

DOCTOR OF PHILOSOPHY

“Feeling like an outsider?”

Comparing the Interpersonal Theory of Suicide in Autistic and non-Autistic Adults

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**“Feeling like an outsider?” Comparing the Interpersonal
Theory of Suicide in autistic and non-autistic adults**



By

Mirabel Kate Pelton

PhD

August 2023

“Feeling like an outsider?” Comparing the Interpersonal Theory of Suicide in autistic and non-autistic adults

*A thesis submitted in partial fulfilment of the University's requirements for the
Degree of Doctor of Philosophy*



August 2023

i. Ethical approval



Certificate of Ethical Approval

Applicant:

Mirabel Pelton

Project Title:

Understanding and reducing suicidal thoughts and behaviours amongst autistic people: exploring contributory mechanisms and measurement differences

This is to certify that the above named applicant has completed the Coventry University Ethical Approval process and their project has been confirmed and approved as Medium Risk

Date of approval:

12 December 2018

Project Reference Number:

P61841

ii. Abstract

Suicide is a leading cause of premature death amongst autistic adults and there is limited support for autistic adults who experience suicidal thoughts and behaviours. One limiting factor in designing interventions is that suicide research amongst autistic people has not applied a theoretical framework and it is unclear whether suicide models designed for non-autistic people are applicable to the experiences of autistic people. One reason for this is that the way that autism and suicide research are carried out typically precludes the capture of the experiences of autistic people. The programme of studies described in this thesis aims to address this gap by working in partnership with autistic people to explore whether the Interpersonal Theory of Suicide (ITS) operates equivalently for autistic and non-autistic people.

This thesis comprises four studies: an evaluation of the participatory methods used in this PhD and three empirical studies. Study 1 used tools from health research to report partnership working had many positive impacts on the research, researcher and autistic collaborators. Studies 2, 3 and 4 used an online survey dataset (n=865) of autistic, non-autistic and possibly autistic adults. Study 2 used structural equation modelling to report pathways from ITS proximal risk factors - perceived burdensomeness, thwarted belonging and lifetime trauma - to suicide were consistent, but pathway strengths were attenuated amongst autistic adults compared to non-autistic adults. Study 3 used measurement invariance analysis to report measurement properties of ITS questionnaires measuring perceived burdensomeness and thwarted belonging were not equivalent for autistic and non-autistic people. Study 4 used network analysis to co-produce, with autistic collaborators, the first conceptual suicide model for autistic people.

Findings suggest partnership working led the research to be more relevant and meaningful, and built trust between researchers and autistic people. Perceived burdensomeness and thwarted belonging have extended our understanding of suicide amongst autistic people, but overall, the ITS lacks specificity and accuracy when applied to autistic people. Suicide prevention could promote belonging and self-worth in a meaningful manner for autistic adults. Clinicians should be aware that belonging and burdensomeness may be experienced differently by autistic adults requiring tailored care pathways and personalised support. Future research should explore the role of trauma and mental health in suicide for autistic people and follow developments in understanding of suicidal behaviour. Theoretical research should continue to improve the evidence-base for participatory working with autistic collaborators and develop a suicide model for autistic people, independent of the experiences of non-autistic people.

iii. Author contributions

The research in this thesis is an extension of an idea generated by the author, Mirabel Pelton, to explore the role of autistic traits within the Interpersonal Theory of Suicide (ITS) in a general population sample as a MSc thesis dissertation undertaken at Coventry University 2014-2016, supervised by Dr Sarah Cassidy, published as Pelton & Cassidy (2017). A proposal for a programme of doctoral study was developed in collaboration with Dr Sarah Cassidy during 2016-2017 to extend this study to explore whether the ITS can inform our understanding of suicide amongst autistic people.

In Study 1 (Chapter 2) Mirabel Pelton extended ideas proposed by a member of the advisory group of autistic adults (termed the 'Design Group'), led and undertook all participatory activities, designed the evaluation framework, undertook data collection analysis, and wrote the paper. Study 2 (Chapter 3) and Study 3 (Chapter 4) were proposed and devised by the Mirabel Pelton in collaboration with Dr Sarah Cassidy. Study 4 (Chapter 5) was devised by Mirabel Pelton following discussions with Dr Derek de Beurs about the potential of network analysis to extend the findings of study 1. For studies 2, 3 and 4, Mirabel Pelton designed the data collection, undertook recruitment, designed, and undertook all data analyses and wrote the papers. A detailed description of the role of the Design Group in these studies is provided in Study 1.

Supervision and guidance for all studies was provided by Dr Sarah Cassidy, Dr Hayley Crawford, Dr Ashley Robertson and Prof. Jacqui Rodgers with the addition of Dr Kim Bul in 2019 for Studies 1 and 4. Jon Adams, autistic advocate and researcher, is a co-author on Studies 1 and 4. Sharon Gardner, another autistic collaborator, preferred to be named in the acknowledgement section of Studies 1 and 4. Prof. Simon Baron-Cohen and Paula Smith supported data collection for all empirical studies via the Cambridge Autism Research Database and is a co-author on Studies 2, 3 and 4. Training in network analysis for Study 4 was undertaken at the PsychoSystems Winter School 2020 and 2021 led by Dr Sacha Epskamp.

This thesis follows the alternate format outlined in Coventry University thesis guidelines (section 4, Coventry University, 2022) and comprises one draft manuscript and three papers published in peer-reviewed journals. A signed author collaboration agreement is included in Supplementary 1.

iv. Publications and presentations

First author papers:

Chapter 5 of this thesis:

Pelton, M., Crawford, H., Bul, K., Robertson, A., Adams, J., De Beurs, D., Rodgers, J. & Baron-Cohen, S. (2023). The role of anxiety and depression in suicidal thoughts for autistic and non-autistic people: A theory-driven network analysis. *Suicide and Life-threatening Behavior*. 00, 1-17. <https://doi.org/10.1111/sltb.12954>

Chapter 4 of this thesis:

Pelton, M. K., Crawford, H., Robertson, A. E., Rodgers, J., Baron-Cohen, S., & Cassidy, S. (2020). A measurement invariance analysis of the Interpersonal Needs Questionnaire and Acquired Capability for Suicide Scale in autistic and non-autistic adults. *Autism in Adulthood*, 2(3), 193-203. <https://doi.org/10.1089/aut.2019.0055>

Chapter 3 of this thesis:

Pelton, M. K., Crawford, H., Robertson, A. E., Rodgers, J., Baron-Cohen, S., & Cassidy, S. (2020). Understanding suicide risk in autistic adults: Comparing the Interpersonal Theory of Suicide in autistic and non-autistic samples. *Journal of Autism and Developmental Disorders*, 50(10), 3620-3637. <https://doi.org/10.1007/s10803-020-04393-8>

MSc thesis, which informs the design of this programme of study:

Pelton, M. K., & Cassidy, S. A. (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*, 10(11), 1891-1904. DOI: <https://doi.org/10.1002/aur.1828>

Joint author papers:

Cassidy, S., McLaughlin, E., McGranaghan, R., **Pelton, M.**, O'Connor, R., & Rodgers, J. (2023). "Is camouflaging autistic traits associated with defeat, entrapment and suicidal thoughts? Expanding the Integrated Motivational-Volitional Model of Suicide". *Suicide and Life-threatening Behavior*. 00, 1-17.

Practitioner guide drawing on work in this thesis:

Morgan, L., Maddox, B., Cassidy, S., Benevides, T., Donahue, M., Pelton, M. (2021). Warning Signs of Suicide for Autistic People: An autism-specific resource based on research findings and expert consensus. Available from: <https://988lifeline.org/wp-content/uploads/2023/01/Warning-Signs-Resource-Sept-2021-2.pdf>

Cassidy, S. A., Gould, K., Townsend, E., **Pelton, M.**, Robertson, A. E., & Rodgers, J. (2020). Is camouflaging autistic traits associated with suicidal thoughts and behaviours? Expanding the interpersonal psychological theory of suicide in an undergraduate student sample. *Journal of Autism and Developmental Disorders*, 50(10), 3638-3648. DOI: <https://doi.org/10.1007/s10803-019-04323-3>

Chisholm, K., **Pelton, M.**, Duncan, N., Kidd, K., Wardenaar, K. J., Upthegrove, R., ... & Wood, S. J. (2019). A cross-sectional examination of the clinical significance of autistic traits in individuals experiencing a first episode of psychosis. *Psychiatry Research*, 282, DOI: <https://10.1016/j.psychres.2019.112623>

Upthegrove, R., Abu-Akel, A., Chisholm, K., Lin, A., Zahid, S., **Pelton, M.**, ... & Wood, S. J. (2018). Autism and psychosis: Clinical implications for depression and suicide. *Schizophrenia Research*, 195, 80-85. <https://doi.org/10.1016/j.schres.2017.08.028>

Papers from the PRONIA (Prognostic Tools for Psychosis Management) Consortium¹:

Koutsouleris, N., Pantelis, C., Velakoulis, D., McGuire, P., Dwyer, D. B., Urquijo-Castro, M., Paul, R., Dong, S., Popovic, D., & Oeztuerk, O. & PRONIA consortium (2022). Exploring links between psychosis and frontotemporal dementia using multimodal machine learning: Dementia praecox revisited. *JAMA Psychiatry*, 79(9), 907-919.

Wenzel, J., Haas, S. S., Dwyer, D. B., Ruef, A., Oeztuerk, O. F., Antonucci, L. A. & Kambeitz-Illankovic, L. & PRONIA consortium (2021). Cognitive subtypes in recent onset psychosis: Distinct neurobiological fingerprints? *Neuropsychopharmacology*, 46(8), 1475-1483.

Penzel, N., Antonucci, L. A., Betz, L. T., Sanfelici, R., Weiske, J., Pogarell, O. & Kambeitz, J. & PRONIA consortium (2021). Association between age of cannabis initiation and gray matter covariance networks in recent onset psychosis. *Neuropsychopharmacology*, 46(8), 1484-1493.

Upthegrove, R., Lalouis, P., Mallikarjun, P., Chisholm, K., Griffiths, S. L., Iqbal, M. & PRONIA Consortium. (2021). The psychopathology and neuroanatomical markers of depression in early psychosis. *Schizophrenia Bulletin*, 47(1), 249-258

Haidl, T. K., Schneider, N., Dickmann, K., Ruhrmann, S., Kaiser, N., Rosen, M., ... & Piccin, S. & PRONIA Consortium (2020). Validation of the Bullying Scale for Adults-Results of the PRONIA-study. *Journal of Psychiatric Research*, 129, 88-97.

¹ The PRONIA project was a multi-site study gathering clinical, biological, brain imaging data for machine learning analysis to inform our understanding of the development of psychosis. My role was undertaking comprehensive clinical assessments of participants with depression, at-risk (early indicators of emerging psychosis) or psychotic symptoms.

Oral presentations (* indicates invited presentation):

Forthcoming

Pelton, M., Bul, K., Crawford, H., Robertson, A., Adams, J., Rodgers, J., & Cassidy, S., 'Show and tell': working with autistic adults to explore suicide theory. Competitively selected presentation at *Early Career Workshop, International Association for Suicide Prevention World Congress, Piran, 19th September 2023*

Cassidy, S., **Pelton M.**, (presenting author), Newell, V., French, B., & Townsend E., 'Using a novel task to explore self-harm with autistic adults. Abstract accepted for presentation at *Early Career Workshop, International Association for Suicide Prevention World Congress, Piran, 19th – 23rd September 2023 (schedule to be confirmed)*

2023

Nicolaidis, C. & Pelton, M. (co-chairs), Annual Student and Trainee pre-conference workshop, *Annual Meeting of the International Society for Autism Research (International Society for Autism Research Annual Meeting 2023), Stockholm, Sweden, 3rd May 2023**

Pelton, M., Bul, K., Crawford, H., Robertson, A., Adams, J., Rodgers, J., & Cassidy, S., 'Show and tell': working with autistic adults to explore suicide theory. Presentation at *Research Showcase, Coventry University, 25th April 2023*.

Pelton, M., & Balmer, A., Suicide Prevention for Autistic People: Research evidence (an update). Presentation for *West Yorkshire Neurodiversity Community of Practice (online), 13th April 2023*

'Show and tell': An evaluation of partnership working with autistic adults to explore suicide theory as an early career researcher. Presentation for Equality, Diversity and Inclusion Research Café, Coventry University, 9 February 2023*

2022

Pelton, M., Feeling like an outsider? What do we know about suicide theory and prevention for autistic people? Invited presentation at University of Glasgow, School of Psychology and Neuroscience Mental Health Network, 14 November 2022*

Maddox, B., Morgan, L., Donahue, M., Pelton, M., Cassidy, S., & Benevides, T., Warning signs for suicide for autistic individuals. Paper presented at the *Suicide Research Symposium, online, June 2022*, https://www.youtube.com/watch?v=bO2H0QZm9_o

Pelton, M., Crawford, H., Robertson, A., Bul, K., De Beurs, D, Rodgers, J., Baron-Cohen, S, & Cassidy, S. Where next for suicide theory in autistic people? A network analysis of anxiety and depression within the Interpersonal Theory of Suicide in autistic and non-autistic adults. Paper presented at the *Early Mid-Career Researchers Forum in Suicide and Self-harm, June 2022*.

Pelton, M., Newell, V., French, B., Townsend, E., Cassidy, S., Using a novel task to explore patterns of self-harm for autistic and non-autistic adults paper presented at the *Early Mid-Career Researchers Forum in Suicide and Self-harm, June 2022*.

Pelton, M., & Balmer, A., Suicide Prevention for Autistic People: Research evidence, presentation for *West Yorkshire Suicide Prevention Network, 26th April 2022**

2021

Pelton, M., Crawford, H., Robertson, A., De Beurs, D, Rodgers, J., Baron-Cohen, S, & Cassidy, S. Where next for suicide theory in autistic people? A network analysis of anxiety and depression within the Interpersonal Theory of Suicide in Autistic, possibly autistic and non-autistic adults. Invited paper at the *PsyPAG Annual Conference 29-30 July 2021**

Pelton, M., Crawford, H., Robertson, A., De Beurs, D, Rodgers, J., Baron-Cohen, S, & Cassidy, S. Where next for suicide theory in autistic people? A network analysis of anxiety and depression within the Interpersonal Theory of Suicide in Autistic, Possibly autistic and non-autistic adults. Paper presented at the *Autistica Discover Conference Mental Health panel 12th- 16th July online conference 2021*.

Pelton, M., Crawford, H., Robertson, A., De Beurs, D, Rodgers, J., Baron-Cohen, S, & Cassidy, S. Suicide prevention in autistic adults: what can we learn from the Interpersonal Theory of Suicide? Within the panel Novel Findings to Inform Suicide Prevention for Autistic Individuals with US and UK collaborators. *Paper presented at International Society for Autism Research Annual Meeting May 3rd – May 7th online conference 2021*.

2020

Pelton, M., Crawford, H., Robertson, A., Rodgers, J., Baron-Cohen, S & Cassidy, S. Applying suicide theory to prevention in autistic people. Paper presented at International online workshop 'Supporting Autistic People Experiencing Suicidal Thoughts and Behaviors: Emerging Evidence and Resources' due to cancellation of *International Society for Autism Research Annual Meeting 2020* due to COVID pandemic *online workshop 3rd June 2020*.

Pelton, M., Crawford, H., Robertson, A., De Beurs, D, Rodgers, J., Baron-Cohen, S & Cassidy, S. A moderated network analysis of depression within the Interpersonal Theory of Suicide. Paper presented at the *netECR e-Conference 2020 27th November online conference 2020*.

Pelton, M., Crawford, H., Robertson, A., Rodgers, J., Baron-Cohen, C & Cassidy, S. A measurement invariance analysis of the Interpersonal Needs Questionnaire and the Acquired Capability for Suicide Scale. Paper presented at the *29th June - 3rd June Autistica Discover Conference online conference 2020*

Pelton, M. Latest evidence on autism & suicide, as part of Support young autistic people in crisis, webinar for crisis service staff & volunteers, *Autistica (online), 23rd November 2020 **

Pelton, M. 'What does it mean to belong?' Presentation of Coventry City of Culture project. Paper presented as a part of the *HOPE for the Community programme for parents of autistic children (online), 30th June 2020. **

Cassidy, S. & Pelton, M. Autistic Social Belonging and Connectedness in Uncertain Times. Workshop presented for *Autistica online workshop 1st April 2020**

Pelton, M., Crawford, H., Robertson, A., Rodgers, J., & Cassidy, S. Autism, women and suicide prevention, Paper presented for *Harmless Annual Conference February 26th Nottingham, UK, 2020**

2019

Pelton, M., Crawford, H., Robertson, A., Rodgers, J., & Cassidy, S. Understanding and predicting suicidality amongst autistic adults: Applying the interpersonal theory of suicide. Paper presented as a part of the symposium 'Learning about suicidality in partnership with autistic people and their allies at the *International Association of Suicide Prevention, 17th-21st September Derry-Londonderry 2019*.

Pelton, M., Crawford, H., Robertson, A., Rodgers, J., & Cassidy, S. Understanding and predicting suicidality amongst autistic adults: Applying the interpersonal theory of suicide Paper presented at the *Autistica Discover Conference, University of Reading 27th June 2019* <https://www.autistica.org.uk/get-involved/research-conference/discover-conference-livestream/session-2-mental-health-and-suicide>

Pelton, M., Robertson, A., Rodgers, J., & Cassidy, S. Understanding and reducing suicidality amongst autistic adults: Testing the interpersonal theory of suicide. Paper presented at the *Early and Mid-Career Researchers Forum in Suicide and Self Harm, University of Glasgow 7-8th June 2019*.

Pelton, M., Robertson, A., Rodgers, J., & Cassidy, S. Understanding and reducing suicidality amongst autistic adults: Applying the interpersonal theory of suicide. Pecha Kucha presentation at the *Doctoral Capability and Development Conference (DCAD19), Coventry University, 30th April-2nd May 2019*.

2018

Invited researcher at drop-in event for MPs *Building Brighter Futures for Autistic People with Mental Health Problems*, hosted by the All-Party Parliamentary Group for Autism and Dame Cheryl Gillan organised by Autistica, 10th July 2018 *

Pelton, M., Crawford, H., Rodgers, J., & Cassidy, S. Are autistic people more likely to acquire capability for suicide? Paper presented at the *Early and Mid-Career Researchers Forum in Suicide and Self-Harm*, University of Glasgow 6-7th June 2018.

Poster presentations

2022

Pelton, M., Bul, K., Robertson, A., Crawford, H., De Beurs, D., Rodgers, J., Baron-Cohen, S. & Cassidy, S., Feeling like an outsider? Mental health, social inclusion and suicide theory for autistic people. Poster presented at *Equality, Diversion and Inclusion research showcase*, Coventry University, 23rd September 2022.

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iv. Dedication

This thesis is dedicated to anyone who has struggled with the difficulties described here.

iv. Acknowledgements

I am grateful to Jon, Sharon and other contributors to the Design Group (the advisory group), the participants who took part in the research and everyone who shared experiences with me at conferences, events and via email. It has been a privilege to hear these stories and I have held them in mind as I write this thesis.

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This PhD would not have been completed without the support of my family, particularly my wife Trudy, for your patience, good humour, more patience, and everything else we have achieved together. This PhD has seen so many unexpected life events that we have fallen back on our family motto '*only in the Pelton house*' more times than I count. I acknowledge here the strength, resilience and determination of our children. Our experiences strengthen my commitment to create a kinder, more accepting society. I am grateful to our extended families, friends and our community in King's Heath, Birmingham, for so many small and large acts of kindness over the course of these studies.



Between thesis chapters, I feature images and words from the public engagement project: 'What does it mean to belong?' The image above was produced by Sharon Gardner, member of the advisory group, to represent the themes of the project.

This image was selected to hang in the viva room, Elm Bank, Coventry University following the Research Images competition, January 2023. Content note: some submissions reflect themes of not belonging, rather than the positive expression we had hoped for.

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Language matters

Language shapes our understanding of the world (Bergen, 2012). As a society, the language we choose influences our perception of people, events, political attitude, moral and causal reasoning (Bergen, 2012; Lakoff & Johnson, 1999; Landau et al., 2010). The discourse on autism and suicide reflects centuries of stigma that have led to inappropriate and unhelpful public policy responses, and have contributed to inequality, marginalisation and blame for some of the most vulnerable people in our society (Botha et al., 2023; Bottema-Beutel et al., 2021; Reali et al., 2016). By contrast, language can influence our thought in the preferred direction of change, improve individual identity and collective public health responses to address structural inequality. This thesis recognises that individual preference exists, and that language choices evolve, but, in line with American Psychological Association (2021) guidance on inclusive language, language choices set out here reflect the published preferences of the majority of those with lived experience of autism and suicide.

This thesis avoids language that reflects the medicalised, deficit-based language used in the past to describe autism. This thesis chooses the term *autistic people*, the term preferred by most autistic people, to encapsulate the importance of autism as a central part of an individual's identity (Bottema-Beutel et al., 2021; Kenny et al., 2016) and avoids *person with autism*, which, in line with the description of an illness, suggests autism is an unwelcome, temporary deficit, that would preferably be alleviated. This thesis refers to: (i) *autistic characteristics* and the impact of those characteristics in terms of difficulties and strengths; (ii) *co-occurring conditions* over the medicalised term *co morbid* to avoid implying that autism is an illness to be cured; and (iii) *support, services* and *adjustments* that can promote quality of life in a non-autistic world. These language choices present a view of autism as a different way of being human equally valid with that of non-autistic people.

This thesis avoids the use of language that reflects the former criminalisation of suicide, which negatively impacts the likelihood of vulnerable individuals to seek help when in crisis, public policy towards suicide prevention, and public attitudes towards those grieving by suicide (Chapple et al., 2015; Nielsen et al., 2016; Overvad & Wagoner, 2020; Padmanathan et al., 2019). Similarly, I avoid the term '*commit(ted)*' suicide, that implies intentional criminal activity and wrongdoing rather than escape from unbearable mental pain (De Leo et al., 2021; Silverman, 2006; Silverman et al., 2007) and the use of *successful* or *completed* suicide to avoid giving any suggestion of success or positivity to a death by suicide. Person-first language is intentionally chosen to avoid conflating an individual's identity with their suicidal thoughts and behaviours. Terms such as *suicide attempters* are avoided to separate the individual from their suicidal experience to encourage the belief that recovery is possible. Instead, *suicide attempt* describes non-fatal behaviour and *died by suicide* describes fatal suicidal behaviour. Collectively, these language choices promote positive individual identity, compassion, open discussion of difficult thoughts, safety, inclusivity and respect (American Psychological Association, 2021b).

This item has been removed due to 3rd Party Copyright. The unabridged version of the thesis can be found in the Lanchester Library, Coventry University.

“.. with belonging comes our being, our fulfilment, positive self worth and the richness of idea and innovation we can bring. So, who or what enables you to belong?”

Jon Adams, Design Group member, from the blog ‘Without Belonging there is no Being’
<https://belong.coventry.domains/without-belonging-there-is-no-being/>

Chapter 1: Introduction

1.1 Problem statement

Reducing suicide rates is a global public health priority: across the world, 703,000 people die each year by suicide (World Health Organization, 2021). In England and Wales, 10.7 deaths per 100,000 of the population were attributed to suicide in 2021. For each person who dies, around 135 people – friends, family colleagues, emergency services, and professionals – are impacted, needing support with complex trauma for many years (Cerel et al., 2014; Cerel et al., 2019; Peters et al., 2016; World Health Organization, 2014). Data describing neurodevelopmental conditions, such as autism, are not systematically collected by international and national data services, but in the past decade, population studies have confirmed that death by suicide is at least 3 times more common for autistic than non-autistic adults (Hirvikoski et al., 2016; Kirby et al., 2019; Kölves et al., 2021). High suicide rates contribute to estimated life expectancy of between 20 and 36 years lower for autistic than non-autistic adults (Hirvikoski et al., 2016). Overall, this points to an urgent need for suicide prevention efforts to target autistic adults.

A key component of reducing deaths by suicide is to provide support for those who experience suicidal thoughts or who self-harm with or without suicidal intent (World Health Organization, 2012). Autistic people report far more frequent suicidal thoughts (pooled prevalence 34.2% versus 20.6%) and behaviours (24.3% versus 6.7%) than people who are not autistic but report an absence of effective support (McManus et al., 2016; Newell et al., 2023). Autistic adults report services fail to meet their sensory and communication needs, and staff lack understanding of autism. They report being disbelieved in their distress meaning that seeking support can exacerbate rather than alleviate distress (Belcher, 2022; Camm-Crosbie et al., 2019; Crane et al., 2017; Nicolaidis et al., 2013). One limiting factor in providing evidence-based, effective interventions to support autistic adults is an absence of theoretical models to describe the development of suicidal thoughts and behaviours for autistic people (Cassidy, Cogger-Ward, Robertson, Goodwin, & Rodgers, 2021). The studies in this thesis contribute to filling this knowledge gap.

1.2 Context: Suicide prevention as an autism research priority

The neurodiversity paradigm argues that autism is best understood as a collection of neurological differences between majority non-autistic people and minority autistic people (Chapman, 2019; Kapp, 2020; Pellicano & Houting, 2022). Neurological differences lead to different social communication preferences and sensory sensitivities and relatively limited range of interests and repetitive behaviours amongst autistic people compared to non-autistic people (American Psychological Association, 2013). The ‘double empathy problem’ argues that autistic and non-autistic communication styles are equally valid, but difficulties arise due to mutual misunderstanding of communication styles (Milton, 2012; Milton et al., 2022). Autistic differences are experienced as individual strengths and challenges, but challenges are exacerbated by a physical and social world designed to meet the needs of non-autistic people (Doherty et al., 2023; Milton et al., 2022; Woods, 2017). The neurodiversity movement grew out of autistic self-advocacy in line with broader disability rights

movement that with appropriate support and understanding autistic people can be socially fulfilled economically productive members of society (Bury et al., 2019; Kapp, 2020; Milton & Sims, 2016). Researchers should address historical bias against under-represented groups, promote social justice and avoid the continuation of embedded prejudice, such as *ableism* (a system of oppression that places a value on people's bodies and minds based on ideas of normality and desirability) (American Psychological Association, 2021a; Botha & Cage, 2022). Thus, this thesis adopts a neurodiversity approach to autism.

A key component of research undertaken according to the neurodiversity paradigm is to work in partnership with autistic people (Botha & Cage, 2022; Pellicano & Houting, 2022). Partnership working is defined as 'incorporating the views of autistic people and their allies about what research gets done, how it is done and how it is implemented' (Cornwall & Jewkes, 1995; Fletcher-Watson et al., 2019). Autism research has, in the past, judged autistic people from the outside, leading research to be dominated by biological and genetic research, theories of autism that autistic people consider inaccurate and interventions that have sought to eliminate or mask autistic characteristics (O'Dell et al., 2016; Pellicano & Houting, 2022). The neurodiversity approach acknowledges the validity of the inner experiences of autistic people and advocates that it is the responsibility of autism researchers to address community priorities (Kapp, 2020; Pellicano & Houting, 2022). Partnership working reflects established practice in the UK of public-patient involvement and engagement (PPIE) in health research (Shippee et al., 2015; Thornton, 2008) and recognised benefits of working with those with lived experience of suicide (O'Connor et al., 2023). This thesis prioritises working in partnership with autistic people to explore suicide prevention.

Autism was initially conceptualised as a childhood condition (Kanner, 1943) and remains widely understood as such (Akhtar et al., 2022). Most autism research is focussed on children, notwithstanding most autistic people are adults (Kirby & McDonald, 2021). Research has only relatively recently begun to focus on priorities identified by autistic adults such as addressing health inequality (Nicolaidis et al., 2013), improving access to education and employment (Davies et al., 2023). Two priority setting exercises have identified that improving mental health and reducing suicide rates are urgent priorities to improve wellbeing and quality of life for autistic adults (Cassidy et al., 2021; Cusack & Sterry, 2020). Autistic adults are more likely to experience co-occurring conditions, such as auto-immune disorders, gastrointestinal disorders or intellectual disability than non-autistic adults (Croen et al., 2015; Hirvikoski et al., 2016; Nicolaidis et al., 2013; Schott et al., 2021; Taylor & Henninger, 2015). Around 25% of autistic adults have a co-occurring intellectual disability (defined as IQ <70) (Idring et al., 2015), though studies suggest autism is under-diagnosed in those with intellectual disability (Metcalf et al., 2020). By contrast, consistent research reports that suicide risk is particularly high in autistic adults without intellectual disability (Hirvikoski et al., 2016). Thus, the current thesis explores a community-identified priority for autistic adults without an intellectual disability.

One challenge to undertaking research amongst autistic adults is that many autistic adults remain undiagnosed. Autism is estimated more prevalent in the UK amongst children (1 in 68) (Maenner et al., 2021)

than adults (1 in 100) (Brugha et al., 2016). Changes in diagnostic criteria mean many adults did not have access to diagnostic services as children (Lai & Baron-Cohen, 2015) with most recent estimates that over 1,000,000 autistic adults in England may be undiagnosed (O’Nions et al., 2023). Autism is less frequently diagnosed in women and non-white ethnic minorities due to bias in diagnostic instruments and criteria, cultural concerns and limited access to healthcare (Constantino et al., 2020; McCrossin, 2022; Roman-Urrestarazu et al., 2021; Zeidan et al., 2022). Late diagnosis is associated with isolation, mental health difficulties, missing out on needed support and lack of positive self-identity (Aggarwal & Angus, 2015; Belcher, 2022; Brugha et al., 2011; Geurts et al., 2016) and undiagnosed autism has been identified as a suicide risk factor (Carbone et al., 2018; Cassidy et al., 2022). Researchers have sought to capture possible undiagnosed autism by measuring autistic traits in vulnerable populations, such as homeless people (Churchard et al., 2019) or prisoners (Fazio et al., 2012; McCarthy et al., 2015) or by including those who self-identify as autistic or are awaiting diagnosis (Cassidy, Bradley, Shaw, & Baron-Cohen, 2018). Thus, to include the experiences of autistic adults with, and without, formal autism diagnosis, this thesis employs these approaches.

1.3 Background: What do we know about suicide in autistic adults?

Research to explore why autistic adults are at risk of suicide has explored risk factors. Risk factors are variables observed to associate with an increased occurrence of an outcome (Franklin et al., 2017; Van Orden et al., 2010; Wagner, 1997). Suicide risk factors have been applied to determine vulnerability, treat, and prevent suicide through interventions and public health responses (Franklin et al., 2017; World Health Organization, 2012). In non-autistic people, risk factors are well established (Nock et al., 2016), and many similar risk factors are reported amongst autistic people, such as self-harm (Duarte et al., 2020; Moseley et al., 2020), mental health difficulties (Harris & Barraclough, 1997; Kölves et al., 2021; Nock et al., 2009; Zahid & Uptegrove, 2017), loneliness (Calati et al., 2019; Hedley et al., 2018) bullying (Holden et al., 2020; Holt et al., 2015) and abuse (Angelakis et al., 2020; Richa et al., 2014). Many of these risk factors are more frequently experienced by autistic than non-autistic adults. This suggests that one approach to exploring suicide prevention amongst autistic adults is to explore suicide risk factors.

Risk factor research has, however, been criticised for having little impact on suicide rates over the last 50 years (Franklin et al., 2017) because it has provided little insight into the *mechanisms* driving suicide. By contrast, research driven by *suicide theory* is argued to be more effective than risk factor research because it transforms risk factors into dynamic processes (Millner et al., 2020). Theories are sets of propositions that help us understand and explain phenomena that we see in the world (Fried, 2020a). Applying theory allows us to represent theoretical models in data models to manipulate and explain psychological processes to provide insight into *how* interventions work (Fried, 2020b). Research into suicide amongst autistic adults supports this view with longstanding calls in the literature for models that can extend the understanding of suicide provided by risk factor research (Segers & Rawana, 2014). At the time of design of this programme of study, research exploring suicide amongst autistic adults had produced simple models based on limited number of risk factors (Hedley et al., 2017) but no research had yet employed a theoretical approach. This suggests using a

theoretical approach to exploring suicide amongst autistic adults will be more effective for suicide prevention for autistic adults than risk factor research.

One challenge in applying a theoretical approach is that statistical models only offer accurate insight if they closely match lived experience (Smaldino, 2020). Theories specify a set of components (risk factors or constructs) and the relationships between (pathways) describing the way they interact to bring about the outcome of interest (Fried, 2020b). Tailored models have been devised to describe pathways to symptoms of eating disorders (Brede et al., 2020) and anxiety (South & Rodgers, 2017) that derive from unique experiences of autistic people. One possibility could be that a tailored model may be required to describe the mechanisms driving suicide amongst autistic adults. Research has already identified unique risk factors for suicide amongst autistic adults, such as social camouflaging (masking autistic characteristics to be socially acceptable), having unmet support needs and experiencing autistic burnout (exhaustion and de-skilling from the pressures of a non-autistic world) (Cassidy et al., 2018; Raymaker et al., 2020). A starting point is to understand extent to which suicide models accurately describe the experiences of autistic adults. This has been identified as one of the top 10 research priorities with, and for, suicide prevention for autistic adults (Cassidy et al., 2021), and represents the principle aim of the programme of work presented in this thesis.

1.4 Approach: Applying suicide theory to the experiences of autistic adults

Suicide theorists have sought to explain suicide since Durkheim's 1897 sociological account of suicide (Durkheim, 1951). Approaches have ranged from Freudian (Freud, 1917), psychodynamic (Menninger, 1938; Rogers, 2001) to cognitive (Beck, 1986; Williams, 2001) and biological approaches (Mann, 2003; Oquendo et al., 2014). Theories agree that suicide is best understood as the escape from intolerable psychological states (Baumeister, 1990) and have devised constructs, such as psychache (Shneidman, 1993; Shneidman, 1998), hopelessness (Beck, 1986), defeat and entrapment (Williams, 2001) to describe this. The *ideation-to-action* frameworks emerged in 2005 with the publication of the Interpersonal Theory of Suicide (ITS) (Joiner, 2005). Along with the Integrated Motivational Volitional (IMV) model (O'Connor, 2011) and the Three-step theory (3ST) (Klonsky & May, 2015), this 'new generation' of suicide theories aims to address the lack of specificity in previous theories by arguing that distinct risk factors lead to suicidal thoughts versus suicidal behaviours (Klonsky & May, 2014). The theories draw on research describing a wide range of risk factors associated with suicidal desire, whereas few are associated with suicidal behaviour (May & Klonsky, 2016; Nock et al., 2008; Nock et al., 2016). The ideation-to-action frameworks, thus, represent the most accurate models available to apply to the experiences of autistic people.

The ITS argues that interpersonal needs are a fundamental human need, which, if unmet, can lead to the development of suicidal desire (Joiner, 2005). Those unmet social needs are defined as the temporary cognitive states of thwarted belonging ('an enduring absence of reciprocal social relations') and perceived burdensomeness ('a false belief of social worthlessness'). If activated simultaneously, these two constructs lead to active suicidal desire (Joiner, 2005; Van Orden et al., 2010). Suicidal desire will only be acted upon if an

individual has suicidal capability: a change in the body's fear and response system that allows, rather than inhibits, fatal self-injury (Joiner, 2005; Van Orden et al., 2010). Suicidal capability is partly innate but also develops in a similar manner to increasingly severe self-harm: opponent process theory (Solomon & Corbit, 1974) habituates to the comfort provided by self-harm, thus, substituting pain and fear with physical and emotional pain relief (Smith & Cukrowicz, 2010). Attempting suicide is hypothesised to most efficiently increase suicidal capability but any painful, frightening experience, such as self-harm, physical violence, abuse, painful or frightening mental health symptoms, can contribute (Brown et al., 2018; Joiner, 2005; Smith & Cukrowicz, 2010).

The IMV draws on the theory of planned behaviour to describe a three-phase model where the individual moves from a pre-motivational phase where early life experience and genetic factors may increase vulnerability to triggering negative life events leading to a motivational phase (O'Connor, 2011; O'Connor & Kirtley, 2018). The motivational phase draws on Williams' *cry of pain* theory of suicide describing experiences of defeat, humiliation, and entrapment, which can lead to suicidal ideation (O'Connor, 2011; O'Connor & Kirtley, 2018). Threat-to-self (such as social problem-solving) and motivational (such as thwarted belonging) moderators can hasten or attenuate the development of suicidal ideation. Volitional moderators, such as access to means, suicidal capability, or impulsivity, make it more likely that an individual will act on suicidal intent. The 3St argues that suicide ideation results from the combination of multi-dimensional psychological pain and hopelessness, which significantly intensifies in the absence of connectedness. Suicidal behaviour is enacted upon in the presence of dispositional (personality traits or genetic), acquired (habituation to fear and pain) and practical capability (access to means and knowledge of lethality) (Klonsky & May, 2015; Klonsky et al., 2021).

The ITS resonates with the case of autistic adults because its' *central* focus on unmet interpersonal needs is conducive with views in the autism community that social marginalisation of autistic adults should not be overlooked when considering high rates of suicide (Milton, 2017). The ITS argues that wide-ranging distal risk factors lead to suicidal desire because they increase the likelihood an individual will experience the proximal risk factors thwarted belonging and perceived burdensomeness. Autistic adults experience observable indicators of thwarted belonging (such as loneliness (Mazurek, 2014) and of perceived burdensomeness (such as unemployment (Riedel et al., 2016) more often than adults who are not autistic. At the time of design of the studies in this thesis, the ITS was the only theory with empirical data suggesting that it may be relevant to autistic adults. My Master's thesis (Pelton & Cassidy, 2017) reported that, in a non-autistic young adult sample, the association between autistic characteristics and suicidal thoughts and behaviours was through perceived burdensomeness and thwarted belonging. This relationship was maintained even at high levels of autistic characteristics, suggesting the theory is potentially helpful to understand suicide in those with clinically significant autistic traits (Pelton & Cassidy, 2017). Thus, the ITS is relevant to the experiences of autistic people and this is supported by preliminary empirical data.

The ITS is relatively parsimonious meaning that the nature of its core constructs, the pathways and relationships between them, can be efficiently compared between autistic and non-autistic adults using statistical models (van Orden 2010). The ITS is conducive with the possibility that both risk factors experienced by autistic and non-autistic adults (such as mental health difficulties) (Kölves et al., 2021; Zahid & Upthegrove, 2017) and autism-specific risk factors (such as social camouflaging) could increase levels of thwarted belonging, perceived burdensomeness and suicidal capability. Comparative path analyses can reveal whether pathways between constructs, and their strengths of association, are consistent for autistic and non-autistic adults. The ITS hypothesises that the interaction of the proximal risk factors, perceived burdensomeness and thwarted belonging is associated with suicidal thoughts, whereas the interaction of these two with suicidal capability is associated with suicidal behaviour. This thesis will explore hypothesised ITS pathways and interactions of thwarted belonging, perceived burdensomeness and suicidal capability are consistently upheld for autistic and non-autistic adults.

Understanding suicidal behaviour is of particular concern to autistic adults given high rates of suicide attempts (Chen et al., 2017) and death by suicide (Cassidy et al., 2022; Kölves et al., 2021) and research describing autistic adults select more lethal means when attempting suicide than non-autistic adults (Kato et al., 2013). The ITS argues that suicidal capability is necessary to engage in suicidal behaviour and develops in response to lifetime painful and traumatic events (Joiner, 2005). Autistic adults are widely reported to experience wide-ranging traumas across the life course, from sexual abuse in childhood, through bullying in adolescence and adulthood, abusive relationships and self-harm continuing into older adulthood (Griffiths et al., 2019; Pearson et al., 2022; Sreckovic et al., 2014; Stewart et al., 2022). Childhood trauma has been associated with suicidal thoughts and behaviours in autistic adults (Storch et al., 2013) but has yet to explain how these experiences are associated. Thus, this thesis will explore whether the ITS hypothesis that high rates of trauma lead to higher suicidal capability is upheld amongst autistic and non-autistic adults.

One phenomenon of particular concern is reported high rates of suicidal behaviour and death by suicide amongst autistic women. Gender is a known risk factor for suicide for autistic and non-autistic adults, but amongst autistic adults, women are relatively more likely to die by suicide than autistic men (Hirvikoski et al., 2016; Kirby et al., 2019; Kölves et al., 2021), a pattern noticeable for its opposite effect to that observed in non-autistic people (McIntosh, 2002; Nock et al., 2008; Windfuhr & Kapur, 2011). Autistic women are reported to experience unique pressures because of late diagnosis, lack of access to services (Cassidy et al., 2014) and are more likely to experience suicide risk factors such as interpersonal abuse (Pearson et al., 2022) and self-harm (Cassidy et al., 2018; Maddox et al., 2017) than non-autistic men. The ITS argues that gender differences in suicidal thoughts and behaviours reflect relative vulnerability to experiences of thwarted belonging and perceived burdensomeness and suicidal capability (Joiner, 2005). This thesis will explore whether ITS gender hypotheses are upheld for autistic and non-autistic adults.

The ITS has validated questionnaires that describe its core constructs of thwarted belonging, perceived burdensomeness (The Interpersonal Needs Questionnaire) (Van Orden et al., 2012) and suicidal capability (The Acquired Capability for Suicide Scale – Fearlessness About Death) (Ribeiro et al., 2014). Our earlier study reported that the association between depression and thwarted belonging was significantly attenuated at high levels of autistic traits (Pelton & Cassidy, 2017). One possibility is that this suggested having high levels of autistic traits made it less likely one would experience thwarted belonging, which is unlikely as both autistic traits and depression are associated with relatively few social contacts. A more likely explanation could be under-reporting of depression or thwarted belonging due to alexithymia (difficulty expressing emotional states) (Bird & Cook, 2013). This reflects wide-ranging research that questionnaires designed to capture mental health conditions, such as depression and suicidal thoughts and behaviours do not have equivalent measurement properties and do not accurately capture the experiences of autistic adults (Cassidy et al., 2018; Cassidy, Bradley, Bowen, Wigham, & Rodgers, 2018; Cassidy et al., 2020). Thus, this thesis will explore whether measurement properties of validated ITS questionnaires are equivalent between autistic and non-autistic adults.

The ITS argues that mental health difficulties impact suicidal thoughts and behaviours because their symptoms make it more likely that an individual will experience either thwarted belonging, perceived burdensomeness or develop suicidal capability (Davidson et al., 2011; Silva et al., 2015). Mental health difficulties are reported by up to 80% of autistic adults (Lever & Geurts, 2016) and have been consistently associated with suicidal thoughts and behaviours. Depression is the most consistent suicide risk factor reported for autistic people (Zahid & Upthegrove, 2017) but conditions associated with increased suicide risk, such as anorexia nervosa (Westwood & Tchanturia, 2017), borderline personality disorder (Rydén et al., 2008) and psychosis (Kincaid et al., 2017) are also more prevalent amongst autistic than non-autistic adults. However, there are currently no detailed descriptions of *how* mental health difficulties contribute to suicidal thoughts and behaviours amongst autistic adults. Thus, this thesis will explore whether ITS hypotheses describing how mental health difficulties contribute to suicidal thoughts and behaviours are consistently upheld for autistic and non-autistic adults.

1.5 This thesis

This thesis aims to explore the extent to which the Interpersonal Theory of Suicide describes the experiences of autistic adults. To this end, this thesis asks:

1. How participatory methods were used to guide the research undertaken in this thesis? What was the impact of participation processes on the research and the individuals involved? What lessons can be learned for future early career researchers?
2. Whether there are significant differences in the extent to which ITS hypotheses are upheld for autistic and non-autistic adults? Hypotheses state that: (i) thwarted belonging and perceived burdensomeness are proximal risk factors for suicidal ideation; (ii) the presence of suicidal ideation with reduced fear of death (suicidal capability) enables suicidal behaviour; (iii) gender differences in suicidal thoughts and behaviour

reflect gender differences in thwarted belonging, perceived burdensomeness and suicidal capability (Study 2, Chapter 3).

3. Whether measurement properties of ITS questionnaires that describe proximal risk factors, thwarted belonging, perceived burdensomeness and suicidal capability, are equivalent for autistic and non-autistic adults (Study 3, Chapter 4)?
4. Whether there are significant differences in the extent to which ITS hypotheses regarding the role of anxiety and depression are upheld for autistic and non-autistic adults? Hypotheses state that anxiety and depression are distal risk factors for suicidal thoughts through perceived burdensomeness and thwarted belonging (Study 4, Chapter 5).

In sum, these studies will, for the first time, describe mechanisms for suicide amongst autistic adults. This will provide vital evidence to develop tailored intervention for autistic adults to reduce suicide rates.

1.5.1 Data availability

Data for the analyses presented in chapters 3-5 of this thesis were gathered through an online survey, designed in partnership with autistic adults (as described in study 1) between 18th December 2018 and 26th May 2019. The survey included self-report measures of thwarted belonging, perceived burdensomeness, anxiety, depression, lifetime trauma, suicidal capability, and autistic traits. This dataset (n=865) allowed us to undertake statistical modelling determining whether models operate consistently in an age and gender matched sample of autistic non-autistic adults. In line with open science principles, a record of the data is available at UK Data Service (DOI to be confirmed). Data records of those participants who consented to sharing data with other researchers is available on a safeguarded basis. Following the advice of the Design Group, participants were given the option to withhold consent for data sharing and the data is available upon request to limit potential use of the data to purposes that aim to bring better outcomes for autistic people in line with the work in this thesis. This reflects ongoing concern about harm to autistic people by researchers (Dawson & Fletcher-Watson, 2022) and mistrust between autistic people and autism researchers (Cascio et al., 2020). Survey data also informs Study 1 (methods evaluation), however, the evaluation draws on other data sources described in that Chapter and contained in Supplementary Information 3.

1.5.2 Chapter 2: Study 1: ‘Show and tell’: an evaluation of working in partnership with autistic adults to explore suicidal thoughts and behaviours as an early career researcher

Chapter 2 (Study 1) expands the justification for the use of participatory methods given in this introduction and describes how this evaluation extends current good practice guidance available to autism researchers seeking to work in a participatory manner. Drawing on tools from long-established Public Patient Involvement and Engagement (PPIE) in health research in the UK, I use the Public Involvement Impact Assessment Framework (Popay et al., 2014) and other tools from health research to describe and evaluate the impact of participatory activities. Study 1 reports many positive benefits from participatory working for the research, autistic collaborators, and the researcher. This study reflects on how context and process factors influenced

the impact of participation, reflects the theoretical approach to participation, shares materials and discusses funding and cost-benefit. This study concludes with recommendations for future research teams, and particularly for early career researchers, exploring suicidal thoughts and behaviours with autistic adults. This chapter consists of a draft paper for submission to a peer-reviewed journal.

