The Truth Hurts : An Online Qualitative Study on Self-harm on the Autism Spectrum

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I declare that this thesis is my own work and has not been submitted for the award of a higher degree elsewhere

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This thesis is dedicated to the online autistic community, who show such self-awareness, positivity, empathy and support to one another.

I have achieved this project both despite of, and because of my autism. I would like to thank my autism for giving me the single-subject focus, all-consuming drive and self-discipline, and intense flow-state of working that has allowed me to see this through from start to end. I would also like to acknowledge my autism for attempting to self-sabotage this, by changing jobs five times, and moving house twice over the course of the PhD. The project has remained my sole constant throughout all of this, a source of focus, a dependable anchor in my autistic storm, and a true joy to complete.

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Abstract

Autistic people experience a higher prevalence of self-harming behaviours than the general population. Due to a combination of self-harm being a taboo subject, the isolation created by the intersection of multiple marginalised identities, and a belief held by professionals that many mental health related problems are inherently part of autism and therefore immune to treatment or help; many autistic people are left unable to access the help and support that they desperately need. This thesis uses an online qualitative methodology to explore this under-researched phenomenon, thematically analysing online forum posts from non-intellectually impaired autistic adults seeking help and support from each other; to determine what forms of self-harm are described, what precipitates the self-harm, and how forum users help each other. Qualitative methodologies are under-represented in autism research, due to the dominance of psychology and neuroscience, the historical representation of autism by third parties such as parents, carers and health care professionals, and the belief that autistic people are unable to truthfully present their own narrative. Using the neurodiversity paradigm as a fresh lens through which to view the subject of autistic self-harming behaviours, I give the adult autistic online community a voice through my insider-researcher status. I discover that self-harming behaviours are nuanced and complex, highlighting the connections between sensory overload, meltdowns, and impulsive repetitive blunt trauma seen as autistic self-injurious behaviours (SIBS); as well as the interactions between anxiety, depression and more controlled self-harming, seen as classic non-suicidal self-injury. These two phenomena are not mutually exclusive, as they can co-occur, and one can precipitate the other. SIBs are found to be not just the domain of the intellectually impaired child, but are a taboo activity for an autistic adult without intellectual disability, creating shame and self-hatred. Other repetitive behaviours such as stimming are also revealed as socially unacceptable harmful behaviours used to reduce the build-up of sensory overload and meltdown SIBs, and I use the neurodiversity paradigm to argue why these behaviours should be left alone and accepted more by society. I discuss my findings in relation to theories such as the minority-stress framework, the double empathy theory, intersectionality, and social identity theory, to reconceptualise the issues raised as a wider societal problem, and not just a burden of autism. I conclude with suggestions for improvement, including education of professionals and the public to increase awareness and acceptance, alongside provision of tailored support including written communication options for autistic people.

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Abbreviations

APA – American Psychological Association

ASD – Autism Spectrum Disorder

BPD – Borderline Personality Disorder

CBT – Cognitive Behaviour Therapy

DSM – Diagnostic and Statistical Manual of Mental Disorders

JBI – Joanna Briggs Institute

LGBTQ+ Lesbian, Gay, Bisexual, Transgender, Queer and other non-heterosexual identities

MMAT – Mixed Methods Appraisal Tool

NAS – National Autistic Society

NSSI – Non-Suicidal Self-Injury

RTA – Reflexive Thematic Analysis

RRBs – Repetitive and Restricted Behaviours

SIBs – Self-Injurious Behaviours

Chapter 1 - Introduction

I have always felt different to everyone else since childhood, but had not managed to link all of my differences together into something coherent and identifiable until I came across autism during my Master’s studies in cognitive neuroscience. In autism, I recognised my differences as not so different after all, in fact shared by many others; and I realised that I was not alone, and that my daily struggles could be explained somewhat by gaining an official diagnosis. At age 40, after yet another failed attempt at conventional attendance at university, this time at PhD level, I decided to use my medical knowledge and inherent persistence positively to self-advocate and pursue an adult diagnosis of autism. Fortunately, due to the Autism Research Centre being based at Cambridge University, there is a clinic dedicated to diagnosing adults at the higher-functioning end of the spectrum. After a six month wait for an assessment, my diagnosis was borderline until my sister testified independently to my childhood autistic traits; and I left the clinic in July 2016 with an official diagnosis of Asperger syndrome, clutching a leaflet in my hand, but with no real idea as to what happens next.

