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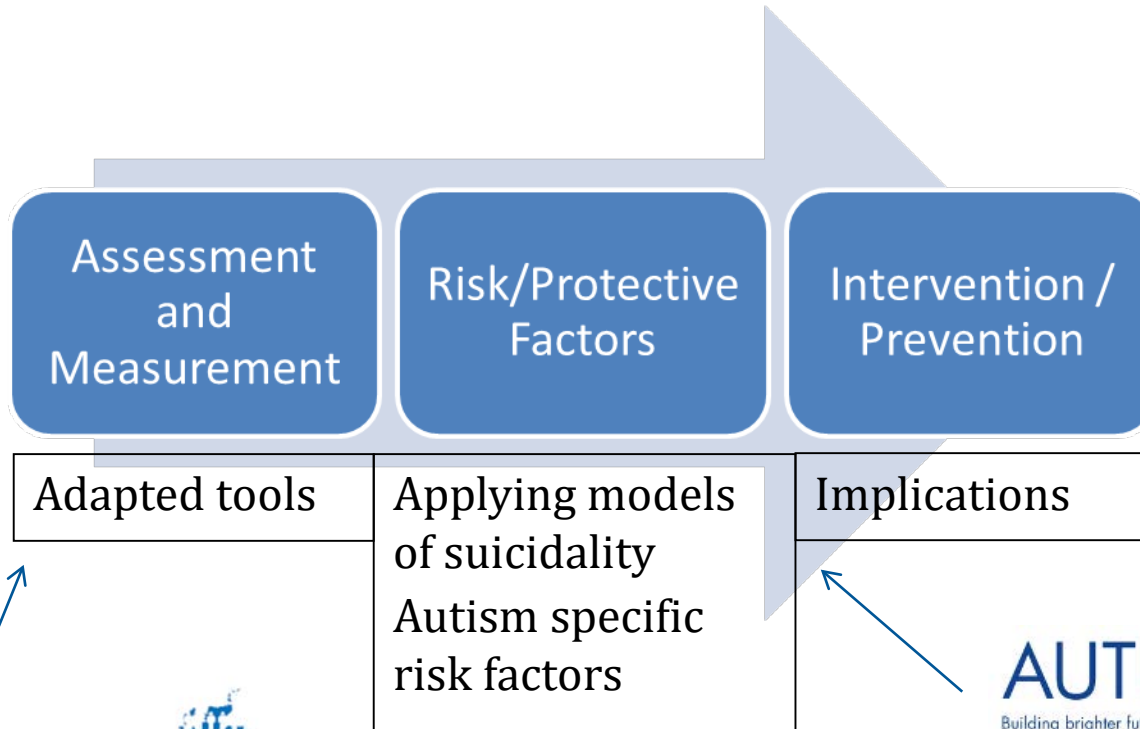
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ECONOMIC
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Suicidality in Autism

Dr. Sarah Cassidy
@MHAutism

- **Mental Health Autism (MHAutism)**

- Understanding and reducing mental health problems and suicide in autism



Collaboration for leadership in applied health research and care
East of England



- **Recent research showed that the autism community use a range of terms to describe themselves:**
 - Autistic
 - Aspie
 - On the spectrum
 - Person with autism
- **On the whole, ‘autistic person’ was most preferred by the autism community, and ‘person with autism’ was preferred by professionals**



- **Majority of autistic adults (79%) meet criteria for at least 1 mental health condition (Lever and Guerts, 2016)**
- **A significant risk factor for suicide in the general population (Kasper et al. 1996; Baraclough et al. 1974)**

What about suicide in autism?

Suicidality in Autism

- **374 newly diagnosed adults with Asperger Syndrome; suicidal ideation 66%; suicide plans/attempts 35%, depression 31%**
 - Autistic traits and depression risk factors for suicidality (Cassidy et al. 2014)
- **Autistic adults significantly more likely to die by suicide than the general population**
 - Being female, autism without LD, and depression are risk factors (Hirvikoski et al. 2015)



Growing number of ‘counting’ studies

Not enough about *Why*



Overview

Assessment
and
Measurement

Adapted tools

Risk/Protective
Factors

Applying models
of suicidality
Autism specific
risk factors

Intervention /
Prevention

Implications



Assessment and Measurement

- **Alexythymia:** under/over reporting of suicidality?
- **Theory of Mind, literal interpretation:** over reporting of suicidal feelings?
- **Overlapping behaviours?** E.g. social withdrawal, sleep problems ...
- **Unique aspects of suicidality in Autism:** Reduced cognitive flexibility ...

Involve autism community in development
of Qs ...