1.5.3 Chapter 3: Study 2: Understanding suicide risk in autistic adults: Comparing the Interpersonal Theory of Suicide in Autistic and Non-autistic samples

Chapter 3 (Study 2) expands the description in this introduction of the relevance of the ITS to suicide amongst autistic adults and sets out evidence to explain *why* the ITS may not operate equivalently for autistic and non-autistic adults. Statistical comparisons explore whether gender patterns, proposed statistical interactions and mediation pathways that explain the role of perceived burdensomeness, thwarted belonging and suicidal capability are observed, whether and how these models differ between autistic and non-autistic adults. Results suggest models that include thwarted belonging and perceived burdensomeness are less accurate for autistic compared to non-autistic adults, and trauma has less impact for autistic than non-autistic adults. This study concludes by suggesting future research should explore measurement properties of questionnaires designed to measure thwarted belonging, perceived burdensomeness and suicidal capability and the role of other risk factors beyond these three ITS proximal risk factors. This chapter consists of a peer-reviewed journal article published in Journal for Autism and Developmental Disorders (Pelton, Crawford, Robertson, Rodgers, Baron-Cohen, & Cassidy, 2020)

1.5.4 Chapter 4: Study 3: A measurement invariance analysis of the Interpersonal Needs Questionnaire and the Acquired Capability for Suicide in Autistic and Non-autistic adults

Chapter 4 (Study 3) builds on the findings of Chapter 3 (Study 2) by exploring whether measurement properties of validated questionnaires that measure perceived burdensomeness and thwarted belonging (the Interpersonal Needs Questionnaire 10 (Hill et al., 2015; Van Orden et al., 2012), and suicidal capability (the Acquired Capability for Suicide Scale - Fearlessness about Death (Ribeiro et al., 2014) are equivalent between autistic and non-autistic adults. Measurement invariance analysis is used to identify the source of non-invariance (difference) between autistic and non-autistic adults and discusses possible reasons. This study concludes that research should not compare total scores of perceived burdensomeness and thwarted belonging between autistic adults using the INQ-10 and that suicidal capability needs more detailed definition for autistic and non-autistic adults. This chapter consists of peer-reviewed journal article published in Autism in Adulthood (Pelton et al., 2020).

1.5.5 Chapter 5: Study 4: The role of anxiety and depression in suicidal thoughts for autistic and non-autistic adults: a theory-driven network analysis

Chapter 5 (Study 4) builds on Chapter 3 (Study 1) by exploring whether mental health difficulties play a more important role in the development of suicidal thoughts for autistic than non-autistic adults. This study builds on the results of Study 2 by exploring whether anxiety and depression contribute to suicidal thoughts as hypothesised through perceived burdensomeness and thwarted belonging and whether anxiety and

depression account for some of the reduced variance of thwarted belonging and perceived burdensomeness with suicidal thoughts and behaviours. Study 4 extends the findings of Study 3 by using a transdiagnostic approach, an item level network analysis, to avoid the need for statistically equivalent latent constructs. This study generates putative pathways to explain *how* being autistic may be a distal suicide risk factor through perceived burdensomeness, thwarted belonging, anxiety, and depression and explores whether networks differ significantly between autistic and non-autistic adults. This Chapter concludes by proposing a conceptual model of suicide co-produced with autistic collaborators with clinical implications and directions for future research. This chapter consists of a peer-reviewed journal article published in *Suicide and Life-threatening Behavior* (Pelton et al., 2023)

1.5.6 Chapter 6: General discussion

Chapter 6 provides a general discussion of the findings of the empirical chapters of this thesis, with an overview of findings of each chapter, synthesised contributions to theoretical literature, clinical implications, strengths and limitations and directions for future study.

Chapter 2: Study 1: ‘Show-and-tell’: An evaluation of working in partnership with autistic adults as an early career researcher examining suicide theory

This Chapter consists of a draft paper for submission to a peer-reviewed journal: ‘Show-and-tell’: An evaluation of working in partnership with autistic adults as an early career researcher examining suicide theory.’

Study 1 contributes to the overall thesis aim by describing how the views of autistic adults were sought in this programme of study and provides an evaluation of the impact of the partnership activities. Study 1 extends previous ‘how-to’ guidelines for researchers seeking to work in partnership with autistic adults and seeks to promote transparent and accountable reporting. The advisory group (termed ‘the Design Group’ in this programme of study) provided the initial idea for this paper, provided critical reflection on their experience, reviewed the draft paper and one group member is a co-author. Specifically, Study 4 applied the Public Involvement Assessment Framework (PiiAF) (Popay et al., 2014) to evaluate the impact of participation activities on the research, autistic collaborators, and the research and how context and participation process influenced the impact of participation.

Study 1 reported many positive outcomes of participation for the research, more relevant study focus, accessible methods, meaningful interpretation of results and identification of novel areas of study. Shared commitment to participatory methods, demand for research to improve our understanding of suicidal thoughts and behaviours supported participatory impacts. Accessing funding and lacking trusted networks of potential collaborators were challenges for an early career researcher, whilst increased knowledge and confidence about the topic were benefits. I discussed these findings with the Design Group, and we agreed that this could suggest that future study programmes could consider their theoretical position, and proposed outcomes of participation at the outset and draw on our materials, experience and recommendations proposed here. Developing suicide prevention that fully addresses the experiences of autistic people may involve indirect and longer-term impacts than a single study.

Supplementary information for study 1 is provided in Supplementary 3.

'Show-and-tell': an evaluation of working in partnerships with autistic adults as an early career researcher examining suicide theory.

Abstract

Research to improve our understanding of mental health and suicidal thoughts and behaviours typically excludes the voices of autistic people and there is an absence of transparent reporting and critical evaluation of participatory processes in autism research. We sought to reflect the views of autistic people in a programme of doctoral studies by establishing an advisory group, conducting a community-based creative project, developing a database of participation volunteers, and garnering views via Twitter. We used the Public Involvement Impact Assessment Framework to evaluate: (i) the impact of participation activities on the research, autistic collaborators and the researcher; (ii) how context (being an early researcher, the subject of suicide); (iii) how participation process impacted these outcomes; (iv) theoretical approach; and (v) cost-benefit analysis. Impact on the research, autistic collaborators and the researcher were largely positive. Shared commitment to collaborative working, supervisor experience of participatory methods and researcher transferable skills were important. Early career status provided funding challenges. Future research could more clearly state theoretical position and proposed outputs of participation. Researchers should continue to develop and share good practice in working in partnership with autistic people.

Keywords

Autism; participation; lived experience; suicidal thoughts and behaviours

Background

Autistic people die more often by suicide than non-autistic people (Cassidy et al., 2022; Kölves et al., 2021) yet research to date does not fully explain *why*. The way that we understand, measure, and explain suicide for non-autistic people is not necessarily valid for autistic people (Cassidy et al., 2018; Pelton et al., 2020; Pelton, Crawford, Robertson, Rodgers, Baron-Cohen, & Cassidy, 2020) leading to a weak evidence base to design support for autistic people who experience these difficulties (Camm-Crosbie et al., 2019; Cassidy et al., 2020a). One reason for this could be that the *way* that autism and suicide research is typically carried out precludes the capture of the lived experience of autistic people (Cassidy et al., 2021; Hedley, Cassidy et al., 2022). Autism research has traditionally followed a 'medical model' of autism where priorities are decided by non-autistic researchers and progress is measured by improving our understanding of autism prevention, 'cure' or eliminating autistic characteristics (Chown et al., 2017; Milton & Bracher, 2013). Such an approach is highly problematic when exploring suicidal thoughts and behaviours with autistic people: medical model research, which views autism as 'pathological' or 'flawed', has been associated with known suicide risk factors, such as de-humanisation, marginalization, burdensomeness and masking autistic characteristics (Botha & Frost, 2020; Cadman et al., 2012; Cage et al., 2019; Cassidy, Bradley, Shaw, & Baron-Cohen, 2018; Ou et al., 2015). This suggests that research to inform suicide prevention for autistic people needs to apply an alternative and more holistic approach.

Participatory research is proposed to address these difficulties by including autistic people and their allies in decisions about 'what research gets done, how it is done and how it is implemented' (Fletcher-Watson et al., 2019) but there is a weak evidence-base for researchers seeking to implement participatory methods (Jivraj et al 2014). Participatory methods are argued to be a pre-requisite to emancipatory research that will bring about real-life improvements for autistic people through a shift in the balance of power from researchers to autistic people (Chown et al., 2017). Research to improve our understanding of suicidal thoughts and behaviours amongst autistic people has already incorporated participatory approaches: the doctoral studies that are the subject of this paper (Pelton et al., 2020; Pelton et al., 2020) and other empirical studies (Cassidy et al., 2018; Hedley, Batterham et al., 2022) include clear mention of consultation with autistic people. However, descriptions of participatory processes typically fall short of open science principles that advocate that sufficient detail should be given to allow methods to be reproducible and open to scrutiny (Munafò et al., 2017; Nosek et al., 2015). Descriptions of participatory processes typically lack detailed mention of impact on research outcomes and impacts on autistic volunteers (Jivraj et al., 2014; Pellicano & Houting, 2022). This is particularly concerning given ongoing concerns about 'tokenism' or autistic people being undervalued or harmed by research processes (Dawson & Fletcher-Watson, 2022; Michael, 2021). Thus, there is an urgent need for greater transparency and scrutiny of participatory processes in autism research.

Evaluation allows transparent sharing of participation methods and impacts but has not yet been widely applied to autism research (Popay et al., 2014). It allows researchers to reflect on impact of participation at each stage of the research, document and understand intended and unintended consequences for volunteers

(Popay et al., 2014). In the UK, public engagement in health research - termed PPIE 'Patient and Public Involvement and Engagement' argued to make research outcomes more relevant to patients (Price et al., 2018) - has, since 1996, systematically collected and disseminated experience via the INVOLVE advisory group. Reporting tools include creating an impact log to record outcomes of involvement (Kok, 2018), the Public Involvement Impact Framework to support researchers to develop a plan to evaluate PPIE (Popay et al., 2014), the GRIPP2 (Guidelines for Reporting Involvement of Patients and the Public) reporting checklists to improve reporting of patient and public involvement (Staniszewska et al., 2017). Such an approach extends existing good practice guidelines (Fletcher-Watson et al., 2019; Nicolaidis et al., 2019; Pellicano, E., Crane, L., Gaudion, K., and the Shaping Autism Research Team, 2017) and consolidated experiential guidance, such as the ASPIRE partnership (<https://aspire.org>) and the Participatory Autism Research Collective (<https://participatoryautismresearch.wordpress.com>). Thus, the current study sets out to apply tools from health research to participatory research about suicidal thoughts and behaviours amongst autistic people to openly share our methods and the impact of those methods on research outcomes, volunteers, and researcher.

Finally, evaluation allows researchers to reflect on *why* participation activities impacted research outcomes and the individuals involved. Such an approach is helpful to inform decisions about proposed participation methods in another context (Popay et al., 2014). Context factors of this research included working with people who experience suicidal thoughts and behaviours, being a doctoral researcher and the COVID-19 pandemic. Working with people who experience suicidal thoughts and behaviours is recognised to require additional safeguards in research (Lakeman & Fitzgerald, 2009), particularly for autistic people who may be unconnected with clinical services or have had poor experience of previous research involvement (Camm-Crosbie et al., 2019). Early career researchers are recognised to face greater challenges than more established researchers in implementing participatory methods due to greater restrictions in timing and funding and lack of confidence (Pickard et al., 2022). Furthermore, the COVID-19 pandemic had significant impact for suicide prevention, autistic people and research involving both (Cassidy et al., 2020b; Niederkrotenthaler et al., 2020; Townsend et al., 2020). Thus, the current study sets out to apply evaluation tools from health research to evaluate how context influenced the planned participation activities from a programme of doctoral studies to explore suicide theory with autistic people.

Methods

Participation methods

This programme of doctoral studies sought to understand the extent to which a leading suicide theory, the Interpersonal Theory of Suicide, helps us understand and explain suicide for autistic people. This paper is informed by reporting standards set out in GRIPP2 (Staniszewska et al., 2017). Participatory activities planned at the outset of the doctoral programme were:

An advisory group: following previous studies in the Mental Health in Autism Group (Cassidy et al., 2018), 6 autistic adults (3 male, 3 female) were recruited following approaches to autism support groups in or near

Coventry, West Midlands, United Kingdom. Referred to as the *Design Group*, up to 3 volunteers met 8 times between April 2018 and January 2023 to make decisions across the three empirical studies from deciding initial study focus to interpretation of results. Volunteers gave informed consent in response to the Design Group Brief (in Supplementary Information). Meetings were guided by an agenda and notes shared with volunteers one week in advance, which included background information, points for discussion, actions from previous meetings, ground rules. Ethical permission was given in line with Coventry University procedures for PPIE on 6.3.2018.

Twitter: from the outset, the Design Group, supervisors, and researcher were keen to engage broader views from the autism community, to better reflect the diversity of experiences across the autism spectrum. A Twitter account @MiraPel1 was set up by the researcher in January 2018. In line with advice from autism advocacy organisations, we shared tweets with videos and blogs sharing details of the proposed research (<https://twitter.com/MiraPel1/status/1081247430392324097>) and asked for reflections on findings (<https://twitter.com/MiraPel1/status/1171326749642305537>).

The following participatory activities emerged during the doctoral programme:

Creative Community-based project: emerging from discussions with the Design Group about why a questionnaire designed to measure thwarted belonging may not accurately capture the experiences of autistic people (Study 2 (Pelton et al., 2020), this project aimed to (i) use creative methods to inform future research to conceptualise and harness the protective capacity of belonging for autistic people (protocol in Supplementary Information); and (ii) represent a wider range of autistic experiencing by engaging with autistic people who cannot attend the University for any reason. Autistic and non-autistic people were to be invited, in face-to-face sessions within their community groups, to represent, in any medium, what belonging meant to them and/or complete a postcard with a statement of what belonging meant to them with a free text box to express any aspect of their identity they felt important. Funding was competitively accessed from Coventry City of Culture student projects and ethical approval from Health and Life Sciences Research Ethics Committee, Coventry University (P103325) on 13th March 2020. This project was transferred to an online format in April 2020 following the UK COVID-19 pandemic lockdown (23rd March 2020) to a dedicated Twitter handle (@isbelonging, initiated May 2020) and website gallery (<https://belong.coventry.domains>). In May 2020, an extension was granted from Coventry City of Culture disburse funding by July 2021.

Setting up a database: emerging from discussions with supervisors about how to extend the range of autistic voices, an ethics application was approved by Health and Life Sciences Research Ethics Committee, Coventry University (P93917, approved 20.4.22) to set up a database of autistic adults to consult with via email (protocol in Supplementary Information).

Capturing impact of participation activities

Shown in Supplementary information, an impact assessment framework was designed retrospectively, in December 2022, using the Public Involvement Impact Assessment Framework (PiiAF) to explore the extent to which theoretical impact of participatory methods were achieved (Popay et al., 2014). The PiiAF requires

researchers to state their 'intervention theory' and then to describe evidence to support this. Intervention theories describe:

(i) how participation impacted each stage of the research: for example, 'partnership working leads research to ask relevant questions to explore suicidal thoughts and behaviours with autistic people'. Stages of research were included across the current doctoral studies from preparatory phase (agenda setting and funding) to translational phase (dissemination, implementation, evaluation) as in (Shippee et al., 2015).

(ii) consequences (intended and unintended) for autistic volunteers (for example, 'participation processes to explore suicidal thoughts and behaviours amongst autistic people should be a positive experience for autistic collaborators').

(iii) how context influenced the outcome of each participation method (for example, 'understand how institutional factors - doctoral study - influenced the outcomes of participation'), including how activities were financed and whether they are considered cost effective.

Sources of evidence used for the evaluation include:

Design Group: ongoing (referred to as *formative assessment* in Popay 2014) was undertaken via evaluation questionnaires/informal feedback shared with volunteers after each Design Group meeting asking volunteers about their experience of the group. Retrospective (or *summative assessment*, Popay et al 2014) was undertaken via an NIHR impact assessment log (shown in Supplementary Information). We did not record demographic information about Design Group members though 5 members mentioned receiving a diagnosis in adulthood.

@MiraPel1 Twitter account: retrospective assessment was undertaken by downloading tweets using Twitter analytics, retaining tweets aimed at generating participation, coding tweets according to stage of research for quantitative assessment of 'impressions' (number of times a unique twitter user is 'served' - or shown - a tweet in a timeline or search) and 'engagements' (total number of times that a user interacted with a tweet). Qualitative analysis of twitter comments is also used to evidence relevance of research, interpretation of results and novel areas for future research. We downloaded tweets aimed at other such as recruitment and dissemination, to gain a broader picture of how and when Twitter users engaged with Tweets.

Creative community-based project: retrospective assessment was undertaken by quantitative assessment of submissions versus numbers expected, download @isbelonging tweets, quantitative assessment of numbers of tweets, qualitative analysis of comments.

Other available data: data collection for the doctoral studies was via an online survey (in Qualtrics), which included a free text box where participants had the option to share views or thoughts on any aspect of the survey or research at the end. Retrospective quantitative assessment was undertaken by downloading comments, coding comments according to the stage of research they referred to, quantitative assessment of numbers of tweets at each stage and qualitative analysis of comment content.

Critical reflection was undertaken with autistic volunteers to explore their experiences of the Design Group. Critical reflection of impacts was undertaken with doctoral supervisors and autistic volunteers to reflect how context factors had impacted research outcomes and impact on the researcher.

Community involvement statement

The idea for this paper emerged in discussions at the third meeting of the Design Group (August 2019) with a proposal for a paper which reflected the perspectives of researcher, autistic collaborators, and supervisors in this programme of doctoral study. A critically reflective online discussion took place in December 2022, guided by questions sent by the researcher to explore the experience of taking part in the Design Group. The discussion was video recorded, and a summary shared with to comment further or correct any aspect. A further meeting took place to reflect on how the collaborative working had been presented in the draft manuscript, specifically, the impacts on the Design Group, reflections on the experiences of autistic people who took part through other processes and recommendations for researchers. Autistic collaborators were given the choice of being an author or being named in the acknowledgements and information was shared regarding time/commitment implications, of each option with time to reflect. Those who chose authorship reviewed the final manuscript prior to submission in line with author requirements.

Results

What were the outcomes of collaboration activities?

The PiiAF and impact log (both in Supplementary Information) show that collaboration led the focus of PhD programme to shift to exploring the validity of the ITS for autistic people. Participant documentation, survey guidance and risk management were clarified to better meet autistic communication styles. The Generalised Anxiety Disorder 7 (GAD7) and Patient Healthcare Questionnaire 9 (PHQ-9) replaced the proposed Hospital Anxiety and Depression Scale to try to mitigate response difficulties resulting from measurement tools validated for non-autistic people. Detailed hypotheses were developed for (Pelton et al., 2020) regarding which questionnaire items may be differently interpreted by autistic people. Interpretation of results for all studies reflected autism-specific experiences, such as daily trauma, social camouflaging, somatic experiences and experiences of being misunderstood and “othered”. A conceptual model of the development of suicidal thoughts was co-produced from a data driven approach, leading to co-authorship between researcher, collaborator and supervisors. Novel ideas for future research were regularly generated; one idea resulting from study 2 focussed on the nature of autistic belonging, which became the focus of the community-based creative project. For this project, materials were co-produced, recruitment worked on collaboratively, decisions taken collaboratively about how to manage the project in the context of the pandemic. This suggests outcomes of collaboration across many research phases, including study focus, methods, and interpretation of results.

What were positive and negative impacts of collaboration on research, collaborators, and researcher?

Survey recruitment figures (816 participants) indicated the survey was accessible. This was supported by positive comments in the Survey Free Text Box regarding study focus (22 comments), accessibility (3 comments) and safety guidance (2 comments). Survey Free Text box negative comments related to survey software (Qualtrics) on some devices (iPads) (5 comments) and standardised questionnaires (42 comments)

received most negative feedback, specifically: (i) absence of meaningful response options; (ii) the AQ-S (Autism Quotient Short Form (Hoekstra et al., 2011) is not valid for autistic women; and (iii) being asked to repeatedly report autistic traits is stigmatising. Twitter analytics suggest interpretation of results was meaningful (study 1=8124 impression, 463 engagement, comments describe as 'robust evidence'). Creative project recruitment suggests the novel topic proposed was relevant (15 submissions, total 59,304 Twitter impressions). Reflection with autistic collaborators indicated that building personal connections, contributing to better outcomes for autistic people, building trust between autistic people and researchers were positive impacts. Researcher reflection indicated partnership working led to personal connections, increased knowledge, confidence and motivation for the research. Collaboration was experienced as positive by research, autistic collaborators, study participants and researcher. Notwithstanding collaboration, standardised questionnaires were the most frequently cited negative experience.

How did context factors (subject, institutional, personal) hinder or enable collaboration?

Reflection indicated that research on suicide theory for autistic people addressed an area identified as a research priority for autistic people. Novel study areas proposed by the Design Group, Survey Free text box, Twitter analytics, creative project suggests high demand for further research. Supervisor and researcher reflection indicated this could reflect an absence of meaningful insight provided by existing suicide and autism research. Design Group reflection indicated motivation to be involved in suicide research and that a feeling of safety and personal connection had created an environment in which it felt safe to share. Reflection indicated supervisors, researcher and host institution shared commitment to collaborative working: supervisors had previous experience in organising collaborative processes, were able to offer explicit support with Design Group processes, and enthusiasm for developing new methods to include autistic collaborators beyond the Design Group. Reflection indicated that early career status meant it was time consuming to recruit collaborators to the Design Group at the outset and early tweets received no responses. No previous experience in autism research and commitment to collaboration meant a genuine open interest and motivation to learn from autistic collaborators. Previous experiencing working with people who experience suicidal thoughts and behaviours was enabling, as was understanding trauma-informed approaches. Funding constraints hindered impact of collaboration but development opportunities, such as Twitter training and senior colleague support enabled collaboration. Confidence increased with learning about the history of autism research. Thus, exploring suicidal thoughts and behaviours may be appropriate to do in collaboration, if a safe space can be created. Commitment from supervisors, institution and researcher are enabling. Working in partnership provides early career researchers with opportunities for self-development and personal connections, but patience and persistence is required to build trust and overcome funding challenges.

How did process factors hinder or enable collaboration?

Impact logs report most impacts of collaboration resulted from the Design Group, which was enabled by supervisor experience: examples of consent form, meeting notes, group norms were shared with the

researcher, monitoring in supervision sessions, support to debrief from difficult conversations, and informed problem-solving around emerging issues. Design Group evaluation questionnaires indicated meetings were considered accessible (mean score =5.83/7 for advance information; 6.83/7 for meeting structure). More time for personal connection was added to meeting agendas following collaborator feedback (qualitative feedback on evaluation questionnaires)². Design Group reflection indicated personal connections, open communication about changes that could and could not be implemented led to trust and safety, which led collaboration to be experienced as 'real' rather than 'tokenistic'. The impact log shows the Design Group played a more active role in the creative project, including deciding study focus, recruitment, study decisions around the pandemic for the community project and reflected this was their most enjoyable aspect. Two potential collaborators agreed to attend the Design Group but did not: one stated they found the accessibility arrangements patronising and the other gave no reason. This suggests that the Design Group provided a safe space with personal connections where collaborators felt able to share sensitive information. This space was devised with patience at trust-building, underpinned by procedures based on learned experience, and collaborators played a more active role in the process as the group developed. More could be done to ensure broader accessibility.

Twitter analytics demonstrate no responses were received in response to videos and blogs. Reflection suggests that collaboration via Twitter was hindered by a lack of researcher experience, and trusted profile, regular tweeting was not maintained, and Twitter analytics not reviewed. The creative study generated 15 novel submissions on the topic of autistic belonging. Reflection shows that recruitment was hindered by the pandemic. In April 2020, the funder confirmed the deadline to disburse funding of July 2020 would not be extended so, with the Design Group, we moved the project online without re-designing materials (April 2020) that had been designed for in-person administration in community settings. In May 2020, funding deadline was extended to July 2021 but we did not reverse the decision to proceed online. The database did not develop beyond an ethics application due to time constraints. This suggests that novel methods should be prioritised, focus on building experience and trust to create a safe space to share, underpinned by appropriate methods and materials, with regular monitoring to adjust process and ensure full accessibility.

Did any conceptual or theoretical developments in PPI emerge?

We did not state a theoretical position towards participation at the outset of this programme of study. In compiling the PiiAF, we drew from the Design Group brief (in Supplementary Information) our stated aim: 'to produce research that really makes a difference and improves people's lives'. This extends the definition put forward by Fletcher-Watson: 'what research gets done, how it is done and how it is implemented' (Cornwall & Jewkes, 1995), to emancipatory principles that collaborative research is pre-requisite to improved quality of life for autistic people (Chown et al., 2017). We did not state how outcomes of participation processes could be measured and impacts on the research noted are at earlier stages of the research with less impact to date

² Each meeting finished with an item 'show-and-tell' where researcher and collaborators shared information about anything of their choice in a positive mood-inducing task to mitigate any negative feelings. Collaborators requested more time for show-and-tell in questionnaires, informing the title of this paper.

on policy and ‘real-life’ outcomes. Other conceptual issues emerged in our critical reflection about whether recruitment and dissemination via Twitter constituted participation. Researchers could more carefully plan and define participation and its hoped-for outcomes at the outset of the study, including stating a theoretical position.

Were any instruments developed to support collaboration?

Template meeting notes, design group brief and consent form, evaluation questionnaire were developed, with protocols for the community-based project and for the database of volunteers (available in Supplementary Information). Impact log recorded impacts of each Design Group meeting and the PiiAF describes intervention theories applied to this evaluation with available data (available in Supplementary Information). Protocols for Creative Project and Database of volunteers are contained in Supplementary Information.

What was the cost-benefit of collaboration?

Total cost for (i) the Design Group is estimated³ at £590; (ii) the Community project is £500; and using Twitter was free with a free version of Adobe Spark for producing videos. We did not undertake formal cost-benefit analysis, but reflection indicates these costs represent good value for money in context of overall autism research spending. Collaborators were initially reimbursed £10 plus local travel to attend meetings due to limited funding⁴. Following successful funding applications, collaborator payment increased to £20/ hour for meeting time and preparation in line with guidance from Autistica with payments made via bank transfer or voucher depending on collaborator preference. This suggests that relatively small amounts of funding can be impactful but limited, fragmented funding creates challenges of fairly rewarding collaborators and being able to demonstrate formal cost benefit analysis.

Discussion

This study set out, for the first time, to apply evaluation tools from health research to describe and evaluate the impact of a collaboration activities within a programme of doctoral studies to explore suicide theory with autistic people. Outcomes of collaboration included were across research stages from defining study focus, methods and interpretation of results. Impacts were largely perceived as positive for the research, autistic collaborators, study participants and researcher. Standardised questionnaires were the most frequently cited negative experience. Exploring suicidal thoughts and behaviours may be particularly appropriate for partnership working, but researchers need to create safe space. Commitment is required from supervisors and researcher and early career status provides challenges and opportunities. Processes to govern safe collaborative spaces benefit from clearly set out processes, regular monitoring and paying attention to ongoing, personalised accessibility. Researchers could state a theoretical position and some proposed aims at

³ Costs are estimated because they were managed within distinct grants (e.g. Coventry City of Culture, PsyPAG) or accounting periods (e.g. Research costs 2019) as required by funders.

⁴ Funding of £125 (increased to £150 in 2019) was allocated on an annual basis for this programme of doctoral study to cover all research costs.

the outset of participatory work and account for these. Developed tools from this programme of study are shared alongside materials in Supplementary Information. Activities represent good value for money but limited, fragmented funding creates challenges for early career researchers. In summary, this study adds to the limited body of evidence available to autism researchers to support collaborative research, particularly in the sensitive field of exploring suicidal thoughts and behaviours.

Partnership working impacted many research stages, including refining study focus and language, improving safety guidance and reflecting specific autistic experiences in results interpretation. This reflects thinking that PPIE can potentially impact all research stages (Shippee et al., 2015). Changes were largely positive, in line with existing reports that partnership working can make research more relevant (Jivraj et al., 2014; Nicolaidis et al., 2011) accessible (Cassidy et al., 2018; Nicolaidis et al., 2013; Nicolaidis et al., 2020) and meaningful (Fletcher-Watson et al., 2019; Gowen et al., 2019). Notwithstanding partnership working, negative comments reflected the importance of ensuring technology is usable and accessible (Valencia et al., 2019) and well-documented difficulties for autistic people answering standardised questionnaires designed to describe the experiences of non-autistic people (Cassidy et al., 2020a). Where research question dictates standardised questionnaires, more guidance and preparation could be devised in partnership with autistic collaborators to support autistic participants.

Positive outcomes for the Design Group collaborators included positive wellbeing, improving outcomes for autistic people in the future, trust between autism and research communities, personal insight and connections with other autistic people. This reflects previous research describing improved wellbeing and reflection on personal experience for those with lived experience of suicidal thoughts and behaviours (Hasking et al., 2015; Lewis & Hasking, 2019; Watling et al., 2022; World Health Organization, 2012), improved trust (Gowen et al., 2019; Keating, 2021) and benefits of autism acceptance and personal connections (Botha et al., 2022; Cage et al., 2022). Benefits for the researcher extended previous findings of researcher prestige and recognition (Pickard et al., 2022). Benefits to the researcher included increased confidence in knowledge and approach to the subject reflecting research describing working with those with lived experience is an important aspect of doctoral education (Karlsson & Janssens, 2023) and could counter lack of confidence (so-called *imposter syndrome*) that can cause anxiety to early career researchers (Sverdlik et al., 2020).

Many novel areas of study were proposed to inform our understanding of suicidal thoughts and behaviours amongst autistic people. This could suggest particularly high demand for new types of knowledge and new approaches to understanding suicide amongst autistic people given the nature of the problem and the lack of evidence in the extant literature (Cassidy & Rodgers, 2017; Cassidy et al., 2021). Creating a safe space was vital for autistic collaborators to be able to share sensitive information about suicidal thoughts about behaviours, in line with longstanding research stressing ethical commitments of suicide researchers (Lakeman & FitzGerald, 2009). Shared commitment to collaborative working, supervisor experience enabled safe collaborative working in line with research describing the importance of supportive infrastructure (Fletcher-

Watson et al., 2019), shared views and values (Popay et al., 2014) and a supportive environment for early career autism researchers (Pickard et al., 2022). Time to build trust was substantial though lack of experience and knowledge of an early career researcher could provide the opportunity of a more equal relationship between researcher and autistic collaborator than a more experienced researcher. Openness and commitment to collaborative learning may be more important than in-depth autism knowledge. Previous experience working with people who experience suicidal thoughts and behaviours, being aware of the history of autism research and approaches to understand trauma may be helpful. Funding was another significant challenge (discussed below) reflecting previous research (Pickard et al., 2022) however, if challenges can be overcome, doctoral study offers the opportunity to pilot novel approaches and develop new skills in a supportive environment.

Most impacts of collaboration resulted from the Design Group, which reflects the widespread use of advisory groups as a participatory process in autism research (Pellicano & Stears, 2011). This could suggest that an advisory group is the most impactful collaborative mechanism, but a more likely explanation is that our previous experience in organising advisory groups underpinned the creation of a 'safe space' with clear procedures and learned norms. This reflects research describing the importance of building infrastructure (Fletcher-Watson et al., 2019) and knowledge base for participatory activities (Nicolaidis et al., 2019). The Design Group also benefitted from persistence in trust-building at the outset and regular monitoring, which led to adjustments to the process. Our commitment to extend methods to include those beyond the Design Group reflected autistic collaborator feedback, but also well-documented in the literature that autism research needs to be more representative. Our results, however, suggest that researchers should be realistic about the investment required to establish trust and a safe space to share, and the need for regular monitoring and adjustments. Researchers should carefully prioritise methods, build clear procedures based on 'what works' and continue to learn, adjust and develop. Our results suggest as the Group develops collaborators take on a more active role in the research.

Our creative project reflects the experience of researchers in the early stage of the pandemic attempting to re-organise research to be carried out online. The short funding timescale meant the study was moved online without re-organising materials, which had been designed for iterative use in face-to-face community sessions. This also reflects the time and nature of decision-making in participatory projects. Having made the decision to move online during April 2020, it was not easy to reconsider this following an extension to funding announced in May 2020.

We retrospectively considered our theoretical approach to collaborative working in response to the prompt from the GRIPP2 reporting format and the requirements of the PiiAF to state exactly *how* collaborative working will lead to stated outcomes. We based this on the definition of 'what research gets done, how it is done and how it is implemented' and extended this to reflect the aspiration of our Design Group brief 'to make a real improvement to people who experience these difficulties', which extends participatory research into

emancipatory research. Policy impacts of this research were not, to date, the outcome of collaboration activities organised by the researcher, which could suggest that collaborative research does not lead to policy impact or 'real-life' outcomes. One possibility could be that we over-stated our theoretical position in our design group brief and that a more accurate aim would have been to work in respectful, humane partnership with autistic people to explore suicide theory, notwithstanding limitations that we are already aware of. Had we stated this aim, then our aspirations were met as this matched the Design Group's report of the group as 'real' because of open, trusting, safe and humane. Researchers could state a more accurate theoretical position at the outset and think about some simple indicators for what they are trying to achieve by partnership working, which might clarify expectations and avoid accusations of tokenism and help maintain focus. Future research could consider a theoretical position, such as community-based participatory research, endorsed by AASPIRE (Nicolaidis & Raymaker 2015), depending on the nature of the research question. And could choose a theoretical approach to participation in line with the transformative nature of the research proposed.

Materials developed include Design Group brief, consent forms and protocol for community-based project. We also designed an evaluation form to monitor the ongoing experience of collaborators and to produce 'impact data' and used this where collaborators found it acceptable. We also reported that two potential collaborators signed up for the Design Group but did not attend any sessions with one indicating dissatisfaction with accessibility. Based on this experience and other projects in our group, we have created a safety plan, which has been successfully used to meet personal access requirements in other studies (Pelton et al., under preparation) and can be re-visited to maintain accessibility. This reflects advice from the AASPIRE programme and advice regarding working with those lived experience of suicide of the importance of clearly identifying support needs at the outset (Nicolaidis et al., 2019; Webb et al., 2023). We encourage researchers to use these materials and develop and share their own materials.

The overall cost of all collaboration activities was estimated at £1090 pounds, which we believe represents good value for money given overall spending on autism research (£4million/ year (Fletcher-Watson et al., 2019). Our experience reflects funding difficulties faced by early career researchers specifically (Pickard et al., 2022; Staniszewska et al., 2018) and more generally for participation (Fletcher-Watson et al., 2019). The need to re-negotiate and administer multiple budgets adds to the time and stress burdens of doctoral researchers (Byrom et al 2022), particularly those who feel a strong commitment to participatory methods without accessible funding source.

This evaluation has several strengths. For the first time evaluation tools from health PPIE have been used to systematically describe and measure the impact of participation activities within a programme of doctoral study to explore suicide theory with autistic adults. Sharing this information will improve the evidence base for participatory autism research and for the involvement of those with lived experience in suicide research. It is important to mention this study's limitations: this evaluation was designed retrospectively, drawing on

existing data sources, which means that in analyses are formed drawing on limited data. Data is at risk of bias due to self-reflection and self-report and, importantly, those who chose not to or were unable to collaborate are not reflected here. Future research should seek to extend accessibility. These issues could be addressed by designing a simple evaluation plan at the outset, including gaining anonymous feedback from collaborators.

Conclusion

This study reports that undertaking research in a collaborative manner had positive outcomes for the research, collaborators and the researcher. Suicidal thoughts and behaviours may present a particular need for researchers to collaborate with autistic people due to the lack of extant evidence. Researchers should focus on creating 'safe spaces', and early career status may offer opportunities as well as challenges. Future research collaborations should continue to consider theoretical position, invest time to build trust, monitor the impact of their actions and document and share good practice. This will be vital for research to fully achieve the stated aims of participatory research.

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Society

When people put me in a box I am not in.

Trap me .

They corner me .

I have no where to go, to move.

No space to breath.

No clean air.

I am not me.

I don't know who I am any more.

17.6.20

Chapter 3: Study 2: Understanding suicide risk in autistic adults: Comparing the Interpersonal Theory of Suicide in Autistic and Non-autistic samples

This Chapter consists of a peer-reviewed paper published in the Journal of Autism and Developmental Disorders, Special Issue (50) on Self-harm, Suicidal Thoughts and Behaviours in Autistic Adults: Pelton, M. K., Crawford, H., Robertson, A. E., Rodgers, J., Baron-Cohen, S., & Cassidy, S. (2020). Understanding suicide risk in autistic adults: Comparing the Interpersonal Theory of Suicide in autistic and non-autistic samples. *Journal of Autism and Developmental Disorders*, 50(10), 3620-3637, DOI: <https://doi.org/10.1007/s10803-020-04393-8>.

Study 2 contributes to the overall thesis aim by providing an initial comparison of the extent to which the principal hypotheses of the ITS are upheld for autistic adults with a sample of non-autistic adults. This study focus was devised in discussion with the Design Group. Study 2 extends the background information in the introduction describing the relevance of the ITS to autistic adults and explains the rationale for believing the ITS may operate differently. Specifically, this study explored whether gender patterns, proposed statistical interactions and mediation pathways that include perceived burdensomeness, thwarted belonging and suicidal capability were observed in autistic adults. Statistical analyses then explored whether and how these models differed between autistic and non-autistic adults.

Study 2 reported gender hypotheses were only upheld amongst non-autistic adults and models including perceived burdensomeness and thwarted belonging were less accurate or operated differently for autistic people than non-autistic adults. Trauma had less impact on suicidal thoughts and behaviours for autistic than non-autistic adults. I discussed these results with the Design Group, and we agreed these results suggest that other risk markers may be more important for autistic than non-autistic people. However, before exploring the role of other risk markers, another possible explanation was that the way that perceived burdensomeness and thwarted belonging were described and measured may not be meaningful to autistic people.

Understanding suicide risk in autistic adults: comparing the Interpersonal Theory of Suicide
in autistic and non-autistic samples

Abstract

This study explored whether the Interpersonal Theory of suicide informs our understanding of high rates of suicidality in autistic adults. Autistic and non-autistic adults (n=695, mean age 41.7 years, 58% female) completed an online survey of self-reported thwarted belonging, perceived burden, autistic traits, suicidal capability, trauma, and lifetime suicidality. Autistic people reported stronger feelings of perceived burden, thwarted belonging and more lifetime trauma than non-autistic people. The hypothesised interaction between burdensomeness and thwarted belonging were observed in the non-autistic group but not in the autistic group. In both groups autistic traits influenced suicidality through burdensomeness/thwarted belonging. Promoting self-worth and social inclusion are important for suicide prevention and future research should explore how these are experienced and expressed by autistic people.

Introduction

Research reports higher suicidality rates amongst adults diagnosed with an autism spectrum condition (ASC) than the general population, but research has yet to explain *how* the unique challenges facing autistic adults lead to suicidality (Cassidy & Rodgers, 2017; Segers & Rawana, 2014). A recent population study reported a nine-fold increase in death by suicide amongst autistic adults⁵ (Hirvikoski et al., 2016) and higher rates of suicide ideation have been noted in autistic samples than general population, psychotic and student samples (Cassidy et al., 2014). Autistic adults more frequently experience general population suicide risk factors, such as abuse (Storch et al., 2013) and depression (Cassidy et al., 2014), but also report greater impact of less commonly reported risk factors, such as camouflaging (masking autistic characteristics to fit in) or coping with life without required support (Cassidy, Bradley, Shaw, & Baron-Cohen, 2018). However, studies to date have not applied theoretically based empirical models and so do not provide the detailed insight into suicide mechanisms required to design interventions that meet the specific needs of autistic people (Cassidy & Rodgers, 2017; Franklin et al., 2017; Joiner, 2005; Segers & Rawana, 2014; Van Orden et al., 2010). The current study, thus, explores for the first time how a widely cited theory of suicide, the Interpersonal Theory of Suicide (Joiner, 2005), applies to suicide in autistic adults and whether this is different from non-autistic adults.

(FIGURE 1 ABOUT HERE)

⁵ This study refers to adults without intellectual disability who are reported to be at greatest risk of suicidal behaviour (Hirvikoski 2016).

The ITS proposes that three proximal risk factors for suicide, shown in Figure 1, lead to a lethal or near lethal suicide attempt: 1) strong feelings of ‘thwarted belonging’ (absence of reciprocal relationships with family, friends and society) and 2) ‘perceived burdensomeness’ (a belief that others are better off without oneself) (Joiner, 2005) are proposed to jointly lead to a desire for suicide. A suicide attempt will only be made if an individual has 3) ‘suicidal capability’, a biological change in the body’s pain and fear systems that allows rather than inhibits a suicide attempt. The theory suggests this stable trait develops in response to lifetime exposure to painful and frightening experiences (Chu et al., 2017; Joiner, 2005; Van Orden et al., 2010). The ITS has been tested in a range of populations (Anestis, J. C. et al., 2018; Bryan, Hernandez, Allison, & Clemans, 2013; Cole et al., 2013; Czyz, Berona, & King, 2015; Heelis, Graham, & Jackson, 2016; Miller, Esposito-Smythers, & Leichtweis, 2016; Wilson, Kowal, Henderson, McWilliams, & Péloquin, 2013; Wolford-Clevenger et al., 2017) with broad support for the theory reported in a meta-analysis of 122 studies (Chu et al., 2017), and its associations have under-pinned evidence-based efforts to increase identification of suicide risk (Ribeiro, Bodell, Hames, Hagan, & Joiner, 2013) and treatments (Joiner Jr, Van Orden, Witte, & Rudd, 2009a). Our earlier study reported that, in a non-clinical sample, thwarted belonging and perceived burden were associated with suicidality and that this association was not attenuated by high levels of autistic traits (Pelton & Cassidy, 2017). Further, an online survey of 98 autistic adults, reported that thwarted belongingness and perceived burdensomeness were associated with social dissatisfaction and current suicidal ideation (Dow et al., 2019). These studies were small in scale, and concluded with the recommendation that future research should assess the hypotheses of the ITS in a sample of autistic adults with a matched comparison group of non-autistic people. This is the aim of the current study.

The ITS may be of particular relevance to autistic people: its emphasis on the fundamental human needs of social self-worth and inclusion are conducive with views in the autistic community that the social marginalisation of autistic people should be central to understanding high rates of suicidality (Milton & Moon, 2012). The clinical diagnosis of an ASC comprises social, relationship and sensory differences, narrow interests and repetitive behaviours (APA 2013). Participatory research has reported that poor understanding and acceptance of such differences is associated with reduced social belonging, independence and quality of life and increased mental health difficulties for autistic people (Cage, Di Monaco, & Newell, 2018; Crane, Laura, Adams, Harper, Welch, & Pellicano, 2019; Mason et al., 2018). Autistic people are more likely to report behaviours indicative of thwarted belonging, such as loneliness (Haertl, Callahan, Markovics, & Sheppard, 2013; Hickey, Crabtree, & Stott, 2018; Müller, Schuler, & Yates, 2008), family stress, childhood maltreatment and intimate partner violence (Griffiths et al., 2019) than people who are non-autistic. ‘Social camouflaging’ (masking autistic mannerisms to ‘fit in’) (Hull et al., 2017), and the ‘double empathy problem’ (expectation that autistic people communicate social preferences and emotional states according to non-autistic norms) (Milton, 2012) reduce reciprocity in social interactions and could confer additional risk for thwarted belonging that feels hopeless and permanent (Joiner, 2005). Autistic adults frequently report experiences indicative of perceived burdensomeness, such as higher levels of unemployment (National Autistic Society 2016), incarceration (Fazio, Pietz, & Denney, 2012), homelessness (Stone, 2019), physical illness (Cashin, Buckley, Trollor, & Lennox, 2016; Hirvikoski et al., 2016) and lower self-esteem (Williamson, Craig, & Slinger, 2008) than non-autistic people. Research reports associations between unmet support needs, burdensomeness, poor mental health and suicidality (Camm-Crosbie, Bradley, Shaw, Baron-Cohen, & Cassidy, 2018; Cassidy et al.,

2018). Overall, this could suggest that autistic people experience stronger feelings of thwarted belonging and perceived burden than people who are not autistic.

The ITS proposes that suicidal capability develops in a dose-response relationship with lifetime experience of painful and frightening experiences (Joiner, 2005; Van Orden et al., 2010). Research reports shockingly high rates of trauma amongst autistic people (Griffiths et al., 2019): autistic children report higher rates of maltreatment (McDonnell et al., 2019), removal from their biological birth family (Green, Leadbitter, Kay, & Sharma, 2016), bullying (Mañano, Normand, Salvas, Moullec, & Aimé, 2016) school discipline (including exclusion), police contact and psychiatric hospitalisation (Humphrey, 2008; Turcotte, Shea, & Mandell, 2018). Autistic adults are more likely to be victims of hate crime (Beadle-Brown et al., 2014; Chaplin & M., 2018), sexual victimization (Brown-Lavoie, Vecili, & Weiss, 2014; Weiss & Fardella, 2018), incarceration (Fazio et al., 2012) and engage in non-suicidal self-injury (Cassidy et al., 2018; Maddox, Trubanova, & White, 2017). Overall, this suggests that autistic people experience more painful and frightening traumatic life events, which the ITS hypothesises suggests higher rates of suicidal capability than non-autistic people.

The ITS also proposes that gender differences in suicidal behaviour results from gender differences in the prevalence of thwarted belonging, perceived burden and suicidal capability. Amongst non-autistic people, men are reported to more frequently die by suicide because they are more likely to develop suicidal capability through violent sports, fighting or aggression. Women are more likely to think about suicide as they attach greater importance to social connections making them more vulnerable to thwarted belonging (Joiner, 2005). However, in contrast to the general population, autistic women have been reported more likely to die by suicide than autistic men (Hirvikoski et al., 2016). Autistic women are reported to be more socially motivated than autistic men (Lai, Lombardo, Auyeung,

Chakrabarti, & Baron-Cohen, 2015; Sedgewick, Crane, Hill, & Pellicano, 2019) but struggle to find genuine social reciprocity which could make them more vulnerable to thwarted belonging (Hull et al., 2017; Tint et al., 2018). Autistic women present distinct autistic characteristics which reduce likelihood of diagnosis (Duvekot et al., 2017; Dworzynski, Ronald, Bolton, & Happé, 2012; Evans, Boan, Bradley, & Carpenter, 2018; Ratto et al., 2018) typically associated with poor access to services (Cassidy et al., 2014), employment problems (Cassidy et al., 2014), and poor mental health (Hull et al., 2017; Trubanova, Donlon, Kreiser, Ollendick, & White, 2014), which could contribute to feelings of burdensomeness. Combined unmet support and social needs could explain higher incidence of mistreatment, such as abusive or coercive sexual relationships (Ohlsson Gotby, Lichtenstein, Långström, & Pettersson, 2018), maladaptive coping strategies such as controlled eating (Bargiela, Steward, & Mandy, 2016; Lai et al., 2015) or non-suicidal self-injury (Cassidy et al., 2018; Maddox et al., 2017) than autistic men. Overall, this could suggest that autistic women are more likely to experience thwarted belonging, perceived burden, lifetime trauma and suicidal capability than autistic men.

However, the Interpersonal Theory of Suicide argues that, in addition to being present, it is the *interaction* of theory constructs that provides the unique conjunction consistent with the rarity of suicide (Joiner, 2005; Van Orden et al., 2010). Thus, the theory proposes that the interaction of perceived burden and thwarted belonging are significantly associated with the presence of suicidal desire. Empirically, this interaction has been observed in a range of non-autistic groups, such as American (Van Orden, Witte, Gordon, Bender, & Joiner, 2008) and Chinese undergraduates (Zhang, Lester, Zhao, & Zhou, 2013), community samples (Campos & Holden, 2016), military personnel (Shelef, Fruchter, Mann, & Yacobi, 2014) and American Indians (O'Keefe et al., 2014) with a meta-analysis of 58 studies finding that the interaction of perceived burden and thwarted belonging added unique

variance in suicidal ideation beyond the main effects of each construct (Chu et al., 2017). However, our earlier study suggested that high levels of autistic traits could lead to under-reporting feelings of thwarted belonging, in line with well-documented reports of alexithymia (difficulty in expressing internal emotional states) in autistic people (Bird & Cook, 2013; Pelton & Cassidy, 2017). Furthermore, research has suggested that alternative risk factors such as social camouflaging (Cassidy et al., 2018), social support (Hedley, Uljarević, Wilmot, Richdale, & Dissanayake, 2017) or unmet support needs (Cassidy et al., 2018) may play a more significant role in the development of suicidal thoughts and behaviours in autistic people than non-autistic people. Overall, this could suggest that the model operates differently in autistic people. Thus, this study will explore for the first time whether the hypothesised interaction of perceived burden and thwarted belonging is associated with suicidal ideation in autistic adults and whether this is similar in non-autistic adults.

