London)

Lived experience insights

- Negative self-appraisals and burnout also commonly reported by middle-aged and older autistic people in interview studies.



Dr Dayna Francis (KCL)

Contents lists available at [ScienceDirect](#)

Research in Autism

journal homepage: www.elsevier.com/locate/rasd






“Bigger lows, but higher highs”: A qualitative exploration of the similarities and differences in quality of life of middle-aged and older autistic and non-autistic adults

Dayna Francis ^{a,1}, David Hershman ^{a,1}, Rebecca A. Charlton ^b, Francesca Happé ^a, Gavin R. Stewart ^{a,*}



“My memory is getting worse. I forget names more than before, lose my train of thought mid-sentence, take longer to finish what I’m saying and sometimes struggle to find the word I’m looking for.”

– *Autistic woman, early 50s*

“[A parent] controlled my life so much it stopped me breaking down. Straight after [they] died I had burnout and needed hospitalisation.”



– *Autistic woman, mid-60s*



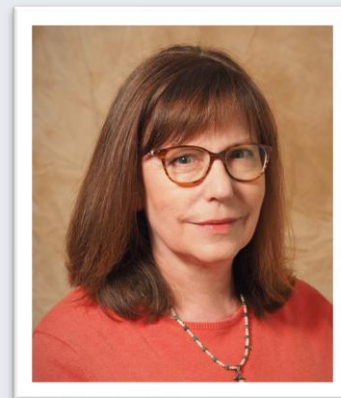
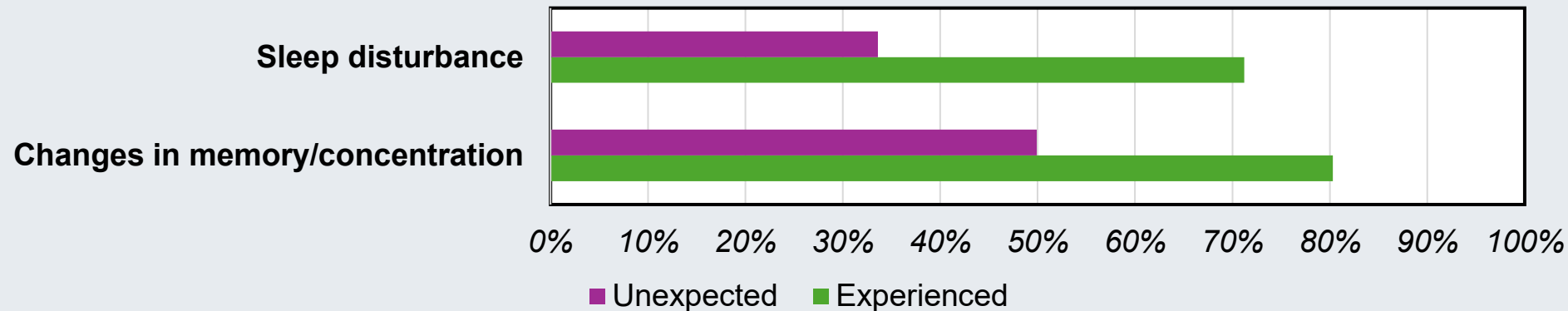
Menopause?

- Autistic women may experience more challenges during the menopausal transition.
 - Likely due to higher number of pre-existing risk factors for menopause difficulties.
- Brain fog and sleep disturbances were some of the most common experiences reported by autistic people.
 - Unexpected symptom for many.

“Struggling for Years”: An international survey on Autistic experiences of menopause

Christine A. Jenkins^{1,†} , Rachel L. Moseley^{2,†} , Rose J. Matthews³, Margaret Janse van Rensburg⁴, Julie M. Gamble-Turner⁵ and Miranda J. Brady⁶

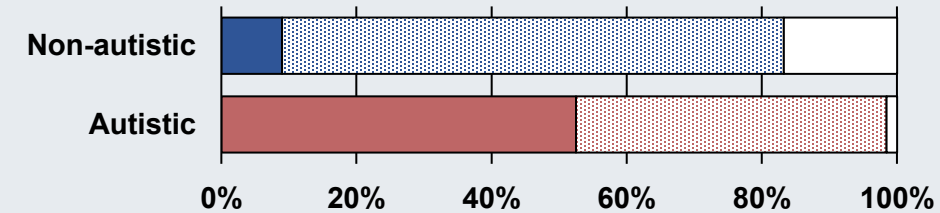
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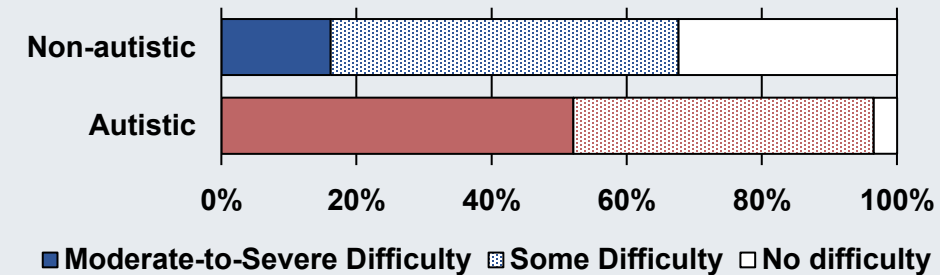
Christine Jenkins
(Canada)

- Middle-aged and older people with high autistic traits have been found to have higher rates of sleep problems compared to non-autistic comparison.
- AWA Wave 1: 276 autistic adults aged 40-91 (mean age = 60) compared to matched non-autistic comparisons.
- While sleep problems are common, autistic people report more moderate-to-severe problems than comparisons.