- **Stage 1: Systematic review of measurement tools to assess suicidality in adults with/without autism diagnosis**
- **Stage 2: Focus groups, cognitive interviews and survey to inform and test adaptations**
- **Stage 3: Explore measurement properties of adapted tools**
- **Stage 4: Establish prevalence of suicidality in autistic adults in the UK**



Adaptation: Stage 1 - 2

- **No validated suicidality assessment tools used in autism, or validated for this group**
- **Suicide Behaviours Questionnaire Revised (SBQ-R) brief 4-item candidate tool selected**
- **Four focus groups with variety of stakeholders (autistic adults, service providers, clinicians)**
 - How clear are the questions, how important are the questions, are any important questions missing?
- **2 x 15 cognitive interviews with autistic adults**
 - Tell me what you are reading and thinking about as you work through the questionnaire
- **Next step – online survey to feedback on candidate tool**

Adaption Stage 2

- **Difficulties with language** - break up questions, fewer options
- **Difficulties with memory and time** – diary/calendar?
- **Literal interpretation** – exactly how many thoughts, accidentally overdosing without intent to end life, “What is a plan ... you always have a plan ...”
- **Insensitive language** – “commit suicide”, “kill yourself”
- **Purpose of the assessment** – “Why are these cells blue?”
- **Rapport and trust** – “What will happen to me?”



Risk / Protective Factors



- **Study 1: Exploration of autistic traits and the Interpersonal Psychological Theory**
- **Study 2: Co-designed suicidality survey with the autism community**
- **Study 3: Preliminary findings from first Psychological Autopsy study of suicide in autism**

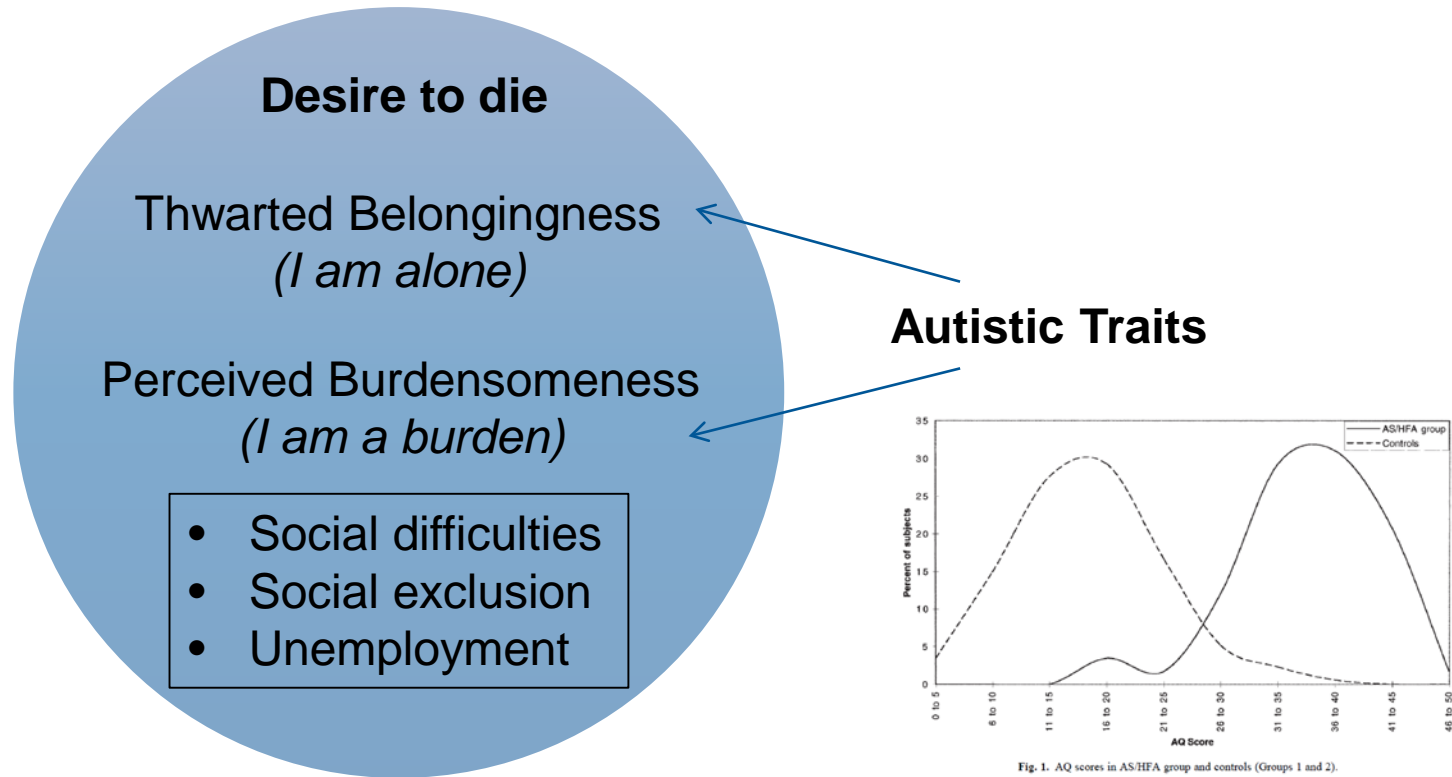


Fig. 1. AQ scores in AS/HFA group and controls (Groups 1 and 2).

Pelton and Cassidy (2017). Are autistic traits associated with suicidality? A test of the Interpersonal-Psychological Theory of Suicide in a non-clinical young adult sample. Autism Research.