The ITS represents a novel innovation in suicide theory as it argues that risk factors for suicide ideation are distinct from those for suicide attempt. The construct of suicidal capability is proposed to uniquely enable a suicide attempt when present alongside the temporary cognitive states of thwarted belonging and perceived burden. Thus, suicidal capability theoretically doesn't exert a main effect on suicidal behaviour but, the three-way interaction of thwarted belonging, perceived burden and suicidal capability will transform suicidal ideation into a lethal or near lethal suicide attempt (Joiner, 2005; Van Orden et al., 2010). This three-way interaction has been upheld in samples of firefighters (Chu, Buchman-Schmitt, Hom, Stanley, & Joiner Jr, 2016) and military personnel (Anestis, M. D., Khazem, Mohn, & Green, 2015), but it has received less empirical attention than the two-way interaction described above: the same meta-analysis (Chu et al., 2017) included only 13 studies of the three-way interaction and reported that it was only significantly associated with suicide attempt when suicide attempt history was measured continuously (Chu et al., 2017).

Factors that trigger transition from suicidal thoughts to behaviours are of great concern in autistic people given reports that autistic people are more likely to attempt suicide (Chen, Pan, Lan, Hsu, Huang, Su, Li, Lin, Wei, Chen, & Bai, 2017), select lethal methods for a suicide attempt yet be unknown to clinical services (Kato et al., 2013) and die by suicide (Hirvikoski et al., 2016) than non-autistic people. Commentators have speculated on the reasons for this suggesting, for example, that autistic people may relate differently to death than non-autistic people or may be more likely to persevere on death (Gillberg, 2002; Lai, J., Rhee, & Nicholas, 2017). However, empirical research to date has not yet explored how distinct risk factors may lead to suicide attempt versus ideation in autistic people. Thus, this study will explore, for the first time, whether the theoretical three-way interaction of thwarted belonging, perceived burden and suicidal capability is significantly associated with suicide attempt in autistic and non-autistic people.

Furthermore, the ITS argues that suicidal capability is developed through opponent process theory: repeated painful and frightening experiences ultimately render future painful and frightening experiences as bringing emotional and/ or physical pain relief (Joiner, 2005; Solomon & Corbit, 1974). As outlined above, autistic people are more likely to experience lifetime trauma compared to non-autistic people but, in addition, autistic people have been reported to experience a more profound effect of trauma due to absent social support, differences in pain and emotional communication and cognitive rigidity (Kerns, Newschaffer, & Berkowitz, 2015; Rumball, 2018). The functional model of suicidal capability argues that the development of suicidal capability depends on innate vulnerabilities in interaction with the environment (Smith & Cukrowicz, 2010). Thus, differences in pain (Rattaz, Dubois, & Baghdadli, 2016), emotional processing and expression, high trait anxiety and sensory sensitivities (Mazefsky et al., 2013) could suggest that suicidal capability is more quickly developed in autistic people. Thus, this study will explore whether the pathway from

traumatic life events to suicidal thoughts and behaviours is through suicidal capability and compare whether this is similar to non-autistic people.

Finally, the ITS proposes that distal factors, including oft-cited suicide risk factors - such as mental health difficulties - lead to suicidal behaviour because they increase the likelihood that an individual will experience thwarted belonging, perceived burden (Davidson, Wingate, Grant, Judah, & Mills, 2011; Silva, Ribeiro, & Joiner, 2015; Van Orden et al., 2010). In clinical and non-clinical samples autistic characteristics are independently associated with suicidality beyond other factors, such as psychiatric disorder (Pelton & Cassidy, 2017; Upthegrove et al., 2018), previous suicide attempts (Chen et al., 2017), depression, anxiety, unemployment and satisfaction with living arrangements (Cassidy et al., 2018). Understanding *how* autistic traits associate with lifetime suicidality is vital to inform suicide prevention interventions: autistic traits are not modifiable but support can be provided to reduce the negative social impacts (Joiner Jr, Van Orden, Witte, & Rudd, 2009b; Milton & Moon, 2012). Our earlier study reported that in a non-clinical young adult sample the association between autistic traits and lifetime suicidality was mediated by perceived burden and thwarted belonging suggesting (Pelton & Cassidy, 2017). This study will seek to replicate this finding and compare whether a similar pathway exists for autistic people.

The current study

In summary, the current study aimed to fill a gap in previous research by examining how the ITS explains suicide in autistic people and comparing this to non-autistic people. This study will explore (i) prevalence rates of ITS constructs in autistic and non-autistic people, (ii) whether hypothesised interactions between ITS variables are present in autistic and non-autistic groups (iii) putative pathways from distal factors to suicidal thoughts and

behaviours through theory constructs are similar in autistic and non-autistic people.

Specifically, this study hypothesises that,

- (i) Given more frequent reports of loneliness, unmet support needs and trauma, autistic people will report stronger feelings of thwarted belonging and perceived burdensomeness, higher suicidal capability and more frequent lifetime trauma than non-autistic people.
- (ii) Given gender differences in the autistic female phenotype, autistic women will report stronger feelings of thwarted belonging and perceived burden, higher suicidal capability and more frequent lifetime trauma than autistic men.
- (iii) Given broad published support, the respective interactions in ITS variables in association with suicidal ideation and suicide attempt will be observed in the non-autistic group but - given suggested differences in suicidality in autistic people - these may not be observed in the autistic group.
- (iv) In both groups, given the proposed development of suicidal capability in response to lifetime trauma there will be a significant pathway from lifetime trauma through suicidal capability to suicidality but – given reported more profound effect of trauma – the pathway from lifetime trauma to suicidal capability will be stronger in autistic people.
- (v) In both groups, the previously reported pathways from autistic traits to suicidality (Pelton & Cassidy, 2017) through perceived burden and thwarted belonging will be observed.

Methods

Participants

Participants were 695 autistic (64.6% female, mean age= 41.9, 18-90 years) and non-autistic people (58.7% female, mean age = 41.3, 18-73 years) described in Table 1. Autistic participants self-reported a diagnosis of ASC from a trained clinician. Mean AQ-S scores in the autistic group were consistent with published clinical cut off score of >65 indicative of ASC (Hoekstra et al., 2011a), with AQ-S scores significantly lower in the non-autistic compared to the autistic group ($t(636.98)=-31, p<.001$).

There was no significant difference in age ($t(672.7)=-.55, p=.59$) or proportion of female participants ($X^2(1)=2.53, p=.11$) between the autistic and non-autistic group. Significantly more non-autistic people reported being in full time employment ($X^2(1)=14.47, p<.001$) and holding a post-graduate degree ($X^2(1)=7.30, p<.01$) than autistic people. Autistic people were more likely to report at least one additional neurodevelopmental condition ($X^2(1)=55.45, p<.001$) and at least one mental health condition ($X^2(1)=106.32, p<.001$) than non-autistic people.

Non-autistic people reported significantly lower lifetime suicidality ($t(656.98)=-14.52, p<.001$) than autistic people. Reported rates of past suicide attempt were higher in the autistic (38.3%) than the non-autistic group (10.5%), our earlier study of 8.6% (Pelton & Cassidy, 2017) and the UK Adult Psychiatric Morbidity study (6.7%) (McManus, Bebbington, Jenkins, & Brugha, 2016).

The autistic group was recruited through the Cambridge Autism Research Database, the Autistica Discover network, local and national autism organisations and social media. The

non-autistic group was recruited through the Cambridge Psychology Database with opportunity sampling, Coventry University psychology research participation scheme, social media channels and suicide-focussed research websites to balance group size, mean age and gender frequency with the autistic group. Adverts clearly stated that the study would ask about suicidal thoughts and behaviours but did not specify inclusion criteria based on these.

Materials

Demographics: participants indicated age, gender, living status, employment status, mental health, autism diagnoses and the presence of any other neurodevelopmental disorders.

Thwarted belonging and **perceived burden** were measured using *The Interpersonal Needs Questionnaire 10 (INQ-10)*. The INQ 10 is a 10 item validated scale containing two subscales for distinct but related interpersonal constructs that represent the desire to die: ‘thwarted belonging’ and ‘perceived burdensomeness’ (Van Orden, Cukrowicz, Witte, & Joiner, 2012). It contains statements such as ‘These days the people in my life would be better off if I were gone’ and ‘these days I think the people in my life wish they could be rid of me’ which are responded to on a 7-point scale from ‘strongly agree’ to ‘strongly disagree’. Our steering group of autistic adults advised choosing the INQ-10, with comparable validity (Hill et al., 2015) over the INQ-15 to avoid frustration from questions that could be perceived as similar by autistic people. They also advised changing the instructions to clearly communicate the intended meaning to autistic people without disadvantaging non-autistic people: *‘Please read the items below. Click on the option that best describes how you have been feeling. Where the questionnaire refers to ‘these days’ please consider how you have been feeling in general over the past two weeks’* (original wording in Appendix). The scale author confirmed that change was acceptable prior to administration. (Burdensomeness subscale Cronbach’s alpha = .93, Thwarted belonging Cronbach’s alpha=.92)

Capability for Suicide was measured using *Acquired Capability for Suicide Scale – Fearlessness of Death (ACSS-FAD)* (Ribeiro, Witte, Van Orden, Selby, Gordon, Bender, & Joiner, 2014a). The ACSS-FAD is a validated 7-item scale measuring a sense of fearlessness around the concept of death. Scale items include ‘the prospect of my own death arouses anxiety in me’ and ‘I am not at all afraid to die’. Responses are given on a five point Likert scale with scores from 0 to 4 with higher scores indicating a higher capability for suicide (Ribeiro, Witte, Van Orden, Selby, Gordon, Bender, & Joiner Jr, 2014). Cronbach’s alpha =.85.

Traumatic life events were measured using *Vulnerability Experience Quotient (VEQ)* (Griffiths et al., 2019). The VEQ is a 60-item scale which has been developed through participatory methods with autistic adults to reflect adverse life experiences across 10 themes, such as childhood maltreatment, non-suicidal self-injury, bullying and victimisation as a child or adult and discrimination. This scale reflects many of the themes of Painful and Provocative Events scale designed for use in the ITS but has been developed and validated to reflect the experiences of autistic people (Griffiths et al., 2019). The response scale has been amended to give an indication of frequency as this is hypothesised to enable transition from suicide ideation to attempt. A simplified scale of ‘not applicable’, ‘never’, ‘once’ or ‘more than once’ assessed frequency without repeated need for counting instances of traumatic life events. This response scale has been recommended in a recent psychometric evaluation of the Painful and Provocative Events Scale (Brown, Roush, Marshall, Mitchell, & Cukrowicz, 2018) and was confirmed with the scale author prior to administration. Cronbach’s alpha=.93

Lifetime suicidal thoughts and behaviours were measured by *Suicide Behaviours*

Questionnaire – Revised (SBQ-R), item 1: The first item of the SBQ-R measures lifetime suicidal ideation and/ or attempt with the question ‘Have you ever thought about or attempted to kill yourself?’. There are six possible responses from ‘never’ to ‘I have attempted to kill myself and really hoped to die’ (Osman et al., 2001). Participant responses are categorised in four subgroups from non-suicidal to suicide attempt. Item 1 was employed in our previous study (Pelton & Cassidy, 2017) and has been reported to demonstrate comparable measurement properties amongst autistic and non-autistic adults (Cassidy et al., 2018)

Autistic characteristics were measured using *Autism Quotient Short Form (AQ-S)*: The AQ-S is a 28-item subset of the full 50 item Autism Quotient based upon DSM-IV criteria for autism (APA 2000). The scale includes items such as ‘it does not upset me if my daily routine is disturbed’ and ‘I find it easy to work out what someone is thinking or feeling’ with a four item response scale from 1 “definitely agree” to 4 “definitely disagree (Hoekstra et al., 2011b). It is scored using the full four-point Likert scale giving a total range from 28-112 and a cut off of 65 for potential consideration of a clinical diagnosis of autism. Scores are highly correlated with the full AQ-50 and the AQ-S is reported to demonstrate the same latent traits in autistic and non-autistic people (Murray, Booth, McKenzie, Kuenssberg, & O’Donnell, 2014). Cronbach’s alpha = .95.

Procedure

Participants were invited to complete a survey of online self-report measure of self-report questionnaires using Qualtrics. The dataset from which participants were drawn also includes possibly autistic people and four-week repeated measures of anxiety and depression. Analyses planned with these data are described in the discussion. Research reports that people feel more able to disclose potentially sensitive information about stigmatised

behaviours such as suicide and self-harm online than in situations where they cannot remain anonymous (Michaels, Chu, Silva, Schulman, & Joiner, 2015; Nock et al., 2008).

Participants indicated informed consent to participate via an online form. They were warned of the content of questions in each section, prompted to take breaks and given information about support services throughout the survey. The study materials and scales were designed with the assistance of autistic adults (one male, one female) who suggested modifications to instructions to clarify meaning, suggested substitutions of scales to maximise clarity for autistic people, suggested amendments to online instructions and guidance to reduce risk to ensure that the study was equally accessible for autistic and non-autistic people. The study received ethical approval from Coventry University Psychology Ethics Committee and was approved by the scientific advisory group at the Autism Research Centre, University of Cambridge.

(TABLE 1 ABOUT HERE)

Results

Analytic Approach

Data were analysed in SPSS version 25. Boxplots were examined for univariate outliers and multivariate outliers were identified using Mahalanobis distance. Non-normal distribution of burdensomeness in the non-autistic group was addressed with square root transformation: kurtosis reduced from 5.22 to 2.14 and extreme outliers came within normal distribution. Independent samples t-tests and three-way ANOVA were used to explore differences in group means (thwarted belonging, perceived burden, suicidal capability, lifetime trauma). Multinomial logistic regression explored whether the ITS hypothesised interactions were associated with past suicide ideation and suicide attempt. Simple linear regressions explored the association between ITS constructs and suicidal thoughts and behaviours. Mediation analysis explored the pathways from distal factors to suicidality through ITS constructs using ordinary least squares path analysis (PROCESS version 3.3 model 4) and employing bootstrapping for non-normal distribution. PROCESS model 59 explored whether mediation models were moderated by autism diagnosis.

Hypothesis (i) autistic people report stronger feelings of thwarted belonging, perceived burden, higher suicidal capability and more prevalent lifetime trauma than non-autistic people

As shown in Table 1, autistic people reported significantly higher burdensomeness ($t(635.09)=-11.33, p<.001$), thwarted belonging ($t(652.28)=-16.43, p<.001$) and traumatic life events ($t(648.83)=-17.46, p<.001$) than non-autistic people, but there was no significant difference in the mean score for suicidal capability between groups.

Hypothesis (ii) autistic women report stronger feelings of thwarted belonging, perceived burden, higher suicidal capability and more frequent lifetime trauma than autistic men

Three-way ANOVA reported there was no significant difference in mean scores for thwarted belonging ($F(2,337)=.55$, $p=.575$), perceived burdensomeness ($F(2,337)=.27$, $p=.762$), suicidal capability ($F(2,337)=2.87$, $p=.058$) and traumatic life events ($F(2,331)=1.21$, $p=.332$) between autistic men and autistic women and those who identify as other gender. As this finding was against the direction of our hypothesis, moderation analysis explored whether the association between any predictor variables (burden, capability, thwarted belonging and traumatic life events) and lifetime suicidality was moderated by gender. We found no significant moderation. Furthermore, in this sample, there was no significant difference in reported lifetime suicidality between autistic men and autistic women ($F(2,337)=2.08$, $p=.126$). Thus, data from autistic men and women were analysed together in subsequent analyses.

In the non-autistic group⁶, independent t-tests showed that non-autistic men reported significantly higher suicidal capability ($t(325)=2.02$, $p=.044$) and significantly lower perceived burdensomeness ($t(296.74)=-2.24$, $p=.026$) than non-autistic women. There was no significant difference in thwarted belonging ($t(328)=1.02$, $p=.27$) between non-autistic men and non-autistic women.

Hypothesis (iii)(a) The interaction of thwarted belonging and perceived burden is significantly associated with suicidal thoughts.

⁶ The 'other' gender group were not included as $n = 2$.

A multinomial logistic regression was undertaken with the categorical outcome variable SBQ-R item 1 (frequencies shown in Table 1) and the predictors thwarted belonging, perceived burden and their interaction term.

As shown in Table 2, in the non-autistic group, participants who reported significantly lower scores of thwarted belonging (Wald $X^2(1)=18.16$, $p<.001$), and perceived burden (Wald $X^2=10.06$, $p=.002$) were more likely to endorse the ‘no past suicidality’ response option versus ‘past suicidal thoughts’ and their interaction was significant within the regression (Wald $X^2=10.67$, $p=.001$).

(TABLE 2 ABOUT HERE)

In the autistic group, participants who reported higher perceived burden (Wald $X^2(1)=4.13$, $p=.04$) and thwarted belonging (Wald $X^2(1)=6.25$, $p=.01$) were more likely to endorse ‘past suicide attempt’ than ‘past suicidal thoughts’ and the interaction between thwarted belonging and perceived burden was not significant within the model. The model explained only 10% of the variance in the autistic group versus 31% in the non-autistic group.

Hypothesis (iii)(b): the three-way interaction of thwarted belonging, perceived burden and suicidal capability will be significantly associated with past suicide attempt

A further multinomial logistic regression was undertaken with the categorical outcome variable SBQ-R item 1 (frequency responses shown in Table 1) and the predictors were thwarted belonging, perceived burden and suicidal capability, the two-way interaction (belong*burden) and their three-way interaction (belong*burden*capability).

As shown in Table 3, in the non-autistic group, participants who reported significantly lower levels of suicidal capability (Wald $X(1)^2=5.98$, $p=.014$) were more likely to endorse past

suicidal thoughts versus past suicide attempt. The three-way interaction of perceived burden, thwarted belonging and suicidal capability was not significant within the model.

In the autistic group, as shown in Table 3, participants who reported significantly lower levels of suicidal capability (Wald $X^2=18.89$, $p<.001$) were more likely to endorse ‘past suicidal thoughts’ versus ‘past suicide attempt’ and the three-way interaction of thwarted belonging, perceived burden and suicidal capability was not significant within the model. In the autistic group, the model explained only 15% of the variance versus 34% in the non-autistic group.

(TABLE 3 ABOUT HERE)

Hypothesis (iv): the association between lifetime trauma and suicidality will be significantly mediated by suicidal capability in both groups. In the autistic group the association between trauma and suicidal capability will be significantly strengthened.

Simple linear regressions, shown in Table 4, reported that autistic traits, perceived burden, thwarted belonging, suicidal capability and traumatic life events were significantly associated with lifetime suicidality.

(TABLE 4 ABOUT HERE)

Simple mediation analysis was undertaken with the predictor, lifetime trauma, the mediator, suicidal capability and the outcome variable, suicidality. There was a direct effect of trauma on lifetime suicidality independent of suicidal capability in autistic ($c'=.02$, $p<.001$) and non-autistic ($c'=.037$, $p<.001$) groups and a weak but significant indirect effect of trauma on lifetime suicidality through suicidal capability in the autistic group ($ab=.0001$, 95% CI $[-.0001, .002]$). As shown in Figure 2, moderation analyses reported an attenuated association between lifetime trauma and lifetime suicidality in the autistic group ($VEQ*diagnosis=-.016$,

SE=.004, $p < .001$) and no significant moderation of other mediation pathway by autism diagnosis.

(FIGURE 2 ABOUT HERE)

Hypothesis (v): the association between autistic traits and suicidality will be significantly mediated by perceived burden and thwarted belonging in autistic and non-autistic groups.

Simple mediation analysis was undertaken with the predictor autistic traits, the mediator thwarted belonging and the outcome variable suicidality. As shown in Figures 3 and 4, results indicated a significant indirect effect of autistic traits on lifetime suicidality through thwarted belonging in both autistic ($ab = .008$, 95% CI [.004, .012]) and non-autistic groups ($ab = .019$, 95% CI [.014, .025]). Moderation analysis revealed that the pathway from thwarted belonging and lifetime suicidality was significantly attenuated in the autistic group (belonging*autism diagnosis = $-.027$, SE=.010, $p = .008$) as shown in Figure 5 but no other mediation pathway was significantly moderated by autism diagnosis.

(FIGURE 3 ABOUT HERE)

(FIGURE 4 ABOUT HERE)

(FIGURE 5 ABOUT HERE)

A further simple mediation analysis was undertaken with the predictor autistic traits, the mediator perceived burden and the outcome variable suicidality. As shown in Figures 6 and 7, there was a significant indirect effect of autistic traits on lifetime suicidality through perceived burden in both autistic ($ab = .004$, 95% CI [.002, .007]) and non-autistic ($ab = .011$, 95% CI [.008, .015]) groups. Moderation analyses reported that the pathway from perceived burden to lifetime suicidality was significantly attenuated in the autistic group

(burdensomeness*autism_diagnosis=-.048, SE=.099, $p<.001$) as shown in Figure 8, but no other pathway was significantly moderated by autism diagnosis.

(FIGURE 6 ABOUT HERE)

(FIGURE 7 ABOUT HERE)

(FIGURE 8 ABOUT HERE)

Discussion

This study aimed, for the first time, to explore whether the associations of the Interpersonal Theory of Suicide are informative for understanding and addressing high rates of suicidality in autistic adults. Autistic adults reported stronger feelings of thwarted belonging, perceived burdensomeness and traumatic life events than non-autistic adults. Autistic men and women reported similar levels of perceived burden, thwarted belonging, traumatic life events and suicidal capability. By contrast, non-autistic men reported higher suicidal capability and weaker feelings of perceived burden than non-autistic women. The proposed interaction between thwarted belonging and perceived burden was present in the non-autistic group but not the autistic group. In both groups, participants endorsing lower suicidal capability were more likely to report suicide ideation versus attempt. In both groups, there was a direct effect of trauma on lifetime suicidality and autistic traits led to feelings of thwarted belonging and perceived burden, which led to lifetime suicidality. Finally, the pathway from each of thwarted belonging and perceived burden and lifetime trauma to lifetime suicidality was significantly attenuated in the autistic group. Overall, these results add to the limited body of knowledge describing the development of suicidal thoughts and behaviours in autistic people (Cassidy et al., 2018; Hedley, Uljarević, Foley, Richdale, & Trollor, 2018a) as well as extending previous explorations of the influence of autistic traits in

the ITS (Pelton & Cassidy, 2017) and how the ITS works in autistic people (Dow et al., 2019).

Our findings echo a well-established body of research reporting higher rates of lifetime suicidality in autistic than non-autistic adults (Chen et al., 2017; Hirvikoski et al., 2016; Kirby et al., 2019). In line with the ITS hypotheses and the hypotheses of this study, this was accompanied by higher levels of thwarted belonging and perceived burden in the autistic group than in the non-autistic group (Joiner, 2005; Van Orden et al., 2010). This finding is consistent with research suggesting that social isolation and burdensomeness may contribute to poor mental health, reduced quality of life and suicidality in autistic adults (Camm-Crosbie et al., 2018; Cassidy et al., 2018; Hedley et al., 2017; McConachie et al., 2018). Autistic people also reported significantly higher rates of traumatic life events than people who were non-autistic, consistent with other recent research (Fuld, 2018; Rumball, 2018; Taylor & Gotham, 2016) and with research suggesting that trauma contributes to suicidality (Storch et al., 2013). Against our expectations there was no significant difference in suicidal capability between the autistic and non-autistic groups.

Against recent research findings, this study reported no significant difference in reported lifetime suicidality between autistic women and men. Recent population studies have reported significantly higher rates of suicidality amongst autistic women than men (Hirvikoski et al., 2016; Kirby et al., 2019), a trend noticeable for its opposite pattern to the non-autistic population. However, this study echoes the findings of another study in our group, which also found no significant difference in suicidality between autistic women and men (Cassidy et al., 2018). Against our hypotheses, there was no significant difference in mean scores on any other study variable between autistic women, men and other gender.

This is in contrast to the non-autistic group where the hypotheses of the ITS (Joiner, 2005) were largely upheld with women reporting higher burdensomeness and men reporting higher suicidal capability. This suggests that suicidal behaviour in autistic people may not reflect expected gender-based patterns and processes observed in the non-autistic population. Clinicians should be aware that, in particular, autistic women may be at increased risk if they are assumed to be at lower risk due to female gender. However, these findings are preliminary and future research should explore whether, and how, gender may influence suicidality in autistic adults.

We examined, for the first time, the hypothesised interactions of the ITS in autistic and non-autistic adults. In the non-autistic group, the hypothesis of the ITS regarding suicide ideation was largely upheld: participants reporting lower perceived burden and thwarted belonging were more likely to report no past suicidal behaviour versus suicide ideation and the interaction between the variables was significant. In the autistic group, by contrast, the ITS was not supported: participants reporting stronger feelings of thwarted belonging and perceived burden were more likely to report suicide attempt than suicide ideation or no past suicidal behaviour. This suggests that there may be differences in how suicidal thoughts and behaviours develop in autistic people and, worryingly, that increases in feelings of thwarted belonging and burdensomeness may lead to suicide attempt rather than ideation. This is in line with commentary and anecdotal report that autistic people may transition to suicide attempt more quickly than people who are not autistic (Kato et al., 2013). Clinicians should be aware that suicidal thoughts and behaviours may develop differently in autistic people and, in the absence of validated care pathways and measures, undertake individualised, detailed risk assessments. Furthermore, there was no hypothesised interaction between thwarted belonging and perceived burden. The ITS proposes that perceived burden and thwarted belonging are related but distinct constructs but our results could suggest that autistic

differences – possibly theory of mind (Baron-Cohen, Leslie, & Frith, 1985) or cognitive rigidity - could render them more separate in autistic than non-autistic people. This is in line with our earlier study, which suggested that differences in theory of mind could reduce the expression of these constructs (Pelton & Cassidy, 2017). Overall, this suggests that future research should continue to explore how risk factors for suicide may be different in autistic people as well as considering whether the expression of such states may present differently.

We found only partial support for the suicidal capability construct in both groups: participants reporting significantly lower suicidal capability were more likely to report suicide ideation rather than suicide attempt suggesting that suicidal capability is uniquely associated with suicide attempt. However, the three-way interaction of thwarted belonging, perceived burden and suicidal capability was not significant in either group. This is in line with recent meta-analysis which reported similar findings when suicide attempt was measured dichotomously as in this study (Chu et al., 2017). This is also in line with suicide theorists who agree with Joiner's assertion that a change in the relationship with fear of death and with pain is necessary to transition from suicide ideation to attempt but have argued that other factors are also significant. For example, the Integrated Motivational-Volitional model describes suicidal capability as only one of many possible volitional moderators that may provide the bridge from suicidal intention to attempt (O'Connor, 2011; O'Connor, Cleare, Eschle, Wetherall, & Kirtley, 2016). This suggests an urgent need for research to explore distinct risk factors for suicide attempt in autistic and non-autistic people. Future research should be theoretically rigorous, explore the applicability of other suicide models and explore alternative pathways to confirm direction of causality. This could also include inductive theoretical research taking as its starting point individual accounts of autistic people, and comparing those against current theoretical accounts to build a valid theory. However, all interpretations of these findings regarding the hypothesised interactions should be considered

in the context that, in the autistic group, the variables together accounted for around half the variance compared to the non-autistic group. This is discussed below.

In both groups, trauma was significantly directly associated with lifetime suicidality. This finding is in line with research in non-autistic people reporting significant negative life outcomes, including mental health difficulties and suicidality resulting from trauma (Luukkonen, Räsänen, Hakko, & Riala, 2009). However, this does not fully explain *how* trauma is associated with lifetime suicidality as the direct path does not support the ITS hypothesis that painful and provocative events lead to a change in the body's fear and pain system (suicidal capability) that enables suicidal behaviour. This could suggest that the measure of suicidal capability employed in this study does not truly represent the changes hypothesised to result from trauma (Joiner, 2005). Within this study, we used the most widely validated measure of suicidal capability – the ACSS-FAD - however, this represents a single construct – a reduced fear of death – and the scale author has already concluded that this may be too narrow to measure the changes that lead to suicidality (Ribeiro, Witte, Van Orden, Selby, Gordon, Bender, & Joiner, 2014b). Clinicians should thus be aware that those with traumatic backgrounds are at increased risk but we don't yet have measures to clearly detail why. Future research should explore whether alternative suicide theories are able to provide detailed empirical evidence regarding the proposed faster transition to suicide attempt amongst autistic people and associated higher rates of death by suicide. An alternative approach would be to take as a starting point the lived experience of those who experience these difficulties and use these to build an inductive theory.

In the autistic group, there was also an indirect effect of trauma on suicidality through suicidal capability but detailed analysis of this finding found this did not support our proposal of a strengthened pathway from trauma to suicidal capability in autistic people. By contrast, we found a significant attenuation of the association between traumatic life events and

lifetime suicidality which suggests that trauma (at least sometimes) occurs in the absence of suicidal behaviour for autistic people. Given such high rates of trauma in autistic people, this could suggest that these are everyday experiences for autistic people, against which they become resilient, rather than rare experiences associated with suicidality. This could, however, also reflect the use of our ‘once’ or ‘more than once’ rating scale that could under-report trauma for autistic people: the original Painful and Provocative Events Scale designed for non-autistic people includes a range of categorical up to 20 incidents of each painful event (Brown, Roush, Marshall, Mitchell, & Cukrowicz, 2018). It is vital that future research continues to explore how trauma contributes to suicidality alongside continuing research to understand of how trauma impacts autistic people. Suicide prevention efforts should continue to address the enforcement of statutory protection for autistic people with a view to reducing trauma.

The findings of our earlier study (Pelton & Cassidy, 2017), and our hypothesised pathways from autistic traits to suicidality through both perceived burden and thwarted belonging, were upheld. This suggests that feelings of social disconnection and reduced self-worth associated with autistic traits provide the bridge to suicidal behaviour. This is in line with research linking autistic traits to increased loneliness and social disconnection in autistic and non-autistic populations (Hedley, Uljarević, Wilmot, Richdale, & Dissanayake, 2018; White & Roberson-Nay, 2009), and in line with research suggesting these concepts may link to suicidality (Hedley, Uljarević, Foley, Richdale, & Trollor, 2018b). This supports the ITS model that, in any population group, distal risk factors contribute to suicidality via the two proximal risk factors thwarted belonging and perceived burden (Christensen, Batterham, Mackinnon, Donker, & Soubelet, 2014; Cole et al., 2013; Corbin, 2017; Horton et al., 2016; Miller et al., 2016; Pennings, Finn, Houtsma, Green, & Anestis, 2017; Van Orden et al., 2008). This also suggests that these two concepts may represent modifiable constructs that

can be targeted in suicide prevention programmes, thus suicide prevention programmes that promote social inclusion and feelings of self-worth are important in autistic and non-autistic people.

However, we also reported attenuated associations between each of perceived burden, thwarted belonging and lifetime suicidality in the autistic group compared to the non-autistic group. This could, similar to the case of trauma, suggest that these are everyday experiences for autistic people, rather than experiences that differentiate those experiencing suicidal thoughts and behaviours from those who are not. Similar findings have been reported in clinical groups: a study of individuals with a first episode psychosis reported that the concepts of the ITS resonated with the experience of psychosis regardless of suicidality (Heelis et al., 2016). An alternative interpretation, however, is that both thwarted belonging and burdensomeness could be proximal risk factors for suicide in autistic people yet may be experienced and expressed differently by autistic adults. This could suggest that the INQ measure, designed for use in the general population, doesn't capture the same concepts for autistic people. This is in line with a wide body of research reporting the need for measures, which accurately describe and capture emotional and psychological processes in autistic adults (Cassidy et al., 2018; Cassidy, Bradley, Bowen, Wigham, & Rodgers, 2018; Gotham, Unruh, & Lord, 2015). Indeed, our design group already identified problematic items: for example, 'These days, I feel like I belong' is confusing in its lack of specificity whereas 'These days I often feel like an outsider at social gatherings' could describe everyday autistic life rather than indicate elevated suicidal feelings. In the case of burdensomeness this attenuation of association could support our earlier assertion that the second latent construct of burdensomeness (Van Orden et al., 2010) described as self-hatred, poor self-esteem and agitation could present in autistic people even if differences in theory of mind reduce the ability to consider oneself a burden on others (Pelton & Cassidy, 2017). This is possibly a

more likely explanation, as recent qualitative research has identified burdensomeness as a significant theme in autistic quality of life and mental health difficulties (Camm-Crosbie et al., 2018; Crane, L., Adams, Harper, Welch, & Pellicano, 2017). Future research should seek to understand the experience of thwarted belonging and burdensomeness from the perspective of autistic people and identify the specific experiences, if any, which could indicate a desire to die. However, as a first step, future research should explore potential measurement differences in the INQ-10 and ACSS-FAD between autistic and non-autistic people.

This study has several strengths: it is the first large-scale study to compare suicidal behaviour in autistic and non-autistic samples within a well-validated theory of suicidal behaviour. This responds to repeated calls within the research literature (Segers & Rawana, 2014) and within the autistic community for theoretically based suicide research in autistic adults (Cassidy & Rodgers, 2017). Thus, it explores an under-researched area and provides a foundation for broader theoretical modelling work within the academic and practitioner communities. This foundation is vital to respond to calls from within the autistic community to explore other specified priorities, including, but not limited to identification of suicidal thoughts and behaviours, appropriate adaptation of interventions and designing and delivering crisis services that facilitate help-seeking (Cassidy et al 2019).

It is also important to acknowledge this study's limitations. This study included a single outcome variable, lifetime suicidality, whereas the ITS specifies current suicidal ideation, attempt and death by suicide as its outcomes. The key focus of this study was to examine differences between the autistic and non-autistic groups, thus, an outcome variable was selected with known measurement similarities across autistic and non-autistic people (Cassidy et al., 2018). This study has also not explored the role of anxiety and depression and complex mental health difficulties in the autistic group, and the ITS makes specific hypotheses regarding how mental health difficulties impact suicidal behaviour, which should

be urgently explored in future research. This study has relied on self-reported autism diagnosis due to sample size required but future research could employ a diagnostic test. Finally, mediation analyses are based upon cross-sectional data so limitations on directions of causality are acknowledged. Future analyses are planned with repeated measures data, which will also explore the role of depression and anxiety. Finally, the study has not explored the potential influence of demographic variables such as age, living or marital status. There is an urgent need to incorporate these into future research studies but these were beyond the scope of this paper.

In summary, this study represents the first large scale study to compare the associations of the ITS in autistic and non-autistic samples. This study provides evidence that perceptions of burdensomeness, reduced social belonging and exposure to traumatic life events are significantly associated with lifetime suicidality in autistic adults and addressing these is vital to reduce suicide rates. However, this study also highlights the importance of understanding how these feelings are experienced and communicated by autistic people and ensuring that our current measures and clinical practices capture these. This study also highlights the fact that a model of suicidal behaviour that works for autistic people may need to be tailored to reflect distinct experiences, communication and social preferences of autistic people. Public policy should urgently address rates of stigmatising and abusive traumatic experiences of autistic people. Overall, improving inclusion and self-worth and reducing trauma could reduce death by suicide in autistic and non-autistic people.

Appendix

Original wording instructions of the Interpersonal Needs Questionnaire:

“The following questions ask you to think about yourself and other people. Please respond to each question by using your own current beliefs and experiences, NOT what you think is true in general, or what might be true for other people. Please base your responses on how you’ve been feeling recently. Use the rating scale to find the number that best matches how you feel and circle that number. There are no right or wrong answers: we are interested in what you think and feel.”

Figure Captions

Figure 1. Pathways of the Interpersonal Theory of Suicide to be tested in this study

Figure 2. A visual representation of the conditional effect of traumatic life events on lifetime suicidality amongst autistic and non-autistic adults at low, moderate and high frequency of traumatic life events

Figure 3. Simple mediation model for the influence of autistic traits on suicidality through feelings of thwarted belonging in autistic adults

Figure 4. Simple mediation model for the influence of autistic traits on suicidality through feelings of thwarted belonging in non-autistic adults

Figure 5. A visual representation of the conditional effect of thwarted belonging (M) on lifetime suicidality (Y) in autistic ($W=0$) and non-autistic ($W=1$) at low, moderate and high levels thwarted belonging

Figure 6. Simple mediation model for the influence of autistic traits on suicidality through feelings of burdensomeness in autistic adults

Figure 7. Simple mediation model for the influence of autistic traits on suicidality through feelings of burdensomeness in non-autistic adults

Figure 8. A visual representation of the conditional effect of burdensomeness on lifetime suicidality in autistic and non-autistic adults amongst those experiencing low, moderate and high feelings of burdensomeness

Figure 1 top

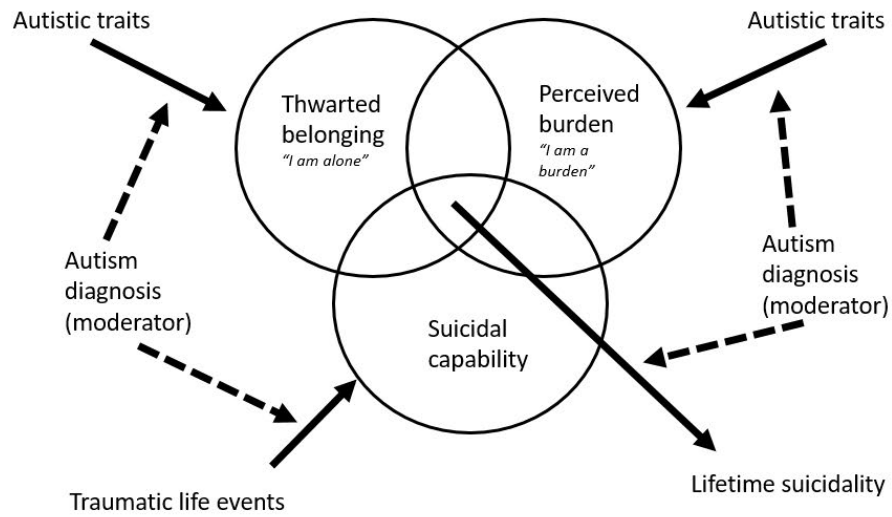


Figure 2 top

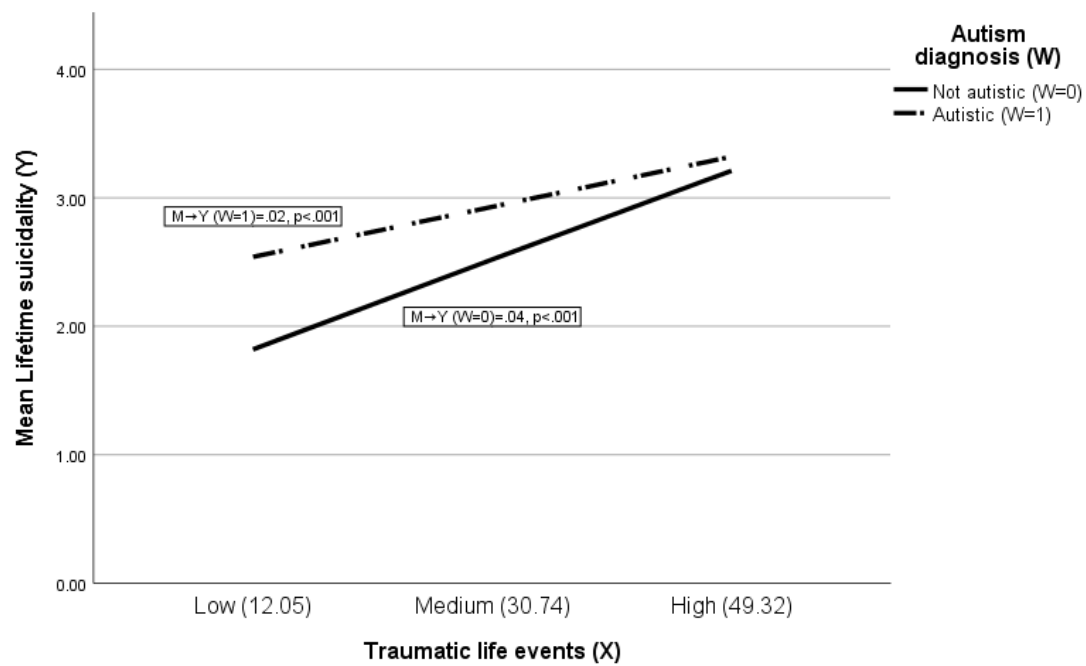
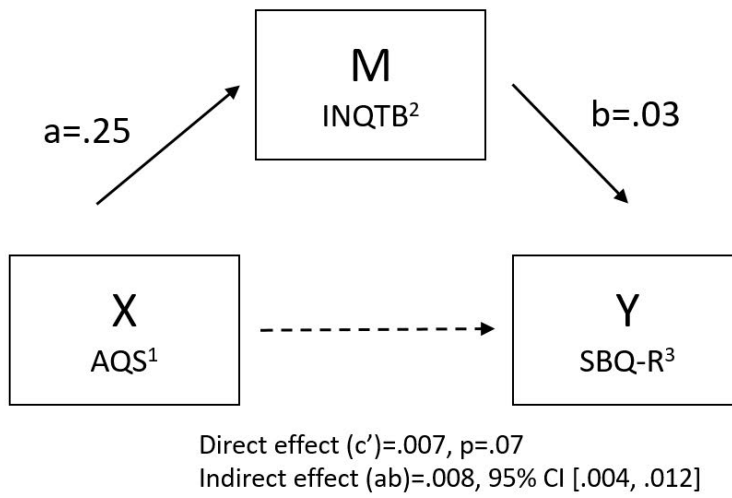


Figure 3 top



1. AQS=Autism Quotient short form, 2. INQTB=Interpersonal Needs Questionnaire 10 Thwarted belonging subscale, 3. SBQ-R=item 1 Suicidal Behaviours Questionnaire revised

Figure 4 top

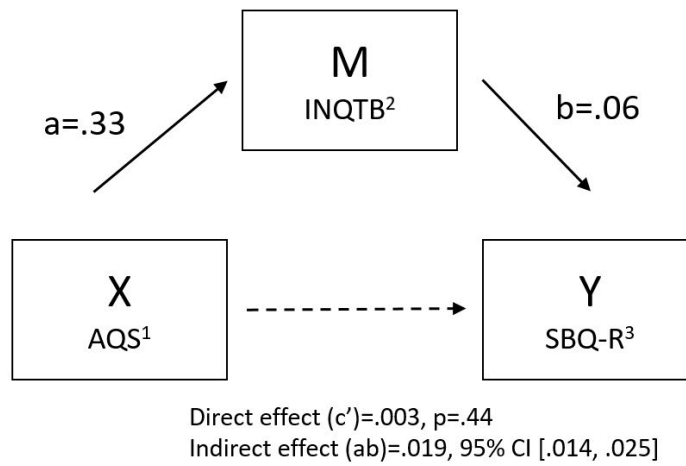


Figure 5 top

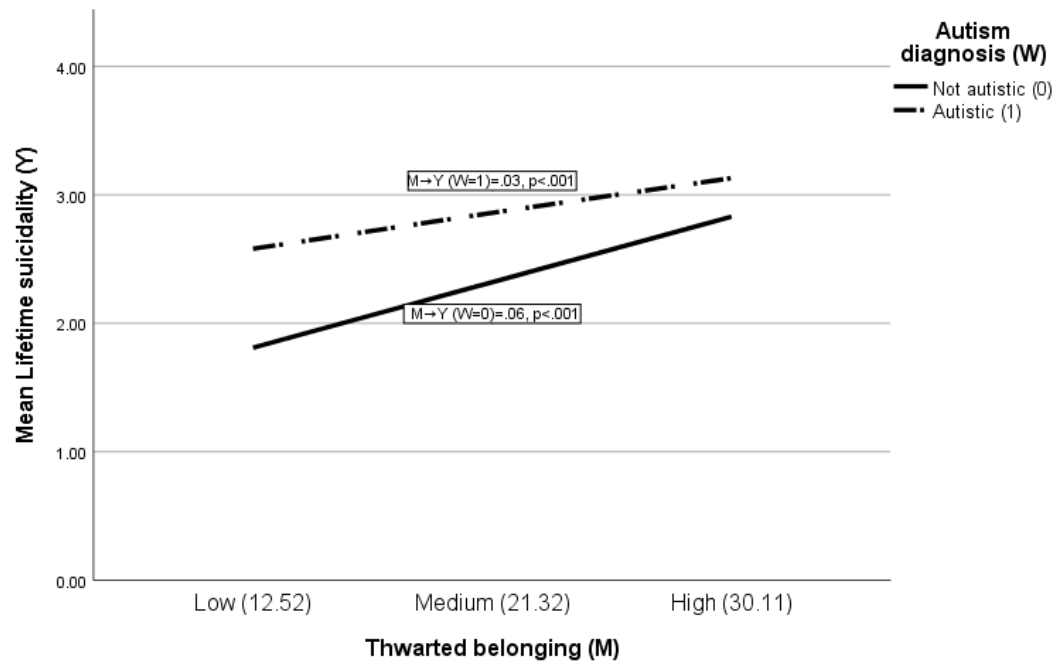
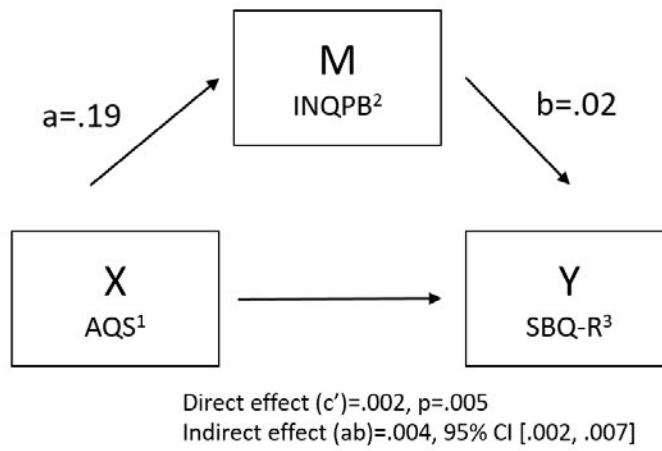
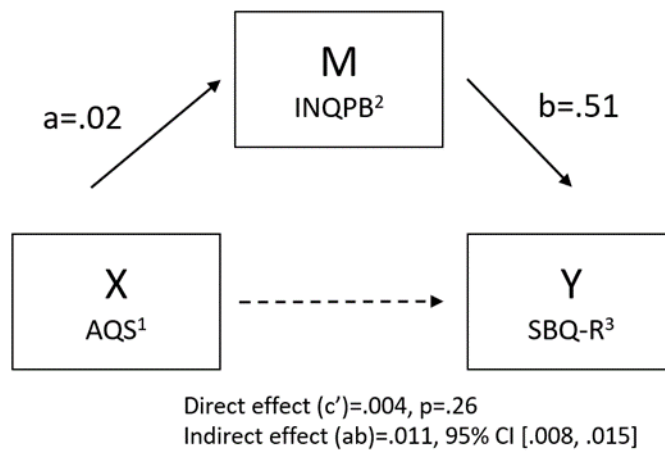