Sleep Disturbances



Daytime dysfunction



■ Moderate-to-Severe Difficulty ■ Some Difficulty □ No difficulty



Sophie Roper
(KCL)

Sleep problems and mental health difficulties in older adults who endorse high autistic traits

Gavin R. Stewart^{a,*}, Anne Corbett^b, Clive Ballard^b, Byron Creese^b, Dag Aarsland^a, Adam Hampshire^c, Rebecca A. Charlton^{d,1}, Francesca Happé^{a,1}

^aInstitute of Psychiatry, Psychology and Neuroscience, King's College London, SE5 8AF, UK

^bCollege of Medicine and Health, University of Exeter, EX1 2LU, UK

^cDepartment of Medicine, Imperial College London, SW7 2AZ, UK

^dDepartment of Psychology, Goldsmiths University of London, SE14 6NW, UK

Under Review

Sleep quality and mental health in middle-aged and older autistic and non-autistic adults.

Sophie Roper, Andreea Barbinta, Rebecca A. Charlton, Francesca Happé, and Gavin R. Stewart

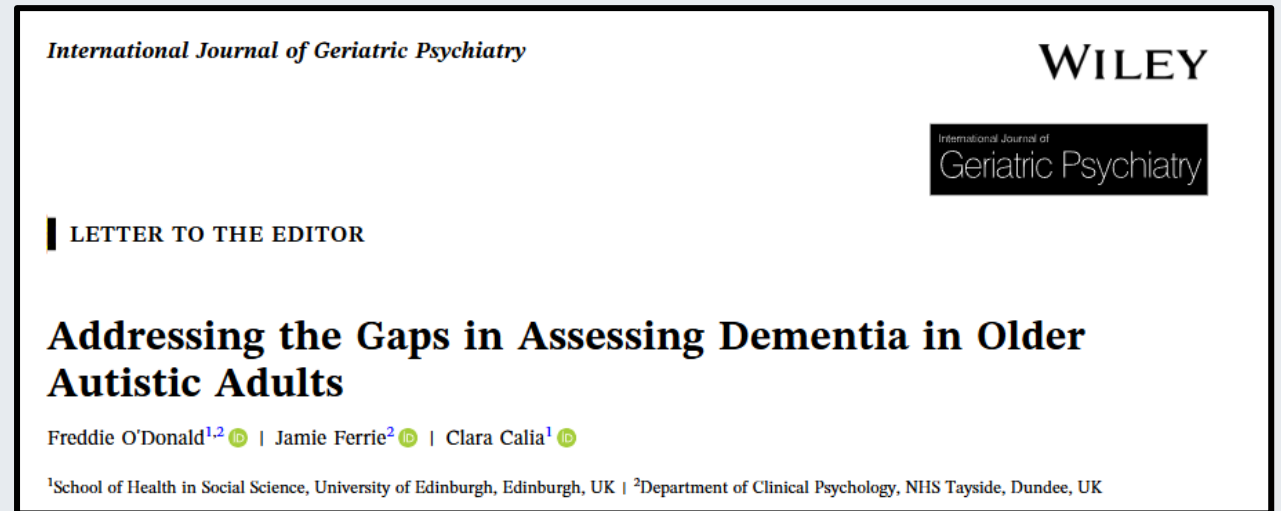
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Challenges in the clinic

- There have been concerns raised by clinicians that we lack validated tools for assessing dementia in autistic populations.
- May result in accurate assessments.
- We need more applied clinical research to test and develop the tools being used in practice to ensure they are fit for purpose.
- We also need to improve adult service clinical awareness of autism.