I soon realised that there was very little in terms of either information or support for someone gaining an adult diagnosis of a shared difference that has existed since birth, which still holds stigma as a disability. As a natural researcher, I turned to the internet for sources of information and support, and quickly discovered an online community of fellow adults with Asperger syndrome or high-functioning autism, who were both sharing their own experiences, and supporting others who were asking for help. I slowly gained confidence in my true identity and decided to have another attempt at applying for a PhD, following my proven successful route of distance learning, and was accepted at Lancaster in their blended learning by distance programme studying mental health in the Faculty of Health & Medicine in 2018. I have never regretted a single minute, having thoroughly enjoyed the whole experience, and have flourished in my self-disciplined routines and controllable environment where others would fail. I didn’t begin with the project that I have subsequently completed, but as autism has become a topic of special interest for me, it soon became obvious that I should use this unique opportunity to undertake my own research project on mental health in autism.

1.1 Autism as a mental disorder

Autism has a diagnostic classification as one of the American Psychological Association’s (APA) mental disorders (APA, 2013), which stigmatises autism as a mental illness, and attaches a negative disorder label to what is essentially just a cognitive difference – a different style of processing sensory input, and interacting with the world around us. To reinforce the negative association between autism and mental ill health, research has shown that there are comorbidities linked to autism and mental illness, the most prevalent being depression and anxiety (Crane et al., 2019; Hollocks et al., 2019).

Anxiety is reported to be inherent and constant by many autistic people, existing at a level that appears to be increased in relation to the general population (Sedgewick et al., 2021); and increases further when stressful situations or environments create pressure points (Robertson et al., 2018). Autism is identified as having three main diagnostic criteria, difficulties in social and communicative interactions, altered sensory sensitivities, and the need for repetition and routine (Cashin, 2009); and these all contribute to raised anxiety levels in different ways. As humans are a social species, difficulties in interpreting spoken or body language, slower cognitive processing, and an inability to maintain eye contact make being autistic in a predominantly neurotypical world frustrating, which generates anxiety (Robertson et al., 2018). If sensory sensitivities create hypersensitivity to light, smells, and sounds, it is harder to leave the controllable environment of home and venture out into the wider unpredictable world, especially if anxiety levels can raise to the point of meltdown in public (Robertson et al., 2018). Creating predictable routines and environments can mitigate these difficulties somewhat, but if subjected to change from outside influences, this also produces unbearable levels of anxiety (Robertson et al., 2018).

The build-up of anxiety can induce physical responses that are stigmatised by society. Self-stimulatory behaviours, or stimming, are repetitive physical movements that are believed to dissipate anxiety before it reaches a critical pressure point (Kapp et al., 2019). If unable to release this pressure, meltdowns can be an intense mental and physical response to this (Belek, 2019), losing control to the point where a recovery period is needed, and shame is felt. Depression, self-harm and suicidal ideation can potentially follow on from overload, anxiety, and taboo behaviours; as the knowledge of having these differences, and having to conform to a society and environment created by and for a predominantly neurotypical population, can create a sense of thwarted belongingness, isolation, burdensomeness and inadequacy (Cage et al., 2018; Moseley et al., 2022).

1.2 A historical overview

It is obvious that the difficulties that autistic people face are complex and multifactorial. These difficulties can have elements of physiological reactions and differences in cognitive style and processing within the person, but are also influenced directly and indirectly by the environment and wider society around them. This is labelled a biopsychosocial model by researchers in the field (Gillespie-Lynch et al., 2017; Kapp, 2020). Since autism was identified in the 1930s, research has predominantly remained within the medicalised domains of psychology and neuroscience, concentrating purely upon what is different on a cellular, genetic or physiological level, with a negative focus on what is wrong with autistic people, and how they can be made to be more like neurotypical people (O’Dell et al., 2016). Autism is a spectrum condition ranging from the severely intellectually impaired at one end, with no ability to live independently and limited verbal communicative abilities; to those who appear almost ‘normal’ at the other end, with maybe some eccentricities and strange hobbies, but with an average or increased intellectual capacity and an ability to ‘pass’ as non-autistic in most situations (Giles, 2014; Howlin, 2021).