Figure 6 top



1. AQS=Autism Quotient short form, 2. INQPB=Interpersonal Needs Questionnaire 10 Perceived burden subscale, 3. SBQ-R=Item 1 Suicidal Behaviours Questionnaire revised

Figure 7 top



1. AQS=Autism Quotient short form, 2. INQPB=Interpersonal Needs Questionnaire 10 Perceived burden subscale, 3. SBQ-R=item 1 Suicidal Behaviours Questionnaire revised

Figure 8 top

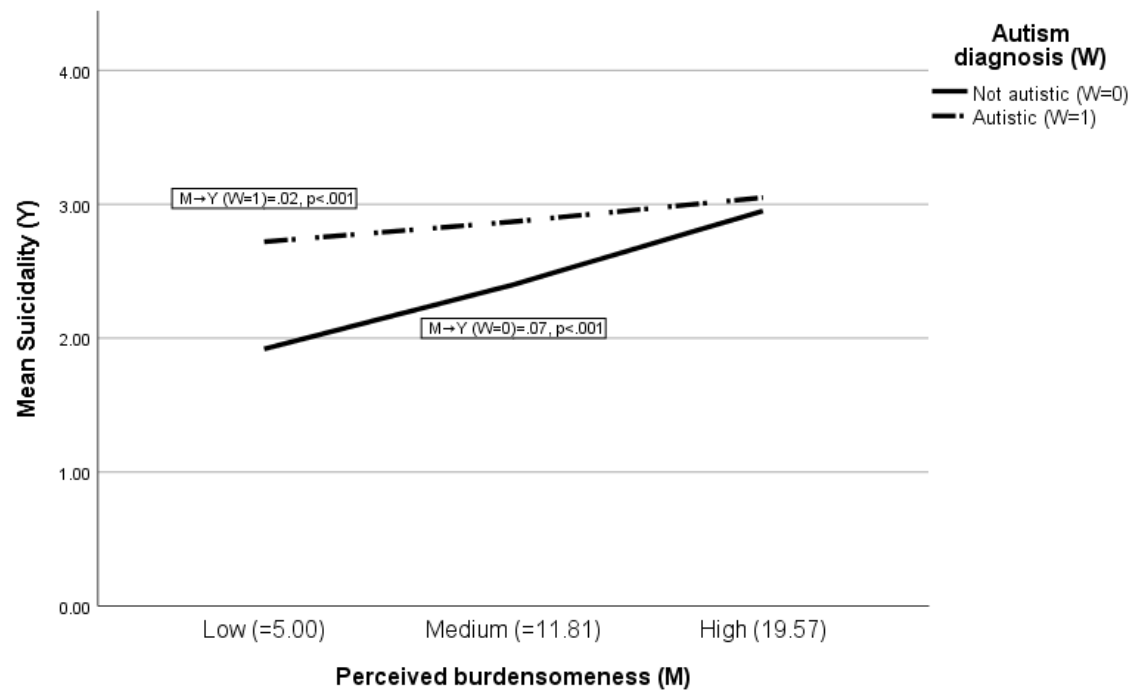


Table 1. Participant characteristics and descriptive statistics

	Non-autistic group			Autistic group		
Participant characteristics	Male (n=118)	Female (n=219)	Other gender (n=2)	Male (n=124)	Female (n=206)	Other gender (n=20)
Age mean (SD)	43.68 (18.47)	40.0 (13.95)	24.5 (3.54)	44.65 (13.82)	41.13 (13.29)	33.05 (10.56)
Range (min-max)	72 (18-90)	56 (18-74)	5 (22-27)	52 (18-70)	55 (18-73)	36 (18-54)
N (%) endorsing postgraduate degree	48 (40.7%)	103 (47%)	0	48 (38.7%)	67 (32.5%)	7 (35%)
Living with support n (%)	21 (17.8%)	21 (9.6%)	1 (50%)	42 (33.9%)	43(20.9%)	5 (25%)
Employed full time n (%)	55 (46.6%)	86 (39.3%)	1 (50%)	40 (32.3%)	55 (26.7%)	5 (25%)
Diagnosed with neurodevelopmental condition endorsing n=yes (%)	14 (11.9%)	14 (5.9%)	1 (50%)	36 (29%)	62 (30.1%)	8 (40%)
Diagnosed with at least one co-occurring mental health condition n=yes (%)	26 (22%)	75 (34.2%)	1 (50%)	76 (61.3%)	148 (71.8%)	16 (80%)
Descriptive statistics mean (sd)	Male (n=118)	Female (n=219)	Other gender (n=2)	Male (n=124)	Female)(n=206)	Other gender (n=20)
Burdensomeness (INQ10 PB)	6.19 (12.49)	7.25 (5.11)	22 (8.49)	14.61 (7.65)	14.85 (8.20)	16.05 (9.05)
Thwarted belonging (INQ10 TB)	17.18 (8.06)	16.16 (7.91)	31.5 (4.95)	26.43 (6.70)	25.61 (6.93)	26.15 (5.67)
Suicidal capability (ACSSFAD)	17.23 (6.87)	15.61 (6.91)	15.5 (16.26)	17.38 (6.63)	15.77 (7.58)	18.65 (5.64)
Traumatic life events (VEQ)	17.80 (12.65)	22.37 (15.66)	51.5 (31.82)	42.67 (18.46)	45.80 (17.81)	43.75 (14.78)
Mean autistic traits (AQ-S)	63.45 (12.49)	59.64 (12.55)	76.5 (7.78)	89.62 (12.04)	91.85 (11.15)	89.75 (9.00)
Mean lifetime suicidality (SBQ-R)	2.00 (.90)	2.16 (1.01)	3 (1.41)	3.01 (.90)	3.19 (.82)	3.30 (.73)
Breakdown of past suicidal behaviour by type n (%)	Non-autistic combined male, female and other gender			Autistic combined male, female and other gender		

No past suicidal thoughts or behaviours	106 (31.7)	16 (4.7)
Past suicidal thoughts	120 (35.9)	55 (16.1)
Past suicide plans	73 (21.9)	140 (40.9)
Past suicide attempt	35 (10.5)	131 (38.3)

Table 2: Logistic regression exploring the association between thwarted belonging, perceived burden and their interaction and past reported suicidal thoughts and behaviours in autistic and non-autistic adults

	Non-autistic adults				Autistic adults			
		95%CI for Odds ratio				95% CI for Odds ratio		
Non-suicidal versus suicide ideation	b(SE)	Lower	Odds ratio	Upper	b(SE)	Lower	Odds ratio	Upper
Intercept	8.57 (2.23)				.41 (.90)			
Belong	-.39 (.092)*	.57	.68	.81*	-.06 (.06)	.85	.95	1.06
Burden	-3.01 (.95)*	.01	.05	.32*	-.05 (.04)	.87	.95	1.04
Belong*burden	.117 (.036)*	1.05	1.12	1.21*				
Suicide plan versus suicide ideation								
Intercept	-3.39 (1.82)							
Belong	.029 (.09)	.87	1.03	1.22	-.58 (.60)			
Burden	.936 (.67)	.69	2.55	9.39	.02 (.03)	.97	1.02	1.07
Belong*burden	-.007 (.03)	.94	.99	1.05	.05 (.03)	1.00	1.05	1.11
Suicide attempt versus suicide ideation								
Intercept	-2.65 (2.24)				.			
Belong	-.09 (.10)	.74	.91	1.11	.64			
Burden	.28 (.79)	.28	1.32	6.17	.05 (.03)*	1.0	1.05	1.11
Belong*burden	.04 (.03)	.97	1.03	1.10	.07 (.03)*	1.01	1.07	1.31
Note $R^2=.31$ (Cox & Snell), .34 (Nagelkerke). Model $\chi^2(9)=128.29$, $p<.001$					Note $R^2=.10$ (Cox & Snell), .11 (Nagelkerke). Model $\chi^2(6)=36.67$, $p<.001$. * $p<.001$.			

Table 3 Logistic regression exploring the association between thwarted belonging, perceived burden, suicidal capability and their interactions and past reported suicidal thoughts and behaviours in autistic and non-autistic adults

	Non-autistic people				Autistic people			
		95%CI for Odds ratio				95%CI for Odds ratio		
	b(SE)	Lower	Odds ratio	Upper	b(SE)	Lower	Odds ratio	Upper
Non-suicidal versus suicide attempt								
Intercept	7.91 (1.47)*				2.78 (1.14)			
Belong	-.22 (.06)**	.72	.80	.90	-.11 (.06)**	.81	.90	.99
Burden	-.61 (17)*	.39	.54	.76	-.12 (.04)**	.82	.89	.97
Suicidal capability	-.05 (.04)	.89	.95	1.02	-.04 (.04)	.89	.96	1.04
Belong*burden	.02 (.01)**	1.01	1.02	1.03				
Suicide ideation versus suicide attempt								
Intercept	4.23 (2.4)				3.32 (.79)			
Belong	.08 (.11)	.90	.91	1.12	-.05 (.03)**	.90	.95	1.00
Burden	-.36 (.82)	.71	.92	1.17	-.07 (.82)**	.88	.93	.99
Suicidal capability	-.08 (.03) *	.87	.87	.98	-.11 (.03)*	.86	.90	.94
Belong*burden	-.03 (.03)	.99	.99	1.01				
Suicide plan versus suicide attempt								
Intercept	-.12 (2.33)				1.53 (.62)			
Belong	.11 (.10)	.93	1.03	1.14	-.03 (.02)	.94	.97	1.00
Burden	.58 (72)	.87	1.06	1.31	-.02 (.02)	.94	.98	1.03
Suicidal capability	.04 (.03)	.92	.98	1.05	.03 (.02)	.94	.97	1.01
Belong*burden	-.04 (.03)	.99	.99	1.00				
	Note $R^2=.34$ (Cox & Snell), .36 (Nagelkerke). Model $X^2(12)=136.46$, $p<.001$ * $p<.001$ ** $p<.05$				Note $R^2=.15$ (Cox & Snell), .17 (Nagelkerke). Model $X^2(9)=56.88$, $p<.001$ * $p<.001$ ** $p<.05$			

Table 4. Simple linear regressions showing associations between lifetime suicidality and all predictor variables (thwarted belonging, perceived burden, capability, traumatic life events and autistic traits) in autistic and non-autistic groups

	Autistic group			Non-autistic group		
Predictor	R ²	F statistic (df)	p value	R ²	F statistic (df)	p value
Thwarted belong (INQTB)	.078	29.74 (1,340)	<.001	.211	90.293 (1,332)	<.001
Perceived burden (INQPB)	.063	23.86 (1,340)	<.001	.227	97.476 (1,332)	<.001
Capability (ACSS)	.037	9.77 (1,341)	<.001	.010	4.489 (1,330)	.035
Traumatic life events (VEQ)	.190	103.07 (1,335)	<.001	.349	173.856 (1,322)	<.001
Autistic traits (AQS)	.042	15.35 (1,330)	<.001	.040	14.412 (1,317)	<.001

Compliance with ethical standards

All procedures performed in studies involving human participants were in accordance with the ethical standards of Coventry University (ref p61841) and with the 1964 Helsinki declaration and its later amendments or comparable ethical approval standards. Informed consent was obtained from all individual participants included in the study. This article does not contain any studies with animals performed by any of the authors.

The authors declare that they have no conflict of interest.

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‘I use my artwork to help me to express my feelings ... to develop my own practice around my experiences as an autistic person’

Chapter 4: Study 3: A measurement invariance analysis of the Interpersonal Needs Questionnaire and Acquired Capability for Suicide Scale in autistic and non-autistic adults

This chapter consists of a peer-reviewed paper, published in *Autism in Adulthood* (vol 2, issue 3), Special Issue on Advancing our understanding of measurement: Pelton, M. K., Crawford, H., Robertson, A. E., Rodgers, J., Baron-Cohen, S., & Cassidy, S. (2020). A Measurement Invariance Analysis of the Interpersonal Needs Questionnaire and Acquired Capability for Suicide Scale in Autistic and Non-Autistic Adults. *Autism in Adulthood*, 2(3), 193-203. 10.1089/aut.2019.0055.

Study 3 contributes to the overall aim of this thesis by exploring whether the way in which perceived burdensomeness, thwarted belonging and suicidal capability are conceptualised and measured is meaningful to autistic adults. This study focus was devised in discussion with the Design Group, who also devised detailed hypotheses regarding how item interpretation may differ between autistic and non-autistic adults. Study 3 extends the findings of Study 2, which reported that statistical models that included thwarted belonging and perceived burdensomeness operated differently or were less accurate for autistic people than non-autistic people. Specifically, Study 3 explored whether measurement properties of the Interpersonal Needs Questionnaire (measures perceived burdensomeness and thwarted belonging) and the Acquired Capability for Suicide Scale – Fearlessness About Death (measuring suicidal capability) were equivalent for autistic and non-autistic people.

Study 3 reported that the Interpersonal Needs Questionnaire was non-invariant (i.e., items interpreted differently) at the factor level meaning that totals scores on subscales measuring perceived burdensomeness and thwarted belonging do not provide an accurate comparison between autistic and non-autistic adults. The Acquired Capability for Suicide Scale (ACSS-FAD) met criteria for strict invariance (i.e., items interpreted in a similar manner) for autistic and non-autistic adults, but both groups experienced response difficulties. I discussed these results with the Design Group, and we agreed that clinicians and researchers should be aware that perceived burdensomeness and thwarted belonging may be experienced differently by autistic than non-autistic people. Suicidal capability may be broader than the single construct of reduced fear of death.

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Suicide

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Abstract

Background: Autistic adults are more likely to engage in suicidal thoughts and behaviors, but there is little research to explore the underlying reasons. It is unclear whether self-report suicide scales that have been designed for non-autistic people accurately measure suicide risk constructs in autistic people. Therefore, this study explored, for the first time, whether the measurement properties of the self-report scales of the Interpersonal Theory of Suicide are equivalent in autistic and non-autistic adults.

Methods: In this study, responses from 342 autistic and 353 non-autistic people on the Interpersonal Needs Questionnaire-10 (INQ-10) and Acquired Capability for Suicide Scale–Fearlessness about Death (ACSS–FAD) were compared by using measurement invariance analysis. Data were gathered through an online cross-sectional survey of the self-report measures.

Results: Results suggest that measurement properties of the INQ-10 were different in autistic people. Autistic characteristics, such as different theory of mind and preference for concrete language, may have led the scale items to load differently on the factors in the autistic group than in the non-autistic group. The measurement properties of the ACSS–FAD were invariant between autistic and non-autistic people.

Conclusions: Scores on the INQ-10 cannot be meaningfully compared between autistic and non-autistic people due to different measurement properties. Future research could explore how autistic people experience the concepts of burdensomeness and belonging, to consider how measures could accurately capture this. This would allow researchers to explore the role of these constructs in the development of suicidal thoughts and behaviors in autistic people. Clinicians should be aware that suicide risk factors may present differently in autistic people. Scores on the ACSS–FAD can be meaningfully compared, but the negatively worded scale items may pose similar response difficulties to autistic and non-autistic people.

Keywords: suicide, measurement, interpersonal theory, burdensomeness, belonging, suicidal capability

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Lay Summary

What was the purpose of this study?

The purpose of this study was to explore whether two questionnaires designed for non-autistic people create response difficulties for autistic people. If autistic people experience difficulties interpreting the questions, this can mean that the scales do not work in the same way, which means that scores between autistic and non-autistic people cannot be compared. This is important, as these questionnaires are designed to measure risk factors for suicide: feeling like a burden on others, feeling as if you don't belong, and not fearing death. We know that for non-autistic people these feelings increase the risk of suicide, but we do not yet know whether this is the case for autistic people.

What did the researchers do?

We collected questionnaire responses online from 342 autistic people and 335 non-autistic people. We then used statistical analyses to identify whether the questionnaires operated differently in autistic and non-autistic people. A steering group of autistic adults identified which questions were likely to be interpreted differently by autistic people.

What were the results of the study?

We found that on the questionnaire designed to test feeling like a burden, autistic people appeared to have interpreted all items differently. This means that we cannot compare scores on this scale between autistic and non-autistic people. We found that on the questionnaire designed to test feelings of not belonging total scores could not be compared, because autistic people seemed to have interpreted two items differently. On the questionnaire measuring a reduced fear of death, total scores can be compared as all items appear to have been interpreted similarly between autistic and non-autistic people.

What do these findings add to what was already known?

These findings provide evidence that the questions in these questionnaires may be differently interpreted by autistic people, meaning that scores cannot be meaningfully compared. This could mean that feelings of burdensomeness and belonging are experienced differently by autistic people.

What are the potential weaknesses in the study?

This study has not investigated whether other factors, such as other neurodevelopmental conditions, may influence how someone responds to these scales. Also, future research should also include the experiences of autistic people with intellectual disability.

How will these findings help autistic adults now or in the future?

These findings will alert clinicians immediately to the fact that autistic people may show risk factors for suicide differently from non-autistic people. They may need to ask different questions or look out for different signs. In future, this may help us to understand how different factors may contribute to suicidal thoughts and behaviors for autistic and non-autistic people.

Introduction

RESEARCH CONSISTENTLY REPORTS more frequent suicidal thoughts and behaviors¹ and significantly higher rates of death by suicide among autistic* compared with non-autistic people.^{2,3} However, there is a lack of research to explore how proximal risk factors may lead to the development of suicidality in autistic people, and there are no validated tools to identify such constructs and assess risk severity.⁴ This study explores the appropriateness and measurement properties of

the self-report scales of one of the most highly cited models of suicide—the Interpersonal Theory of Suicide (ITS).^{5,6} This affords the opportunity to compare the extent to which the ITS operates similarly in autistic and non-autistic people. Understanding differences will inform suicide interventions that meet the needs of autistic people and identify autism-specific risk markers.

The ITS proposes that, in any population group, the unmet need for social connections (termed “thwarted belonging”) and unmet need for self-worth (termed “perceived burdensomeness”) together lead to suicidal thoughts.^{5,6} Individuals who have repeatedly experienced painful and frightening events may develop *suicidal capability*—a habituation to fear and pain that enables suicidal thoughts to be actioned.^{5,6}

*This study focusses on the experience of autistic adults without intellectual disability. This population has been reported to be at increased risk of suicide.²

The concepts of burdensomeness and belonging are measured by distinct subscales of the *Interpersonal Needs Questionnaire* (INQ)⁷, and suicidal capability is measured by the 7-item *Acquired Capability for Suicide Scale-Fearlessness about Death* (ACSS-FAD).⁸ The INQ and ACSS-FAD have been validated in U.S. undergraduates, psychiatric outpatients, and adolescent inpatients⁹ but their measurement properties have not yet been explored in an autistic sample. This is the aim of the current study.

The ITS may be of particular relevance to autistic adults, as it highlights the importance of constructs such as autonomy for quality of life^{10,11} and the risks to mental health of burdensomeness^{12,13} and social exclusion,^{14,15} which have been identified as important issues for autistic people. In both childhood and adulthood, autistic people experience significantly more traumatic life events than non-autistic people, such as being bullied or exploited.^{16,17} Our earlier research reported that, in a non-clinical sample of young adults, the ITS hypotheses were upheld even at high levels of autistic traits.¹⁸ Our recent survey showed that autistic people reported more suicidal thoughts and behaviors and stronger feelings of burdensomeness and thwarted belonging than non-autistic adults. However, in the autistic group, the association between each of thwarted belonging and perceived burden with suicidal thoughts and behaviors was significantly attenuated compared with the non-autistic group.¹⁹

One possible explanation for this attenuation is that autistic characteristics influenced responses to the scale items and, thus, the scale measurement properties in the autistic group. Autistic adults could have less confidence than non-autistic people to infer how others feel about them (termed "theory of mind"),²⁰ infer their internal emotional state (termed "alexithymia," which is more common in autistic than non-autistic people),²¹ and may prefer concrete terms to describe social emotional states.²² Thus, autistic people may endorse a lower score on the burdensomeness sub-scale than non-autistic people, because they are unsure how others feel about them, rather than because they feel less of a burden. This could result in a different factor structure, reduced convergent validity, and reduced strength of correlations between the variables of interest, which, in turn, could explain the attenuated associations in the autistic group. Measurement invariance analysis can quantitatively identify differences in measurement structure between groups with increasing stringency, which allows researchers to explore the extent to which results between groups are comparable (invariant) or different (non-invariant).²³ Summarized in Table 1, we hypothesized, with our autistic steering group (described in Methods section), that, compared with non-autistic people, autistic people would (i) interpret all items of the INQ-10 differently given differences in theory of mind and preference for concrete language; and (ii) interpret four of the ACSS-FAD scale items differently due to difficulties with negatively worded questions and preference for concrete language.

Methods

Involvement of autistic adults

Our steering group of autistic adults (one male, one female) identified the focus of this study in our first meeting when they reported difficulty interpreting scale items. This group comprises autistic adults without intellectual disability

recruited by open invitation to local autism groups. The group meets two to three times a year to provide feedback on each stage of the research process. In this study, they reviewed materials, suggested modifications to survey wording including clear risk signposting, and guided detailed hypotheses and analysis strategy.

Participants

Data were retained from 343 autistic and 335 non-autistic participants from a larger survey dataset of online cross-sectional and repeated measures undertaken in Qualtrics.¹⁹ Participants provided informed consent, were warned about the content of questions in each section, were advised that they may skip sections if they wished, were prompted to take breaks, and were given information about support services. This study received ethical approval from Coventry University ethics committee.

Participants self-reported autism diagnosis by a specified medical professional, and mean Autism Quotient scores were within clinical levels. Autistic participants were recruited through the Cambridge Autism Research Database, Autistica Discover network, social media, and local and national autism organizations. Non-autistic participants were recruited through the University of Cambridge Psychology Database, suicide-focused websites, Coventry University research participation scheme, and opportunity sampling to match group size, mean age, and gender frequency with the autistic group. The samples self-selected whether to respond to either or both of the INQ-10 and ACSS-FAD (Table 2).

Measures of interest. The INQ-10²⁴ is a 10-item scale measuring *thwarted belonging* and *perceived burden*. Our steering group revised instructions to clarify the meaning of the scale instructions for autistic people (agreed with the scale author before administration): "Please read the items below." Click on the option that best describes how you have been feeling. Where the questionnaire refers to "these days" please consider how you have been feeling in general over the past 2 weeks. Items include "these days I feel like I belong" and "these days I think the people in my life would be happier without me" with a 7-point response scale from "strongly agree" to "strongly disagree," with higher scores indicating stronger feelings of thwarted belonging and perceived burden. The INQ is reported to measure the same latent traits in U.S. undergraduates, psychiatric outpatients,⁹ older adults,^{7,25} and men and women.²⁶ The 10-item version employed here demonstrates a more consistent model fit and predictive validity than other versions⁹ (Non-autistic burdensomeness subscale $\alpha=0.93$, autistic=0.92, non-autistic belonging subscale $\alpha=0.90$, autistic=0.86).

ACSS-FAD⁸ is a 7-item scale measuring *suicidal capability* with a response scale from 0 "not at all like me" to 4 "very like me," with higher scores indicating higher suicidal capability. Items include "the prospect of my own death arouses anxiety in me" and "I am not at all afraid to die," with items 2, 3, and 5 describing fear of death and, thus, reverse coded. The ACSS-FAD has been validated in undergraduate samples, measures the same latent traits in men and women, and demonstrates convergent/divergent validity with associated constructs in psychiatric samples⁸ (Non-autistic $\alpha=0.85$, autistic=0.84).

TABLE 1. DETAILED HYPOTHESES OF ITEM INVARIANCE FOR INTERPERSONAL NEEDS QUESTIONNAIRE-10 AND ACQUIRED CAPABILITY FOR SUICIDE SCALE—FEARLESSNESS ABOUT DEATH

Item number	INQ items	How would autistic/non-autistic adults answer?	Consensus within design group?	Reason
	Construct: Perceived burdensomeness			
1	These days, the people in my life would be better off if I were gone	Differently (non-invariant)	No consensus	These items rely on the non-autistic theory of mind
2	These days, the people in my life would be happier without me		Consensus	
3	These days, I think my death would be a relief to the people in my life		No consensus	
4	These days, I think the people in my life wish they could be rid of me		No consensus	
5	These days, I think I make things worse for people in my life		No consensus	
	Construct: Thwarted belonging			
6	These days, I feel like I belong	Differently (non-invariant)	Consensus	Non-concrete language: "I belong"
7	These days, I am fortunate to have many caring and supportive friends		Consensus	Non-concrete language: "many," "supportive"
8	These days I feel disconnected from other people		No consensus	Non-concrete language: "disconnected"
9	These days, I often feel like an outsider at social gatherings		Consensus	Overlap with autistic characteristics
10	These days I am close to other people		Consensus	Non-concrete language "close" and "other" people
	ACSS–FAD items			
	Construct: Reduced fear of death			
1	The fact that I am going to die does not frighten me at all	Differently (non-invariant)	Consensus	Negatively worded item leading to difficulty identifying correct (negative) response on scale
2	The pain involved in dying frightens me	Same (invariant)	Consensus	Clear item wording
3	I am very much afraid to die	Differently (non-invariant)	No consensus	Non-concrete language "very much"
4	It does not make me nervous when I talk about death	Differently (non-invariant)	Consensus	Negatively worded item leading to difficulty identifying correct (negative) response on scale. This item was identified as most difficult to identify correct response.
5	The prospect of my own death arouses anxiety in me	Same (invariant)	Consensus	Clear item wording
6	I am not disturbed by death being the end of life, as I know it	Differently (non-invariant)	Consensus	Negatively worded item leading to difficulty identifying correct (negative) response on scale
7	I am not at all afraid to die	Differently (non-invariant)	Consensus	Non-concrete language "at all"

ACSS–FAD, Acquired Capability for Suicide Scale–Fearlessness about Death; INQ, Interpersonal Needs Questionnaire.

Demographic variables. Autism Quotient Short Form (AQ-S)²⁷ measured *autistic characteristics*. The AQ-S is a 28-item subset of the AQ-50 and includes items such as "it does not upset me if my daily routine is disturbed" and "I find it easy to work out what someone is thinking or feeling," with a 4-item response scale from 1 "definitely agree" to 4 "definitely disagree."²⁷ The AQ-S demonstrates the same latent traits in clinical and non-clinical groups²⁸ ($\alpha = 0.88$ non-autistic, 0.87 autistic).

Suicide Behaviors Questionnaire—Revised, item 1 measured *Lifetime suicidal thoughts and behaviors* asking "Have you ever thought about or attempted to kill yourself?" Par-

ticipants self-reported previous suicidal behavior by choosing one of six possible responses from "never" to "I have attempted to kill myself and really hoped to die."²⁹ Item 1 demonstrates comparable measurement properties in autistic and non-autistic adults.^{4,30}

Analysis strategy

Establishment of a baseline model. Analyses were undertaken in AMOS 25. Confirmatory factor analysis (CFA) tested how well previously published models account for the correlations between variables (termed "model fit"). Good

TABLE 2. DESCRIPTIVE STATISTICS AND SAMPLE CHARACTERISTICS FOR AUTISTIC AND NON-AUTISTIC SAMPLES

	INQ sample autistic n = 343, 58.6% female	INQ sample not autistic n = 335, 64.5% female	ACSS-FAD sample autistic n = 343, 58.5% female	ACSS-FAD not autistic n = 332, 64.8% female	Significant differences between autistic and non-autistic group*
Age (mean/SD)	42.1 (13.6), 18-90	41.5 (15.7), 18-73	42.2	41.6 (15.7), 18-90	$U = 54,212.5, p = 0.31$
AQ-S (mean/SD)	91.1 (11.45)	60.9 (12.7)	91.08 (11.45)	60.9 (12.7)	$U = 4851, p < 0.001$
Perceived burden subscale (mean/SD)	14.87 (8.02)	8.70 (6.04)	14.87 (8.03)	8.71 (6.06)	$U = 27,602.5, p < 0.001$
Thwarted belonging (mean/SD)	25.94 (6.77)	16.54 (8.01)	25.96 (6.78)	16.59 (8.04)	$U = 21,801.5, p < 0.001$
Capability for suicide	16.48 (7.18)	16.17 (6.94)	16.50 (7.18)	16.17 (6.94)	$U = 54,533.5, p = 0.34$
Reporting at least one past suicide attempt, n (%)	131 (38.3)	35 (10.4)	131 (38.2)	35 (10.5)	$\chi^2 (1) = 58.36, p < 0.001$
Full-time employed, n (%)	97 (28.3)	141 (42.1)	98 (28.6)	140 (42.2)	$\chi^2 (1) = 13.66, p < 0.001$
Living with support, n (%)	85 (24.8)	41 (12.2)	85 (24.8)	41 (12.3)	$\chi^2 (1) = 17.17, p < 0.001$
Currently diagnosed with at least one mental illness, n (%)	240 (70)	98 (29.3)	239 (69.7)	97 (29.2)	$\chi^2 (1) = 110.48, p < 0.001$
Diagnosed with at least one neurodevelopmental condition (in addition to autism), n (%)	105 (30.6)	28 (8.4)	105 (30.6)	27 (8.1)	$\chi^2 (1) = 54.19, p < 0.001$
% with post-graduate degree, n (%)	121 (35.3)	151 (45.1)	122 (35.6)	151 (45.5)	$\chi^2 (1) = 7.08, p = 0.008$

*Differences between groups are based on the ACSS-FAD sample.

model fit was assessed by using fit indices: comparative fit index (CFI) of at least 0.95 (excellent or above 0.9 acceptable), root mean square of approximation of <0.05 (excellent or <0.1 acceptable), standardized root mean square residual of <0.09, p of Close Fit of at least 0.05, and chi-square/degrees of freedom of <3 (excellent or <5 acceptable).³¹ Convergent validity was assessed by using a score of more than 0.5 of average variance extracted, which measures variance captured by items and variance due to error.³²

In case of poor model fit, alternative models were tested by using: (i) alternative published models or (ii) suggested modification indices, our hypotheses, and review of item meaning. Models were then tested in the autistic group. The best fitting "baseline" model in each group was taken forward for measurement invariance analysis.

Measurement invariance analysis

Multi-group CFA allows researchers to test the extent to which measurement properties are equivalent (invariant) across groups.²³ Termed "measurement invariance analysis," increasing parameters, such as factor loadings or error terms, are held equal in both groups and the model is tested for significant change (degradation) in fit indices. A significant degradation in model fit indices indicates lack of evidence for measurement invariance between the groups, suggesting that the measure operates significantly differently in each group (non-invariant).

First, the configural model tests whether the sets of items measure the same latent construct in both groups with no equality constraints. In the case of configural invariance, factor loadings are subsequently constrained equal between groups to test whether scale items associate similarly with each factor in each group ("metric invariance"). In the case of metric non-invariance (factor loadings significantly different between groups), the individual non-invariant items are identified by constraining the factor loadings for each item in turn. In the case of metric invariance, factor loadings and intercepts are subsequently constrained equal to test whether total scores consist of similar individual item scores in each group ("scalar invariance"). In the case of scalar invariance, error terms and error co-variances are constrained equal to test whether the scale items measure the same latent construct with comparable measurement error ("residual" or "strict invariance").³³ To consider a tool measurement invariant between two groups, scalar invariance has to be demonstrated, as this suggests that mean scores will be broadly comparable between groups.³³

A reduction in CFI of <0.01 alongside non-significant change in chi-square indicate measurement invariance, suggesting that the items of the tool operate similarly between the two groups.³⁴ Greater differences in fit statistics indicate lack of evidence for measurement invariance, suggesting that the items operate significantly differently between the groups (non-invariant). For example, lack of evidence for metric invariance indicates that the groups attribute different meaning to the items, and they are therefore metric non-invariant.

Results

Interpersonal Needs Questionnaire-10

Baseline model. Data were screened for outliers and normality. In the non-autistic group, data were significantly

TABLE 3. MODEL FIT INDICES FROM INTERPERSONAL NEEDS QUESTIONNAIRE-10 BASELINE CONFIRMATORY FACTOR ANALYSIS

Non-autistic group	χ^2/df	CFI	SRMR	RMSEA	pClose
Model 1	2.903	0.843	0.118	0.075	0.008
Model 2	2.239	0.904	0.119	0.061	0.160
Autistic group					
Model 1	2.939	0.969	0.050	0.075	0.021
Model 2	2.595	0.976	0.045	0.068	0.046

Model 1=two factor model, no error terms co-varied. Model 2=previously published model with two pairs of error terms co-varied.^{7,9} Bold indicates adequate or excellent model fit: CMIN/df <5, CFI >0.9, SRMR <0.09, RMSEA <0.1, pClose >0.05. Model run by using asymptotic distribution-free estimation in the non-autistic group and maximum likelihood estimation in the autistic group.

CFI, comparative fit index; CMIN/df, chi-square/degrees of freedom; pClose, p of Close Fit; RMSEA, root mean square of approximation; SRMR, standardized root mean square residual.

multivariate kurtotic (standardized kurtosis = 59.99, >5)²³ and four burdensomeness items had significant univariate kurtosis (>7).³⁵ Kurtosis represents significant problems in tests of variance and co-variance structures, resulting in inflated chi-square statistic.^{23,36} Thus, given sufficient sample size (at least 10×number of parameters estimated)³⁷ asymptotic distribution-free (ADF) estimation was used. In the autistic group, data were normally distributed so maximum likelihood (ML) estimation was used. We tested a two-factor solution (five items each) with no co-varied error terms (model 1) and with two error terms co-varied (model 2) as in previous studies^{7,9} and suggested by similar item meaning. As shown in Table 3, model 2 (in Fig. 1) achieved at least acceptable fit across four indicators in the non-autistic and autistic groups and was retained for invariance analysis.

Measurement invariance

Table 4 shows results of measurement invariance analysis. The configural model (1) was estimated in both groups

by using ADF estimation to reflect the theorized non-normal distribution of INQ experiences. This model suggested degradation of fit with respect to baseline models despite no factor cross-loadings indicated. Given the difference in distribution in burdensomeness in each group, we explored factor differences. The measurement model (2a) demonstrated significant degradation in model fit as did the constraint of each factor in turn (perceived burden 2b) and (thwarted belonging 2c). The constraint of each item of the burdensomeness factor resulted in significant degradation of model fit, indicating metric non-invariance across all items of the burdensomeness scale (models 2d–2h). Constraint of each item of the belonging factor indicated that two items (models 2i and 2j) resulted in significant model degradation, thus suggesting metric non-invariance for these two items of the belonging scale. However, three items (models 2k–2m) did not result in significant degradation of model fit, suggesting evidence for metric invariance for these three items of the belonging scale. Overall, we did not find evidence of metric invariance so stricter tests were not undertaken.

Acquired capability for suicide scale: fearlessness about death

Baseline models. Data were normally distributed so ML estimation was used. Model 1 tested a single factor structure (seven items) consistent with previous literature; model 2 added two co-varied error terms; and model 3 included a subset of those educated to at least degree level.⁸ Due to poor convergent validity, we removed item 4 (the weakest loading item) with a factor loading of 0.41. This item—“It does not make me nervous when people talk about death”—was viewed as the most confusing by our steering group. We co-varied error terms of other negatively worded items in line with hypotheses/modification indices (model 4). Table 5 shows that model 4 achieved good fit in all fit indices in the non-autistic and autistic groups and was retained for measurement invariance analysis (Fig. 2).

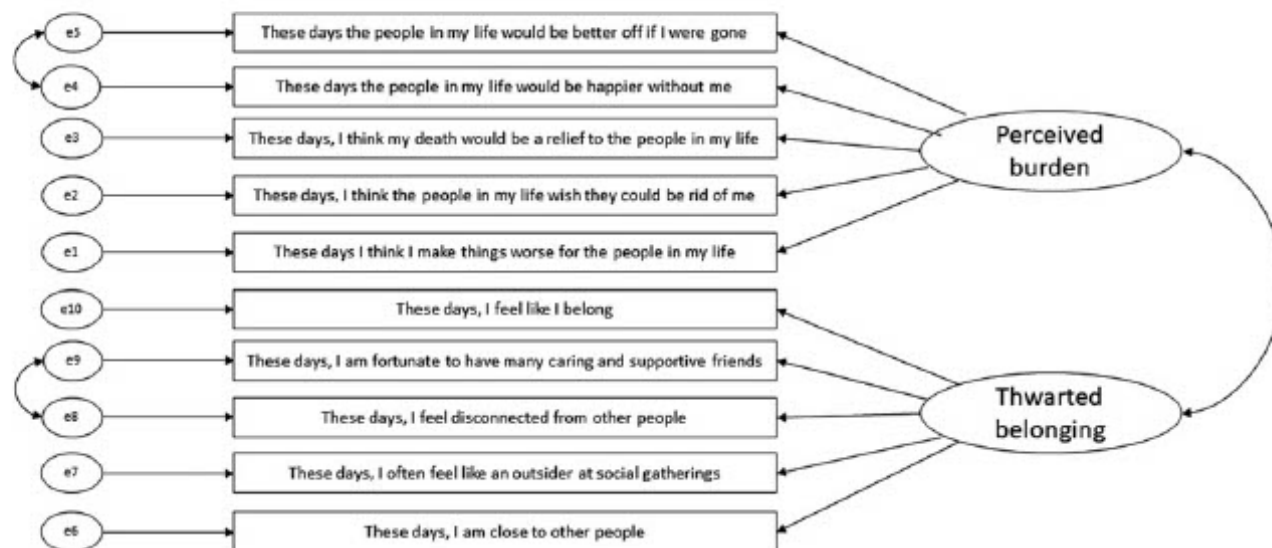


FIG. 1. Interpersonal Needs Questionnaire-10 model 2 retained for measurement invariance analysis in autistic and non-autistic groups.

TABLE 4. SUMMARY OF GOODNESS-OF-FIT STATISTICS FOR MULTIGROUP INVARIANCE TESTS FOR THE INTERPERSONAL NEEDS QUESTIONNAIRE-10

Model no	Description	Contrast	χ^2	df	χ^2/Δ	df Δ	Δp	CMIN/df	CFI	ΔCFI	SRMR	RMSEA	pClose
1	Configural model (unconstrained)		159.45	64				2.491	0.883		0.119	0.047	0.695
2a	Measurement model (all factor loadings constrained equal)	2a vs. 1	262.733	74	77.01	10	<0.001	3.550	0.769	0.082	0.091	0.695	0.010
2b	Burden factor (burden subscale factor loadings constrained equal)	2b vs. 1	219.314	69	43.419	5	<0.001	3.178	0.816	0.055	0.097	0.057	0.182
2c	Belong factor (belong subscale factor loadings constrained equal)	2c vs. 1	185.902	69	26.452	5	<0.001	2.694	0.857	0.034	0.169	0.050	0.480
2d	Configural model + "these days I make things worse for the people in my life"	2d vs. 1	197.926	65	38.476	1	<0.001	3.045	0.838	0.045	0.087	0.055	0.166
2e	Configural model + "these days I think the people in my life wish they could be rid of me"	2e vs. 1	191.685	65	32.235	1	<0.001	2.949	0.845	0.038	0.077	0.054	0.234
2f	Configural model + "these days I think my death would be a relief to the people in my life"	2f vs. 1	213.713	65	54.263	1	<0.001	3.288	0.818	0.065	0.097	0.058	0.058
2g	Configural model + "these days, I think the people in my life would be happier without me"	2g vs. 1	204.115	65	33.963	1	<0.001	3.140	0.830	0.053	0.087	0.056	0.113
2h	Configural model + "these days, the people in my life would be better off if I were gone"	2h vs. 1	208.415	65	38.864	1	<0.001	3.206	0.825	0.058	0.091	0.057	0.085
2i	Configural model + "these days, I am close to other people"	2i vs. 1	169.249	65	37.822	1	<0.001	2.604	0.873	0.010	0.126	0.049	0.578
2j	Configural model + "these days, I feel like an outsider at social gatherings"	2j vs. 1	175.772	65	16.321	1	<0.001	2.704	0.865	0.018	0.153	0.050	0.469
2k	Configural model + "these days, I feel disconnected from people"	2k vs. 1	161.008	65	1.558	1	0.212	2.477	0.883	0	0.122	0.047	0.710
2l	2k + "these days I am fortunate to have many caring and supportive friends"	2l vs. 2k	165.262	66	4.254	1	0.039	2.504	0.879	0.004	0.129	0.047	0.685
2m	2l + "these days I feel like I belong"	2m vs. 2l	169.229	67	3.967	1	0.046	2.526	0.875	0.004	0.138	0.048	0.664

Bold indicates non-invariant measurement model and individual items (factor loadings significantly different between groups indicating metric non-invariance).

TABLE 5. BASELINE MODELS OF THE ACQUIRED CAPABILITY FOR SUICIDE SCALE–FEARLESSNESS ABOUT DEATH IN AUTISTIC AND NON-AUTISTIC ADULTS

<i>Not autistic group</i>	<i>CMIN/df</i>	<i>CFI</i>	<i>SRMR</i>	<i>RMSEA</i>	<i>pClose</i>	<i>AVE</i>
Model 1	11.813	0.866	0.079	0.181	0.000	0.486
Model 2	8.836	0.917	0.076	0.154	0.000	0.467
Model 3	8.588	0.865	0.080	0.177	0.000	0.475
Model 4	1.541	0.997	0.021	0.040	0.563	0.509
<i>Autistic group</i>						
Model 1	7.177	0.929	0.063	0.135	0.000	0.489
Model 2	7.195	0.939	0.060	0.135	0.000	0.482
Model 3	3.773	0.955	0.050	0.109	0.001	0.513
Model 4	2.018	0.995	0.020	0.055	0.372	0.545

Model 1 = all scale items, no co-variances.⁵ Model 2 = model 1 with error terms co-varied “The fact that I’m going to die does not affect me” and “I am not at all afraid to die” and “The pain involved in dying frightens me” and “I am very much afraid to die”. Model 3 = all scale items those endorsing at least undergraduate level education ($n = 242$ not autistic, $n = 233$ autistic). Model 4 = exploratory model with item 4 removed “It does not make me nervous when people talk about death” and error terms co-varied between other negatively worded items. Bold indicates adequate or good model fit. CMIN/df < 5, CFI > 0.9, SRMR < 0.09, RMSEA < 0.1, pClose > 0.05. AVE (Average Variance Extracted) > 0.5 for adequate convergent validity.

Measurement invariance. Table 6 shows the results of measurement invariance analysis. The configural model (1) showed similar fit to the baseline model and no degradation in model fit. The measurement model (2) with constrained factor loadings also showed similar fit and no degradation in model fit, as did the scalar model with intercepts also constrained (3). Finally, with error terms and co-variances also constrained, the residual model (4) indicated reduced and marginally significant degradation of model fit. Constraining error terms and co-variance for the individual negatively worded items showed non-significant degradation in model fit. This analysis suggests that the ACSS–FAD meets criteria for scalar invariance between the groups, with evidence for residual or strict invariance for negatively worded items.

Discussion

This study compared the measurement properties of the INQ-10 and the ACSS–FAD in autistic and non-autistic adults to assess their appropriateness for measuring the ITS proximal risk factors for suicide in autistic adults. This is the first time that the scales of a well-validated suicide theory have been compared in autistic and non-autistic people. We reported configural and metric non-invariance in the thwarted belonging and burdensomeness subscales of the INQ,

whereas a modified ACSS–FAD met criteria for scalar invariance, with negatively worded items meeting criteria for strict invariance. This will allow us to make informed comparisons of suicide mechanisms between autistic and non-autistic people.

Overall, results suggest that the INQ-10 operates differently in autistic adults compared with non-autistic adults. Configural non-invariance suggests that the latent constructs are experienced differently by autistic and non-autistic people. Viewed alongside our data screening information, the INQ may capture experiences—such as feeling socially isolated or experiencing low self-worth—that frequently occur for autistic people rather than the hypothesized rare experiences proposed by the ITS.⁷ Consistent with our hypotheses, there was evidence of metric non-invariance for the burdensomeness subscale, with each individual item indicating metric non-invariance, suggesting that autistic people interpret these items differently from non-autistic people. This could suggest that autistic people had difficulty interpreting and responding to items that required them to infer the mental states of others—such as attributing feelings of being “happier” or “better off” to the “people in my life”—in line with well-established literature describing differences in theory of mind among autistic people.²⁰ Overall, this subscale cannot provide a comparable measure of burdensomeness between

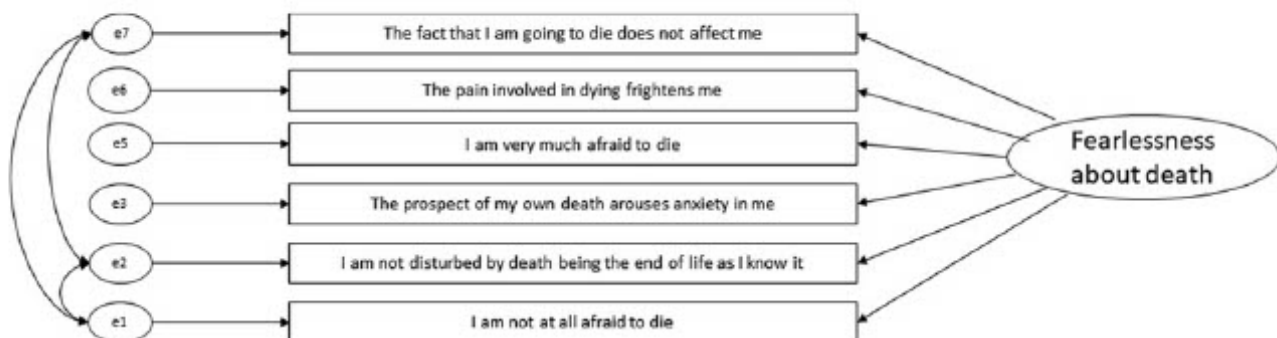


FIG. 2. Acquired Capability for Suicide Scale–Fearlessness about Death model 4 retained for measurement invariance analysis in autistic and non-autistic groups.

TABLE 6. SUMMARY OF GOODNESS-OF-FIT STATISTICS FOR MULTIGROUP INVARIANCE TESTS FOR THE ACQUIRED CAPABILITY FOR SUICIDE SCALE-FEARLESSNESS ABOUT DEATH

Model no.	Description	Contrast	χ^2	df	$\chi^2 \Delta$	df Δ	Δp	CMIN/df	CFI	ΔCFI	SRMR	RMSEA	pClose
1	Configural model (unconstrained model)		21.355	12				1.780	0.996		0.0212	0.034	0.860
2	Measurement model (factor loadings constrained equal)	2 vs. 1	28.732	18	7.377	6	0.287	1.596	0.995	0.001	0.0289	0.030	0.956
3	Scalar invariance (factor loadings and intercepts constrained to be equal)	3 vs. 2	53.321	24	24.589	6	0.001	2.222	0.987	0.008	0.0283	0.043	0.767
4	Residual invariance (factor loadings, intercepts, error co-variances, and error residuals constrained to be equal)^a	4 vs. 3	84.573	33	31.252	9	<0.001	2.563	0.977	0.010	0.0324	0.048	0.568

Bold indicates the non-invariant model (error co-variance and error residuals significantly different between groups).