**Dr Jamie Ferrie
(NHS Scotland)**

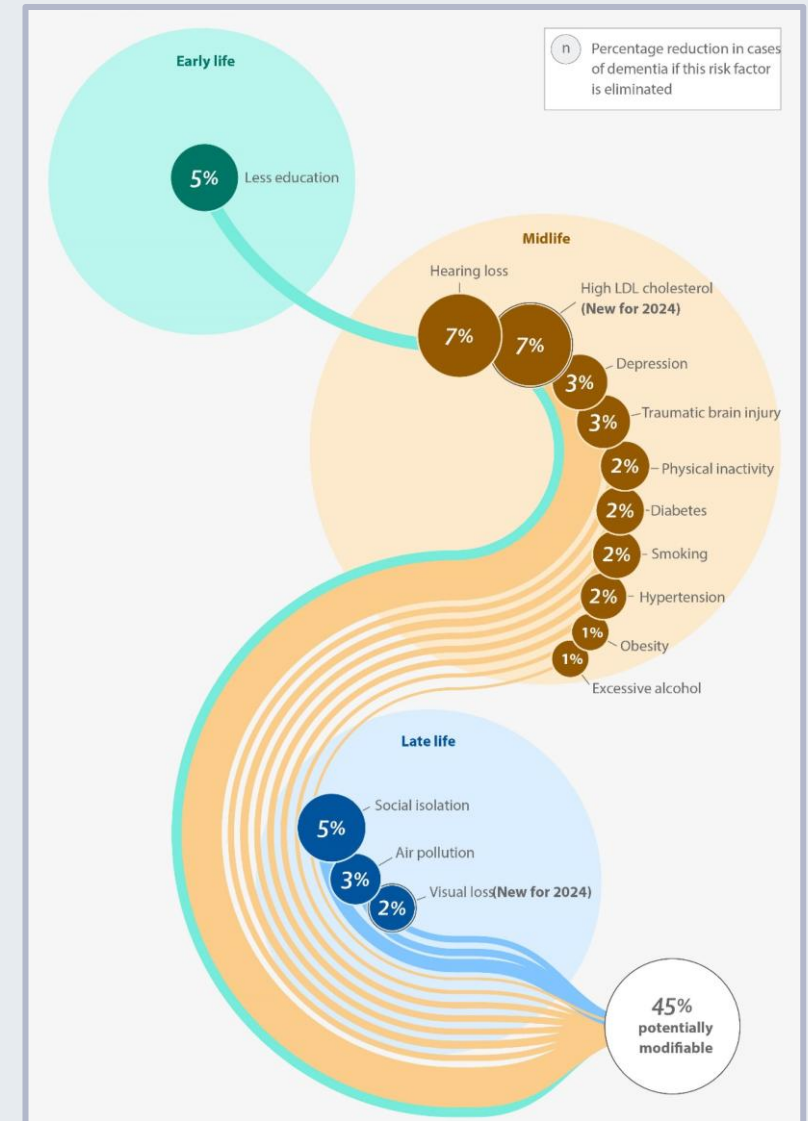
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- **Opportunities for the future and conclusions**

Opportunities for future research

- Lancet Commission has set out 14 modifiable factors for dementia that have scarcely been tested in relation to autism.
- Studies need to focus on those with a diagnosis, but also those who are undiagnosed.
 - Does risk look the same for both groups?



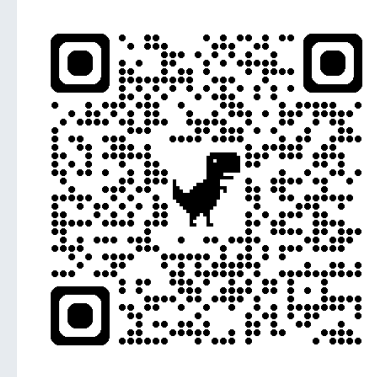
- Some evidence that autistic people may be more likely to develop early-onset dementia.
- However, issues with generalisability of this research due to underdiagnosis of autism in adults.
- Our tools for assessing dementia in autistic populations are limited.
- We need to validate (and potentially develop new) assessment tools for use in autistic populations.

Conclusions

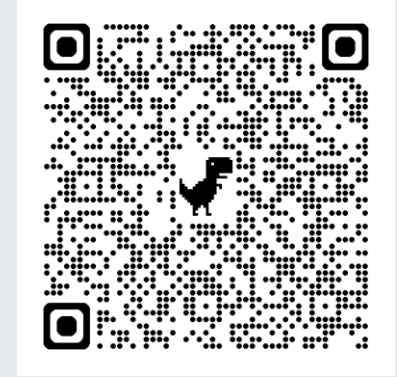
- We need to continue study dementia in autistic populations.
- Autistic people should be involved in how we do this research.
- We need to ensure this information is reaching autistic people, their supporters, and those supporting them.

Thank you

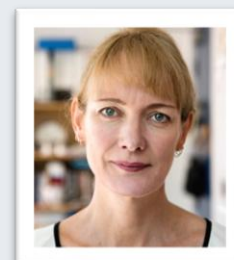
- Thank you for listening.
- And thank you to the British Academy for funding my current work.
- And collaborators at KCL, UCL and Goldsmiths.



Scan here for a recent narrative review on ageing and autism



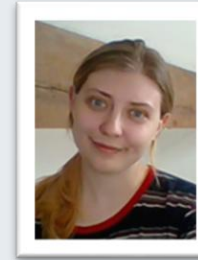
Scan here to sign-up to the ReSpec Lab Newsletter



Prof Francesca Happé



Prof Rebecca Charlton



Dr Amber John



Prof Josh Stott



Dr Dayna Francis



Sophie Roper

+ many more involved in my other ageing research!