Initially, it was believed that autism only existed as a childhood diagnosis, and research focused upon the diagnosis and management of severely intellectually impaired children, driven by their parents, who were keen for information, support, and potentially a cure (Howlin, 2021; Evans, 2013). This has led to a culture within autism research of the autistic population being entirely represented by and advocated for by parents, relatives, medical professionals and researchers (Leadbitter et al., 2021; Davidson & Henderson, 2010); with a belief that they are both a vulnerable population (O’Dell et al., 2016), and also unable to truthfully represent themselves due to the features of autism rendering them unreliable witnesses to their own lives (Botha et al., 2020; Botha, 2021).

Autism has essentially spent the majority of its diagnostic existence viewed solely through the perspective of outsiders, and it is only since the wider availability of the internet from the 1990s that the existence of not only adult autistic people, but also those at the higher-functioning end of the spectrum, who can articulately and assertively self-advocate; have had to be acknowledged by the medical and research professions (Giles, 2014; Howlin, 2021). It is this same population from which a generation of insider-researchers has sprung, opening up the possibilities of a more qualitative approach towards understanding what it is to be autistic, told through the hidden voice of autism (Leadbitter et al., 2021). Autistic adults without intellectual disability can go undiagnosed until later in life when often a stressful life event precipitates the need to seek help from professionals (Lai & Baron-Cohen, 2015; Jones et al., 2014). Because they have had to navigate life previously masquerading as neurotypical, autistic adults can find it hard to be believed by others (Davidson & Henderson, 2010), as there is a lack of both knowledge and services for this specific sub-population (Lai & Baron-Cohen, 2015; Jones et al., 2014). With an inherent preference for written communication, the most useful source of information, advice and support for many autistic adults has been online autistic communities (Brownlow & O'Dell, 2002, 2006; Jordan, 2010).

1.3 The research project

It is with all this information that I identified the gap in the knowledge that my research project aimed to fill. With a preference for quantitative scientific methods still prevailing in autism research, a more subjective qualitative approach presented by an insider researcher would help to create a more holistic picture of what it is like to live with autism and mental illness. From my own positive experience seeking information from within the online community, I knew that rich discussions existed out there on all topics concerning autism. Also, with the knowledge that many autistic people prefer written communication (Davidson & Henderson, 2010; Jaarsma & Welin, 2012), and would be likely to be more truthful and open towards fellow autists than researchers or medical professionals (Brownlow & O'Dell, 2006; Dekker, 2020), I felt that analysing threads on discussion forums would be a way of representing the truth without opening up any potential distress that discussing sensitive topics such as mental illness can incur. The appearance of the Coronavirus pandemic in 2020 consolidated this online qualitative approach as a valid methodology (Peyton et al., 2021). Inspiration for the precise subject matter came from within Lancaster University, as online qualitative methodologies had been successfully adopted within another marginalised and pathologized population, the LGBTQ+ community. The topic of self-harm was explored within this population, and the taboo and hidden nature of this subject also lent itself well to the use of non-intrusive online methodologies (McDermott et al. 2013a; McDermott, 2015).

Self-harm in autism has been historically framed as something that occurs as part of repetitive and restricted behaviours observed in intellectually impaired children (Minshawi et al., 2014); and not something that is also experienced in autistic adults without intellectual disability. Self-harm in the general population has been linked to mental disorders such as borderline personality disorder (BPD) (Chandler et al., 2011). The neoliberal context of the UK means that responsibility for mental disorders, including autism and self-harm, is placed directly upon the individual. Therefore, typically the contributions made by society to these conditions are overlooked (Inckle, 2020). I decided to explore these intersections of autism, mental illness and self-harm in greater depth, to tease out the subtle nuances of how these are experienced within the marginalised population of autistic adults without intellectual disability.