^aTests of error co-variances and error residuals for each individual negatively worded item of the ACSS-FAD showed non-significant degradation in model fit, suggesting strict invariance (same between groups).

autistic and non-autistic adults. Future research could consider how autistic people experience burdensomeness and specifically whether other latent constructs, such as self-worth and agitation, may be relevant for autistic people. Clinicians should be aware that burdensomeness may be experienced and communicated differently by autistic people but that it does represent a risk factor.

Consistent with our hypothesis, there was evidence of metric non-invariance for the thwarted belonging subscale. In line with our hypothesis, the item "I often feel like an outsider in social gatherings" was metric non-invariant, indicating that autistic people interpret this item differently from non-autistic people. This supports the proposal of our steering group that feeling uncomfortable in social gatherings may be a core experience of autistic people, rather than an indicator of non-typical social isolation. Clinicians should take account of personal social preferences of autistic individuals when assessing risk. Surprisingly, items that contained abstract concepts, such as "disconnected" and "I belong," demonstrated metric invariance, suggesting that these items were interpreted similarly by both autistic and non-autistic people. This could reflect reports that autistic people experience similar social needs to non-autistic people.³⁸ Thus, these two items, along with the item describing satisfaction with the number and quality of friends could be compared between autistic and non-autistic people. Future research could explore *how* autistic people experience belonging and social connection in general and as protective factors.

We reported that, contrary to our hypotheses, there was evidence of scalar invariance in a modified ACSS-FAD, with evidence for strict invariance of negatively worded items. This suggests that non-concrete language ("not at all" and "very much") and negative response options did not hinder

autistic people any more than non-autistic people in choosing the correct response. Other researchers³⁹ have reported similar response difficulties in non-autistic groups, which could suggest that the scale may benefit from revision. Any revision should consider the broader suggestion that the single construct of a reduced fear of death may be too narrow to reflect the changes that enable a suicide attempt: Clinical advice recommends broad screening for past painful and frightening experiences to identify possible suicidal capability,⁴⁰ and recent innovations include a broader Acquired Capability with Rehearsal for Suicide scale.⁴¹ Future research could consider how these constructs are experienced by autistic people and the guidance required by clinicians for accurate risk assessment.

This study has several strengths. It is the first study to explore the measurement properties of self-report scales of a well-established suicide theory in a large sample of autistic adults and compare the responses with a matched sample of non-autistic adults. This is vital to inform how suicide assessment tools may need to be tailored to enable clinicians to accurately identify risk in autistic people. This study also has limitations, including reliance on self-report autism diagnosis. Variance between groups could be due to other confounds, such as higher prevalence of neurodevelopmental conditions in the autistic group, which could be explored in future research. This could also include exploring how autistic individuals with intellectual disability experience and express proximal risk factors for suicide.

In conclusion, this study reported that scores on the INQ-10 cannot be meaningfully compared between autistic and non-autistic people. However, with one item removed scores on the ACSS-FAD are comparable between these groups. Burdensomeness and thwarted belonging may represent

proximal risk factors for suicide in autistic people but may be experienced and expressed differently in autistic compared with non-autistic people. Clinically, this suggests that tailored measurement tools and specific training may be required to identify risk and target interventions for autistic people.

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Authorship Confirmation Statement

This project was conceived by S.C. and M.K.P. M.K.P. designed the detailed protocol, gathered the data, designed and undertook the data analysis, and wrote the initial draft. S.C., J.R., H.C., A.E.R., and S.B.-C. provided feedback on that draft. All co-authors have reviewed and approved of the article before submission. This article has been submitted solely to this journal and is not published, in press, or submitted elsewhere.

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9.5.20

'my emotional response when I feel a sense of belonging'

Chapter 5: Study 4: The role of anxiety and depression in suicidal thoughts for autistic and non-autistic people: a theory-driven network analysis

This Chapter consists of a peer-reviewed paper published in *Suicide and Life-threatening Behavior*: Pelton, M. K., Crawford, H., Bul, K., Robertson, A. E., Adams, J., de Beurs, D., Rodgers, J., Baron-Cohen, S., & Cassidy, S. (2023). The role of anxiety and depression in suicidal thoughts for autistic and non-autistic people: A theory-driven network analysis. *Suicide and Life-Threatening Behavior*, 53(3), 426-442. DOI: 10.1111/sltb.12954



Study 4 contributes to the overall thesis aim by comparing the extent to which the ITS hypotheses explaining how mental health difficulties contribute to suicide are upheld for autistic adults with a sample of non-autistic adults. Study 4 extends the findings of Study 2, which proposed that other suicide risk markers may be more important than perceived burdensomeness and thwarted belonging for autistic adults. Study 4 builds on the findings of Study 3 by using item-level network analysis to avoid modelling techniques that require statistically equivalent latent constructs. This study focus was devised in discussion with the Design Group and followed a data driven approach to generate networks, which I then discussed with the Design Group. Specifically, Study 4 explored how being autistic may be a distal suicide risk marker through individual items describing anxiety, depression, perceived burdensomeness, and thwarted belonging. Statistical analyses then explored whether and how these models differed between autistic and non-autistic adults.

Study 4 reported putative pathways from being autistic to suicidal thoughts through: (i) feeling like an outsider through not belonging, feeling like a burden to suicidal thoughts; and (ii) from anxiety through mood and appetite difficulties, to failure and hopelessness to suicidal thoughts. Networks were less accurate for autistic than non-autistic adults. I discussed these results with the Design Group, and we co-produced the first conceptual model of suicide for autistic adults, which proposed a progression from stressors in the environment through reduced coping to low mood and suicidal thoughts. We proposed future theory research should start with the lived experiences of autistic adults to fully capture autistic experience.

Supplementary Information for this paper is in Supplementary 4 of this thesis.

ORIGINAL ARTICLE

The role of anxiety and depression in suicidal thoughts for autistic and non-autistic people: A theory-driven network analysis

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Abstract

Background: Autistic adults experience more frequent suicidal thoughts and mental health difficulties than non-autistic adults, but research has yet to explain how these experiences are connected. This study explored how anxiety and depression contribute to suicidal thoughts according to the Interpersonal Theory of Suicide for autistic and non-autistic adults.

Methods: Participants (autistic adults $n = 463$, 61% female; non-autistic $n = 342$, 64% female) completed online measures of anxiety, depression, thwarted belonging, and perceived burdensomeness. Network analysis explored whether: (i) being autistic is a risk marker for suicide; and (ii) pathways to suicidal thoughts are consistent for autistic and non-autistic adults.

Results: Being autistic connected closely with feeling like an outsider, anxiety, and movement, which connected to suicidal thoughts through somatic experiences, low mood, and burdensomeness. Networks were largely consistent for autistic and non-autistic people, but connections from mood symptoms to somatic and thwarted belonging experiences were absent for autistic adults.

Conclusion: Autistic people experience more life stressors than non-autistic people leading to reduced coping, low mood, and suicidal thoughts. Promoting belonging, reducing anxiety, and understanding the role of movement could

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inform suicide prevention for autistic people. Research should accurately capture autistic lived experience when modeling suicide to ensure suicide prevention meets autistic needs.

KEYWORDS

autism, interpersonal theory of suicide, network analysis

INTRODUCTION

Suicide accounts for the deaths of over 700,000 people each year (World Health Organization, 2021) and autistic people¹—recently estimated to number at least 80 million worldwide (Lord et al., 2022)—are now recognized as over-represented in those figures (Cassidy et al., 2022; Hirvikoski et al., 2016; Kirby et al., 2019; Kølves et al., 2021). Autism is diagnosed by the observable presence of social communication, sensory differences, and restricted interests (American Psychiatric Association, 2013) and a recent UK study reported evidence of autism or possible autism in around 41% of those who died by suicide (Cassidy et al., 2022). Thus, there is an urgent need to understand and provide evidence-based interventions for autistic people to meet global suicide prevention targets (Cassidy, Cogger-Ward, et al., 2021; Cassidy, Robertson, et al., 2020). One limiting factor in guiding interventions is the absence of suicide theory and models that accurately describe the experiences of autistic people (Cassidy, Cogger-Ward, et al., 2021). Our earlier research reported the Interpersonal Theory of Suicide (ITS) may be relevant for autistic adults (Pelton & Cassidy, 2017), but the model explains only one-third of the variance in lifetime suicidal thoughts and behaviors for autistic adults compared with non-autistic adults (Pelton et al., 2020b). One possibility is that mental health difficulties, such as anxiety and depression, could have a greater influence on suicidal thoughts and behaviors for autistic than non-autistic adults. Mental health difficulties, such as anxiety and depression are reported by up to 80% of autistic adults (Lever & Geurts, 2016) and have been significantly associated with suicidal thoughts, behaviors, and death by suicide for autistic young people and adults (Jokiranta-Olkonien et al., 2021; Kølves et al., 2021; Zahid & Upthegrove, 2017), but we do not yet know *how* these experiences are connected. Reducing persistent distress caused by suicidal thoughts has been identified as a clinical priority for autistic adults (South et al., 2020) that could reduce future death by suicide (Large et al., 2021). Thus, in this study, we set out to explore the role of anxiety and depression in the development of suicidal desire according to the ITS and whether this differs for autistic and non-autistic adults.

According to the ITS, in any population group, suicidal desire develops from the interaction of perceived burdensomeness (social worthlessness) with thwarted belonging (hopeless social isolation) (Joiner, 2005; Van Orden et al., 2010). As shown in Figure 1, mental health symptoms hypothetically contribute to suicidal desire because they increase the experience of these proximal risk markers (Davidson et al., 2011; Kleiman et al., 2014; Silva et al., 2015). Testing these pathways for autistic adults, however, requires a transdiagnostic approach to modeling mental health (Lombardo et al., 2019; Weiss, 2014). Higher rates of misdiagnosed and co-occurring mental health difficulties (Camm-Crosbie et al., 2019) are attributed to differences between autistic and non-autistic people in the way that mental health—such as depression (Cassidy,

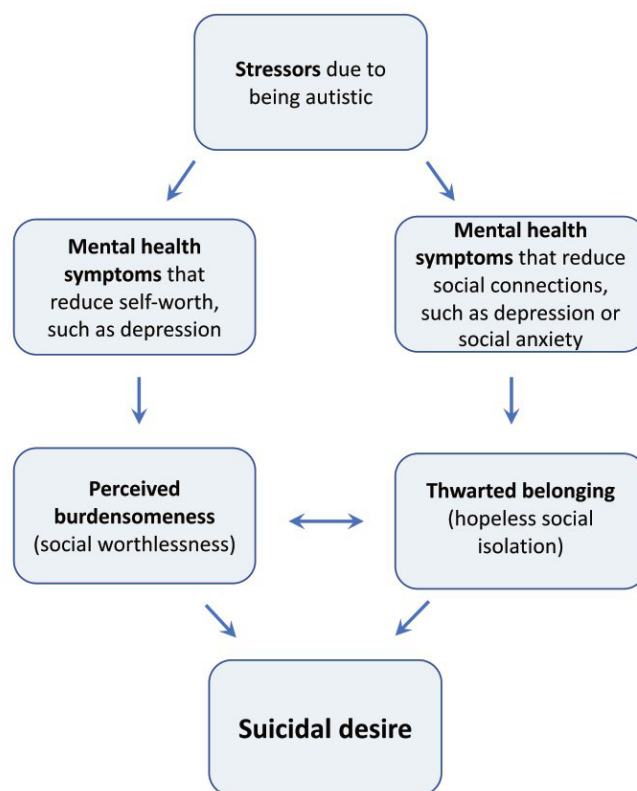


FIGURE 1 Hypothesized association between mental health difficulties, interpersonal theory of suicide proximal risk markers and suicidal thoughts showing possible influence of minority stress for autistic people.

Bradley, Bowen, et al., 2018; Cassidy, Bradley, Cogger-Ward, et al., 2021), anxiety (Boulter et al., 2014; Rodgers et al., 2020; Rodgers & Ofield, 2018), thwarted belonging, and perceived burdensomeness (Pelton et al., 2020a)—are conceptualized and measured so comparisons based on scale total scores may not be accurate. One alternative is the network approach, which conceptualizes mental health difficulties as the interaction of their individual symptoms in contrast with the *common cause* or *medical model* (Borsboom, 2017; Borsboom & Cramer, 2013; Borsboom et al., 2021). Individual symptoms or experiences, such as hopelessness, feeling nervous, or like an outsider are *nodes* within the network while *edges* describe the strength of association between two nodes (Borsboom, 2017). Network analysis is particularly recommended for estimating and visualizing the complexity of suicidal thoughts (De Beurs, 2017) and specifically for (i) generating novel, putative theoretical pathways (Haslbeck et al., 2022) and (ii) understanding differences between patient groups (De Beurs, 2017). Thus, these are the aims of the current study.

One possibility is that being autistic represents a distal risk marker for suicide due to minority stress (Botha & Frost, 2020). As shown in Figure 1, being autistic could lead to multiple life stressors, making it more likely that an individual experiences anxiety and depression (Lever & Geurts, 2016), thwarted belonging, burdensomeness (Pelton et al., 2020b) and suicidal thoughts (Cassidy et al., 2014) than a non-autistic person. Empirical research supports this: autistic traits are a unique risk marker for suicidal thoughts and behaviors in autistic and non-autistic samples (Cassidy et al., 2022; Cassidy, Bradley, Shaw, et al., 2018; Pelton & Cassidy, 2017; Richards et al., 2019; Takara & Kondo, 2014; Uptegrove et al., 2018). Simple pathways have been described from (i) autistic traits through perceived burdensomeness and thwarted belonging (Pelton et al., 2020b); (ii) loneliness through depression (Hedley, Uljarević, Foley, et al., 2018); and (iii) social dissatisfaction and loneliness through perceived burdensomeness (Dow et al., 2021); to suicidal thoughts and behaviors for autistic adults. However, these modeling studies have included only simply linear relationships and have employed scale totals using measures designed for non-autistic adults. Furthermore, network analysis has already extended our understanding of the interaction of these variables for non-autistic people: perceived burdensomeness and low mood symptoms (such as feeling depressed or hopeless) are reported closely, directly connected to suicidal thoughts while thwarted belonging and anxiety are more distal or less strongly connected (Beard et al., 2016; De Beurs et al., 2019; Fried et al., 2016; Ordóñez-Carrasco

et al., 2021; Schönfelder et al., 2021; Suh et al., 2021), but studies, to date, have not included autistic samples. Thus, this study will use network analysis to visualize and estimate more complex interactions than traditional statistical analytic techniques to understand the role of, for example, restlessness or appetite preferences, without needing to attribute these to anxiety, depression, or autistic characteristics.

Finally, researchers propose that being autistic may moderate connections between risk markers (Lai et al., 2017; Pelton & Cassidy, 2017) and network analysis provides a range of tools to simultaneously test a range of propositions: first, autistic thinking styles, such as perseverative thinking (Arwert & Sizoo, 2020; Lai et al., 2017; South et al., 2020), may make it harder to switch away from negative thoughts and relatively hasten the development of suicidal thoughts compared with non-autistic people. This is in line with the network approach which argues that connections between risk markers are stronger in vulnerable compared with less vulnerable groups (van Borkulo et al., 2015). Second, differences in emotional experience, such as alexithymia (difficulty identifying and expressing emotional states (Bird & Cook, 2013)) could mean that emotional symptoms are understated, attenuating connections between emotional risk markers, such as low mood or anxiety, with other risk markers (Costa et al., 2020; Pelton & Cassidy, 2017; Pelton et al., 2020b). Third, overlapping autistic characteristics and somatic depression symptoms (such as appetite or sleep differences) (Gotham et al., 2015) could suggest that somatic experiences are more influential in maintaining the symptom network for autistic compared with non-autistic adults (Montazeri et al., 2020). However, to date, none of these propositions have been tested in a matched sample of autistic and non-autistic adults. Thus, the current study will undertake exploratory analyses to explore whether and how connections between risk markers differ between autistic and non-autistic adults.

Thus, the current study will undertake an item-level network analysis to explore (i) whether and how being autistic represents a distal risk marker for suicide and (ii) whether and how risk markers interact differently for autistic compared with non-autistic adults. We regard these analyses as exploratory due to an absence of previous research and are open to data-driven results. Based on previous empirical research we expect to find autistic adults report more frequent experiences of anxiety, depression, thwarted belonging, perceived burdensomeness, and suicidal thoughts. In line with the network approach, there will be multiple interactions within and between items measuring distinct constructs.

MATERIALS AND METHODS

Participants and procedure

Data in this study are described elsewhere (Pelton et al., 2020a, 2020b). Participants were 805 complete records retained from an online survey of general population autistic ($n = 463$ [58% sample], 61% female) and non-autistic ($n = 342$ [42%], 64% female) adults (Table 1). We recruited autistic adults via Cambridge Autism Research Database, West Midlands and UK autism organizations, including Autistica (UK-based autism research charity), and non-autistic adults via Cambridge Psychology Database, Coventry University psychology research participation scheme, suicide-focussed websites, and social media.

Participants gave informed consent via Qualtrics, were informed about question content in each section, prompted to take breaks, and given information about support services. Autistic adults (one male and one female) reviewed study materials, clarified instructions, advised on questionnaire selection, interpreted results, and developed the model. Coventry University Faculty of Health and Life Sciences Ethics Committee (ethics approval P61841, approved on 12.12.2018) and the Autism Research Centre, University of Cambridge approved the study.

Measures

Demographics: Participants' self-reported age, gender, employment status, mental health difficulties, additional neurodevelopmental conditions, and autism diagnosis.

Thwarted belongingness and perceived burdensomeness were measured using *The Interpersonal Needs Questionnaire 10 (INQ-10)*, a 10-item scale containing thwarted belonging and perceived burdensomeness subscales (Van Orden et al., 2012). We chose the INQ-10 over the INQ-15 to avoid frustration from similarly worded questions raised by our design group and given equivalent validity (Hill et al., 2015; Thwarted belonging $\alpha = 0.93$, perceived burdensomeness $\alpha = 0.91$ in this sample).

Depression was measured using 9-item *Patient Health Questionnaire (PHQ-9)* (Kroenke et al., 2001) which asks how frequently depression symptoms are experienced over the past 2 weeks with a four-item ordinal scale: "not at all" (0), "several days" (1), "more than half the days" (2), and "nearly every day" (3). Item 9 measures thoughts of suicide and self-harm and has been used here to measure current suicidal thoughts as in previous studies (de la Torre et al., 2021; Penfold et al., 2021; Quinlivan et al., 2017) ($\alpha = 0.92$ in this sample).

Anxiety was measured using 7-item *Generalized Anxiety Disorder (GAD-7)* (Spitzer et al., 2006), which measures cognitive and emotional symptoms of anxiety on the same four-item ordinal scale as the PHQ-9. PHQ9 and GAD7 have been designed for non-autistic population but used in research amongst autistic adults (Griffiths et al., 2019; Vasa & Mazurek, 2015; $\alpha = 0.92$ in this sample).

Autistic characteristics were measured using the *Autism Quotient Short Form (AQ-S)*. The AQ-S is a 28-item subset of the AQ-50 with a four-item response scale from 1 "definitely agree" to 4 "definitely disagree" (Hoekstra et al., 2011). The AQ-S demonstrates the same latent factors in autistic and non-autistic adults (Murray et al., 2014; $\alpha = 0.88$ non-autistic, 0.87 autistic in this sample).

Self-reported autism diagnosis shows up to 99.6% concordance with clinical diagnosis in validation studies (Allison et al., 2012; Daniels et al., 2012; Fombonne et al., 2022). Self-reported diagnosis allows for larger samples for statistical modeling and online participation, which can increase disclosure of sensitive information, as in previous studies (Cassidy, Bradley, et al., 2020; Cassidy, Bradley, Shaw, et al., 2018). In this sample, total scores on the AQ-S are above/below suggested cut-off of 65 indicative of autism for autistic (mean = 89.44) and non-autistic people (mean = 60.92) respectively (shown in Table 1; Hoekstra et al., 2011). We also included self-diagnosed and possibly (awaiting diagnosis) autistic people because many autistic adults remain undiagnosed due to the historic development of diagnostic criteria (Lai & Baron-Cohen, 2015; Russell et al., 2022). Bias in diagnostic tests and difficulties accessing services mean autism is less likely to be diagnosed in women and ethnic minority groups and, thus, these may represent high-risk groups (Constantino et al., 2020; McCrossin, 2022; Roman-Urrestarazu et al., 2021; Russell et al., 2022; Tromans et al., 2020).

Lifetime suicidal thoughts and behaviors are measured using item 1 of the *Suicidal Behaviors Questionnaire* revised (Osman et al., 2001), which demonstrates equivalent measurement properties in autistic and non-autistic adults (Cassidy, Bradley, et al., 2020) and as in previous studies (Pelton & Cassidy, 2017). Total scores on the SBQ-R are recommended not to be compared between autistic and non-autistic people due to non-invariance of items 3 and 4 (Cassidy, Bradley, et al., 2020).

Analytic approach

Network models or Gaussian graphical models

Gaussian graphical models (GGMs) are novel network estimation techniques for ordinal and continuous variables

TABLE 1 Demographic information.

	Non-autistic (<i>n</i> = 342)	Autistic (<i>n</i> = 463)	<i>p</i>
Age (mean (SD))	41.31 (15.7)	41.55 (13.9)	0.82
AQ-S total (mean (SD))	60.92 (12.7)	89.44 (12.0)	<0.01
Gender (%)			
Male	118 (34.7)	150 (32.5)	0.01
Female	219 (64.4)	282 (61.0)	
Not male or female	2 (0.6)	28 (6.1)	
Prefer not to say	1 (0.3)	2 (0.4)	
PHQ-9 total (mean (SD))	7.64 (6.77)	13.81 (7.43)	<0.01
GAD-7 total (mean (SD))	6.56 (5.39)	12.02 (6.08)	<0.01
INQ-10 thwarted belonging (mean (SD))	16.55 (8.02)	25.57 (6.77)	<0.01
INQ-10 burdensomeness (mean (SD))	8.70 (6.04)	14.30 (7.92)	<0.01
In full-time employment (<i>n</i> (%))	144 (42.1)	143 (30.9)	0.01
Highest academic qualification (<i>n</i> (%))			
GCSE/O-Level/NVQ level 1 or 2	17 (5.0)	45 (9.7)	<0.01
A-Level/Higher/NVQ level 3/BTEC/GNVQ	43 (12.6)	59 (12.8)	
Higher national diploma	11 (3.2)	26 (5.6)	
Undergraduate degree	83 (24.4)	137 (29.7)	
Postgraduate degree	153 (45.0)	156 (33.8)	
No school certificate or any qualifications	5 (1.5)	8 (1.7)	
Other	28 (8.2)	31 (6.7)	
Additional neurodevelopmental condition (<i>n</i> (%))			
Yes	28 (8.2)	127 (27.5)	<0.01
No	312 (91.5)	332 (71.9)	
Prefer not to say	1 (0.3)	3 (0.6)	
Dyspraxia (%)	2 (0.6)	40 (8.6)	<0.01
Learning disability (%)	2 (0.6)	13 (2.8)	0.04
Learning difficulty (%)	2 (0.6)	14 (3.0)	0.03
Dyscalculia (%)	2 (0.6)	14 (3.0)	0.03
Dyslexia (%)	9 (2.6)	45 (9.7)	<0.01
Attention-deficit hyperactivity (%)	14 (4.1)	64 (13.8)	<0.01
Developmental delay (%)	0 (0.0)	8 (1.7)	0.04
Other (%)	2 (0.6)	19 (4.1)	<0.01
Current mental health diagnosis (<i>n</i> , (%))			
Yes	102 (30.0)	298 (64.6)	<0.01
No	235 (69.1)	162 (35.1)	
Prefer not to say	3 (0.9)	1 (0.2)	
Depression (%)	76 (22.2)	238 (51.4)	<0.01
Anxiety (%)	73 (21.3)	248 (53.6)	<0.01
OCD (%)	7 (2.0)	46 (9.9)	<0.01
Bipolar (%)	4 (1.2)	30 (6.5)	<0.01
Personality disorder (%)	5 (1.5)	46 (9.9)	<0.01
Schizophrenia (%)	2 (0.6)	7 (1.5)	0.37
Anorexia (%)	3 (0.9)	33 (7.1)	<0.01
Bulimia (%)	1 (0.3)	12 (2.6)	0.02

(Continues)

TABLE 1 (Continued)

	Non-autistic (<i>n</i> = 342)	Autistic (<i>n</i> = 463)	<i>p</i>
Epileps			
Chronic fatigue (%)	11 (3.2)	31 (6.7)	0.04
Tourette's (%)	0 (0.0)	8 (1.7)	0.04
Other (%)	10 (2.9)	59 (12.7)	<0.01
Lifetime reported suicidal thoughts and behaviors (<i>n</i> (%))			
No past suicidal thoughts/ behaviors	106 (31.7)	24 (5.4)	<0.01
Past suicidal ideation	120 (35.9)	79 (17.7)	
Past suicide plan	73 (21.9)	187 (41.8)	
Past suicide attempt	35 (10.5)	157 (35.1)	

in between-subject data. Edges connecting nodes represent partial correlations: the connection strength between two nodes while controlling for all others in the network. See Borsboom et al. (2021) for primer on the network approach. Analyses were conducted in R (v 4.0.5; R Core Team, 2021).

Summary of the analyses

We explored data distribution and how the data split according to autism diagnosis (autistic, non-autistic, and possibly autistic) and gender (female, male, not male or female) using the *networktree* package (Jones et al., 2020). Next, to avoid problems of multi-collinearity between nodes we combined theoretical knowledge with the *goldbricker* function from the *networktools* package (Jones, 2020) to identify potential overlapping constructs and combine node scores using principal component analysis, similar to (Barthel et al., 2020; Lass et al., 2020). We estimated two networks using individual items of the INQ-10, PHQ-9, GAD-7: first, in the whole sample network, we used all variables plus the categorical variable *autism* to estimate a network using *mgm* package (Haslbeck & Waldorp, 2020) to explore whether and how being autistic is connected to suicidal thoughts through network items. Second, we split the data and used the *EstimateGroupNetwork* package (Costantini et al., 2019) to estimate networks for autistic and non-autistic people. We used the *NetworkComparisonTest* (van Borkulo et al., 2017) to test for differences between autistic and non-autistic networks in (i) overall inter-connectivity (“*global density*”: total sum of edges in each network); (ii) individual edge weights; and (iii) or relative inter-connectedness of nodes (termed *centrality estimates*). We use *expected influence* (total sum of edge weights on a given node taking into account negative edge weights) as other centrality estimates are less reliable (Robinaugh et al., 2016). See Appendix S1 for technical details and r script.

RESULTS

Descriptive statistics

Table 2 shows mean individual item scores for autistic and non-autistic people. Ninety-five percent of autistic people (68% non-autistic) reported past suicidal thoughts and behaviors, including 35% of autistic people (10% non-autistic) who had previously attempted suicide. The mean total score of the 8 items on the PHQ-9 was 12 for autistic people, which is above cutoff for possible clinical depression. The mean score on item 9 of the PHQ-9 was 1 indicating that on average the autistic people in this sample had experienced suicidal thoughts for several days for the preceding 2 weeks. The mean score on each scale item was significantly higher for autistic than non-autistic people.

Data splitting

As shown in Figure S1a, the data split primarily on autism diagnosis: the data differed significantly between those formally diagnosed, self-diagnosed, and awaiting autism diagnosis (autistic) compared with those who had never considered they might be autistic (non-autistic). The non-autistic data then split significantly according to gender (male vs. non-male), but there was no gender split in the autistic data. Thus, we proceeded with the analysis of autistic compared with non-autistic people with combined gender groups.

Item selection

As shown in Table 2, we combined items as follows: the belief that life would improve for others in the event of your death (“better”), combined items 1, 2, and 5, INQ-10. Believing others aspire for your death (“rid”) combined items 3 and

TABLE 2 Individual items included in the analyses.

	Not autistic (<i>n</i> = 342) (mean (SD))	Autistic (<i>n</i> = 463) (mean (SD))	<i>p</i>	Results of goldbricker/ nodename
GAD-7				
1. Feeling nervous, anxious, or on edge	1.18 (0.96)	1.96 (1.04)	<0.01	Anxiety
2. Not being able to stop or control worrying	0.95 (0.98)	1.74 (1.09)	<0.01	Anxiety
3. Worrying too much about different things	1.01 (0.99)	1.82 (1.07)	<0.01	Anxiety
4. Trouble relaxing	1.17 (1.04)	1.98 (1.07)	<0.01	Relax
5. Being so restless that it is hard to sit still	0.57 (0.85)	1.36 (1.14)	<0.01	Movement
6. Being easily annoyed or irritable	1.00 (0.90)	1.66 (1.05)	<0.01	Annoy
7. Feeling afraid as if something awful might happen	0.67 (0.90)	1.49 (1.15)	<0.01	Anxiety
PHQ-9				
1. Little interest or pleasure in doing things	0.79 (0.97)	1.45 (1.05)	<0.01	Interest
2. Feeling down, depressed, or hopeless	0.86 (0.98)	1.56 (1.10)	<0.01	Depressed
3. Trouble falling or staying asleep or sleeping too much.	1.30 (1.12)	1.89 (1.13)	<0.01	Sleep
4. Feeling tired or having little energy	1.34 (1.05)	1.97 (1.03)	<0.01	Tired
5. Poor appetite or overeating	0.99 (1.12)	1.69 (1.18)	<0.01	Appetite
6. Feeling bad about yourself—or that you are a failure or have let yourself or your family down	0.96 (1.09)	1.76 (1.14)	<0.01	Failure
7. Trouble concentrating on things, such as reading the newspaper or watching television	0.82 (0.98)	1.64 (1.18)	<0.01	Concentrate
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?	0.25 (0.65)	0.87 (1.05)	<0.01	Movement
9. Thoughts that you would be better off dead, or hurting yourself in some way	0.33 (0.76)	0.97 (1.09)	<0.01	Dead
INQ-10—Perceived burdensomeness				
1. The people in my life would be better off if I were gone.	1.73 (1.34)	2.87 (1.83)	<0.01	Better
2. The people in my life would be happier without me.	1.72 (1.33)	2.78 (1.78)	<0.01	Better
3. I think my death would be a relief to the people in my life.	1.48 (1.18)	2.45 (1.79)	<0.01	Rid
4. I think the people in my life wish they could be rid of me.	1.61 (1.28)	2.50 (1.65)	<0.01	Rid
5. I think I make things worse for the people in my life.	2.18 (1.67)	3.7 (2.03)	<0.01	Better
INQ-10 Thwarted belonging				
6. I feel like I belong.	3.33 (1.95)	5.15 (1.69)	<0.01	Belong
7. I am fortunate to have many caring and supportive friends.	2.95 (1.92)	4.53 (1.94)	<0.01	Friends

(Continues)

TABLE 2 (Continued)

	Not autistic (<i>n</i> = 342) (mean (SD))	Autistic (<i>n</i> = 463) (mean (SD))	<i>p</i>	Results of goldbricker/ nodename
8. I feel disconnected from other people.	3.39 (1.88)	5.14 (1.69)	<0.01	Belong
9. I feel like an outsider at social gatherings.	3.65 (1.89)	5.86 (1.47)	<0.01	Outsider
10. I am close to other people.	3.23 (1.86)	4.90 (1.69)	<0.01	Close

4, INQ-10. Not belonging (“belong”) combined items 6 and 8, INQ-10. Movement differences (“movement”) combined item 8 PHQ-9 (restlessness and shutdown) and item 5, GAD-7 (restlessness); (v) anxiety, including uncontrollable worry, feeling nervous and believing something terrible will happen, (“anxiety”) combined items 1, 2, 3 and 7, GAD-7. Items representing sleep (PHQ-9 item 3) and appetite difficulties (PHQ-9 item 5) were flagged but we retained these as distinct constructs.

1. Is being autistic a distal risk marker for suicide? How does being autistic connect to other nodes to suggest pathways to suicidal thoughts?

Single network estimation

The network contained 138 edges between the 19 nodes. Eleven edges directly connected with thoughts of suicide and self-harm. The strongest connections (shown in Figure 2) were with feeling depressed and hopeless (partial correlation, $r = 0.19$), believing others wish to be rid of you ($r = 0.16$), believing life would be better for others if you were gone ($r = 0.16$), feeling like a failure ($r = 0.12$) and movement differences ($r = 0.14$). Being autistic connected directly to feeling like an outsider, lacking caring and supportive friends, movement differences, and anxiety. Overall, this suggests that being autistic is a distal risk marker for suicide, which activates the network through anxiety, feeling like an outsider, lacking caring and supportive friends, and movement differences.

As shown in Figure 2, movement differences connected directly to thoughts of suicide and self-harm. Feeling like an outsider and lacking caring and supportive friends connected to thoughts of suicide and self-harm through feeling like you do not belong and feeling like a failure. Anxiety connected to thoughts of suicide and self-harm through feeling depressed and hopeless. Overall, this suggests simultaneous pathways from autism diagnosis to thoughts of suicide and self-harm through (i) movement differences; (ii) feeling like you do not belong, that others would be better off without

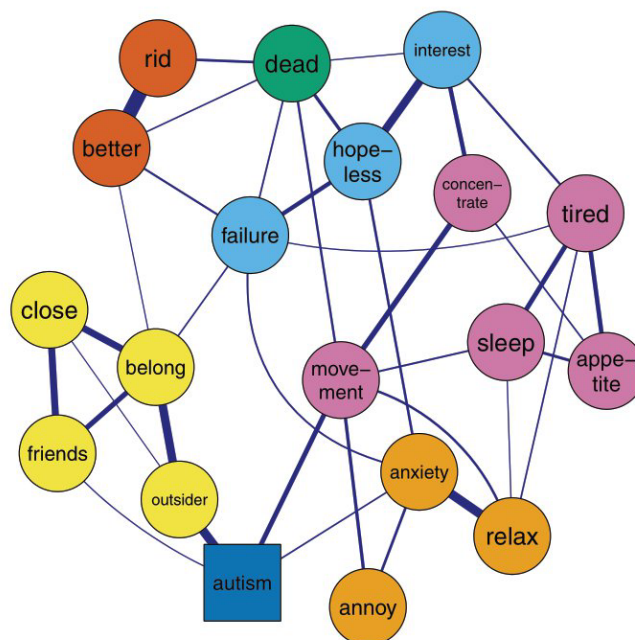


FIGURE 2 Whole sample network graph showing how being autistic connects with network nodes to thoughts of suicide and self-harm. Note: Yellow = thwarted belongingness, light blue = low mood, green = thoughts of self-harm or suicide, orange = anxiety, dark orange = perceived burdensomeness, pink = somatic experiences and dark blue = autism diagnosis. For full details and node names see Table 2. Graph minimum = 0.09, max = 0.14, cut = 0.09 for ease of interpretation. Theme = colorblind.

you and feeling like a failure; (iii) anxiety and feeling depressed/ hopeless; and (iv) anxiety, somatic experiences, and low mood.

2. Are the network structure and global strength consistent for autistic and non-autistic people? How do connections between risk markers differ for autistic compared with non-autistic people?

Joint network estimation

There were consistent edges in the autistic ($n = 160$) and non-autistic ($n = 162$) between 18 nodes with strongest connections shown in Figure 3. In both networks, nine

nodes connected to thoughts of suicide and self-harm and in both groups the strongest edges were with feeling hopeless (autistic $r = 0.21$, non-autistic $r = 0.13$) and believing others would be better off if you were gone (autistic $r = 0.12$, non-autistic $r = 0.14$). In the autistic group, strongest edges also included feeling like a failure ($r = 0.15$), and in the non-autistic group, believing others wish to be rid of you ($r = 0.22$).

Network comparisons

The Network Comparison Test (NCT) reported that global density was greater in the non-autistic network (global density = 8.47) than in the autistic network (global density = 8.30), but this was not statistically significant ($p = 0.30$).

Eight edge strengths differed significantly between autistic and non-autistic networks. First, four edges connected mood symptoms with somatic experiences for the non-autistic network but were absent in the autistic network. These edges connected: (i) losing interest and sleep difficulties (autistic network $r = 0$, non-autistic network $r = 0.36$, $p = 0.02$), (ii) feeling annoyed and feeling tired (autistic network $r = 0$, non-autistic network $r = 0.10$, $p < 0.01$), (iii) feeling like a failure and appetite difficulties (autistic network $r = 0$, non-autistic network $r = 0.23$, $p = 0.02$), and (iv) sleep difficulties and thoughts of self-harm and ending life (autistic network $r = 0$, non-autistic network $r = 0.04$, $p = 0.01$). Overall, this suggests mood symptoms are associated with somatic experiences for non-autistic people but are independent for autistic people.

Second, three edges connected thwarted belonging experiences with mood symptoms or burdensomeness for non-autistic people but were absent for autistic people. These were edges between: (i) feeling like an outsider with (a) feeling annoyed (autistic network = 0, non-autistic network = 0.07, $p = 0.05$) and (b) losing interest (autistic network = 0, non-autistic network = 0.04, $p = 0.03$); (ii) lacking caring and supportive friends and believing other would be better off if you were gone (autistic network = 0, non-autistic network = 0.04, $p = 0.02$). Furthermore, (iii) not feeling close to other people was negatively connected to having difficulty relaxing (autistic network = -0.02 , non-autistic = 0, $p = 0.04$) in autistic people but unconnected in non-autistic people. Overall, this suggests that thwarted belonging is independent of, or differently connected to affective symptoms or burdensomeness for autistic compared with non-autistic people.

As shown in Figure 4, similar nodes were most influential in each group; the 75th percentile expected influence nodes in both groups were as follows: (1) feeling like you do not belong, (2) feeling depressed, (3) believing others wish you were gone, (4) feeling anxious, and (5) having difficulty relaxing (autistic network) and feeling tired (non-autistic network). Unstandardized expected influence is reported in Figure S1b. Expected Influence was similar in each network, however, two nodes were significantly more inter-connected in the non-autistic than autistic networks. Feeling like an outsider (total sum of edges on this node in autistic network = 0.60, non-autistic network = 0.78, $p = 0.01$) and feeling tired (autistic network = 0.88, non-autistic network = 1.03, $p = 0.05$) had significantly greater expected influence in the non-autistic than autistic networks.

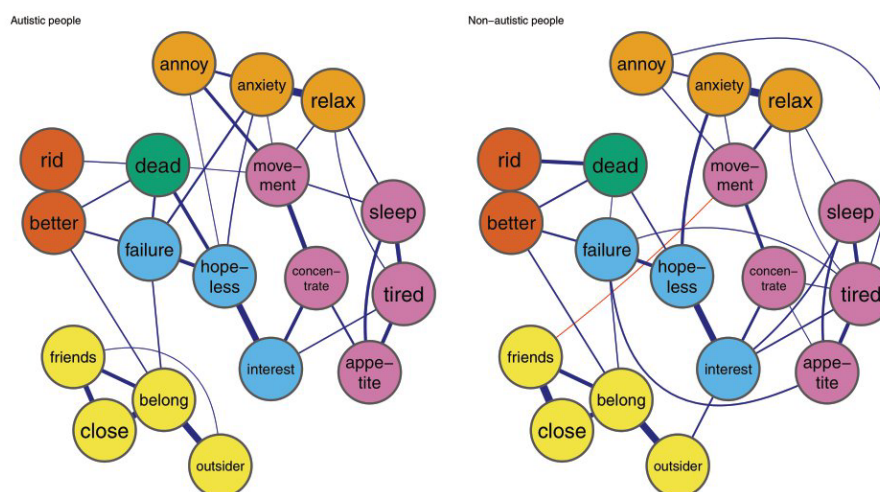


FIGURE 3 Network graphs for autistic (left) and non-autistic (right) adults. Note: Yellow = thwarted belongingness, light blue = low mood, green = thoughts of self-harm or suicide, orange = anxiety, dark orange = perceived burdensomeness, pink = somatic experiences. For full details and node names, see Table 2. Graph minimum = 0.08, max = 0.95, cut = 0.08 for ease of interpretation. Theme = colorblind. We use the *averagelayout* function to provide a consistent layout for networks.

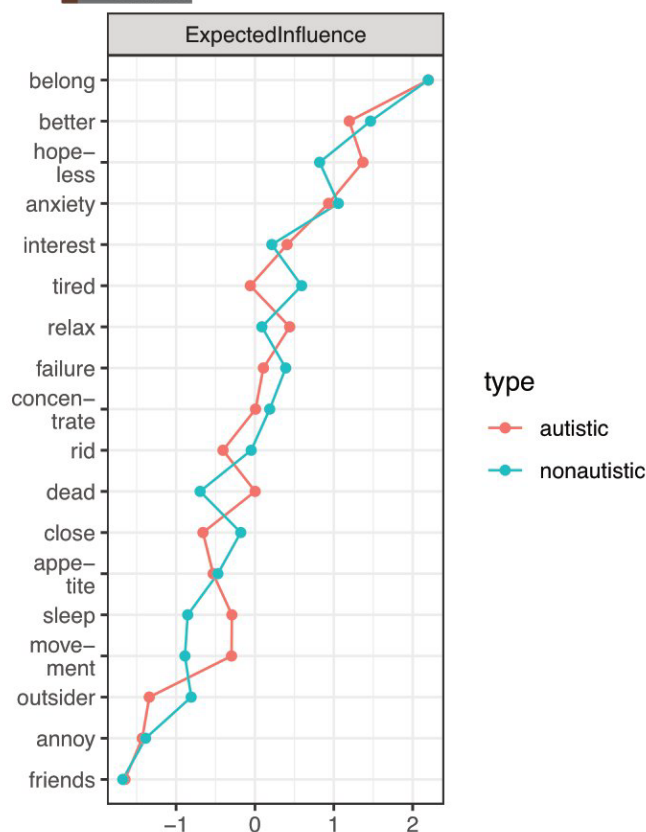


FIGURE 4 Standardized relative expected influence of nodes within autistic and non-autistic networks.

Network stability

As shown in Figures S2–S7, the edge weights were accurately measured. The centrality stability coefficient was 0.52 in the non-autistic network and 0.75 in the autistic network suggesting that expected influence scores were stable.

DISCUSSION

For the first time, we used network analysis to extend our theoretical understanding of how anxiety and depression contribute to suicidal thoughts for autistic and non-autistic adults. In line with our expectations, autistic adults reported more frequent suicidal thoughts, anxiety, depression, thwarted belonging, and perceived burdensomeness than non-autistic adults. Exploratory analyses reported that being autistic connected directly to feeling like an outsider, lacking caring and supportive friends, anxiety, and movement (such as restlessness). These experiences connected to suicidal thoughts through feelings of low mood (hopelessness or failure) and burdensomeness (believing others wish you were gone), except movement, which connected directly to suicidal thoughts. Group

difference tests reported that overall inter-connectedness was consistent for autistic and non-autistic networks. In the non-autistic network, mood symptoms connected to thwarted belonging and somatic experiences, but these were independent in the autistic network. Feeling tired and like an outsider were less inter-connected for autistic than for non-autistic adults.

In line with previous research, autistic adults reported more frequent suicidal thoughts (Cassidy et al., 2014), burdensomeness (Camm-Crosbie et al., 2019; Pelton et al., 2020b), unmet need for belonging (Milton & Sims, 2016), anxiety and depression (Lever & Geurts, 2016) than non-autistic adults. In line with the network approach, there were multiple interactions within and between items designed to measure distinct constructs (Borsboom, 2017; Borsboom & Cramer, 2013; Cramer et al., 2010) and more experiences connected to suicidal thoughts than epidemiology studies suggest (De Beurs, 2017; De Beurs et al., 2017, 2021). Overall, this suggests network analysis is a helpful transdiagnostic alternative to research boundaried by non-autistic categories (Lombardo et al., 2019; Weiss, 2014) to extend our understanding of the development of suicidal thoughts and behaviors.

Our results describe, for the first time, how being autistic may be a distal risk marker for suicide. As described in conceptual model Figure 5, being autistic is connected directly to daily stressors, feeling like an outsider, lacking friends, and anxiety in line with research describing that autistic adults report loneliness (Causton-Theoharis et al., 2009; Hedley, Uljarević, Wilmot, et al., 2018), feeling “othered” (being treated as intrinsically different or inhuman) (Cage et al., 2019; Michael, 2021) and experience significant daily anxiety (Uljarević et al., 2020), which negatively impacts quality of life (Mason et al., 2018). In line with previous research, there was no connection between anxiety and thwarted belonging (Rath et al., 2019). Anxiety is connected with somatic experiences, such as sleep difficulties, which is a particular concern for autistic people in the development of suicidal thoughts and behaviors (Cassidy, Cogger-Ward, et al., 2021). In our network, sleep was strongly inter-connected with tiredness and appetite, suggesting inter-dependency, and linked with movement and concentration difficulties. This could suggest anxiety erodes somatic coping mechanisms to decrease mood. Thwarted belonging connected to feelings of burdensomeness as in previous network analyses (De Beurs et al., 2019) and to feeling like a failure: a more nuanced description of how thwarted belonging contributes to depression (Kleiman et al., 2014), resonating with “failed social struggle” described by the Integrated Motivational Volitional model of suicide (O'Connor, 2011). Both burdensomeness items

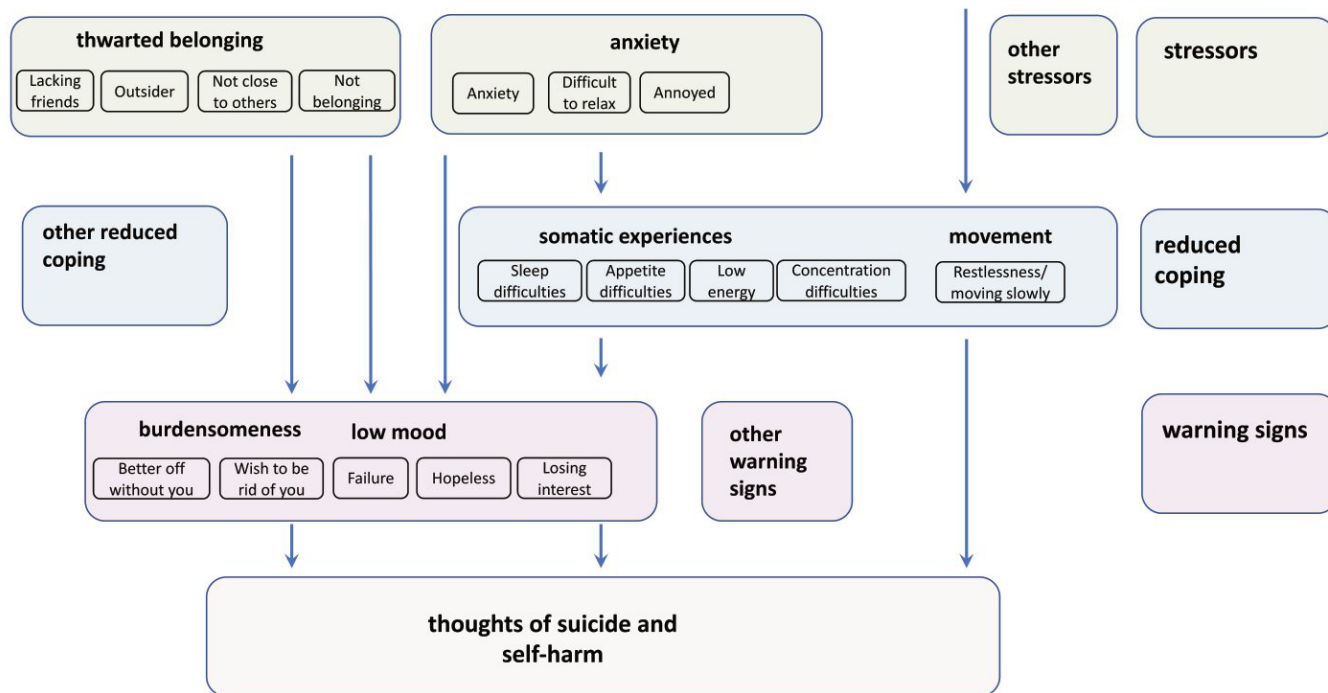


FIGURE 5 Conceptual model of progression from environmental stressors, reduced coping, and warning signs to suicidal thoughts.