Joiner, T. E. (2005). Why people die by suicide. Cambridge, MA: Harvard University Press.



- **163 general population young adults (18-30 years)**
- **Autistic traits significantly predicted Perceived Burdensomeness and Thwarted Belongingness (controlling for age, gender and depression)**

Autistic traits associated with risk of suicidality through thwarted belonging and perceived burdensomeness



Participatory Research

- **Models and measures developed for the general population**
- **So we formed a steering group of 8 autistic adults who had experienced mental health difficulties and/or suicidality:**
 - Identify themes which may increase or decrease risk of experiencing mental health problems and/or suicidality
 - Develop a survey to capture these areas

Themes identified from the focus groups

- Isolation – social and non-social
- Lack of belonging in an autism unfriendly world – thoughts of ‘leaving’
 - Lack of opportunities – employment, education etc.
- Social and communication difficulties, and tendency to mask these – mental health problems, difficulties accessing help
- Lack of autism friendly services
- Late diagnosis, misdiagnosis, diagnostic overshadowing
 - Lack of post diagnostic support
- Not supporting autistic people to have a positive identity – strengths as well as weaknesses – lack of resilience



Results

- 168 autistic adults (67 male, 101 female), and 108 control females, aged 20-60 years old
- Autism group mean SBQ-R (10.31) significantly higher than the recommended cut off for psychiatric populations (≥ 8); 69.8% at or above this cut off
- Significantly higher SBQ-R in autistic than control females (10.61 vs 6.27) (controlling for age, education, occupational status, living arrangements, co-morbid developmental and mental health conditions)
- Autism group - history of NSSI, at least one mental health condition, unemployment, and camouflaging associated with significantly higher SBQ-R

- **Preliminary results from first stage of a Psychological Autopsy study aiming to:**
 - establish whether definite/possible autism diagnoses are over-represented amongst people who died by suicide in the UK
 - compare the characteristics of those with and without autism who have died by suicide in the UK
- **Involve analysis of coroners inquests and interviews with friends and family of the person who died**
- **Results could identify targets to prevent suicide in autism**

Psychological Autopsy

- Coroners records for the period 2014-2015 recording a suicide, open, drug/alcohol or narrative conclusion were analysed for:
 - Evidence of autism (diagnosed and un-diagnosed)
 - Inter-rater reliability was >80% for evidence of autism

Evidence of autism?	Definition
Definite Diagnosis	Clinical diagnosis of autism noted in the inquest.
Strong Evidence	Possible diagnosis noted, <i>and</i> clear indicators in ≥ 2 areas: 1) Social/Communication difficulties; 2) Narrow interests; 3) Routines; 4) Sensory difficulties; 5) Special educational needs in childhood.
Possible Diagnosis	Clear indicators in ≥ 2 areas (as above), but not noted in record.
No Evidence	No clear indicators of autism in record.

Results

- 219 coroners inquest records were assessed, 150 which were ruled a likely suicide according to ICD-10 criteria.
- 11% had evidence of autism, significantly higher than the general population rate (1%)

Evidence of Autism?	Likely Suicide			Self harm / vulnerability		
	Suicide N (%)	% Male	Mean age	Self-harm N (%)	% Male	Mean age
No Evidence	133 (88.7)	80.4	46.8	39 (90.7)	82	45.5
Possible Diagnosis	14 (9.3)	71.4	47.23	4 (9.3)	75	36.2
Strong Evidence	2 (1.3)	100	33.5	0	0	-
Definite Diagnosis	1 (0.7)	100	20	0	0	-
Evidence of Autism	17 (11.3)	76.5	44.1	4 (9.3)	75	36.2
Total	150 (100)	80	46.5	43 (100)		



Implications for Intervention / Prevention

- **Suicidality in autism significantly higher than psychiatric groups**
 - However, unclear whether this is under/over-estimated
- **Late diagnosed / undiagnosed adults without ID appear most at risk**
- **Increased vulnerability to risk factors for suicidality:**
 - Reduced sense of belonging, isolation
 - Difficulty accessing support and treatment
 - Unemployment, co-morbid mental health conditions
- **Suicidality in autism beyond co-morbidities:**
 - One new potential autism specific risk factor - camouflaging



Implications

- **Timely diagnosis of autism, and post diagnostic support.**
- **Identifying and supporting ‘the lost generation’ of autistic adults.**
- **Promoting inclusion, independence and autonomy of autistic people:**
 - access to education and employment, positive identity and esteem, resilience – sense of belonging.

Mental Health Autism: Dr. Louise Bradley, Dr. Rebecca Shaw.

Newcastle University: Dr. Jacqui Rodgers, Dr. Sarah Wigham, Dr. Jeremy Parr.

ARC and CLASS clinic: Prof. Simon Baron-Cohen, Dr. Carrie Allison, Dr. Paul Bradley, Dr. Janine Robinson, Meghan McHugh, Dr. Gareth Richards, Dr. Rebecca Kenny.

Sarah.Cassidy@Nottingham.ac.uk

[@MHAutism](https://twitter.com/MHAutism)

MHAutism.coventry.ac.uk