1.3.1 Aim, objectives and research questions

The overarching aim of this research project was to gain an understanding of the relationship between autism and self-harm, from the perspectives of people at the high-functioning end of the autism spectrum. This was reflected in the primary research question ‘How is self-harm experienced and shared within the online autism community?’

This aim and primary research question were supported by four objectives, and four secondary research questions. The objectives were to -

1. Explore and present experiences of self-harm as described by those at the high-functioning end of the autism spectrum, and how they make sense of self-harm as an autistic person.

2. Identify any perceived barriers to help-seeking for self-harm in autism.

3. Explore whether there is a relationship between self-harm experiences and autism-specific mental health phenomena.

4. Examine the ways in which the autistic community provide online support for self-harm.

And the secondary research questions were -

1. What reasons do autistic people give for their self-harm in online forums?

2. What are the forms of self-harm described by autistic people?

3. Are there any perceived barriers to seeking professional help for self-harm in autism?

4. How does the online autistic community support and respond to descriptions of self-harm?

1.4 Thesis structure by chapter

Following on from this introductory chapter, chapter two of the thesis aims to provide some background to the research in terms of the development of autism as a concept, the evidence supporting associations between mental illness and autism, and defining and describing the differences between self-harm and self-injurious behaviour, and how they relate to autism.

Chapter three seeks to establish the current knowledge base on the specific topic of self-harm within the non-intellectually impaired adult autistic community, presenting findings from a systematic literature review. The literature review highlights not only the dominance of quantitative studies and gap in the knowledge, but also the increased risk of self-harm in autistic people, and the ongoing ambiguity and blurring of the concepts of self-harm versus self-injurious behaviours.

Chapter four presents the theoretical perspectives underpinning both the specific approach to the research, and through which the analysis and interpretation were focused. I draw parallels between the medicalisation of both self-harm and autism, which has led to stigmatisation and marginalisation; and explore alternative sociological explanations that seek to change this, by refocusing the responsibility from being solely upon the individual, onto society as a whole. The chapter concludes with the introduction of the neurodiversity paradigm as a fresh lens through which to view the topic of self-harm in autism.

Chapter five introduces the methodology for the study, including the rationale for using an online qualitative methodology, and a discussion of the associated ethical debate surrounding sensitive topics and accessing marginalised populations. The underpinning philosophical assumptions of this online qualitative approach are justified, and the study methods are described in detail, including sampling strategy, data collection and analysis using Braun and Clarke's thematic analysis.

Chapter six is the empirical chapter which presents the results of the thematic analysis, creating a rich experiential description. I reveal what types of self-harm are being discussed, and the reasons given for self-harming, what barriers to seeking help are described, and how the online community responds to posts concerning self-harm.

Chapter seven takes the analysis further into a critical discussion, creating a higher-order interpretation by explaining the findings in light of existing theoretical knowledge, including the minority-stress framework, intersectionality, social identity theory, double-empathy theory, and the neurodiversity paradigm.

Chapter eight concludes the thesis, as I summarise the research findings, locate my findings within current policy and strategy, acknowledge limitations, and identify areas for future research.

1.5 Reflexivity and positionality

My positionality as an insider researcher has been made clear from the start, but as a relatively new autist in terms of diagnosis and active self-awareness, I am still evolving as I am exposed to new concepts, ideas and opinions, especially from fellow self-advocates and insider researchers. I began my academic life as a purely scientific researcher, immersed in positivism as the only paradigm, upholding objectivity and quantifiability as the gold standard within research; and neuroscience, genetics and psychology presented as the only disciplines through which to study autism. As I have had the privilege of viewing this anew though my autistic lens at doctoral level, I have become more critical of these one-sided outsider observations and measurements, which claim to understand the concept of autism through theories such as mind-blindness, extreme male brain, or a biological trade-off reduction in empathy for an increased capacity to systemise; all suggesting that to be autistic is to have a reduced capacity for humanity (Botha et al. 2020; Bottema-Beutel et al., 2021). I chose to represent the autistic online community as an insider researcher to try and redress this imbalance somewhat, as there are still relatively few qualitative studies within autism research, and even fewer that present the experiences of autistic adults, or those at the intellectually able end of the spectrum, whom I directly identify with.