(believing others are better off without you/wish to be rid of you), feeling like a failure, hopeless, and losing interest in life connected closely and directly to suicidal thoughts, suggesting these are potent warning signs of those most at risk. Thus, in sum, as shown in Figure 5, our results suggest a progression from daily stressful or traumatic experiences through reduced coping and warning signs to suicidal thoughts.

The connection between being autistic and movement reflects the long-standing role of repetitive behaviors as a diagnostic criterion. More surprising is the direct connection from movement to suicidal thoughts though one study reported agitation as a unique risk marker for suicide attempts in individuals with high autistic traits (Takara & Kondo, 2014). One possibility is that other experiences, such as sensory overload, may be coped with through movement and/or other warning signs that mediate the relationship with suicidal thoughts. However, “stimming” (self-stimulation) is important for autistic people to regulate uncontrollable emotions (Kapp et al., 2019; Pearson & Rose, 2021) so future partnership research could explore the meaning of our findings and how stimming and movement regulate emotional distress.

Our model allows interventions to be identified at each level; for example, understanding and reducing anxiety (Parr et al., 2020), promoting belonging (Milton & Sims, 2016) and autism acceptance (Cage et al., 2018) could reduce the extent to which the network is activated. Maintaining relationships (Hedley, Uljarević, Foley, et al., 2018; Hedley, Uljarević, Wilmot, et al., 2018), peer

relationships (Cage et al., 2022), enabling a healthy lifestyle, and meeting support needs (Cassidy, Bradley, Shaw, et al., 2018) could prevent the progression from stressors to warning signs. Identifying hopelessness, burdensomeness, loss of interest in life and failure could be incorporated into safety planning/risk assessments to improve crisis care (Schwartzman et al., 2021). Our model extends the ITS suggesting that, in addition to burdensomeness, low mood is proximal and significant in the development of suicidal thoughts. The distal role of thwarted belonging reflects previous network analyses (De Beurs et al., 2019; Ordóñez-Carrasco et al., 2021) and the protective role of connectedness outlined in the 3Step theory (Klonsky & May, 2015). Our results emphasize the role of burdensomeness as a proximal risk marker, but failure and hopelessness also resonate with broader emotional pain proposed by the Three-step Theory (3ST) (Klonsky & May, 2015). Caution should be exercised that our model includes only a subset of risk markers and those at greatest risk of suicide are likely to experience a wide range of risk markers (Cassidy et al., 2022).

However, before pursuing future research, we should consider the comparison between autistic and non-autistic networks. Overall connectedness was consistent between autistic and non-autistic networks, but connections from mood symptoms with somatic and thwarted belonging experiences were absent for autistic adults, and feeling tired and like an outsider were significantly less inter-connected in the autistic than non-autistic network. These results suggest that somatic experiences described

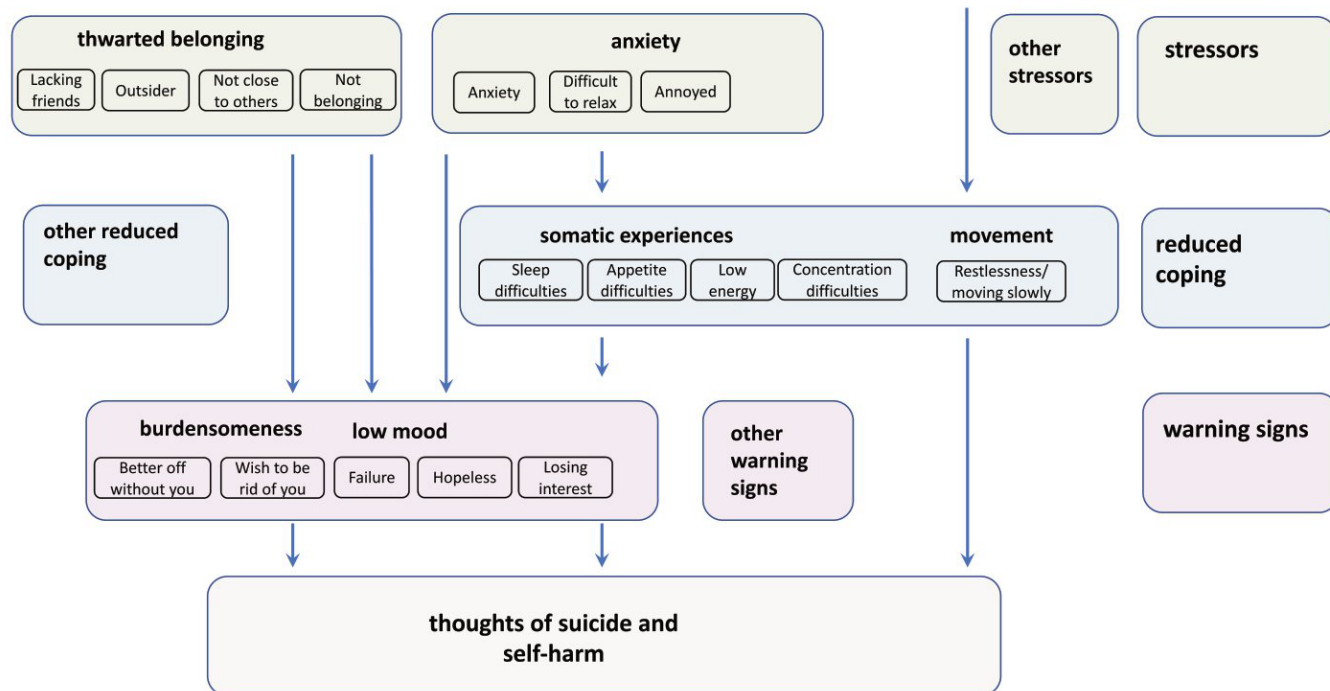


FIGURE 5 Conceptual model of progression from environmental stressors, reduced coping, and warning signs to suicidal thoughts.

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The connection between being autistic and movement reflects the long-standing role of repetitive behaviors as a diagnostic criterion. More surprising is the direct connection from movement to suicidal thoughts though one study reported agitation as a unique risk marker for suicide attempts in individuals with high autistic traits (Takara & Kondo, 2014). One possibility is that other experiences, such as sensory overload, may be coped with through movement and/or other warning signs that mediate the relationship with suicidal thoughts. However, “stimming” (self-stimulation) is important for autistic people to regulate uncontrollable emotions (Kapp et al., 2019; Pearson & Rose, 2021) so future partnership research could explore the meaning of our findings and how stimming and movement regulate emotional distress.

Our model allows interventions to be identified at each level; for example, understanding and reducing anxiety (Parr et al., 2020), promoting belonging (Milton & Sims, 2016) and autism acceptance (Cage et al., 2018) could reduce the extent to which the network is activated. Maintaining relationships (Hedley, Uljarević, Foley, et al., 2018; Hedley, Uljarević, Wilmot, et al., 2018), peer

relationships (Cage et al., 2022), enabling a healthy lifestyle, and meeting support needs (Cassidy, Bradley, Shaw, et al., 2018) could prevent the progression from stressors to warning signs. Identifying hopelessness, burdensomeness, loss of interest in life and failure could be incorporated into safety planning/risk assessments to improve crisis care (Schwartzman et al., 2021). Our model extends the ITS suggesting that, in addition to burdensomeness, low mood is proximal and significant in the development of suicidal thoughts. The distal role of thwarted belonging reflects previous network analyses (De Beurs et al., 2019; Ordóñez-Carrasco et al., 2021) and the protective role of connectedness outlined in the 3Step theory (Klonsky & May, 2015). Our results emphasize the role of burdensomeness as a proximal risk marker, but failure and hopelessness also resonate with broader emotional pain proposed by the Three-step Theory (3ST) (Klonsky & May, 2015). Caution should be exercised that our model includes only a subset of risk markers and those at greatest risk of suicide are likely to experience a wide range of risk markers (Cassidy et al., 2022).

However, before pursuing future research, we should consider the comparison between autistic and non-autistic networks. Overall connectedness was consistent between autistic and non-autistic networks, but connections from mood symptoms with somatic and thwarted belonging experiences were absent for autistic adults, and feeling tired and like an outsider were significantly less inter-connected in the autistic than non-autistic network. These results suggest that somatic experiences described

in the PHQ-9 and GAD-7 are not the most pertinent to capture emotional change for autistic people. New tools to measure depression and anxiety have identified more precise somatic indicators for autistic adults, such as a *change* in fatigue, rather than the *presence* of fatigue (Cassidy, Bradley, Cogger-Ward, et al., 2021) and anxiety indicators, such as *feeling shaky* (Rodgers et al., 2016, 2020). Similarly, *feeling like an outsider* has already been identified as a less meaningful indicator of thwarted belonging for autistic than for non-autistic adults (Pelton et al., 2020a). Thus, our model takes an important first step in demonstrating how autistic adults experience general population risk markers but, may not yet capture unique risk markers for autistic adults. Additional stressors could include uncertainty (Boulter et al., 2014), pressures contributing to autistic burnout (Higgins et al., 2021; Mantzalas et al., 2022; Raymaker et al., 2020), and research could explore how the experience of those stressors is influenced by age (Stewart et al., 2022) or gender (Kölves et al., 2021) for autistic people to contribute to unique risk.

Our study highlights methodological challenges in comparing suicidal thoughts and behaviors for autistic and non-autistic adults. First, drawing on non-clinical samples, autistic adults report shockingly more frequent experiences of depression, suicidal thoughts, and behaviors than non-autistic adults; researchers should carefully consider recruitment and statistical methods for accurate comparison. Second, our findings suggest we may be reaching the limits of what we can infer about suicidal thoughts and behaviors for autistic adults using constructs and measurement tools designed for non-autistic adults. Commentary argues that research should focus on *relevant* experiences for autistic people rather than *statistically valid* non-autistic measurement tools (Jones, 2022) reflecting more general concerns about precise construct definition and accurate measurement for suicide and psychological theory (Bringmann et al., 2022; Lawson & Robins, 2021; Millner et al., 2020). Overall, this could suggest that future theory development take autistic lived experience as its starting point and articulate a model independent of non-autistic experience.

This study has several strengths: this is the first study to apply network analysis to explore suicide theory in autistic people responding to calls to go beyond single risk factor studies and apply novel, rigorous methods in a transdiagnostic approach (Franklin et al., 2017; Lombardo et al., 2019; Millner et al., 2020). The development of support, interventions, risk assessments, and crisis services for autistic adults (Cassidy, Cogger-Ward, et al., 2021; Jager-Hyman et al., 2020) is essential to meet global suicide prevention goals. This study is limited by an absence of valid measurement tools to explore suicidal thoughts and behaviors for autistic people at the time of

design. Researchers should consider using the recently published Suicidal Behaviours Questionnaire-Revised (Autism Spectrum Condition) (SBQ-ASC) (Cassidy, Bradley, Cogger-Ward, & Rodgers, 2021) or the Suicidal Ideation Attributes Scale-Modified (SIDAS-M) (Hedley et al., 2022). This study used self-report autism diagnosis, which falls short of “gold standard” confirmation of autism but allows for wider participation. The sample size is relatively small (see van Borkulo et al., 2022 for discussion on appropriate sample size) for group comparison network analyses); thus, future research could employ cohort, population studies, or simulation studies to replicate and extend our findings. Furthermore, our cross-sectional design cannot infer causality; thus, findings should be considered strictly exploratory, and taking a time-series or longitudinal approach should confirm intervention targets (Rath et al., 2019). Future network analyses could, thus, apply temporal analyses (Haslbeck & Waldorp, 2015) drawing on ecological momentary assessment (Rath et al., 2019), moderation analysis to explore how autistic characteristics (such as difficulty switching attention) moderate connections between risk markers (Haslbeck, Borsboom, et al., 2021) or cluster analysis to accurately define and measure constructs (Forkmann et al., 2018; Golino & Epskamp, 2017).

CONCLUSION

This study reports that being autistic represents a unique distal risk marker for suicidal thoughts and behaviors through feeling like an outsider, anxiety, and movement differences. Research should extend these exploratory findings using longitudinal study designs in partnership with autistic people, ensuring constructs are meaningfully defined to produce suicide theory that accurately reflects lived experience of autistic people. This will be vital to ensure tailored suicide prevention for autistic adults.

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SUPPORTING INFORMATION

Additional supporting information can be found online in the Supporting Information section at the end of this article.

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23.3.21

‘..belonging helps heal the damage caused by rejection and isolation. Providing a space where somebody feels they fit in and are accepted – a place where they belong-is an act of compassion.’

Chapter 6: General discussion

6.1 Overview

The studies in this thesis have extended our understanding of suicide amongst autistic adults by exploring, for the first time, the extent to which a leading suicide theory, the Interpersonal Theory of Suicide (ITS), describes the experiences of autistic adults. This thesis set out, in partnership with autistic people, to meet the research objectives set out in section 1.6 of the introduction. These included exploring whether gender hypotheses, pathways to suicidal thoughts and behaviours, and the role of mental health difficulties were consistent, and whether measurement properties of ITS questionnaires were equivalent, for autistic and non-autistic adults.

This chapter summarises thesis findings: Table 1 provides a breakdown of results showing where: (i) ITS hypotheses were consistently observed for autistic and non-autistic people; (ii) there was divergence between autistic and non-autistic adults; and (iii) ITS hypotheses were extended or not observed in autistic and non-autistic adults. I then set out how these findings contribute to the literature, clinical implications, identify strengths and limitations of the research and directions for future study. This thesis concludes that thwarted belonging and perceived burdensomeness are relevant experiences for autistic people to inform suicide prevention. However, the ITS currently lacks specificity and accuracy in its description of the development of suicidal thoughts and behaviours amongst autistic adults. Understanding and promoting belonging and self-worth in a meaningful manner for autistic adults should inform suicide prevention. Future theoretical suicide research should prioritise fully capturing autistic lived experience.

6.2 Key findings

Study 1 reported that working in partnership with autistic people led to many positive outcomes for the research, autistic collaborators and the researcher. Study focus was relevant, methods were accessible and resulted interpreted in a meaningful manner. Outcomes for autistic collaborators included contributing to better futures for autistic people, and I reported greater knowledge and confidence in my research. Greater consideration of theoretical approach to partnership working and stating planned outcomes could help build greater understanding and trust. Empirical Chapters reported the following key findings:

- **Models including thwarted belonging and perceived burdensomeness were less accurate for autistic than non-autistic people:** Study 2 reported that thwarted belonging and perceived burdensomeness were helpful to inform our understanding of suicide amongst autistic people but had less influence on suicidal thoughts and behaviours for autistic than non-autistic people. Study 3 reported that one reason for this might be that the measurement properties of the Interpersonal Needs Questionnaire-10 (INQ-10) that measure thwarted belonging and perceived burdensomeness were not equivalent for autistic compared to non-autistic people.
- **Anxiety and depression did not account for the reduced variance in thwarted belonging and perceived burdensomeness:** Study 4 added anxiety and depression to the path model set out in Study 3 and used the network approach to try to avoid measurement difficulties reported in Study 3.

Pathways connected being autistic with anxiety, feeling like an outsider and lacking caring and supportive friends. Thwarted belonging and somatic symptoms (sleep and appetite difficulties) connected these to failure, hopelessness, and burdensomeness, which connected directly to suicidal thoughts. With autistic collaborators, we co-produced the first conceptual model suggesting putative pathways from being autistic to suicidal thoughts. This model was less accurate for autistic compared to non-autistic people.

- **Hypotheses regarding suicidal capability were not upheld for autistic or non-autistic people:** The model set out in study 4 included only the development of suicidal thoughts because ITS hypotheses including suicidal capability and suicidal behaviour were not upheld in study 2, and measurement difficulties of the Acquired Capability for Suicide Scale (ACSS-FAD) were found in both autistic and non-autistic people in study 3. Study 2 reported trauma had less impact on suicidal behaviour for autistic than non-autistic people. Furthermore, perceived burdensomeness and thwarted belonging were associated with suicidal behaviour for autistic people.
- **Gender hypotheses were upheld for non-autistic people but not autistic people:** study 2 reported that ITS gender hypotheses were upheld for non-autistic people but not for autistic people. This was extended by study 4, which reported the same effect but additionally included those with possible, in addition to formal, autism diagnosis.

Overall, this suggests that the ITS is less accurate to describe the experiences of autistic compared to non-autistic people. The construct of suicidal capability needs further development for autistic and non-autistic people.

Study	ITS hypotheses observed in autistic people	ITS hypotheses diverge between autistic and non-autistic adults	ITS hypotheses are not observed or are extended in autistic and non-autistic adults
Study 2: Exploring the Interpersonal Theory of Suicide in autistic and non-autistic adults	Autistic people report significantly more frequent thwarted belonging and perceived burdensomeness than non-autistic people	Associations between perceived burdensomeness, thwarted belonging and suicidal thoughts and behaviours were attenuated for autistic people compared to non-autistic people	There was a direct pathway from trauma to suicidal thoughts and behaviours and no mediation via suicidal capability in autistic and non-autistic adults
	For autistic and non-autistic people, autistic characteristics are associated with suicide through perceived burdensomeness and thwarted belonging	Association between trauma and suicidal thoughts and behaviours was attenuated for autistic compared to non-autistic people	Three-way interaction of suicidal capability, perceived burdensomeness and thwarted belonging was not observed in autistic or non-autistic adults
		Two-way interaction of perceived burdensomeness and thwarted belonging with suicidal thoughts was observed in non-autistic but not in autistic adults	
		Gender patterns of proximal risk factors were observed in non-autistic but not for autistic adults	
Study 3: A measurement invariance analysis of the INQ-10 and the ACSS-FAD		INQ-10 Perceived Burdensomeness subscale was non-invariant for autistic and non-autistic people, with all items showing non-invariance	ACSS-FAD met criteria for strict invariance but suggested response difficulties for autistic and non-autistic adults
		INQ-10 Thwarted Belonging subscale was non-invariant between autistic and non-autistic people with two items demonstrating non-invariance	
Study 4: The role of anxiety and depression in suicidal thoughts for autistic and non-autistic adults: a theory driven network analysis	Being autistic connected to suicidal thoughts through perceived burdensomeness and thwarted belonging	The network was less strongly inter-connected for autistic people, despite more frequent reports of each experience amongst autistic than non-autistic people	Thwarted belonging was indirectly connected to suicidal thoughts through perceived burdensomeness for autistic and non-autistic adults
		Edges connecting somatic experiences with mood or thwarted belonging experiences were missing or different for autistic compared to non-autistic people	Failure and hopelessness were proximal to suicidal thoughts alongside burdensomeness for autistic and non-autistic adults
		Nodes 'feeling tired' and 'feeling like an outsider' were relatively less influential in the network for autistic than non-autistic people	
		Data split according to gender in the non-autistic group but not in the autistic group	

Table 1: Summary of key findings of this thesis showing findings indicating (i) the ITS is upheld in autistic people; (ii) ITS models diverge between autistic and non-autistic people; and (iii) hypotheses are not observed or are extended in autistic and non-autistic people

6.3 General discussion: Theoretical implications

Working in partnership with autistic people led to many benefits for the research, researchers, and autistic collaborators. This reflects longstanding research reporting positive potential positive benefits of including those with lived experience in health, suicide and autism research (Fletcher-Watson et al., 2019; Nicolaidis et al., 2019). There may be particular value for researchers in working in partnership with autistic people to explore suicidal thoughts and behaviours because it is a clearly identified community research priority (Cassidy et al., 2021; Cusack & Sterry, 2020) with a lack of meaningful evidence from within the literature (Cassidy et al., 2018). In this programme of study more impacts on the research were recorded at earlier stages of the research, which could reflect the fact that policy and real-life impact take time (Kessler & Glasgow, 2011) and are influenced by a range of other factors, such as population needs, available resources, competing priorities and political power (Gore & Parker, 2019; Reifels et al., 2022). Participatory work could state a theoretical position, which might help researchers to understand *how* participation processes can bring better outcomes. This would reflect established good practice in participatory autism research in the AAspire programme which states a theoretical commitment to community based participatory research principles (Nicolaidis & Raymaker, 2015). Researchers could state planned outcomes for participation processes that can be accounted for at the end of the research. Both of these could build trust, a well-documented principle of partnership working (Nicolaidis et al., 2019; Webb et al., 2023) and avoid treating autistic people in a tokenistic manner in research (Dawson & Fletcher-Watson, 2022). Researchers should continue to extend and develop our practice, share, and learn from our experience and extend our methods to ensure that the lived, inner experiences of autistic people are more widely reflected in suicide prevention.

6.3.1 Thwarted belonging and perceived burdensomeness have informed our understanding of suicide in autistic people
Studies 2 and 4 supported the ITS hypothesis that distal risk factors - such as neurodevelopmental conditions, including autism – contribute to suicidal thoughts because they increase likelihood of experiencing perceived burdensomeness and thwarted belonging. The focus on thwarted belonging and perceived burdensomeness is conducive with views in the autistic community that taking into account the social marginalisation of autistic people is important for suicide prevention (Milton, 2017). This reflects research describing more frequent unemployment (Riedel et al., 2016), support into adult life (Graetz, 2016; Mason et al., 2018), loneliness and relationship difficulties (Causton-Theoharis et al., 2009; Mazurek, 2014) and in line with research describing that improving belonging (such as promoting autism acceptance) (Cage et al., 2018) and reduce burdensomeness (such as promoting employment) (Davies et al., 2023) reflect identified priorities for improving quality of life for autistic adults (Mason et al., 2018) (Mason ...). This extends the findings of my MSc thesis in a non-autistic young adult sample (Pelton & Cassidy, 2017), and is supported by subsequent studies in non-autistic military adults (Smith et al., 2021; Stanley et al., 2021) and in autistic and non-autistic adults (Dow et al., 2021; Moseley et al., 2022). Subsequent research has extended findings in this thesis to explain that social camouflaging (masking autistic characteristics to be socially acceptable) may contribute to suicidal thoughts and behaviours because it increases the experience of thwarted belonging (Cassidy et al.,

2019). This explains how masking the 'real you' to appear socially acceptable precludes the development of genuine reciprocal relationship meaning relationships lack the protective capacity of genuine connectedness (Mitchell et al., 2021; Van Orden et al., 2010) This suggests that thwarted belonging and perceived burdensomeness are meaningful to explain the development of suicidal thoughts and behaviours for autistic people and findings from this thesis have already been used to extend our understanding.

6.3.2 Being autistic may increase risk of general population risk factors
Study 4 extended the model of thwarted belonging and perceived burdensomeness in study 2 by proposing the first model, shown in Figure 1, of *how* being autistic may lead to putative pathways to suicidal thoughts, including common mental health difficulties: anxiety and depression. Being autistic connected to stressors resulting from the physical and social environment, such as feeling like an outsider, lacking friends and anxiety. This reflects longstanding research that being 'othered', excluded, having unmet friendship needs and daily anxiety are common experiences for autistic adults (Chown & Beavan, 2012; Davis et al., 2011; Eaves & Ho, 2008; Mason et al., 2018; Michael, 2021). For the first time, the model describes a distal role for anxiety in the suicidal thoughts for autistic adults, previously only explored in autistic children (Bal et al., 2022; Dickerson Mayes et al., 2015), reflecting research describing that anxiety may be a distal risk factor for suicide for non-autistic people (Bentley et al., 2016; Fisher et al., 2017; Kaiser et al., 2021). Somatic changes, such as sleep and appetite difficulties, represent the erosion of coping strategies providing a bridge from daily traumas to believing others would be better off without you, hopelessness, and failure, which were proximal to suicidal thoughts. This model extends research describing that depression is a consistently reported suicide risk factor in autistic and non-autistic people (Nock et al., 2008; Zahid & Upthegrove, 2017) by identifying hopelessness (Beck, 1986; Weishaar & Beck, 1992), failure (Chatard & Selimbegović, 2011) and burdensomeness (Camm-Crosbie et al., 2019; Hill & Pettit, 2014) as particularly potent indicators of suicidal thoughts. These detailed pathways support research advocating that more helpful insight is provided by considering depression as its individual constituent experiences, rather than total scores (Fried & Nesse 2015). In summary, this model suggests pathways to suicidal thoughts result from stressors in the environment, that are more likely to be activated for autistic people.

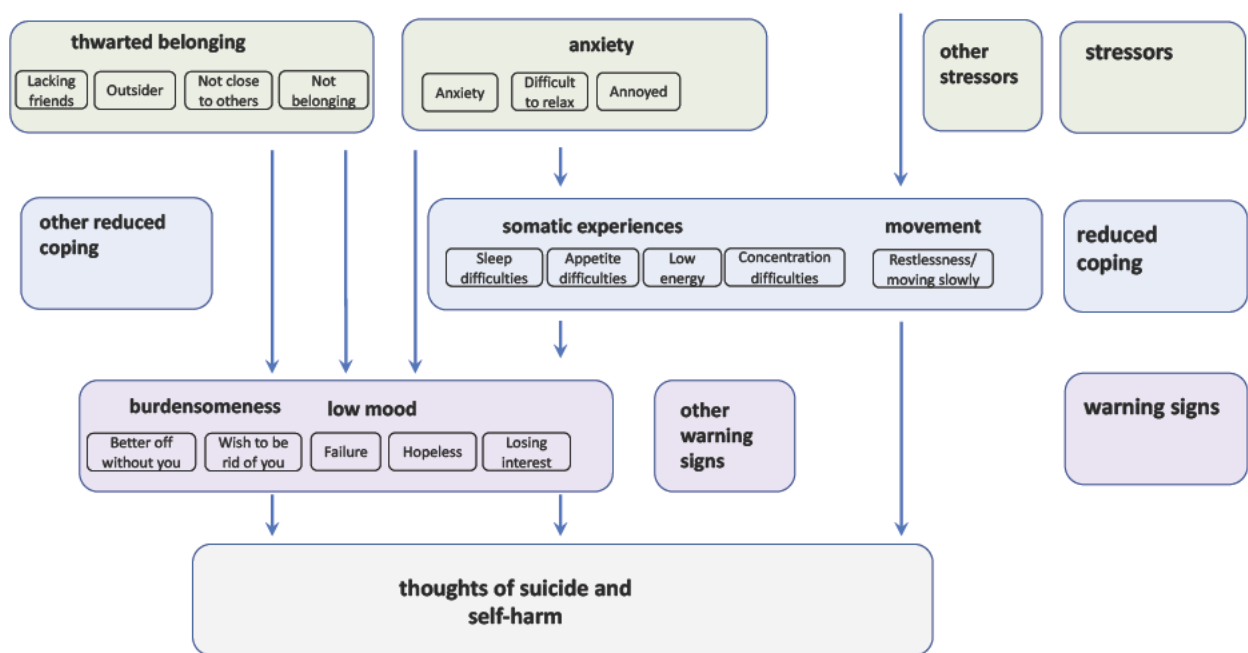


Figure 1: Conceptual model of the development of suicidal thoughts developed from network model (reproduced from Chapter 5)⁷.

Theoretically, thwarted belonging was distal, whilst perceived burdensomeness, hopelessness and failure were proximal to suicidal thoughts. These findings reflect network analyses describing an indirect association of thwarted belonging through perceived burdensomeness with suicidal thoughts (De Beurs et al., 2019; Ordóñez-Carrasco et al., 2021) and a systematic review describing that perceived burdensomeness is more strongly associated with suicidal ideation than thwarted belonging (Chu et al., 2017). An alternative possibility is that the items measuring thwarted belonging describe a more general absence of belonging rather than the chronic, enduring social disconnection that might leave an individual vulnerable to suicide. This may be particularly the case for autistic people: a practitioner guide drawing on work in this thesis advises that *changes* in the nature of socialising and connectedness may be a more accurate risk assessment factor for an autistic person, given different social preferences to non-autistic people (Morgan et al., 2021). These findings represent an extension of the proximal role of thwarted belonging and perceived burdensomeness. Furthermore, connections between not belonging and a sense of failure, could also reflect the failed social struggle of defeat and entrapment (Gilbert & Allan, 1998) central to the Integrated-Motivational Volitional (IMV) model (O'Connor, 2011) and the 'tipping point' in the Three-step theory (3St) where connectedness is overwhelmed by multi-dimensional psychological pain (Klonsky et al., 2021; Shneidman, 1993). This suggests that autistic people may be more likely to experience risk factors, such as mental health difficulties but

⁷ The model is drawn with gaps to suggest that it contains only a subset of many possible risk factors.

pathways from mental health to suicidal thoughts extend hypotheses of the ITS and could reflect conceptual pathways from other theories.

6.3.3 Models including thwarted belonging and perceived burdensomeness and mental health are less accurate for autistic compared to non-autistic people
The conceptual model, shown in Figure 1, should be applied with caution because all statistical models in this thesis, that included perceived burdensomeness and thwarted belonging, were less accurate, explained less of the variance or operated differently for autistic compared to non-autistic adults. Study 2 reported thwarted belonging and perceived burdensomeness had less impact on suicide for autistic than non-autistic people. One compelling explanation for this is that questionnaires designed to measure perceived burdensomeness and thwarted belonging did not fully capture the experiences of autistic people. Study 3 reported all items of the INQ-10 perceived burdensomeness subscale were differently interpreted by autistic compared to non-autistic people. This could suggest that autistic people were less confident in inferring how ‘people in my life’ feel towards them than non-autistic people, in line with the double empathy problem, that describes mutual misunderstanding between autistic and non-autistic people (Milton, 2012; Milton et al., 2022). This could also suggest a fundamentally different experience of burdensomeness: data screening revealed that burdensomeness was normally distributed in autistic people, rather than rarely occurring as hypothesised by Van Orden (2008) and as observed in non-autistic people. This is in line with regular discourse referring to the ‘burden’ of autism on society (Baxter et al., 2015; Leigh & Du, 2015; Solmi et al., 2022) and families (Cadman et al., 2012; Ou et al., 2015) reflecting ‘ableism’ - a system of discrimination, which influences how people talk about and perceive autistic people (Bottema-Beutel et al., 2021). This could suggest that current conceptualisations of burdensomeness are based on assumptions of non-autistic experience and do not reflect the deeper inner experience of burdensomeness resulting from society’s characterisation of the reduced value of autistic people compared to non-autistic people.

Within the thwarted belonging subscale of the INQ-10, those items measuring ‘belonging’, ‘disconnectedness’ and ‘having caring and supportive friends’ were experienced similarly by autistic and non-autistic people. This suggests similarities between autistic and non-autistic people in: (i) the importance of family and friends, connectedness and social identities (Botha et al., 2022; Cage et al., 2022; Lam et al., 2020; Maitland et al., 2021); and (ii) negative impact of loneliness and absent social connections (Causton-Theoharis et al., 2009; Moseley & Sui, 2019). In studies 3 and 4, the items ‘I feel like an outsider at social gatherings’ and ‘feeling close to other people’ operated differently, suggesting that these items are less accurate indicators of significant thwarted belonging for autistic compared to non-autistic people. This could suggest that “outsider-ness” is a fundamental component of the experience of being autistic rather than one uniquely associated with suicide risk (Milton et al., 2023) and that spending time alone may be important for recovery and to avoid burnout. These findings are in line with previous research describing that belonging may comprise distinct experiences for autistic people (Jaswal & Akhtar, 2019; Milton & Sims, 2016) and by subsequent studies extending research in this thesis to describe belonging as a particularly important protective factor (Mournet

et al., 2023). This suggests that there may be distinct behavioural indicators of belonging for autistic people and that the nature of belonging may be influenced by society's lack of inclusion of autistic people.

These findings reflect a broad body of research describing that measurement tools designed to capture mental health and suicidality experiences of non-autistic people do not accurately capture the experiences of autistic people (Cassidy et al., 2018; Cassidy et al., 2018). In study 4 somatic symptoms (e.g., appetite and sleep difficulties) and thwarted belonging experiences were independent of mood symptoms for autistic people, whilst these were connected for non-autistic people. This is in contrast with reports in the literature that somatic experiences, such as difficulties with food and sleep are widely reported in relation to emotional distress for autistic people (Crane et al., 2017). A more likely explanation is that the items of the Patient Healthcare Questionnaire (PHQ-9) (Kroenke et al., 2001), Generalized Anxiety Disorder-7 (GAD-7) (Spitzer et al., 2006) and INQ-10 (Hill et al., 2015; Van Orden et al., 2012) do not fully capture the inner experiences or external indicators of depression, anxiety, thwarted belonging, and perceived burdensomeness for autistic people (Gotham et al., 2015). This is in line with research describing that for autistic people, *changes* rather than the presence of somatic symptoms may be more accurate indicators of depression (Cassidy, Bradley, Cogger-Ward, Graham, & Rodgers, 2021) and anxiety may be measured by distinct somatic experiences, such as feeling 'shaky' (Rodgers et al., 2020). This is consistent with current importance in autism research on measuring *relevant* constructs (Jones, 2022) and the importance of accurate construct measurement and definition in suicide research (Bringmann et al., 2022; Millner et al., 2020). This suggests that the way that we measure and conceptualise mental health and suicide risk factors is currently described using experiences that are relevant for non-autistic people. Descriptions may currently lack meaningful behavioural indicators, meaningful descriptions of the internal experiences of autistic people as well as acknowledging the influence of social context for autistic people.

6.3.4 Suicidal behaviour may develop differently for autistic than non-autistic people, but reduced fear of death may offer little insight
The model (Figure 1) explains only suicidal thoughts because hypotheses regarding suicidal capability, as measured by reduced fear of death, were not upheld in study 2 and study 3 reported measurement difficulties with the ACSS-FAD (Ribeiro et al., 2014) for autistic and non-autistic people. Study 2 reported that suicidal behaviour was not explained by the interaction of suicidal capability with perceived burdensomeness and thwarted belonging. This reflects findings of a systematic review and meta-analysis that reported this finding across most studies that have explored suicidal capability (Chu et al., 2017; Ma et al., 2016). Furthermore, lifetime trauma was directly associated with suicidal thoughts and behaviours rather than through suicidal capability as hypothesised by the ITS. One possibility could be that the broad measure of trauma used here - the Vulnerabilities Experience Quotient (Griffiths et al., 2019) - hid nuances of a more complex relationship. For example, research asserts that different types of traumas differently impact suicidal thoughts versus behaviours: being a victim of violence, such as experiencing abuse, may be associated with suicidal ideation, whilst self-directed violence or self-restraint is associated with suicidal behaviour (May & Victor, 2018). This

could reflect Joiner's assertion that capability is acquired most quickly via attempting suicide and more slowly by other experiences (Joiner, 2005). An alternative explanation could be that our combined outcome measure of suicidal thoughts and behaviours could have inflated the direct effect by also capturing elements of trauma associated with suicidal thoughts through anxiety and depression (Griffiths et al., 2019; May & Victor, 2018). However, results should also consider that research seeking to provide empirical proof of the development of suicidal capability in dose-response relationship to painful and frightening experiences has yet to yield significant results (Bryan et al., 2016; Ribeiro et al., 2020). This suggests that there remains uncertainty regarding the exact nature of the relationship between trauma, suicidal capability and suicidal thoughts and behaviours for non-autistic people (Harris & Ribeiro, 2021), which makes it difficult to infer whether these relationships are equivalent for autistic people.

One possible explanation is that the multiple changes to the body's fear and pain systems described as central to suicidal capability were not fully captured by the single dimension construct of a reduced fear of death as defined by the Acquired Capability for Suicide Scale- Fearlessness About Death (ACSS-FAD) (Ribeiro et al., 2014). The ACSS-FAD operated equivalently for autistic compared to non-autistic people but both groups experienced response difficulties with negatively worded items. This is in line with research reporting weak validity of measures of the ACSS-FAD and measures of suicidal capability (Rimkeviciene et al., 2017; Rogers et al., 2021; Shahnaz et al., 2020) and observations that suicidal capability may be "broadly defined but narrowly measured" (Ribeiro et al., 2021). Research suggests that suicidal capability is broader than Joiner's original conceptualisation, comprising genetic (such as pain tolerance), trait-like (such as agitation) and state-like (such as intoxication or psychotic states) contributions (May & Victor, 2018). Notably, both IMV and 3St have expanded suicidal behaviour beyond suicidal capability: the 3St includes dispositional and practical contributors (Klonsky & May, 2015) and within the IMV suicidal capability is one of several volitional moderators that enable suicidal behaviour (Klonsky & May, 2015; O'Connor & Kirtley, 2018). A broader conceptualisation of suicidal capability is supported by findings from a study in autistic adults that implemented the recommendation from study 3. The multi-dimensional Acquired Capability for Suicide with Rehearsal Scale (ACWRSS) (George et al., 2016) which includes dimensions of pain tolerance and mental preparation for suicide as well as fearlessness about death. As expected, using this measure explained 50% of the variance in suicidal thoughts and behaviours (Moseley et al., 2022) compared to 10% (Pelton et al., 2020) in study 3 of this thesis. In summary, this suggests consensus that the construct of suicidal capability is more broadly defined than by the single dimension of the ACSS-FAD but there remains no clear consensus on an alternative measurement tool.

My results indicate, for the first time, divergence of theoretical risk factors for suicidal behaviour between autistic people and non-autistic people. The association between trauma and suicidal thoughts and behaviours was attenuated for autistic compared to non-autistic adults. Traumatic experiences, such as sexual abuse, interpersonal abuse (Lilley et al., 2022) may be so common for autistic adults, that they are part of 'normal' life (Crane et al., 2017; Pearson et al., 2022) rather than uniquely associated with suicidal thoughts and

behaviours. Furthermore, more frequent perceived burdensomeness and thwarted belonging were associated with suicide attempt, rather than uniquely with suicidal ideation, as hypothesised. This could support a hypothesised quicker transition to suicidal behaviour for autistic compared to non-autistic adults (Kato et al., 2013). However, this result should be interpreted in the context of similar findings of a systematic review (Chu et al 2017) and studies in clinical samples (Hill & Pettit, 2014), such as women with borderline personality disorder (Brown et al., 2002), methadone users (Conner et al., 2007), military samples (Bryan et al., 2010; Bryan, Ray-Sannerud et al., 2013; Bryan, Hernandez et al., 2013). This could reflect criticism of theory testing and building in undergraduate samples where results do not generalise clinical or general population samples (Hanel & Vione, 2016), which could suggest ITS core hypotheses apply less accurately for clinical samples or those with more severe symptoms. A further possible explanation proposed is that particularly intense suicidal ideation (represented by very frequent perceived burdensomeness and thwarted belonging) may be a risk factor for suicidal behaviour (Joiner et al., 2003). Such an explanation may be relevant to autistic people who report particularly enduring, intense suicidal ideation (South et al., 2020). This supports research describing different risk factors for suicidal behaviour amongst autistic than non-autistic adults (Chen et al., 2017). One notable contribution is autistic burnout, which argues that suicidal behaviour can result from the ongoing struggles of coping as an autistic person with the demands of a non-autistic world (Raymaker et al., 2020). Overall, this suggests that there may be differences in the development of suicidal behaviour amongst autistic than non-autistic people, but these were not highlighted in models using the ITS construct of suicidal capability. Suicidal capability may be more broadly defined than the single scale of fearlessness about death.

6.3.5 The ITS lacks specificity regarding gender differences in suicidal thoughts and behaviours

Gender differences proposed by the ITS (Van Orden et al., 2008), were upheld for non-autistic people but not for autistic people and this pattern of results was consistent in study 2 (autistic people with a formal diagnosis) and study 4 (autistic people with formal and possible diagnosis). Study 2 reported that non-autistic men reported significantly elevated suicidal capability and less frequent perceived burdensomeness than non-autistic women, but this effect was not observed for autistic people. Our results reflect other studies reporting no significant difference in frequency of suicide risk factors between autistic men and women (Arwert & Sizoo, 2020; Cassidy et al., 2018). One possibility is that the constructs of thwarted belonging, perceived burdensomeness and suicidal capability do not fully capture the risk that develops as a result of the discriminations experienced by autistic women, including misdiagnosis of mental health difficulties, interpersonal abuse, unmet support needs and identity difficulties (Belcher et al., 2023; Cassidy et al., 2018; Pearson et al., 2022; Stagg & Belcher, 2019). This would support a position that risk factors operate differently for autistic compared to non-autistic women (Kölves et al., 2021) but such differences are not fully captured by the ITS constructs. These results should be considered in the context of evidence of broader differences in gender experience amongst autistic than non-autistic people. In line with other studies, my analysis was influenced by a significant number of autistic people reporting non-male, non-female gender identities (Cooper et al., 2018; Fletcher-Watson & Happe, 2019). This could reflect research describing a broader process

of challenging gender norms as a part of the journey to autistic identity (Moore et al., 2022). This suggests that the ITS does not currently explain gender differences in suicidal behaviour in autistic adults and that gender may be differently experienced by autistic people.

One important contribution is that findings are consistent for autistic women with and without a formal autism diagnosis. Studies reporting gender analyses of suicide amongst autistic people report an overall pattern of relatively increased risk amongst autistic women, but with some differences in *how* this is reported. Here, I reported no significant difference in suicidal thoughts and behaviours between autistic men and women, in line with other studies (Cassidy et al., 2018) and in lined with studies reporting rates of death by suicide (Kölves et al., 2021). By contrast, other studies report more frequent suicidal behaviour by autistic women than men (Kölves et al., 2021), as well as more frequent death by suicide amongst autistic women compared to non-autistic women (Kirby et al., 2019) and autistic men (Hirvikoski et al., 2020; Hirvikoski et al., 2016). Inconsistency in results is typically attributed to bias against, and reduced access to, diagnostic processes for autistic women: Kirby and colleagues (2019) reflect that reported deaths by suicide amongst autistic women increased with increased recognition of autism in women. A study reporting more frequent death by suicide amongst autistic men than women attributed this to lack of awareness of autism in women in Taiwan (Tsai et al., 2023). This suggests that suicide risk may remain under-reported in studies that rely on formal diagnosis. However, our study falls short of including all those who have not even considered the possibility they may be autistic, suggesting that reaching these people could be a significant priority for suicide prevention. This suggests that to accurately capture suicide in autistic women, it is important to consider those without formal diagnosis.

6.3.6 Theoretical conclusion

The work presented in this thesis reports that thwarted belonging and perceived burdensomeness are helpful to inform our understanding of suicidal thoughts and behaviours in autistic adults. However, findings suggest that similar to mental health conditions, current conceptualisations of thwarted belonging and perceived burdensomeness may not reflect inner experiences of autistic people, behavioural indicators and the pressures of the social environment for autistic people. Findings regarding suicidal behaviour were limited by a lack of support for ITS hypotheses which included suicidal capability. Findings suggested some differences in the development of suicidal behaviour, again, reflecting that measures of trauma may not fully capture autistic experience. Results of gender comparisons suggest that gender may be experienced differently by autistic and non-autistic people, and autistic people with possible, rather than autism diagnosis may be at similar risk to those with formal diagnosis. Findings were significantly informed by including those with lived experience of suicidal thoughts and behaviours.

6.4 Clinical implications

6.4.1 Autistic women should not be assumed to be at low risk of suicide

Results of studies 2 and 4 were consistent in reporting that frequency of risk factors differed only by gender in the non-autistic group. This suggests gender differences in suicidal behaviour and risk factors remain less understood for autistic compared to non-autistic people. At the very least, the consistent pattern in non-autistic people of men being at higher risk of suicide than women, should not be assumed for autistic people. Diagnostic bias against autistic women, where women are less likely to be diagnosed as autistic than men even when presenting with the same characteristics (Lai et al., 2015; Mandy et al., 2012) means clinicians should be aware of and consider the possibility of undiagnosed autism given its consistent association with suicide risk (Carbone et al., 2018; Cassidy et al., 2022; Richards et al., 2019). Facilitating access to diagnosis can lead to improved self-identity, access to support and reduce distress (de Broize et al., 2022). Clinicians should further be aware that gender may be experienced differently by autistic than non-autistic people with non-male/female gender identities being much more common amongst autistic people (Warrier et al., 2020). Particular attention should be paid to suicide risk in these groups, where in non-autistic samples, suicide rates have been notably high (Grossman & D'Augelli, 2007). In summary, it is important not to apply non-autistic assumptions about gender-based suicide risk to autistic people, and to consider the possibility of undiagnosed autism, particularly amongst women.

6.4.2 Promote an inclusive environment, autism acceptance and belonging for autistic people

The model outlined in Figure 1 allows interventions to be conceptualised at distinct levels. At the distal level, promoting a supportive, enabling environment for autistic people could prevent development of more severe symptoms: this could include reducing stigma and promoting autism acceptance (Cage et al., 2018; Michael, 2021), promoting belonging and social connections, autistic-led spaces and positive autistic identity (Cooper et al., 2023; Hill & Katusic, 2020; Milton & Sims, 2016). Autism acceptance is associated with reduced need for social camouflaging, particularly less need to mask repetitive behaviours, which reduce anxiety (Griffith et al., 2012; Mandy, 2022). Promoting understanding of autism based on the double empathy problem (i.e., mutual misunderstanding between autistic and non-autistic people) offers validity and acceptance to autistic communication styles and reduces the need for masking (Cassidy et al., 2019; Mitchell et al., 2021). Autism acceptance could include reducing sensory overload in the physical environment and acceptance of the need for routine and support to cope with uncertainty (South & Rodgers, 2017) which can lead to more effective support for individual difficulties (Rodgers & Ofield, 2018). Thus, promoting autism acceptance can reduce environmental stressors.

6.4.3 Reduce experiences of failure, hopelessness, and burdensomeness

The model presented in Figure 1 highlights that failure, hopelessness, and burdensomeness are proximal to suicidal thoughts and behaviours suggesting they could constitute suicide *warning signs*. This suggests that promoting self-worth, autonomy and independence are important as protective factors. The model proposes

that burdensomeness develops from thwarted belonging meaning that promoting coping mechanisms, such as social support (Hedley et al., 2017), and community connectedness (Botha et al., 2022; Cage et al., 2022) can prevent the development of burdensomeness. Meeting support needs, such as financial or physical needs, promoting independence through employment could prevent the development of perceptions of burdensomeness (Cassidy et al., 2018; Scott et al., 2015). Clinician training could raise awareness of expressions of burdensomeness or failure, such as clients stating they feeling unwanted or apologising for needing assistance (Hill & Katusic, 2020). Burdensomeness, hopelessness and failure could be integrated into risk assessments and safety planning (Rodgers et al., 2023; Schwartzman et al., 2021), and interventions could include identifying appropriate and meaningful social supports and psychoeducation on the role of burdensomeness (Hill & Katusic, 2020). This also highlights the importance of access to timely, tailored mental health and crisis services to avoid unsuccessful help-seeking which can contribute to feelings of burdensomeness (Camm-Crosbie et al., 2019; Mandy, 2022; Mournet et al., 2023).

6.4.4 Reduce traumatic experiences but there may be other risk factors for suicidal behaviour

Study 2 reported that autistic people experience more frequent traumatic life experiences than non-autistic people, and these traumatic experiences are associated with suicidal thoughts and behaviours. This means that, as a society, law enforcement, courts, schools, and workplaces should protect the safety of autistic people and reduce incidents of interpersonal violence, stigma, exclusion and bullying (Cage et al., 2018; Maïano et al., 2016; Pearson et al., 2022). Clinical services should provide tailored, effective support for autistic people to recover from the effects of trauma (Allely & Faccini, 2019; Kerns et al., 2015). Study 2 also reported that risk factors for suicidal thoughts amongst non-autistic people may be associated with suicidal behaviour for autistic people. This means that assumptions of 'low-risk' presentation amongst autistic people should be challenged in line with research that autistic people can be mistakenly assumed to be coping due to non-typical presentation of distress (Camm-Crosbie et al., 2019). This suggests the need for effective support for trauma and avoiding assumptions based on our understanding of suicide amongst non-autistic people.

6.4.5 Devise autism-specific interventions and apply a personalised approach

Studies 2, 3 and 4 report the ITS was less accurate to explain suicide for autistic compared to non-autistic people, which suggests that there may be a need for tailored care pathways for autistic people who experience suicidal thoughts and behaviours. This is in line with other research describing distinct models of anxiety and eating disorders that have been used to pilot tailored interventions for autistic people (Brede et al., 2020; Wigham et al., 2015) and community calls for tailored treatments and support for suicidal thoughts and behaviours (Cassidy et al., 2021). Study 1, participatory methods evaluation, provides some guidance that could be potentially useful in co-producing interventions and autism-specific care pathways. Results reflect guidance highlighting the importance of creating safe spaces to explore issues of mental health and suicide (Webb et al., 2023), the need for all parties to be fully committed to a collaborative approach (Nicolaidis et al., 2019), establishing and monitoring personal support needs. Such approaches have been applied to develop an

effective, tailored intervention to cope with anxiety (Rodgers et al., 2017), and are currently being applied in study to develop a tailored suicide safety for autistic people (Rodgers et al., 2023).

Clinicians should pay close attention to the fact that standardised questionnaires do not accurately measure experiences such as anxiety, depression, thwarted belonging, and perceived burdensomeness in autistic adults. During this programme of study, validated measures to capture suicidal thoughts and behaviours, depression and anxiety in autistic adults have been developed, however, these measures are currently only validated for research (Cassidy et al., 2021; Cassidy et al., 2021; Rodgers et al., 2020). One clinical alternative to validated measures is to concentrate on understanding individual needs: the 'know your own normal' allows for self- and clinician- monitoring of mood and somatic changes meaningful to an autistic person (Crane et al., 2017). Taking a personalised approach may constitute good practice given widespread acknowledgement of diverse characteristics, presentation, and co-occurring conditions amongst autistic people (Singhi & Malhi, 2023). Clinicians should be aware autistic people may have had previous poor experiences of help-seeking and should apply a person-centred approach with patience (Camm-Crosbie et al., 2019; Hume, 2022).

6.5 Strengths and limitations

6.5.1 The first large-scale comparison of a suicide theory

This thesis reports the results of the first large scale study of suicidal thoughts and behaviours in autistic and non-autistic people that applies a well-validated suicide theory and responds to calls from within the literature and within the autism community for theoretically based suicide research (Cassidy & Rodgers, 2017; Cassidy et al., 2021; Segers & Rawana, 2014). Thus, it explores an under-researched area and provides a foundation for more detailed theoretical modelling work within the academic community to better describe the experiences of autistic adults using theoretical models. It provides clinicians with a point of reference to adjust suicide models and support for autistic clients. This foundation is vital to respond to inform other practice-based priorities, such as accurate identification of those at risk of suicidal thoughts and behaviours, appropriate adaptation of interventions and designing and delivering crisis services that facilitate help-seeking behaviours (Cassidy et al., 2021). This study is the first to explore measurement properties of suicide theory validated questionnaires in a large sample of autistic adults and compare the responses with a matched sample of non-autistic adults. This is vital to inform how suicide assessment tools may need to be tailored to enable clinicians to accurately identify risk in autistic people. In summary, the studies in this thesis add significantly to the existing evidence in support of the need for tailored approaches to suicide prevention for autistic adults.

6.5.2 Methodologically innovative

This study uniquely applied network analysis, for the first time, to extend findings beyond a latent variable approach and used this data driven model to devise a conceptual model in partnership with autistic people. Using network analysis responds to calls (i) in the autism mental health literature for transdiagnostic approaches (Weiss, 2014) and (ii) in the suicide literature to apply novel, rigorous methods, data-driven

approaches to increase the impact of suicide research (de Beurs et al., 2021; Millner et al., 2020). This data driven approach was particularly helpful to generate novel putative pathways and we extended a purely data driven approach by discussing the results with people with lived experience of suicide and mental health difficulties to produce the first conceptual model of suicide for autistic adults. Such an approach may be particularly applicable to the case of autistic people, where diagnostic categories are widely reported not to describe their experiences (Au-Yeung et al., 2019). Network analysis uncovered and addressed other significant features of the data, such as overlap between items measuring perceived burdensomeness (e.g., the people in my life would be better off if I were gone/ would be happier without me) and that anxiety cognitions (feeling nervous/ feeling afraid) operated similarly within the network. This suggests that extending methodological techniques can provide insight beyond traditional techniques.

6.5.3 Limitations of validated questionnaires

Limitations of this research are that it has used measures designed for non-autistic people due to a lack of validated measures at the time of design. Study 2 employed the single outcome variable of combined suicidal thoughts and behaviours which meant that it was not possible to test specific outcome variables of suicidal thoughts versus suicide attempts, but this item was known to be a statistically valid comparative measure of suicidal thoughts and behaviours at the time of design of this study (Cassidy et al., 2020). We worked with the Design Group to identify their preferred measures of anxiety and depression from amongst those validated for non-autistic people, but standardised questionnaires were still the most widely reported negative experience. Results demonstrate the challenges of measuring trauma and the impact of trauma. In agreement with the scale author, I expanded the published response scale ('yes' or 'no') of the Vulnerabilities Experience Quotient (VEQ) (Griffiths et al., 2019) to use a response scale of 'never', 'once' or 'more than once' to give some indication of the frequency of trauma but this is still likely to more accurately capture breadth and under-report intensity and duration of trauma, given wide-ranging reports of daily traumatic experiences by autistic adults (Pearson et al., 2022). This reflects wide-ranging research describing the difficulty of assessing trauma using standardised questionnaires (Eklund et al., 2018; Weathers & Keane, 2007) given that the impact of trauma is acknowledged to differ between individuals based on wide-ranging context factors (Spence et al., 2019). Furthermore, it is important to note that using network analysis highlighted that measurement difficulties remain even when an item-based approach is applied. In chapter 5, significant differences are reported in mean sum scores of thwarted belonging and perceived burdensomeness between autistic and non-autistic people in Chapter 5. This finding should be considered in the context of non-invariance described in Chapter 4. This highlights the central importance of accurate measurement for understanding trauma, mental health and suicidal thoughts and behaviours.

6.5.4 Representativeness of sample

Both autistic and non-autistic samples may not be representative of the general population suggesting that there may be limitations to the generalisability of results. For example, in the autistic group described in Chapter 3, over 30% of the sample are in full-time employment compared to the only 22% being in any form of

employment in a recent published report (Putz et al., 2021) This could suggest that autistic people beyond this study may be more vulnerable than those described here. The same limitation applies to the non-autistic sample, where 45% of participants have a post-graduate degree, which could suggest the sample is drawn from a university sample. Furthermore, all studies include over 50% of the autistic sample as women, which does not reflect the published prevalence. This was potentially helpful however as it enabled us to explore gender differences in suicidal behaviour. Future studies should continue to seek representative, diverse samples, including those at high risk of suicide, such as non-binary and sexual minorities, and seek representative non-autistic samples. Research should also consider representative datasets, such as population samples and health service client data.

Thesis findings should be interpreted in the context that potential confounding variables were not controlled for in statistical analysis. Including potential confounds increases the accuracy of statistical models and could have informed our insight into whether demographic variables, such as age (Stewart et al., 2022) and gender (Hirvikoski et al., 2016) may operate differently for autistic compared to non-autistic people. However, co-variables also reduce statistical power and choosing co-variables in exploratory suicide research should be approached with caution to avoid potential mediators or antecedents of predictors (Cero et al., 2021). Given many co-variables (such as age, gender, other neurodevelopmental conditions) could influence predictors (such as thwarted belonging or anxiety) or there could be bi-directional effects (e.g., between depression and thwarted belonging or suicidal thoughts) this set of studies prioritised understanding gender and anxiety and depression to reflect published priorities at the time of design. Gender analysis was undertaken prior to exploring other analyses and depression was added to the model in Chapter 5. Future studies could extend the published models by including more co-variables, such as age and additional neurodevelopmental conditions. One recommendation is to use Directed Acyclic Graphs to determine co-variables (Cero et al., 2021) and such an approach would also more fully explain how these experiences impact suicide for autistic people. This could be particularly helpful, given suggested differences in how demographic variables operate between autistic and non-autistic people.

At the time of design, this study prioritised consideration of vulnerability amongst autistic women and the role of co-occurring mental health conditions as these had been identified as salient issues (Segers & Rawana, 2014; Zahid & Upthegrove, 2017). Autistic people with intellectual disability were reported at lower risk of suicide compared to autistic people without intellectual disability, however, evidence now suggests this relationship is more nuanced with research reporting mild intellectual disability may be a suicide risk factor (Hand et al., 2020a). Furthermore, this thesis did not explore the experiences of gender diverse (Grossman & D'Augelli, 2007) and non-white autistic adults (Giwa Onaiwu, 2020), though developments in autism research have highlighted the importance of understanding these such issues in their interaction. Intersectionality refers to 'how an individual's overlapping identities impact their experiences of discrimination and oppression' (Lopez, 2022) and may provide a particularly relevant approach to exploring the role of multiple

marginalisations in suicide amongst autistic people (Botha & Frost, 2020). This is important to address in future research and is described below.

6.5.5 Power analysis and correction for multiple comparisons

Findings should be considered in the context that there was no a priori power analysis to determine sample size required to avoid a type 2 error (failure to reject the null hypothesis when it is false). At the time of design, there was an absence of agreed approach to power analysis for many of the statistical techniques used and an absence of accessible tools. G*Power, for example, (Faul et al., 2007; Faul et al., 2009) does not include multinomial logistic regression, measurement invariance analysis and network analysis. Thus, published priorities for ensuring valid analysis were considered, such as assumptions for linear regressions for mediation analysis and attention to group size and non-normal distribution for measurement invariance analysis. Conservative 'rule of thumb' sample size estimates (e.g., $n > 50 + 8i$ for regression analysis (Green, 1991) or $n = 100 + 50i$ in the case of logistic regression (Bujang et al., 2018)) were also used to account for the need for larger samples if the DV is skewed or the effect potentially small (Tabachnick & Fidell, 2001). For network analysis, Chapter 5 includes appropriate estimation technique and exploration of stability and accuracy as recommended to ensure validity of results (Epskamp et al., 2018).

More recent studies demonstrate that simulation studies can provide more detailed evidence of power analyses for more complex statistical analyses, including structural equation modelling (Wang & Rhemtulla, 2021) and network analysis (Faelens et al., 2019) and future studies in autism and suicide research could apply this approach. This could be particularly helpful, given frequent underpowering in social science studies (Fritz & MacKinnon, 2007) and is particularly recommended to address challenges with sample size in suicide research (Cero, 2021). Thesis findings should also be interpreted in the context that correction, such as Bonferroni, was not applied to avoid type 1 error (reject the null hypothesis when it is true) resulting from multiple comparisons. Findings and methods from research in this thesis have already been subject to extension and replication (Cassidy et al., 2023; Moseley et al., 2020; Moseley et al., 2022) and research should continue to test and expand the work presented here.

6.6 Future research

Here, I outline areas for future research emerging from the findings of this thesis considered in the context of current research and strengths and limitations of the research presented here. Future research ideas coalesce around extending our understanding of: (i) how thwarted belonging and perceived burdensomeness operate as suicide risk factors; (ii) understanding suicidal behaviour; and (iii) how these may be influenced by gender or other intersecting identities. I conclude by proposing that ideas from critical suicidology may be helpful to fully articulate the lived experiences of autistic people.

6.6.1 How are thwarted belonging and perceived burdensomeness experienced? Future research could extend our understanding of how autistic people experience of belonging and perceived burdensomeness and explore how best to conceptualise and measure this. Research could review existing concepts and scales from literature and other suicide theories, such as the protective role of connectedness in the 3St (Klonsky & May, 2015). This could also include qualitative research with autistic people to explore the inner experience, meaningful ways to observe and measure changes in feelings of belonging or burdensomeness and explore factors that influence these feelings. One clinical focus could be to develop a scale to support clinicians to measure the extent to which an individual has their personal belonging needs met.

6.6.2 How does suicidal behaviour develop? The construct of suicidal capability remains central to understanding the transition to suicidal behaviour in all suicide theories notwithstanding issues with definition and measurement (Joiner, 2005; Klonsky & May, 2015; O'Connor, 2011). Thus, developments surrounding our understanding of the construct of suicidal capability should be followed in non-autistic people and relevant components tested for autistic people. This could include testing whether particularly intense enduring suicidal ideation is a risk factor and could explore the role of particularly relevant trait-like experiences for autistic people, such as interoceptive (difficulties inferring internal states of the body) (Forrest et al., 2015) or sensory processing differences (Tavassoli et al., 2014), impulsivity (Hlavata et al., 2018) and could identify relevant state-like components, such as intoxication (Rizk et al., 2021) and practical factors, such as access to means (Klonsky & May, 2015). In the absence of agreed measurement tools to assess suicidal capability, this could include qualitative research to explore how emotional distress transitions to behavioural activation. This could present a kinder and more comfortable research process for autistic participants for whom standardised tests and questionnaires were the most commonly reported source of distress when taking part in this study.

Research could also extend our understanding of the role of trauma in suicidal behaviour. This could include considering the most accurate manner to capture the experience of trauma for autistic people, considering theoretical approaches and response scales from published measurement tools. This could lead to developing a revised response scale for the VEQ so that it measures frequency and duration of traumatic life events rather than breadth of traumatic life events. Our results could also be extended by re-analysing current data to explore whether distinct types of trauma are more strongly associated with suicidal behaviour than others. This could also explore whether trauma also associates with suicidal thoughts through experiences of anxiety and depression, given a reported association between VEQ scores and anxiety and depression in the original validation study of the VEQ (Griffiths et al., 2019). Overall, research could explore a more nuanced understanding of the role of trauma in the development of suicidal thoughts and behaviours.

6.6.3 What is the role of mental health difficulties?

Debate remains whether and how mental health difficulties contribute to suicidal thoughts and behaviours (Jokiranta-Olkonien et al., 2021; Kölves et al., 2021). Results provide a possible method for further exploration of the role of mental health difficulties using a combination of data driven approaches developed into ideas with people with lived experience of suicide. Research could extend our understanding of the role of anxiety and depression and explore the role of other mental health difficulties associated with suicide, such as psychotic spectrum disorders, anorexia nervosa (Tchanturia et al., 2020; Westwood & Tchanturia, 2017), personality disorders, all of which are more frequently experienced by autistic than non-autistic people. Big datasets could be used for cluster analysis to explore how mental health symptoms cluster for autistic people and whether and how clusters associate with suicidal thoughts and behaviours (Borsboom & Cramer, 2013). Research could also explore models based on the models proposed in this thesis but using data gathered using measures of anxiety and depression validated for autistic people.

6.6.4 What is the role of gender and other intersecting identities?

Results suggest research needs to continue to explore the experiences of autistic women to determine how best to reduce suicide rates. Initiatives to improve the accuracy of autism diagnosis amongst women (Brown et al., 2020) but such interventions will take time to bring parity in access to diagnosis. Thus, research could consider risk factors that have been raised as particularly pertinent for autistic women, including being late or un-diagnosed, having unmet support needs, social camouflaging, being mis-diagnosed with a mental illness, trauma, including interpersonal and sexual violence, age and marital status. Recruitment could target groups could be targeted where undiagnosed autistic women are frequently mis-directed, such as organisations supporting people with personality disorders. Research should start from a standpoint of meaningful definitions of gender identity and one possibility would be to explore autistic women independently of other groups given their unique experiences. Alternatively, research could compare differences with non-autistic women to guide clinicians and supporters to better signpost women. It may be particularly important to consider suicide risk in autistic people who do not identify as male or female given high rates of suicide amongst these groups in non-autistic people (Grossman & D'Augelli, 2007; Hatchel et al., 2021). This could also reflect research describing a broader process of challenging gender norms as a part of the journey to autistic identity (Moore et al., 2022). Research may need to gain broader understanding of the experience of gender amongst autistic people to understand how gender operates as a suicide risk factor to ensure meaningful gender identities and comparisons are employed.

This proposal should be considered within the context of widespread concern with intersectionality that has received greater prominence over the course of this PhD (Lopez, 2022). Research also suggests that age may operate differently as a risk factor for suicide amongst autistic and non-autistic people with self-harm and suicidality continuing into older age (Stewart et al., 2022). Our understanding of the role of intellectual disability has developed, suggesting that those with a mild intellectual disability may be at increased suicide risk (Cervantes et al., 2023; Hand et al., 2020b). Studies report that both being Black or Hispanic (Dickerson

Mayes et al., 2015) or being white (Mouridsen et al., 2008) could be risk factors for suicide amongst autistic people, most likely reflecting unequal access to autism diagnosis (Jones et al., 2020). Intersectional approaches have been applied to explore how overlapping marginalisations impact suicide (Standley, 2022), but such approaches have not yet been applied to the case of autistic people. Thus, future research on any of the above topics could explore suicide amongst autistic adults from an intersectional perspective.

6.6.5 Towards a suicide theory for autistic people

Future research should continue to explore constructs and pathways relevant to autistic people. This could extend theoretical work to explore both the IMV (Cassidy et al., 2023) and the 3St model, which has yet to be tested amongst autistic adults (Klonsky et al., 2021). The development of constructs to explore suicide amongst autistic people could include a wide range of suicide-related constructs to try to better understand and express the experiences of autistic people, such as hopelessness, psychological pain, defeat and entrapment (Lawson & Robins, 2021; Millner et al., 2020). Important to note that measures of suicidality validated for autistic people may not be valid for non-autistic people (Cassidy et al., 2021; Hedley et al., 2022), making valid between groups comparisons challenging. Similarly, research now acknowledges different experience and expression of mental health symptoms (Au-Yeung et al., 2019), greater gender diversity (Warrier et al., 2020) and arguably different experience of gender, and in the sample gathered for this programme of study higher rates of suicidal thoughts and behaviours in non-clinical samples amongst autistic compared to non-autistic people. This suggests that we may be reaching the limits of the extent to which it is insightful to compare the experiences of autistic people with non-autistic people. This could suggest that future suicide theory should work in partnership with autistic people to extend a suicide model independent of non-autistic experience.

Themes emerging from this research are that suicide theory needs to continue to extend methods and approaches to better reflect the inner experiences of autistic people, describe meaningful external indicators of suicide risk and better represent the influence of context for autistic people. These themes could be explored using approaches from critical suicidology, which argues that purely psychological models (including the ITS), are limited because they situate suicide uniquely within the individual. Critical suicidology argues that understanding broader cultural and societal context is key to understanding their psychological wellbeing and coping strategies (Hjelmeland et al., 2019). Such an approach is an intuitive extension of the limitations of the model described in this thesis (Figure 1), which highlighted the importance of context factors (Chandler et al., 2022) but fell short of fully explaining the experiences of autistic people. Research has extended theoretical discussion of the role of social context influences in suicide prevention (Mueller et al., 2021) and have extended the ITS to better reflect context factors (Opara et al., 2020) but such approaches have yet to be applied in autism research. Critical suicidology also embraces wide-ranging methods and epistemological positions (Marsh, 2015) that would naturally extend beyond quantitative studies using standardised questionnaires so disliked by study participants and allow for the natural emergence of autism-specific

experiences. This could include identified suicide risk factors, such as autistic burnout, and social camouflaging, but would allow for the emergence of more novel experiences.

6.7 Conclusion

This PhD thesis is the first study to explore the extent to which a leading suicide theory accurately explains the experiences of autistic people. Concepts of thwarted belonging and perceived burdensomeness were helpful to extend our understanding, but models were less accurate for autistic compared to non-autistic people. To date, the ITS remains underdeveloped in its description of the association between trauma, suicidal capability and suicidal behaviour. Interventions should promote belonging and self-worth burdensomeness, but clinicians should be mindful that a personalised approach is required to support autistic people, whilst evidence to guide tailored care pathways is produced. Future research should work in partnership with autistic people to extend our understanding of the role of trauma and mental health in suicide amongst autistic people using an intersectional framework. Critical suicidology may provide opportunity to extend our understanding of how the context of autistic people, which may improve the accuracy of models of suicidal thoughts and behaviours for autistic people.

Supplementary 1: Ethics certificates



Certificate of Ethical Approval

Applicant:

Mirabel Pelton

Project Title:

What does it mean to belong in Coventry 2020?

This is to certify that the above named applicant has completed the Coventry University Ethical Approval process and their project has been confirmed and approved as Medium Risk

Date of approval:

10 March 2020

Project Reference Number:

P103225



Certificate of Ethical Approval

Applicant:

Mirabel Pelton

Project Title:

Understanding and reducing suicidal thoughts and behaviours amongst autistic people: exploring contributory mechanisms and measurement differences

This is to certify that the above named applicant has completed the Coventry University Ethical Approval process and their project has been confirmed and approved as Medium Risk

Date of approval:

12 December 2018

Project Reference Number:

P61841



Certificate of Ethical Approval

Applicant: Mirabel Pelton
Project Title: What do you think? A protocol for including autistic voices at each stage of the research cycle

This is to certify that the above named applicant has completed the Coventry University Ethical Approval process and their project has been confirmed and approved as Low Risk

Date of approval: 20 Apr 2022
Project Reference Number: P93917

Supplementary 2: Table of Author Contributions of Published Work

Author	Role	Paper		
		Understanding suicide risk in autistic adults: Comparing the Interpersonal Theory of Suicide in autistic and non-autistic samples (Pelton et al., 2020)	A Measurement Invariance Analysis of the Interpersonal Needs Questionnaire and Acquired Capability for Suicide Scale in Autistic and Non-Autistic Adults (Pelton et al., 2020)	The role of anxiety and depression in suicidal thoughts for autistic and non-autistic people: A theory-driven network analysis (Pelton et al., 2023)
Mirabel Pelton	Conceptualisation	X	x	x
	Data collection – lead	X	x	x
	Formal analysis – lead	X	x	x
	Writing – lead original draft	X	x	x
Dr. Sarah Cassidy	Conceptualisation	X	x	
	Writing – review and editing	X	x	x
Dr. Hayley Crawford	Writing – review and editing	X	x	x
Dr. Ashley Robertson	Writing – review and editing	X	x	x
Dr. Kim Bul	Writing – review and editing	X	x	x
Prof. Jacqui Rodgers	Writing – review and editing	X	x	x
Dr. Derek de Beurs	Conceptualisation - supporting			x
	Writing – review and editing			x
Prof. Simon Baron Cohen	Data collection - supporting	X	x	x
	Writing – review and editing	X	x	x
Jon Adams	Writing – review and editing			x

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Full paper citations:

- Pelton, M. K., Crawford, H., Robertson, A. E., Rodgers, J., Baron-Cohen, S., & Cassidy, S. (2020a). A Measurement Invariance Analysis of the Interpersonal Needs Questionnaire and Acquired Capability for Suicide Scale in Autistic and Non-Autistic Adults. *Autism in Adulthood*, 2(3). DOI: 10.1007/s10803-020-04393-8
- Pelton, M. K., Crawford, H., Bul, K., Robertson, A. E., Adams, J., de Beurs, D., Rodgers, J., Baron-Cohen, S., & Cassidy, S. (2023). The role of anxiety and depression in suicidal thoughts for autistic and non-autistic people: A theory-driven network analysis. *Suicide and Life-Threatening Behavior*, 53(3). DOI: 10.1089/aut.2019.0055
- Pelton, M. K., Crawford, H., Robertson, A. E., Rodgers, J., Baron-Cohen, S., & Cassidy, S. (2020b). Understanding suicide risk in autistic adults: Comparing the Interpersonal Theory of Suicide in autistic and non-autistic samples. *Journal of Autism and Developmental Disorders*, 50(10), 3620-3637. DOI: 10.1111/sltd.12954

Supplementary 3: Supporting information for study 1 ‘Show and tell’: an evaluation of working in partnership with autistic adults to explore suicidal thoughts and behaviours as an early career researcher

Study 1: Supplementary Table 1: Evidence describing impact of participation activities at each stage of the research process.

Preparatory phase			
Research planning Participation leads research to ask questions perceived as relevant to reducing suicide rates for autistic people?	<ul style="list-style-type: none"> • Design group meeting 1 (Apr 2018) proposed the research shift from the original proposal to explore how far the ITS describes the experiences of autistic people • 12 tweets posted on @MiraPel1 between Mar 2018 and Jan 2019 with 17625 total impressions (mean=1469), including 60 second video shared via @Spectrum (3618 impressions). No substantive feedback was received. • Survey feedback: 22 participants suggested content was relevant, e.g.: ‘really interesting survey - made me realise what a champ I am despite obstacles and adversities’. 	<ul style="list-style-type: none"> • Design group allowed in-depth discussion of study focus • Sharing details via Twitter reached more people but limited substantive feedback • Available but limited feedback suggests study content was relevant to participants 	<ul style="list-style-type: none"> • Plan to initiate partnership working early and from the onset • A Design Group allows in-depth discussion about study focus. • Consider how to consult more widely using Twitter or another social media mechanism and monitor. • Plan how to evaluate relevance of study focus to broader autism community
Execution phase			
Study design and procedures Participation leads to accessible approach to ask autistic people about suicidal thoughts and behaviours	<ul style="list-style-type: none"> • Design group meeting 2 (Oct 2018) confirmed survey as accessible data collection method, instructions, Information Sheet, consent form, recruitment ad prior to ethics application • 3 participants offered survey feedback that it was accessible, for example ‘I enjoyed the survey. The questions were very clear, thank you’, whilst 5 participants reported technical difficulties, for example, ‘The style/ layout of the majority of the questions was very frustrating. I didn’t like how if you clicked on an answer, it automatically moved onto the next answer’ 	<ul style="list-style-type: none"> • The design group agreed a survey for data collection and proposed changes to materials • Limited participant feedback confirmed survey was accessible though some technical frustrations 	<ul style="list-style-type: none"> • Working with a design group can address many accessibility issues. • Consider wider testing of survey software on a range of different platforms by users with a range of needs

Participation leads to safe, sensitive approach to asking about suicidal thoughts and behaviours	<ul style="list-style-type: none"> • Design group meeting 2 proposed risk guidance, content warning and survey signposting for survey for modelling studies • 2 participants reported risk guidance was helpful in survey feedback, for example: 'I thought the opportunities for breaks and giving Samaritans and other details was excellent' 	<ul style="list-style-type: none"> • The design group reduced potential triggering content, informed support signposting 	<ul style="list-style-type: none"> • Working with a design group can contribute to meaningful and effective risk guidance
Participation leads to selection of measurement tools to assess suicidal thoughts and behaviours that are relevant, reliable, appropriate and accessible for autistic people	<ul style="list-style-type: none"> • Design group meeting 2 proposed the Patient Health Questionnaire 9 and Generalized Anxiety Disorder-7 instead of Hospital Anxiety and Depression Scale (HADS), changed instruction wording for INQ-10 and VEQ • Survey feedback reported questionnaire response difficulties: <ul style="list-style-type: none"> ○ 34 participants reported general difficulties: 'some of the questions were worded strangely or written in a confusing manner. I found the double negatives difficult...' ○ 8 participants reported the AQ-S was not valid measure of autistic traits: 'The Autism Quotient test ... doesn't take into account the more subtle nuances of different autistic persons...', particularly in women: "...the questions ..focused on male autistic traits. Women are autistic too.' ○ Asking about autistic traits reduced wellbeing: '...Having to constantly 'prove' you are autistic is part of the reason autistic people experience depression and feel isolated...' 	<ul style="list-style-type: none"> • The design group influenced the selection of standardised measures to mitigate response difficulties for autistic people • More negative comments were received about these than other aspects of the survey 	<ul style="list-style-type: none"> • Consider whether to use standardised questionnaires to assess suicidal thoughts and behaviours amongst autistic people. • Discuss this decision with autistic people via a design group and explain in project materials. • Explain whether it is necessary to measure autistic traits, consider alternatives to the AQ-S • Explain why it is necessary to measure autistic traits
Recruitment Participation leads to project meeting recruitment targets?	<ul style="list-style-type: none"> • Design group log shows that we did not discuss recruitment with the design group • Recruitment was sufficient for planned analyses (study 1=695 complete participant records; study 2 = 655 complete participant records and study 3 retained = 865 complete participant records. Recruitment was undertaken through research databases and Twitter. 	<ul style="list-style-type: none"> • Due to study design, participation did not impact recruitment in this study • Potential participants were able to quickly ask queries about the research 	<ul style="list-style-type: none"> • Consider whether it is appropriate to engage autistic people to support recruitment. • Consider using Twitter for wide sharing as it allows wide sharing • Be available after tweeting to offer support and reassurance
Analysis Participation leads to interpretation of results that is seen as credible explanations for suicidal thoughts and behaviours for autistic people.	<ul style="list-style-type: none"> • Design group meetings 3 (Aug 2019) and 7 (Nov 2022) offered in-depth discussion of autistic perspectives on the interpretation of the data. Study 3 included autistic co-author to reflect contribution of original knowledge to model development. • Twitter analytics show a blog and video shared for World Suicide Prevention Day 2019 via @netECR received 3214 impressions, 10 engagements but no replies to inform interpretation of results • Twitter analytics show tweet (9.3.20) with thread, blog and video to disseminate study 1 received 8124 impressions, 463 engagements, including 3 replies confirming the content was credible, for example: "Vital paper... just so important that people realise the links 	<ul style="list-style-type: none"> • The design group allowed in-depth discussion of interpretation of results • Feedback on Twitter provided limited retrospective feedback regarding credibility 	<ul style="list-style-type: none"> • Use a design group for in-depth discussion of results to inform interpretation • Plan in more detail how to use Twitter (or an alternative social media mechanism) to include a wider range of voices and monitor • Evaluate credibility of results for broader autism community

	between autism, being described continually as a burden, being ostracised and traumatised... and resulting desire to end our lives. Robust evidence.'		
Translational phase			
Participation leads to identification of novel areas of study to explore suicidal thoughts and behaviours for autistic people	<ul style="list-style-type: none"> • Impact log, survey feedback, twitter analytics, survey free-text box and community-based project proposed novel areas to study suicide amongst autistic adults (listed in Supplementary Information). • Design group meeting 3 discussed the findings of study 2 and identified the need to understand the protective role of belonging from the results of study 2: <ul style="list-style-type: none"> ○ Meeting 4 (2/20) confirmed the positive focus, use of creative methods and reviewed materials. ○ Meeting 5 (4/20) established the @isbelonging Twitter account and website (https://belong.coventry.domains) due to the lockdown. ○ 56 tweets were shared (@MiraPel1 and @isbelonging), total 59304 (mean=1333) impressions, including 19 replies, which made substantive comments and 15 creative submissions (see Appendix B) about autistic belonging but without capturing details of self-identity as intended. ○ Design group reflection (1/23) reports that the belonging project was one of their most positive experiences 	<ul style="list-style-type: none"> • There is a high demand for research in this area with many novel areas identified • The design group developed a more active role in the belonging project as the group grew in coherence, confidence and co-working. They got involved in more researcher tasks, felt ownership and reported this highly motivating 	<ul style="list-style-type: none"> • Consider how to capture and prioritise novel areas for future studies and manage expectations • Be prepared for the emergence of novel areas of study, particularly positive protective factors, autism-specific experiences, avoiding standardised measures. • Consider how additional motivation can best be harnessed to inform new research
Participation leads to widespread dissemination of study findings to relevant policy and clinical organisations	<ul style="list-style-type: none"> • Design group log shows design group have not discussed dissemination • Twitter analytics report 144 tweets were shared about dissemination (total impressions = 116718, mean = 810) with 3254 engagements • Academic citations: Study 1 (Pelton et al 2020a) = 48, Study 2 (Pelton et al 2020b) = 18, Study 3 (Pelton et al, 2023) 337 downloads as preprint. • Presentations: 2 invited academic talks, 9 conference oral and 2 poster presentations, (conference list in Supplementary 5), including co-presented with autistic presenters. 	<ul style="list-style-type: none"> • Dissemination has taken place but not directly attributed to participation 	<ul style="list-style-type: none"> • Consider role of partnership working in dissemination depending on study focus
Participation leads to policy change in suicide prevention for autistic adults, clinical guidelines to better support autistic people who experience suicidal thoughts and behaviours	<ul style="list-style-type: none"> • Design group log shows design group have not discussed dissemination • Citations in national policy documents: <ul style="list-style-type: none"> ○ Autistica policy document on crisis support https://www.autistica.org.uk/downloads/files/Crisis-resource-2020.pdf and suicide prevention https://tinyurl.com/Symdvpm8 • Citations in international policy documents: <ul style="list-style-type: none"> ○ INSAR policy brief on suicide prevention https://tinyurl.com/2n34u656 ○ 2021 Australasian Society for Autism Research https://tinyurl.com/3chrrar69) • Invited practitioner presentations (Harmless), invited webinars for autistic people and those who support them (Autistica 'Belonging in uncertain times, Crisis support') (conference list in Supplementary 5). 	<ul style="list-style-type: none"> • Impact has taken place, but there is no evidence this is directly the result of participation • Impact in policy may have been indirect, for example, because research is more relevant that is that increased relevance of research 	<ul style="list-style-type: none"> • Consider whether/ how partnership working directly impacts policy • Consider planning a co-produced policy-focused output • Consider how to capture indirect impact of policy, such as

Study 1: Supplementary Table 2: Evidence describing the experiences of autistic volunteers

Intervention theory	Evidence	Conclusion	Recommendation
Participation processes should be accessible to autistic communication and thinking styles to be able to reflect autistic experiences, opinions, knowledge about suicidal thoughts and behaviours amongst autistic people	<ul style="list-style-type: none"> • Evaluation questionnaire report positive scores for advance information (5.83/7) and meeting structure (6.83/7). Comments report breaks were helpful, but accommodations can be perceived as patronising or enabling • Impact log shows that changes were made in response to suggestions, such as not using communication cards, following feedback (meeting 1, 4 and 18) • Design Group reflection (1/23) confirms overall process was accessible. Volunteers reported feeling safe to raise any adjustments and process helped gain insight into how adjustments can help 	<ul style="list-style-type: none"> • Advance notice, structured meetings, breaks, responding to feedback led to process being considered accessible to share experiences, opinions, knowledge about suicidal thoughts and behaviours • Adjustments led autistic volunteers to better understand their own required adjustments 	<ul style="list-style-type: none"> • Potential adjustments include advance information, structured meetings, breaks, offering communication options • Discuss potential accommodations and design to meet individual needs before meeting • Monitor accessibility and be prepared to adjust
Participation processes to explore suicidal thoughts and behaviours amongst autistic people should be a positive experience for autistic volunteers	<ul style="list-style-type: none"> • Evaluation questionnaires report positive scores for enjoyment (6.67/7). Comments indicate making personal connections, the 'show-and-tell'¹ item, gaining insight into autism were particularly enjoyed • Impact log shows meeting time was added for personal sharing in response to suggestion. Establishing personal connections was important to build trust to share sensitive information • Design group reflection reported bringing better outcomes for autistic people, making social connections. • Volunteer disengagement Two volunteers did not attend any meetings: one reported the accessibility arrangements were patronising whilst the other gave no reason. Three 	<ul style="list-style-type: none"> • Volunteers may have a range of motivations for getting involved • Trust and connectedness may be particularly important to positively experience sharing sensitive content • Exploring support needs before designing accessibility arrangements may help volunteers to feel welcome, accommodated and safe at a first meeting 	<ul style="list-style-type: none"> • Ask volunteers at the outset about why they are motivated to be involved • Consider how best to build trust in participation processes, such as building in time for informal sharing • Consider how best to support volunteers with additional or more complex needs

	volunteers who left after attending meetings did so due to career development.		
Participation processes should be perceived as a 'real', rather than 'tokenistic' commitment to bring about better support and suicide prevention policy by incorporating autistic experience, knowledge and opinions into research	<ul style="list-style-type: none"> • Reflection with the Design Group reported participatory process was experienced as a 'real' commitment to participatory working due to changes being made to research based upon discussions, trust, honesty and openness. This was in contrast with other research experiences • Reasons for delays and lack of achievement of goals were shared openly with design group volunteers, including some disclosure of vulnerability by the researcher. • This was identified as a key trust-building point leading volunteers to feel entirely safe disclosing sensitive information within the group 	<ul style="list-style-type: none"> • Volunteers considered the participatory to be 'real' due to openness and honesty by the researcher and clear communication of decisions • Participation can be perceived as 'real' even where goals remain unachieved • Unexpected life events led to a more balanced power dynamic between researcher and volunteers 	<ul style="list-style-type: none"> • Clearly explain and share decisions about the research in notes of meetings. Recap previous meeting at start of next • Explain reasons for delay and non-achievement of goals. Celebrate and share success • Consider how to address trust and power imbalance between researcher and volunteers.

Study 1: Supplementary Table 3: Critical reflection of impact of context factors on outcomes of participation

Context factor and intervention theory	Opportunities	Challenges	Conclusion	Recommendation
[institutional] What were the impacts of PhD institutional arrangements on outcomes of partnership working to explore suicidal thoughts and behaviours with autistic people?	<ul style="list-style-type: none"> Supervisors committed to partnership working, research to bring about change and positive, progressive attitude to neurodiversity Supervisors explicit experience, knowledge of working with advisory groups to explore mental health, suicidal thoughts, behaviours with autistic adults led to safe, tested risk management procedures Supervisors' tacit knowledge support with process issues and sensitive content Supervisors committed, enthusiastic in piloting new methods to broaden engagement, including using Twitter, the community-based project and the database Doctoral training in using Twitter for academics, including 'tweet my thesis' and 'ten days of Twitter' Supervisors supported using Twitter, endorsements and retweets lead to perceptions of trust 	<ul style="list-style-type: none"> University ethics procedures for participation work, including safeguards for working with those who experience suicidal thoughts and behaviours PhD funding £125/ year (increased to £150/ year in 2019) insufficient to reimburse volunteers at advertised rates Competitive funding accessed offered short timescales, required 'juggling' to meet ongoing commitments Time constraints at key PhD miles, such as annual performance review, writing-up de-prioritise participation activities. In this case, the establishment of the database was never prioritised Career advancement beyond doctoral study may depend 	<ul style="list-style-type: none"> Supervisory commitment and experience were vital to participation impact, including maintaining volunteer safety Supervisor enthusiasm and experience was vital to safely trial new methods of participation Doctoral training and supervisor support can strengthen social media presence Impact can be reduced without adequate funding and due to career 	<ul style="list-style-type: none"> Seek out supervisors committed to participatory methods and neurodiversity affirming approach Build institutional knowledge of other methods, beyond design groups and share beyond institutions Plan how to meet financial requirements and ethics procedures for participation early in the doctoral programme Prioritise participation activities due to time constraints

	<ul style="list-style-type: none"> • Doctoral training on accessing funding for additional research activities 	on academic dissemination rather than policy impact and 'real life' changes.	enhancement goals	
<p>[societal]</p> <p>What were impacts of the UK-wide lockdowns of 2020 and 2021 on undertaking partnership work to explore suicidal thoughts and behaviours with autistic people?</p>	<ul style="list-style-type: none"> • Enabled the Design Group to meet online, saving time and money, improving accessibility. • Most suicide-focused research stopped during the pandemic, but we continued to recruit to the community-based project due to the positive focus of the study 	<ul style="list-style-type: none"> • Community-based project had to be delivered online due to UK-wide lockdown • Short funding timescale meant we moved online without revising materials • Design group suggested novel initiatives – Twitter survey and blogs • Changes to community groups focus and personnel meant face-to-face activities did not restart and local impact activities didn't take place 	<ul style="list-style-type: none"> • Lockdown led to us understanding how to engage with people more effectively, remotely • The community-based project moved quickly online due to short funding deadline • It generated submissions but did not meet broad engagement or impact target 	<ul style="list-style-type: none"> • Online methods offer range of alternative engagement forms • Consider when face-to-face versus online is more appropriate
<p>[personal]</p> <p>How did personal experience/ life events impact outcomes of partnership working to explore suicidal</p>	<ul style="list-style-type: none"> • Commitment to social change led to high level of motivation for participatory work • Openness to learn about neurodiversity approach to autism meant volunteers felt genuinely listened to • Previous research experience with people who experience suicidal 	<ul style="list-style-type: none"> • Learning about the history of autism research • Lack of personal contact in Coventry autism community meant it took a great deal of time to build trust to recruit first design group members. 	<ul style="list-style-type: none"> • Researchers bring a range of strengths and challenges from existing experience 	<ul style="list-style-type: none"> • Design participation activities to reflect strengths • Consider participation activities in development plans

thoughts and behaviours with autistic people?	<p>thoughts and behaviours meant risk management procedures were familiar as was dealing with difficult content</p> <ul style="list-style-type: none"> Understanding the impact of trauma helped to informed listening and sensitivity to cues Experience in financial management and funding applications to apply for and juggle finances 	<ul style="list-style-type: none"> Lack of Twitter profile, confidence, experience in social media 		
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Methods Supplementary Table 4: Record of impact of participation activities, prepared in line with NIHR impact log framework

Meeting date	Present	Stage of research cycle	Topics raised	Research impact	Process feedback/ recommendations	Process score
April 2018	V1, DNAV, MP, CC ²	Agenda setting	Overview of Interpersonal Theory of Suicide Overview of Interpersonal Needs Questionnaire-15 Review Participant Information Sheet	Clarify overall research direction – how theory may not be relevant to autistic people Critical of wording of the INQ Redesign study to focus on exploring whether theory is appropriate rather than assuming it is appropriate	Enjoyed critiquing theory, sharing views on relevance to autistic people Don't use cue cards as these are condescending Some feedback questions unclear. Broaden participation beyond university.	7/7 (enjoyment) 6/7 (structure) 5/7 (clarity of advance information)
October 2018	V1, V2, MP, AR	Study design and procedures	Shared study design of online survey to explore differences in theory and measurement properties	Clarify PIS and consent, shorten these, reduced risks, increased benefits, standardise wording, explore options for hard copy, large print versions	Advance information was helpful to avoid having to think on feet, accurate timing, summarised information.	5/7 (enjoyment) 4/7 structure of meeting 5/7 (clarity of information)

			<p>Feedback on poster, participant information sheet, consent and debrief</p> <p>Select standardised questionnaires</p>	<p>Explain why use standardised questionnaires as these can be frustrating</p> <p>Contact author to propose change to wording on INQ-10</p> <p>Change title on ACSS page</p> <p>Design group predict problems with negatively worded items</p> <p>Change response options on VEQ</p> <p>Replace HADS with PHQ-9 and GAD-7, replace INQ-15 with INQ-10,</p> <p>These documents form basis of ethics application</p>	<p>Things to change included managing other people speaking too much and breaking the session up with a lunch hour</p>	
August 2019	V1, V2, MP, AR	<p>Study 1: Data interpretation, Study 2: hypothesis generation Study 3: research focus</p> <p>Broadening participation</p>	<p>Shared preliminary results of study 1, discussion around meaning of results.</p> <p>Generate hypotheses for study 2; discussion of possible non-invariant questionnaire items</p> <p>Outline discussion of ideas about how anxiety and depression may contribute to suicidal thoughts</p> <p>Outline discussion of broadening participation via a database</p>	<p>All three theory components capture part of the autistic experience. This was as expected. Research should focus on generating a novel theory for suicide for autistic people. Research should prioritise understanding how these things change with age.</p> <p>Hypotheses generated including all burdensomeness, the 'outsider' item of thwarted belonging will be non-invariant. Many items of fearlessness about death.</p> <p>Anxiety would precede depression in the development of suicidal thoughts but the ITS would still be limited by the issues raised above.</p>	<p>Enjoyed learning new things about autism, being in kind, interested company, receiving information in advance, ran to schedule which was reassuring, fascinating and an honour to be included.</p> <p>Sometimes discussion is difficult to follow and research findings hard to digest. Nothing to change for next time.</p> <p>Recommendation to 'get out in the field' to meet autistic people</p>	<p>6/7 (enjoyment)</p> <p>4/7 (structure)</p> <p>4/7 (advance information)</p> <p>5/7 (enjoyment)</p> <p>7/7 (structure)</p> <p>5/7 (advance information)</p>

				Suggestion to broaden participation through community project, visit community groups, database for online consultation and funding application for city of culture.		
February 2020	V1, V2, MP, KC, DNAV	Community project: Study focus, design and procedures	Review of materials for the community-based project Review of process for belonging project	Recommendation to write up experience of design group Clarification of wording for materials for community-based project Recommendation that the project should not be over-structured. People may want different ways to communicate so materials should allow cards and images.		
April 2020 First online meeting	V3, V4, V5, 1 x apologies, KC	Community project: Study design and procedures (revised due to pandemic)	To explore how to redesign the community-based project due to COVID-19 restrictions How to meet the university deadline for spending funding by July 2020	Belonging could mean visiting friends, having good family relationships, feeling part of a tribe, having a cat who likes me for who I am, experiencing the world as others do, not being normalized, feeling human Produce a blog for the project Produce a graphic for the project Set up a twitter and Instagram account Set up a website	Helping progress knowledge, increased knowledge of autism 'Hats' task was unclear. Nothing to change for next time.	5/7 enjoyment 7/7 structure 5/7 clarity of information in advance

				Design a twitter survey about belonging		
April 2021	V2, V4, MP, KC	Community project: Recruitment (restart face-to-face work) Review submissions	Explain project delay due to caring How to recruit more submissions How to curate submissions Review risk guidance How to restart face-to-face project	Discussion about belonging Clarify wording of poster Online curation: include individual's narrative making it clear twitter comments are twitter comments Include a content note about thwarted belonging Consider a poetry workshop, exhibition in Coventry Central library, access funding for physical output such as book Change the emphasis of materials to appeal to community groups	Enjoy space to contribute; show and tell Hard to follow discussion Nothing to change for next time Clarify aims of meeting	6/7 enjoyment 6/7 structure 6/7 clarify of advance information
August 2022	V2, V4, KC	Study 3: interpretation of results, model development	What might network model mean? What is missing from conceptual model? Is language used appropriate? Is it helpful to explain experiences of autistic people?	Simplify the network model 'Everyday trauma' is accurate Ideally, the model should be circular, add influences at the top of the model Future topics should include age, gender, uncertainty, willpower, stimming and sleep		

			Is there a better way to draw this?			
January 2023	V2, V4, MP, KB					

Study 1: Supplementary Table 5: Framework of impact assessment aims and evidence, devised from Popay, J & Collins, M (editors) with the PiiAF (Public Involvement Impact Assessment Framework) study group (download from <https://www.piiaf.org.uk/documents/piiaf-guidance-jan14.pdf>)

State your intervention theory	Impact Assessment Question	Design	Data collection methods	Develop measures/ indicators
Formative/ summative assessment				
Participation processes should meet needs	Did the design group process meet autistic thinking and communication styles?	Quantitative and qualitative	Evaluation questionnaire Impact log Notes of design group process review	Mean evaluation scores and comments indicate needs are met Impact log records changes to meeting process in response to comments Design group report process met needs
Participation processes should be a positive experience for volunteers	Was the process a positive experience for volunteers?	Quantitative and qualitative	Evaluation questionnaire Impact log Notes of design group process review	Mean evaluation scores and comments indicate participation is a positive experience Impact log records changes to meeting process to increase positive experience Volunteers remain engaged, reasons for volunteer dropout Design group report whether and why was positive Suggested improvements for future

Participation in autism research should be 'real' rather than 'tokenistic'	Were changes effected in response to design group suggestions? Did design group reflect a range of autistic voices?	Qualitative	Impact log Notes of design group review Community-based project data	Impact log shows changes were made because of design group input Reflection with design group about whether and why they experienced process as 'real' or 'tokenistic' Community-based project reports broad participation
Summative assessment				
Research focus Participation leads research to focus on relevant questions for autistic people?	Did partnership working lead research to ask questions relevant to reducing suicide rates for autistic people?	Qualitative	Impact log Twitter analytics, survey free text box	Impact log reports autistic people influence study focus Autistic people report content is relevant
Research design and delivery Participation leads to research methods that meet autistic thinking and communication styles	Did partnership working lead to accessible approach to asking about suicidal thoughts and behaviours for autistic people?	Qualitative	Impact log Twitter analytics, survey free text box	Impact log reports autistic people influence methods selection and materials Participants report methods are accessible
Participation leads to survey being perceived as sensitive in approach to asking about difficult topics	Did partnership working lead to safe, sensitive approach to asking about suicidal thoughts and behaviours?	Qualitative	Impact log Twitter analytics, survey free text box	Impact log reports changes made to survey safety and sensitivity Participants report methods are safe and sensitive in asking about difficult topics
Participation leads to measurement tools being used that are relevant, reliable,	Did partnership working lead to selection of measurement tools to assess suicidal	Qualitative analysis of impact record of	Impact log	Impact log reports changes in standardised tools

appropriate and accessible for autistic people?	thoughts and behaviours that are reliable and appropriate for autistic people?	participation activities	Twitter analytics, survey free text box	Participants do not report difficulties with standardised questionnaires
Recruitment Participation leads to project meeting recruitment targets?	Did partnership working lead to meeting recruitment targets?	Quantitative Qualitative	Participant numbers Twitter analytics	Participants are sufficient for planned analyses Indication of whether participants due to social media (versus other recruitment channels)
Data analysis and interpretation Participation leads to interpretation of results means that project findings are perceived as credible by autism community.	Did partnership working in interpreting study results lead to evidence to reduce suicide seen as credible by autistic people?	Qualitative	Impact record of actions taken in response to suggestions Twitter analytics, survey free text box	Impact log reports changes to results interpretation Autistic people report content is credible
Participation leads to identification of knowledge gaps in autism research	Did partnership working lead to novel areas to explore suicidal thoughts and behaviours for autistic people?	Qualitative	Impact assessment records Twitter analytics, survey free text box Submissions to community-based project	Impact log reports design group novel directions for research Suggested novel areas for research Submissions to community-based project suggest novel areas for research
Dissemination Participation leads to research findings having policy impact?	Has partnership working led to policy change in suicide prevention for autistic adults?	Quantitative	Record of invited talks, citations Record of citation in policy documents	Practitioner talks Citation in policy documents
Process assessment aims				

[Topic] Understand how the focus on suicide amongst autistic people influence outcomes of participation	What are the distinct challenges and opportunities related to undertaking participatory work to explore suicide amongst autistic people?	Qualitative	Personal reflection, Supervisor reflection Design group reflection	Opportunities Challenges
[Societal] Understand how the pandemic influenced outcomes of participation	What were impacts of the UK-wide lockdowns of 2020 and 2021 on undertaking partnership work to explore suicidal thoughts and behaviours with autistic people?	Qualitative	Personal reflection, Supervisor reflection Design group reflection	Opportunities Challenges
[Organisation] Understand how context influenced PPI process that affected impact	What were the impacts of PhD institutional arrangements on outcomes of partnership working to explore suicidal thoughts and behaviours with autistic people?	Qualitative	Personal reflection, Supervisor reflection Design group reflection	Opportunities Challenges
[Personal] Understand how personal factors influenced outcomes of participation	How did personal experience/ life events impact outcomes of partnership working to explore suicidal thoughts and behaviours with autistic people?	Qualitative	Personal reflection, Supervisor reflection Design group reflection	Opportunities Challenges

Autistic adults group for Research Design

What do I have to do?