Due to my evolving identity as an autistic person during this research, it was important for me to maintain a reflexive journal throughout, to not just document my decisions to comply with the requirements of a reflexive thematic analysis, but also to have these discussions with myself about the language I chose to use, and how I justified this; and note whenever I was exposed to something new that challenged previously held beliefs. As for any autistic person, I cannot represent the entire community, as it is a combination of uniqueness within a shared difference that identifies us as autistic; so this thesis is entirely my own representation of my chosen research topic, but as the literature cites, the real experts in autism are those with lived experience. (O'Dell et al., 2016, Gillespie-Lynch et al., 2017).

1.6 The language debate

The language used within this thesis reflects my preferred terms at the current time as an autistic person. The use of language is a contentious issue within autism research, and is continuously evolving, and I will explain next why I have used the terminology that I have within this thesis.

1.6.1 Identity

I have used identity-first 'autistic' or 'autistic person' to describe the autism community as opposed to 'person with autism'; as this is how I identify and want to be described myself, as do many others in the community (Kenny et al., 2016; Milton & Moon, 2012; Botha et al., 2020). The use of person-first language was introduced in the 1970s by early disability advocates to make the person more important than their condition; but suggests that the condition can either be separated from the person, which autism cannot, or that the condition is so negative that it should be considered separately, dehumanising the individual (Botha et al., 2020). Identity-first language was historically perceived of as stigmatising, so autistic or autistic person was frowned upon, but neurodiversity advocates have turned this around by taking ownership of the label and making it positive, as autism is an inherent part of their identity (Bottema-Beutel et al., 2021). To 'be' autistic is felt to be better than 'having' autism, which has disease-like connotations (Botha et al., 2020). Some self-advocates have gone as far as suggesting that by being told to reframe their identity to person-first language, that this represents a form of oppression and is a power-imbalance created by the non-autistic population (Botha et al., 2020). I have used the terms autism spectrum disorder or autism spectrum condition as key search terms when undertaking the systematic review, as this is also the language used within the positivist paradigm that dominates autism research, even though disorder-based language adds stigma and negativity to an autistic identity, and I do not use these terms elsewhere.

1.6.2 Functioning

Another area of contention surrounding language in autism is that of using functioning as a describer; and again, I have had to use this as a necessity within the remit of the specificity of my study population in the systematic review searches. Also, I have to defend my choice to use this terminology within my thesis as I do personally identify as high-functioning, and I am comfortable in referring to myself in this way for lack of better terminology. There is an argument against the use of high-functioning versus low-functioning, as functioning in this case is often interpreted as being solely in an intellectual capacity, and as a stable feature. In reality, functioning in autism can be seen to vary widely day by day, in different situations and in different people, and really refers to wider social and physical aspects as well as purely cognitive (Milton & Moon, 2012). The literature refers to autism having a 'spiky' cognitive profile, with increased abilities in some domains, but reduced capacity in others, so functioning is not viewed as an appropriate describer in terms of where anyone appears on the spectrum (Botha et al., 2021). It can also minimise the difficulties experienced by those considered to be high-functioning, while simultaneously under-estimating the capabilities of those considered to be low-functioning (Hughes, 2021; Gillespie-Lynch et al., 2017).

The term high-functioning was originally used diagnostically to distinguish between a diagnosis of Asperger syndrome (those who experience the same differences and difficulties as others on the autism spectrum but with milder symptoms, often harder to diagnose, and with an average or above average intellect) and others with exactly the same characteristics but with a language developmental delay in childhood (Baron-Cohen, 2000; Giles, 2014). This has evolved in a lay-language capacity to distinguish between those with almost ‘normal’ cognitive functioning and abilities, from those at the more severely intellectually disabled end of the spectrum who are unable to self-advocate. In this research project, I am necessarily having to identify a specific population, as I am interested in autistic adults who are able to access online forums and communicate on a level that can be understood by others in the forums. For lack of a better label, I am referring to my study population as at the higher-functioning end of the autism spectrum, which in this case is referring specifically to cognitive and communicative functioning, but does not exclude those who are non-verbal. The preferred terminology for lower-functioning autistic people is currently ‘intellectually disabled’ or ‘intellectually impaired’ (Bottema-Beutel et al., 2021); so I use these terms unless the language of the studies I am discussing uses specific reference to functioning, as well as ‘without intellectual impairment’ or ‘intellectually able’ to sometimes refer to those at the higher-functioning end of the spectrum.