Overview

We are researchers at Coventry University who are interested in the challenges that autistic adults face in relation to mental health problems, self-harm and thoughts of ending life. We want to understand why autistic people experience these feelings and to produce research that really makes a difference and improves people's lives.

We are seeking autistic adults to give their opinions on our research ideas and how we plan to carry out our research. We are interested to hear about your experience of mental health challenges and self-harm if you feel comfortable talking about these things.

Who will you be working with?

You will be working with the researcher, Mirabel Pelton, to shape the research. You will attend a meeting at the University to discuss these issues.

What will I have to do?

Your opinions are really important to us. You may be asked to:

- Share your views on the research ideas and the methods that we are planning to use: are we asking the right questions? Are we asking them in the right way?
- Help us develop questionnaires to explore autistic people's experiences, for example: 'does this questionnaire make sense?'
- Help us develop information leaflets for autistic people taking part in research, for example: 'does this leaflet make sense?'

Person Specification

You aren't required to have any formal qualifications but you do need:

- A diagnosis of an autistic spectrum condition from a clinician
- Ideas about or experience of mental health challenges, self-harm or thoughts of ending life

- Motivation to share your experience and opinions
- An interest in learning about the research process
- The ability to listen to others and express your views politely
- To be trustworthy and non-judgmental
- To understand the need for confidentiality

Main Responsibilities

- Reflect on the questions we ask you and answer anything that you are happy to
- Just let us know if there is something you don't want to answer
- Do not share any information from the meetings outside of the Research Design Group; the information is confidential.
- Highlight any concerns that you have about the process or let us know if you wish to withdraw at any point
- Complete a short questionnaire at the end to give us feedback on how you have found the design group process

Time Commitment

You will be invited to a two-hour meeting at Coventry University. You may spend around half an hour before the meeting reviewing the materials and around half an hour afterwards reflecting on the meeting. You will receive £20 at the end of the session for your time and travel expenses.

Support Provided

The research team will make sure you have a positive experience, which helps you develop and learn. Most people find it rewarding to be involved in research. You can expect that:

- Your contributions will be valued, your views heard and acted upon where practical
- You will be appropriately briefed and supported by Mirabel Pelton prior to your involvement
- Reasonable notice will be given of any meetings to be held
- You should let us know your GP details and if you are receiving any mental health support at the moment
- We will let them know that you are helping us with our research but will not share the ideas and opinions that you share with us
-
- We are obliged to let them know if you share information with us that suggests you are at risk; this is to ensure that you get the correct support

- We will send you details of the outcome of the design group and let you know what to do if you wish to stay involved with the research in the later phases.

We are really grateful to you for taking the time to help us design our research. If you have any questions at all please don't hesitate to get in touch:

Mirabel Pelton, Researcher, peltonm@uni.coventry.ac.uk . This research project is overseen by Dr Kim Bul, kim.bul@coventry.ac.uk

Coventry University
Priory Street
Coventry
CV1 5FB

Study 1: Supplementary Information 2: Design Group Evaluation Questionnaire

How did you find the design group?

Thank you for giving your time to attend this design group. This will really make a difference to my research and ensure that I'm addressing issues that are really considered important to autistic people. I hope you have found this design group a positive experience. Please let me know how you found it so that I can improve it in future.

Did you find the design group enjoyable?

No						Yes
1	2	3	4	5	6	7

What did you enjoy about the research group?

.....

Please tell me about anything that you didn't enjoy?

.....

What, if anything, should we change for next time?

.....

Was the meeting well-structured?

No						Yes
1	2	3	4	5	6	7

Let me know if you have any comments about the structure of the meeting?

.....

How did you find the information that was sent out before the meeting?

Not clear

Clear

1	2	3	4	5	6	7

Let me know if you have any comments about the information that was sent out in advance?

.....

Please comment below if you would like to on any aspect of the design group?

.....

.....

This is the beginning of a four-year research project. Would you like to receive updates about the project?

Yes/ No

How would you like to receive this?

By email

Phone call

Twitter

Facebook

Instagram

Hard copy newsletter

Other:

From time-to-time I post videos online about my research for people to provide opportunities for people to express their opinions about my research. Is there anything else that you think I should do to gather people's opinions?

.....

.....

Study 1: Supplementary Information 3: Protocol for community-based project

Project protocol: What does it mean to belong in Coventry in 2020?

Background

Autistic people (people with a formal diagnosis of an autism spectrum condition) are more likely to experience mental health difficulties, self-harm and suicidal thoughts and behaviours than people who are not autistic but we have little understanding of how to measure and support protective factors in autistic people (Cassidy, Sarah & Rodgers, 2017; Segers & Rawana, 2014). Social belonging and positive social connections are the most commonly cited protective factors in any population group but previous research within our groups suggests that using scales designed for non-autistic people may not capture what is meaningful to autistic people (Pelton et al under review; (Cassidy, S. A., Bradley, Bowen, Wigham, & Rodgers, 2018; Cassidy, Sarah, Bradley, Shaw, & Baron-Cohen, 2018; Cassidy, Sarah, Bradley, Bowen, Wigham, & Rodgers, 2018). This reflects a broader body of knowledge reporting that autistic people experience are socially motivated but may experience and express social preferences differently to people who are not autistic (Milton, Damian & Sims, 2016). **Thus, the aim of this public engagement project is to inform future research about how social belonging and social connectedness may be conceptualised, measured and supported to improve the lives of autistic people.**

Research to date has highlighted many of the challenges faced by autistic people: autistic people are more likely to report loneliness, poor relationship satisfaction, family breakdown and coercive or abusive intimate partner relationships. Research has now documented the impact of social camouflaging ('masking autistic characteristics to fit in') (Cassidy, S. A. et al., 2019; Hull et al., 2017) and the double empathy problem ('expectation of communicating emotional states using non-autistic norms') (Milton, Damian, 2012) as barriers to achieving genuine, reciprocal social relations. However, research also reports that autistic people experience rewarding social relationships, reciprocity and social satisfaction but these may be experienced and expressed differently (Heasman & Gillespie, 2018; Heasman & Gillespie, 2019). In the absence of such knowledge, social support programmes may not fully understand the needs of autistic people, may not use terminology and constructs that are meaningful to them and worryingly, may even exacerbating risk if they encourage autistic people to adopt mannerisms and behaviours of non-autistic people to achieve social success (Cassidy, S. A. et al., 2019). Known as social camouflaging this has been demonstrated to contribute to mental health difficulties and is a unique risk factor for suicide for autistic people. Thus, given an absence of previous research in this area, this public engagement project asks **what constructs and characteristics are important to autistic people in positive social belonging and social connections? How are these experiences and expressed by autistic people?**

Method

Differences in language and communication preference represent core diagnostic criteria of autism (APA 2013) and, thus, autistic people may experience barriers to engaging in interview, focus group and questionnaire-based research methodologies (Ridout & Ridout, 2017). Creative methods have been recommended to fully empower autistic people to ensure that their narratives are seen from an "insider" perspective, to communicate what is of value to them using terminology that accurately reflects their experience (Milton, Damian Elgin Maclean, Ridout, Kourti, Loomes, & Martin, 2019; Ridout & Ridout, 2017; Roth, 2018). Ownership of terminology has been recognised to improve mental health and wellbeing and creative methods have been recommended for research seeking to inform policy and specifically in relation to services related to mental health and wellbeing (Andrews, 2005; Ridout & Ridout, 2017). Overall, this methodology will allow full, flexible articulation of individual experiences and needs across the lifespan.

Within this overall methodological approach, the following activities are planned:

1. Inviting submissions

Participants will be able to either fill in a postcard with a short drawing or phrase or submit an original creative creation in any medium of their choice. These are invited in response to the prompts:

- What does social belonging mean to you?
 - Things I like to do with friends
 - I like to take part in society by ...
- What do social connections mean to you?
 - I feel connected with people when ...
 - I prefer to connect with people by ...

These prompts have been designed in partnership with autistic people and are designed to expand on the research questions and to focus specifically on positive aspects of wellbeing rather than asking potentially triggering questions about experience of suicide, self-harm and mental health difficulties. The sub-prompts aim to facilitate engagement by autistic people who prefer instructions that are more concrete. The participant information sheet stresses that there are no right or wrong answers and participants should express whatever is important to them.

Local Coventry based autism groups – Act for Autism, Coventry and Warwickshire Mind, Papyrus and Rainbow Autism network have been involved in discussions regarding the materials and have expressed interest in using the postcards for group activities supported by the researcher.

This data collection will take place from March 2020.

2. Public discussion of submissions

The submissions will be displayed in Coventry Central Library in June/ July 2020 alongside any interpretation that the participants wish to offer to contextualise their submissions. The aim of this exhibition is to allow participants and visitors to view the themes emerging from the research and to review and discuss the submission. To record the public debate, visitors to the exhibition will be invited to give consent to be filmed giving their reaction to the exhibition. Notices will be clearly displayed on any day when filming takes place visitors will be invited to express interest in undertaking a short video interview. An information sheet will give details of the purpose of filming, which will be fully explained by the researcher and consent for filming will be indicated on the video consent form that has been provided by Coventry City of Culture projects.

3. Outcomes

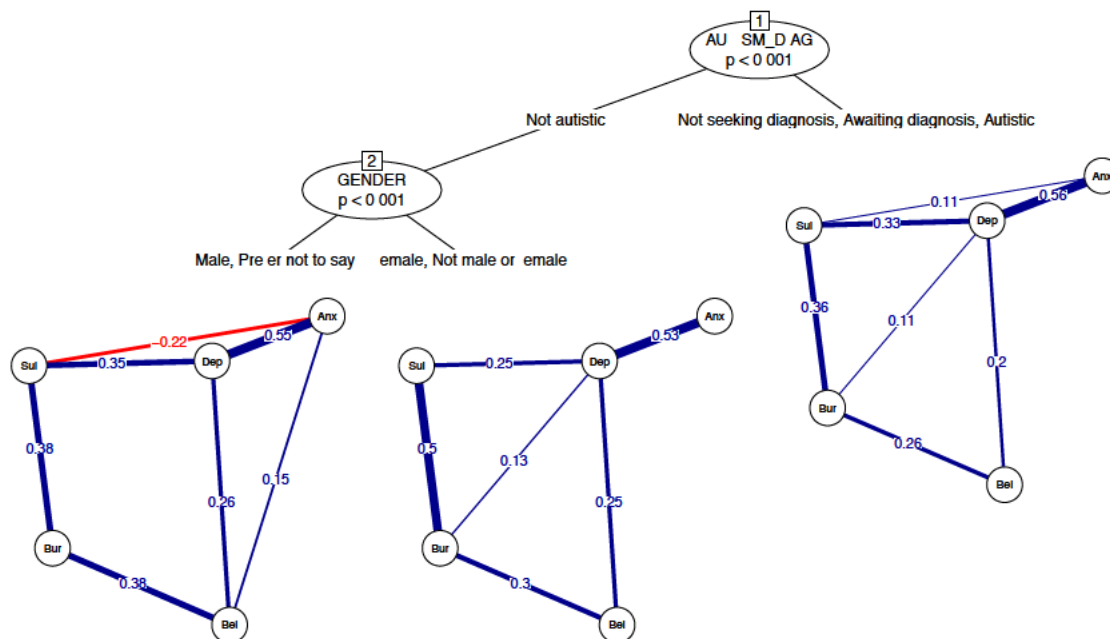
The specified outputs of this process are ideas to inform future research that can explore how we can conceptualise and measure social belonging and social connections and how these may be supported to improve mental health and wellbeing. The project will also aim to create a permanent anonymized online record of the submissions along with the participant/ public reaction. We also plan to produce a short brief for policy makers.

4. Data analysis

This project is planned as public engagement and to generate ideas for future research. However, the researcher has been advised to apply for ethics in the event that the dataset may be suitable for analysis. An arts-based methodology, such as polytextual thematic analysis may be suitable for the analysis of such a dataset as it encompasses many of the values of the creative approach promoted by autistic researchers, such as empowerment and placing autistic people as the “insider” experts. It also allows a range of visual forms to be included in the dataset and to be taken forward for analyses (Gleeson, 2012)

Supplementary 4: Supporting information for study 4: The role of anxiety and depression in suicidal thoughts for autistic and non-autistic people: a theory-driven network analysis

Study 4: Supplementary Information 1



Supplementary Figure 1a: Output of the *networktree* analysis

This shows that the data splits primarily on autism diagnosis with data from non-autistic people showing a different pattern to autistic people and those seeking or not seeking diagnosis. Only the non-autistic data split according to gender.

Study 4: Supplementary Information 2: Technical details of the analysis

Statistical analyses were conducted in R (version 4.0.5; R core team 2021).

Exploring the data: Item distributions were kurtotic as they intend to capture rare experiences (van Orden et al 2008) so data were transformed using the *r* package *huge* to relax the expectation of normality. Items were on an ordinal scale so we used Spearman correlations using the *cor_auto* function in *qgraph*. We used the *networktree* package to explore the most influential split within the data based on autism diagnosis (autistic, not autistic, seeking diagnosis, not seeking diagnosis) and gender (female, male, not male or female).

Item selection: Over-lapping constructs pose a problem for network inference so steps should be taken to ensure that nodes represent distinct conceptual entities (Burger et al 2021; Fried & Cramer 2017). There is currently no *best practice* solution available, thus, we drew on the work of others (e.g. Lass et al 2020; Barthel et al 2020) and used the *goldbricker* function from the *networktools* R package (Jones 2017) to compare correlations between network nodes and flag pairs where few correlations differ. We considered whether flagged pairs: (i) were distinct constructs and should be retained; (ii) over-lapped entirely and thus, one item should be removed; or (iii) over-lapped partially and, thus, items should be combined using the *reduce_net* function from the *networktools* package which combines items using a principal component analysis. We used theoretical understanding, network visualisation and adjacency matrices to inform decisions.

Whole sample network estimation: We used the *Mixed Graphical Models (mgm)* package to estimate the network in the whole sample with the continuous variables measuring individual items and the categorical variable autism diagnosis. We set a random seed at the outset to ensure the analysis is fully reproducible and applied a cross-folds validation with 10 folds as penalization. The partial correlations between each node and others in the network are equivalent to regression coefficients in a regression model, thus, nodes can mediate one another in a putative causal, mediating relationship (as in Isvoranu et al 2017). For a tutorial on *mgm* see (Haslbeck, Jonas & Waldorp, 2015).

Group network estimation: We estimated networks in autistic and non-autistic people using the *Estimate Group Network* package, which allows for greater statistical power by combining datasets and improves network estimates by exploiting similarities across groups (Danaher et al 2014). If this does not improve model fit, separate networks are estimated, which more accurately identify similarities and differences across

groups than individually estimated networks. We report here the model employing Extended Bayesian Information Criterion (EBIC) as regularization. For a tutorial, see (Constantini et al 2017).

Network visualization: We visualised networks using the r *qgraph* package (Epskamp, Cramer, Waldrop, Schmittmann & Borsboom 2012). The Fruchterman-Reingold (FR) algorithm is the most frequently used placing algorithm (Jones, Mair & McNally 2018) and places highly connected nodes towards the centre and less connected nodes to the periphery with as few crossing edges as possible (Fruchterman and Reingold 1991). Edge width is directly proportional to the absolute value of the edge weight with wider edges representing stronger edges.

Expected influence: We selected *expected influence* as centrality estimate (total sum of edge weights on a given node taking into account negative associations between nodes) (Robinaugh, Millner & McNally 2016) as other centrality measures may be less reliably estimated (Epskamp et al 2017).

Network comparison: We calculated the correlation co-efficient between the two networks and the largest absolute differences in edge weights and expected influence between the autistic and non-autistic networks. Next, we used the *Network Comparison Test* (van Borkulo, Epskamp & Milner 2016) to test whether networks are statistically invariant with respect to global strength, individual edge weights and expected influence. For tutorial see (van Borkulo 2018).

Network stability: we used the *estimatebootnet* function in *bootnet* to estimate the accuracy of network edge estimates and stability of centrality indices. For tutorial see (Epskamp et al., 2018).

Supplementary 1b: r script for the analysis

```
## install packages
library("mgm")
library("qgraph")
library("bootnet")
library("networktools")
library("haven")
library("networktree")
library("EstimateGroupNetwork")
library("stringr")
library("networktree")
library("igraph")
library("NetworkComparisonTest")
library("psychTools")
library("summarytools")
library("huge")
library("psych")
library("cyphr")
library("rockchalk")
library("dplyr")

## this is the script for the published paper.
## The shared data includes only a subset of the
## published data as some participants withheld consent for data sharing.
## This script will need to be adjusted accordingly.

inqplusdata<-read.csv('2804_inqplusdata.csv', header=TRUE)

## set categorical variables
inqplusdata$AUTISM_DIAG<-as.factor(inqplusdata$AUTISM_DIAG)
inqplusdata$AUTISM_DIAG <- factor(inqplusdata$AUTISM_DIAG,
                                levels = c(1,2,3,4),
                                labels = c("Not autistic",
                                           "Not seeking diagnosis",
                                           "Awaiting diagnosis",
                                           "Autistic"))

inqplusdata$GENDER<-as.factor(inqplusdata$GENDER)
inqplusdata$GENDER <- factor(inqplusdata$GENDER,
                             levels = c(1,2,3,4),
                             labels = c("Male",
                                         "Female",
                                         "Not male or female",
                                         "Prefer not to say"))

## check totals each category
table(inqplusdata$AUTISM_DIAG)
table(inqplusdata$GENDER)
```

```
#####
##### prepare data: networktree script #####
#####

## to explore where the most influential splits in the data are
## we use the network tree package which uses recursive partitioning
## to identify influential splits in the data on an exploratory basis
## we do this because of systematic bias in access to autism diagnosis
## thus, we ask whether those who think they might be autistic
## are statistically similar to those with or without diagnosis

## select variables for tree analysis
treeData<-subset(inqplusdata, select=c("depression",
                                     "anxiety",
                                     "belonging", "burden",
                                     "AUTISM_DIAG",
                                     "GENDER", "AGE_1",
                                     "Q455", "T1_PHQ9_DEAD"))

## select variables for initial tree analysis
## split variables are gender and autism diagnosis status

tree1<-subset(treeData, select=c("depression",
                                "anxiety", "belonging",
                                "burden", "T1_PHQ9_DEAD",
                                "AUTISM_DIAG",
                                "GENDER"))

## check counts in each group
mytable_autism<-table(tree1$AUTISM_DIAG)
mytable_autism

mytable_gender<-table(tree1$GENDER)
mytable_gender

## create correlation matrix
cor_tree<-cor_auto(tree1[,c(1:5)])

## create labels
tree_names<-c("Dep", "Anx",
              "Bel", "Bur", "Sui")

## visualise network
q1<-qgraph(cor_tree, layout="spring", labels=tree_names)

## specify node variable and split variables
tree_nodevars<-tree1[,1:5]
tree_splitvars<-tree1[,6:7]
```

```

## run network tree
cor_aut2<-networktree(nodevars=tree_nodevars, cor="cor_auto",
                      splitvars=tree_splitvars, method="ctree",
                      transform="glasso")

# print function allows us to view network
print(cor_aut2)

## create average layout of all non-autistic male and female and
## autistic combined
no_aut_female<-getnetwork(cor_aut2, id=4)
no_aut_male<-getnetwork(cor_aut2, id=3)
aut_network<-getnetwork(cor_aut2, id=5)
no_aut_network<-getnetwork(cor_aut2, id=2)

R<-qgraph(no_aut_female, layout="spring")
S<-qgraph(no_aut_male, layout="spring")
U<-qgraph(aut_network, layout="spring")
V<-qgraph(no_aut_network, layout="spring")

laYout<-averageLayout(U,V)

## visualize network

pdf("1601_networktree.pdf", height = 15, width=25)
plot(cor_aut2, edge.labels=TRUE, minimum=0.1, cut=0.06,
     edge.label.cex=1.5, labels=tree_names,label.fill.vertical=1,
     partyargs = list(gp=grid::gpar(cex=2)),
     theme="colorblind", layout=laYout)
dev.off()

#####
## select variables and data screening
#####
#####

## select variables
anxdep_cluster<-subset(inqplusdata,
                      select = c("T1_GAD1_NERVOUS",
                                "T1_GAD2_WORRYSTOP",
                                "T1_GAD3_WORRY", "T1_GAD4_RELAX",
                                "T1_GAD5_RESTLESS", "T1_GAD6_ANNOY",
                                "T1_GAD7_AWFUL",
                                "T1_PHQ1_INTEREST",
                                "T1_PHQ2_HOPeLESS", "T1_PHQ3_SLEEP",
                                "T1_PHQ4_ENERGY", "T1_PHQ5_APPETITE",
                                "T1_PHQ6_FAILURE",
                                "T1_PHQ7_CONCENTRATE",
                                "T1_PHQ8_MOVESLOW", "T1_PHQ9_DEAD",
                                "T1_INQ_1_GONE", "T1_INQ_2_HAPPIER",

```

```

      "T1_INQ_3_RELIEF", "T1_INQ_4_RID",
      "T1_INQ_5_WORSE", "T1_INQ_6_BELONG",
      "T1_INQ_7_CARING", "T1_INQ_8_DISCON",
      "T1_INQ_9_OUTSIDER", "T1_INQ_10_CLOSE",
      "AUTISM_DIAG"))

#####
## prepare data #####
#####

## check alphas
GAD7<-data.frame(anxdep_cluster[,1:7])
PHQ9<-data.frame(anxdep_cluster[,8:16])
INQ_TB<-data.frame(anxdep_cluster[,17:21])
INQ_PB<-data.frame(anxdep_cluster[,22:26])

alpha(GAD7)
alpha(PHQ9)
alpha(INQ_TB)
alpha(INQ_PB)

## remove missing cases, transform non-normal data
## explores for overlapping constructs and combines possibly autistic
## and autistic people

## retain complete cases
data_subset<-anxdep_cluster[,1:27]
anxdep_cluster1<-anxdep_cluster[complete.cases(data_subset), ]

## check missing data
is.na(anxdep_cluster1)
sum(is.na(anxdep_cluster1))

## explore and transform data
## transform data apart from autism diagnosis category
anxdep_cluster1[,-27]<-huge.npn(anxdep_cluster1[,-27])

## check again the type of data
str(anxdep_cluster1)

# rename to be sure this is transformed data
anxdeptrans<-anxdep_cluster1

#####
####
##### check for overlapping constructs using goldbricker #####
#####
####

gb_all<-goldbricker(anxdeptrans[,-27], p = 0.05,

```

```

        method = "hittner2003", threshold = 0.25,
        corMin = 0.5, progressbar = TRUE)
gb_all

badPairs1<-c("T1_GAD3_WORRY", "T1_GAD2_WORRYSTOP",
            "T1_INQ_4_RID", "T1_INQ_3_RELIEF",
            "T1_INQ_8_DISCON", "T1_INQ_6_BELONG",
            "T1_PHQ8_MOVESLOW", "T1_GAD5_RESTLESS",
            "T1_INQ_2_HAPPIER", "T1_INQ_1_GONE",
            "T1_GAD7_AWFUL", "T1_GAD1_NERVOUS")

## run reducenet function to combine items using PCA
anxdeptrans1<-net_reduce(anxdeptrans,
                        badpairs = badPairs1,
                        method=c("PCA"))

## run a second round of goldbricker
gb_all1<-goldbricker(anxdeptrans1[,-15], p = 0.05,
                    method = "hittner2003", threshold = 0.25,
                    corMin = 0.5, progressbar = TRUE)
gb_all1

## this brings up further 'bad pairs' in burdensomeness and anxiety items
badPairs2<-c("PCA.T1_INQ_2_HAPPIER.T1_INQ_1_GONE", "T1_INQ_5_WORSE",
            "PCA.T1_GAD7_AWFUL.T1_GAD1_NERVOUS",
            "PCA.T1_GAD3_WORRY.T1_GAD2_WORRYSTOP")

## run reducenet to combine again because these overlap
anxdeptrans2<-net_reduce(anxdeptrans1,
                        badpairs = badPairs2,
                        method=c("PCA"))

## run 3rd goldbricker on version 3
gb_all2<-goldbricker(anxdeptrans2[,-14], p = 0.05,
                    method = "hittner2003", threshold = 0.25,
                    corMin = 0.5, progressbar = TRUE)
gb_all2

## this time just returns PHQ5 and 3 appetite and sleep which are distinct so
## proceed with next step

## next combine levels as in network tree analysis
anxdeptrans2$AUTISM_DIAG<-combineLevels(anxdeptrans2$AUTISM_DIAG,
                                       c(2,3,4),
                                       newLabel =
                                       "Autistic")

## then rename variables to make it all a bit more manageable using dplyr
anxdeptrans2<-anxdeptrans2 %>%

```

```

rename(relax=T1_GAD4_RELAX,
       annoy=T1_GAD6_ANNOY,
       interest=T1_PHQ1_INTEREST,
       depressed=T1_PHQ2_HOPELESS,
       sleep=T1_PHQ3_SLEEP,
       energy=T1_PHQ4_ENERGY,
       appetite=T1_PHQ5_APPETITE,
       failure=T1_PHQ6_FAILURE,
       concentrate=T1_PHQ7_CONCENTRATE,
       dead=T1_PHQ9_DEAD,
       friends=T1_INQ_7_CARING,
       outsider=T1_INQ_9_OUTSIDER,
       close=T1_INQ_10_CLOSE,
       autism=AUTISM_DIAG,
       rid=PCA.T1_INQ_4_RID.T1_INQ_3_RELIEF,
       belong=PCA.T1_INQ_8_DISCON.T1_INQ_6_BELONG,
       motor=PCA.T1_PHQ8_MOVESLOW.T1_GAD5_RESTLESS,
       gone=PCA.PCA.T1_INQ_2_HAPPIER.T1_INQ_1_GONE.T1_INQ_5_WORSE,

anxiety=PCA.PCA.T1_GAD7_AWFUL.T1_GAD1_NERVOUS.PCA.T1_GAD3_WORRY.
T1_GAD2_WORRYSTOP)
View(anxdeprans2)

## relocate autism diagnosis to end to make it easier to run mgm
anxdeprans2<-anxdeprans2 %>%
  relocate(autism, .after=anxiety)

#####
##### whole sample mgm network #####
#####

## recode autism as numeric for mgm network
anxdeprans2$autism<-as.numeric(anxdeprans2$autism)

## run mgm network to examine influence of
## categorical autism diagnosis on whole sample
## set type and level

str(anxdeprans2)

tyPe<-c(rep("g", 18),"c")
leVel<-c(rep(1,18),2)

set.seed(168)
mgmwhole<-mgm(data=anxdeprans2, type=tyPe, level=leVel,
              lambdaFolds=10,
              lambdaSel = "CV",
              k=2,
              scale=TRUE)

```

```

## it is a 19x19 matrix so total of 361
## how many edges are zero
mgmwhole$pairwise$wadj
colSums(mgmwhole$pairwise$wadj !=0) ## 138 edges are generated

## visualise network
laBels_whole<-c("relax", "annoy", "interest", "hope-\nless", "sleep",
  "tired", "appe-\ntite", "failure", "concen-\ntrate",
  "dead", "friends", "outsider", "close",
  "rid", "belong", "move-\nment", "better", "anxiety", "autism")

## name groups
groUps.whole<-list(c(1:2,16,18), c(3:9, 16), c(10), c(11:13, 15),
  c(14,17), c(19))

groUps.whole1<-list(c(1:2,18), c(3:4, 8), c(10), c(11:13, 15), c(5:7, 9, 16),
  c(14,17), c(19))

names(groUps.whole1) <-
  c("Anxiety", "Low mood", "Suicidal thoughts",
    "Thwarted belonging", "Somatic", "Perceived burdensomeness",
    "Autism diagnosis")

## curve instructions need to be adjusted because they relate to the full
## dataset and we have only consent to share certain records
curve.whole<-c(14, 38, 65, 59)
curve.rel<-(rep(0, 69))
curve.rel[curve.whole]<-c(0.5, -0.9, -0.4, -1.5)

## this is setting autism diagnosis as a square
shape.whole=c("circle", "circle", "circle", "circle",
  "circle", "circle", "circle", "circle",
  "circle", "circle", "circle", "circle",
  "circle", "circle", "circle", "circle",
  "circle", "circle", "square")

## visualise network
pdf("1601_wholenetwork1.pdf")
wholesample <- qgraph(mgmwhole$pairwise$wadj,
  theme="colorblind", layout="spring",
  repulsion=0.9, groups=groUps.whole1,
  legend=FALSE, labels=laBels_whole,
  vsize=10, shape=shape.whole,
  minimum=0.09, cut=0.09,
  maximum=0.14, curve = curve.rel)
dev.off()

## rerun without curvature to measure centrality

```

```

pdf("1601_wholenetwork_nocurve.pdf")
wholesample <- qgraph(mgmwhole$pairwise$wadj,
  title="Whole sample",
  theme="colorblind", layout="spring",
  repulsion=0.9,
  legend=FALSE, labels=laBels_whole,
  vsize=10, shape=shape.whole,
  minimum=0.09, cut=0.09,
  maximum=0.14)
dev.off()

## this shows shortest pathway but it's a bit redundant because the shortest
## pathway is so obvious
pdf("1601_wholesample_pathways.pdf")
patHways<-pathways(wholesample, from = "autism",
  to = "dead")
dev.off()

## test centrality of wholesample plot
## again, this is a bit redundant
pdf("1601_centrality whole.pdf")
centralityPlot(wholesample, include=c("Strength"), orderBy = "Strength")
dev.off()

## have a look at the edge list
wholesample$Edgelist

## check stability of this network through resampling

laBels_whole_res<-c("relax", "annoy", "interest", "depressed", "sleep",
  "tired", "appetite", "failure", "concentrate",
  "dead", "friends", "outsider", "close",
  "rid", "belong", "motor", "better", "anxiety", "autism")

set.seed(1)
res_mgmwhole<-resample(object=mgmwhole, data=anxdeprans2, nB=50)

## visualise bootstraps
pdf("1601_whole sample resample.pdf", height=20, width = 10)
plotRes(res_mgmwhole, axis.ticks = c(-.2, -.1, 0, .1, .2, .3, .4, .5, .6, .7, .8),
  cex.label=0.5, labels=laBels_whole_res,
  layout.width.labels = .40, cex.mean=0.3, cex.bg=1.6)
dev.off()

#####
####
##### group difference network using estimategroupnet #####

```



```
#####
####

## create separate datasets
anxdep_no_aut<-subset(anxdeptrans2,
                      autism == 1)
anxdep_aut<-subset(anxdeptrans2,
                  autism == 2)

## remove autism diagnosis variable
anxdep_aut<-anxdep_aut[-19]
anxdep_no_aut<-anxdep_no_aut[-19]

## run simple networks in each group using bootnet
aut_net <- estimateNetwork(anxdep_aut,
                          default="EBICglasso",
                          corMethod="cor_auto")
no_aut_net <- estimateNetwork(anxdep_no_aut,
                             default="EBICglasso",
                             corMethod="cor_auto")

## plot individual networks
plot(no_aut_net)
plot(aut_net)

## create average layout based on these graphs
laYout<-averageLayout(aut_net, no_aut_net)

## create labels for network graphs
laBels_group<-c("relax", "annoy", "interest", "hope-\nless", "sleep",
                "tired", "appe-\ntite", "failure", "concen-\ntrate",
                "dead", "friends", "outsider", "close",
                "rid", "belong", "move-\nment", "better", "anxiety")

## create groups
groUps<-list(c(1:2,18), c(3:4, 8), c(10), c(11:13, 15), c(5:7, 9, 16),
            c(14,17))

names(groUps) <-
  c("Anxiety", "Low mood", "Suicidal thoughts",
    "Thwarted belonging", "Somatic", "Perceived burdensomeness")

## plot individual networks
pdf("1601_single_group_network.pdf", width=10, height=5)
par(mfrow=c(1,2))
aut_plot <- plot(aut_net, layout=laYout,
                title="Possibly/ autistic group single",
                theme="colorblind", labels = laBels_group,
```

```

        groups=groUps,
        border.width=2, vsize=9, maximum=0.46,
        border.color='#555555', legend=FALSE) # max= 0.46 - set graph max
noaut_plot <- plot(no_aut_net, layout=laYout,
        title="Non-autistic group single", labels = laBels_group,
        theme="colorblind",
        border.width=2, vsize=9, groups=groUps,
        border.color='#555555', legend=FALSE, maximum=0.46) ## maximum is 0.44
dev.off()

## check stability of individually estimated networks and centrality estimates
## Estimate and save stability and accuracy

boot_aut1a <- bootnet(aut_net, nBoots = 1000, nCores = 8)
boot_noaut2a <- bootnet(no_aut_net, nBoots = 1000, nCores = 8)

#### Plot edge weight CI
pdf("1601_Edge weight CIs_aut.pdf")
plot(boot_aut1a, labels = FALSE, order = "sample")
dev.off()

pdf("1601_Edge weight CIs_noaut.pdf")
plot(boot_noaut2a, labels = FALSE, order = "sample")
dev.off()

#### Edge weights diff test
pdf("1601_edge_weight diff_aut.pdf")
plot(boot_aut1a, "edge", plot = "difference",
        onlyNonZero = TRUE, order = "sample", labels=FALSE)
dev.off()

pdf("1601_edge_weight diff_noaut.pdf")
plot(boot_noaut2a, "edge", plot = "difference",
        onlyNonZero = TRUE, order = "sample", labels=FALSE)
dev.off()

#### Centrality diff test
pdf("1601_centrality difference_aut.pdf")
plot(boot_aut1a, "strength", order="sample", labels=FALSE)
dev.off()

pdf("1601_centrality difference_noaut.pdf")
plot(boot_noaut2a, "strength", order="sample", labels=FALSE)
dev.off()

## centrality stability
Centrality_stability_aut<-bootnet(aut_net, nBoots = 1000,
        type = "case",
        nCores=8,
        statistics = c("strength",

```

```

        "betweenness",
        "closeness",
        "expectedInfluence"))

Centrality_stability_no_aut<-bootnet(no_aut_net, nBoots = 1000,
    type = "case",
    nCores=8, statistics = c("strength",
        "betweenness",
        "closeness",
        "expectedInfluence"))

## plot centrality stability
pdf("1601_centrality_stability_aut.pdf")
plot(Centrality_stability_aut,
    statistics = c("strength", "betweenness", "closeness",
        "expectedInfluence"))
dev.off()

pdf("1601_centrality_stability_no_aut.pdf")
plot(Centrality_stability_no_aut,
    statistics = c("strength", "betweenness", "closeness",
        "expectedInfluence"))
dev.off()

### Centrality stability coefficient
cs1 <- corStability(Centrality_stability_aut)
cs2 <- corStability(Centrality_stability_no_aut)

## run jointly estimated network using estimate group network
## and ebic estimation. This takes some time.

EGN_ebic <- EstimateGroupNetwork(list(anxdep_aut, anxdep_no_aut),
    method="InformationCriterion",
    strategy="sequential",
    criterion="ebic",
    simplifyOutput = FALSE,
    seed=756, ncores=8,
    covfun = cor_auto)

## inspect networks
EGN_ebic$network[[1]]
colSums(EGN_ebic$network[[1]] !=0) ## total=160

EGN_ebic$network[[2]]
colSums(EGN_ebic$network[[2]] !=0)## total=162

## visualize jointly estimated networks
## need to check here graph maximum for each graph and include
## again need to check this to reflect intended scale totals

```

```

laYout=averageLayout(aut_plot_ebic, noaut_plot_ebic, repulsion=0.8)

## create curvature of networks
## these need to be adjusted for shared data

curve.aut<-c(7, 15, 35, 72)
curve.a<-rep(0, 80)
curve.a[curve.aut]<-c(-0.6, -0.6, 2.1, 0.2)

curve.noaut<-c(4, 6, 7, 13, 20, 19, 59, 73)
curve.n<-rep(0, 81)
curve.n[curve.noaut]<-c(-0.5, -0.8, 3.3, -0.6, 2.4, -1.0, -0.15, 0.4)

pdf("1601_groupnetwork_ebic_trans1.pdf", width=14, height=8)
par(mfrow=c(1,2))
aut_plot_ebic <- qgraph(EGN_ebic$network[[1]],
  title="Autistic people",
  layout="spring", labels = laBels_group,
  esize=25, curve=curve.a,
  theme="colorblind", groups=groUps,
  border.width=3, vsize=12,
  border.color='#555555', legend=FALSE,
  maximum=0.95, minimum=0.08, cut=0.08)
noaut_plot_ebic <- qgraph(EGN_ebic$network[[2]],
  title="Non-autistic people",
  layout=aut_plot_ebic$layout,
  labels = laBels_group,
  groups=groUps, curve=curve.n,
  theme="colorblind", esize=25,
  border.width=3, vsize=12,
  border.color='#555555', legend=FALSE,
  maximum=0.95, cut=0.08,
  minimum=0.08)

dev.off()

## check absolute edge differences
input<-abs(getWmat(EGN_ebic$network[[1]])-
  (getWmat(EGN_ebic$network[[2]])))

input

which(input==max(input), arr.ind=TRUE)
which(input>=tail(sort(input), n=10)[1], arr.ind=TRUE)

## check centrality
## expected influence
pdf("1601_compare_EI_trans.pdf", height=5, width=4)
centralityPlot(list(autistic=aut_plot_ebic,
  nonautistic=noaut_plot_ebic),
  include="ExpectedInfluence",

```

```

        orderBy = "ExpectedInfluence")
dev.off()

## now run with raw scores and see how it looks as in
## Burger 2020, p.20 footnote
pdf("1601_compare_EI_trans_raw.pdf", height=5, width=4)
centralityPlot(list(autistic=aut_plot_ebic,
                    nonautistic=noaut_plot_ebic),
               include="ExpectedInfluence",
               orderBy = "ExpectedInfluence", scale=c("raw"))
dev.off()

## check strength, closeness and betweenness
pdf("1601_compare_others.pdf", height = 5, width=6)
centralityPlot(list(autistic=aut_plot_ebic, notautistic=noaut_plot_ebic),
               include=c("Strength",
                        "Betweenness", "Closeness"),
               orderBy = "Strength")
dev.off()

## identify 75th centile expected influence nodes
exp_aut1<-expectedInf(aut_plot_ebic, step = 1)
exp_noaut1<-expectedInf(noaut_plot_ebic, step = 1)

exp_inf_aut1 <- exp_aut1$step1
top_exp_inf_aut1 <- names(exp_inf_aut1[exp_inf_aut1>quantile
                               (exp_inf_aut1, probs=0.75,
                               na.rm=TRUE)])

top_exp_inf_aut1

exp_inf_noaut1 <- exp_noaut1$step1
top_exp_inf_noaut1 <- names(exp_inf_noaut1[exp_inf_noaut1>quantile
                                             (exp_inf_noaut1, probs=0.75,
                                             na.rm=TRUE)])

top_exp_inf_noaut1

## run network comparison test
## first check how similar pearson and polychoric correlations are as NCT
## only uses pearson
## we already have missing cases excluded pairwise

## check correlation of pearson, versus spearman correlation
c1 <- cor(anxdep_aut)
c1b <- cor_auto(anxdep_no_aut)
cor(c1[lower.tri(c1)], c1b[lower.tri(c1b)], method="spearman") #0.87
c2 <- cor(anxdep_aut)
c2b <- cor_auto(anxdep_no_aut)
cor(c2[lower.tri(c2)], c2b[lower.tri(c2b)], method="spearman") #0.87

## since transforming the data these now correlate 1

```

```

## then test absolute differences in edge weights and centrality
## check absolute edge differences
input<-abs(getWmat(EGN_ebic$network[[1]])-
           (getWmat(EGN_ebic$network[[2]])))

which(input==max(input), arr.ind=TRUE)
which(input>=tail(sort(input), n=10)[1], arr.ind=TRUE)

## plot edge differences
pdf("1601_differences.pdf", width=6, height=6)
plot.diff<-qgraph(input, title="Largest absolute differences",
                  layout=aut_plot_ebic$layout,
                  labels = laBels_group,
                  groups=groUps,
                  theme="colorblind", esize=25,
                  border.width=3, vsize=12,
                  border.color='#555555', legend=FALSE,
                  maximum=0.14, cut=0.07,
                  minimum=0.00)
dev.off()

## check absolute difference in node centrality
expinfdiff<-exp_aut1$step1-exp_noaut1$step1
expinfdiff

## nodes with greatest real difference in expected influence
## difference >+-0.1 - outsider -0.18
## close -0.14, rid -0.1, tired -0.14, depressed 0.13, dead 0.1

## first run NCT on largest absolute edges and nodes

## then run NCT on largest abs edge differences
set.seed(159)
NCTres1 <- NCT(anxdep_aut, anxdep_no_aut,
              it=5000, binary.data=FALSE,
              test.edges=TRUE,
              edges=list(c(5,3), c(10,4),
                        c(12,9), c(10,14), c(13,11)),
              progressbar=TRUE, test.centraliity = TRUE,
              centraliity="expectedInfluence",
              nodes=c(4,6,10,12,13,14))

## retrieve measurements
NCTres1$glstrinv.real ## 0.38 difference in global strength between networks
NCTres1$glstrinv.sep ## 9.64 autistic group; 10.02 non-autistic group ## gives strength for
each group
NCTres1$glstrinv.pval

NCTres1$nwinv.real ## the value of the maximum difference M in any of the edge weights
NCTres1$nwinv.pval

```

```

NCTres1$seinv.real ## value of difference in edge weight of the observed network
NCTres1$seinv.pvals

NCTres1$seinv.pvals[which(NCTres1$seinv.pvals[,3]<0.05),] ## edges that differ significantly

## retrieve differences in centrality estimates
NCTres1$difccen.real
NCTres1$difccen.pval
NCTres1$difccen.sep

## then run NCT on all edges and nodes
set.seed(17)
NCTres2 <- NCT(anxdep_aut, anxdep_no_aut,
               it=5000, binary.data=FALSE,
               test.edges=TRUE, edges='all',
               progressbar=TRUE, test.centralitiy = TRUE,
               centrality="expectedInfluence",
               nodes='all')

## retrieve measurements
NCTres2$glstrinv.real ## 0.38 difference in global strength between networks
NCTres2$glstrinv.sep ## 9.64 autistic group; 10.02 non-autistic group ## gives strength for
each group
NCTres2$glstrinv.pval

NCTres2$nwinv.real ## the value of the maximum difference M in any of the edge weights
NCTres2$nwinv.pval
NCTres2$seinv.real ## value of difference in edge weight of the observed network
NCTres2$seinv.pvals

NCTres2$seinv.pvals[which(NCTres2$seinv.pvals[,3]<0.05),] ## edges that differ significantly

```

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