1.6.3 Normality

A further note on language used is between the descriptors of neurodiverse and neurotypical. The term neurodiverse was originally coined by researcher Judy Singer in the 1990s in an attempt to make the autism spectrum inclusive of the more subtle presentations such as Asperger syndrome (Stenning & Rosqvist, 2021; Kapp, 2020). Neurodiversity as a category represents any presentation considered to be outside of cognitive ‘normal’, so includes non-autistic conditions such as attention-deficit hyperactive disorder, Tourette’s syndrome, dyspraxia, and dyslexia (Grant & Kara, 2021; Jaarsma & Welin, 2012); but autism is most commonly associated with the term due to the creation of the neurodiversity movement by higher-functioning autistic adults online (Kapp, 2020).

The term neurotypical arose from within the neurodiversity movement, partly as a way of referring to non-autistic people as a collective (Kapp, 2020); but also with a certain amount of contempt, evidenced by the satirical creation of the Institute for the Study of the Neurologically Typical by Engdahl in 1998. Their description of neurotypical syndrome is of ‘a neurobiological disorder characterised by preoccupation with social concerns, delusions of superiority and obsession with conformity’ (Runswick-Cole, 2014). This has led to criticism of the neurodiversity movement as being a form of autistic superiority (Jaarsma & Welin, 2012; Russell, 2020), and it has also been accused of only representing the higher-functioning end of the autistic community due to its origin from within the Asperger or intellectually able population (Leadbitter et al., 2021; Gillespie-Lynch et al., 2017). Some have started to refer to neurotypicals as ‘non-autistic’ instead (Bottema-Beutel et al., 2021), to both acknowledge that there are other neurological differences within the neurodiverse spectrum, and to neutralise any stigma created by negative use of the term neurotypical. Other alternative terms more recently coined include neuromajority, and neurocompliant, but to me these also generate negative connotations towards those who are either viewed as being the minority, or non-compliant, e.g. the autistic or neurodiverse community. In this thesis, I have used the term neurotypical where it is the preferred language, for example, within the systematic review chapter, or within my findings, where the online community refer to non-autistics as neurotypicals; but strive to use the term non-autistic elsewhere.

This chapter has introduced myself as a researcher and has provided some context to my research. The next chapter delves deeper into the specific topics of autism as a diagnosis, mental illness, self-harm, and autism-specific self-injurious behaviours, to lay the foundations of knowledge that underpin my research project.

Chapter 2 – Background

Autism as an area of research has covered much ground over relatively little time and cannot be summarised in its entirety for the purpose of this thesis; but in this chapter, I extend some of the concepts introduced within the previous chapter, and lay the foundations for the research project going forward. I begin by presenting an overview of the evolution of autism as a diagnosis, and the concept of autism as an identity; before introducing mental illness as a comorbidity within autism and illustrating the links with suicidality and self-harm. I then define and differentiate between self-injurious behaviours and self-harm, and conclude by highlighting a need for a review of the literature on the topic of self-harm in autistic people without intellectual impairment.

2.1 The creation of autism as a diagnosis

Autism is a relatively recent construct, as although it has always been present within society, it did not become a recognised diagnostic difference until officially documented in children in 1938 by psychiatrist Leo Kanner (Kanner, 1943). Believed to be a form of psychotic illness, and initially referred to as a form of schizophrenia only seen in children (Wolff, 2004), Kanner documented the children as being somewhat withdrawn from the social world, preferring their own company, self-occupied and absorbed in favourite topics, appreciating repetition and routine, disturbed by changes in their lives, and often mute (Silberman, 2015). Kanner named his discovery as autism, which derives from the Greek word for self; separating this population out from other psychiatric diagnoses, and becoming a diagnosis by merit of its own label (Silberman, 2015). He also noted similarities in behaviour within the children's parents, although not to the same extreme, which led psychologists in the 1950s to theorise upon environmental causes including the 'refrigerator mother' theory, a deprivation of love and affection from the parents believed to cause this social detachment (Volkmar et al., 2012).

Hans Asperger, a fellow psychiatrist at the time, documented similar traits in a separate population of children that he was studying in 1944, but with less communicative impairments, with the children often conversing at adult level using elaborate language and showing intellectual abilities at above the level of their peers in certain subjects (Silberman, 2015). These observations were overlooked at the time, only emerging much later with the label of Asperger syndrome (Wing, 1981), a version of autism placed at the higher-functioning end of the autism spectrum to differentiate between classic autism with levels of intellectual disability, and also high-functioning autism, which is similar to Asperger syndrome, but with language developmental delay (Baron-Cohen, 2000). Autism continued to be considered as solely occurring in children until the 1970s due to the belief that social and communicative impairments improved with age (Wolff, 2004), which is now known to be learnt behaviour copying non-autistic interactions, referred to as masking or camouflaging (Hull et al., 2020; Perry et al., 2022).

2.1.1 The changing diagnostic landscape

Autism moved out of the psychoanalytical field and into a more scientifically studied subject from the 1960s onwards due to the increasing popularity of epidemiology, in combination with the advent of technology delivering both genetic and molecular techniques, and modes of brain imaging (Volkmar et al., 2012; Wolff, 2004). This paradigm shift in the way autism was approached was influenced by multiple factors. In the UK, there was a gradual shift of responsibility from state provided care within institutions back onto community and parental support, following the Mental Health Act in 1959 (Evans, 2013). Parents developed a greater need for information and support, which precipitated a requirement for refined diagnostic criteria and tools, further scientific research into autism, and support organisations created by parents, for parents (Evans, 2013). This also resulted in a move towards a more social care-oriented approach, with diagnosis departing from schizophrenia and the use of negatively descriptive language such as ‘retardation’, towards more generalised diagnostic language such as ‘social and communicative difficulties’ (Evans, 2013; Volkmar et al., 2012; Wolff, 2004). Observational studies and psychogenic theories of autism were superseded by cognitive theories, and a focus on perceptual abnormalities and differences in language development (Verhoeff, 2013); but ultimately, autism has remained firmly within the grip of biomedical research, specifically psychiatry, psychology and neuroscience (Pellicano et al., 2014a).

Autism became formally classified as a diagnosis by the APA in 1980 within their Diagnostic and Statistical Manual of Mental Disorders (DSM) version 3 (Verhoeff, 2013), a manual created to enable clinicians to make a quantifiable diagnosis for patients exhibiting certain cardinal signs. These have changed slightly over the years within iterations of the manual, alongside changes in both language used and perceptions of autism, but broadly meet the observations made by Kanner back in the 1940s (Verhoeff, 2013). The ‘triad of impairments’ as described by Kanner were consolidated as diagnostic criteria by Wing & Gould (1979), and have remained the same throughout, with an autism diagnosis requiring deficits in social interactions, impairments in both verbal and non-verbal communicative abilities, and presence of repetitive and restrictive behaviours. What has changed more significantly over the years has been the number of conditions or separate diagnoses under the autism umbrella that have mushroomed, and subsequently retracted between version 3 in 1980, and the latest iteration, version 5, in 2013 (Wolff, 2004; Verhoeff, 2013).

Version 3 only acknowledged two main diagnoses of autism disorder, and pervasive developmental disorder (PDD); but a diagnosis of autism disorder required all six criteria meeting (Arkowitz & Lilienfeld, 2012). Version 4 was updated in 1994 to reflect the increased knowledge generated from both research and parental charities and associations; and separated autism out into five separate diagnoses of autism spectrum disorder (ASD), Asperger syndrome, Rett syndrome, PDD, and childhood disintegrative disorder (Zeldovitch, 2018). Criteria to recognise ASD were expanded to 16 in total, but diagnosis only required 8 criteria to be met (Zeldovitch, 2018). Regardless of how many separate diagnoses have been identified, diagnostic language has remained focused upon the negative aspects that are sought by clinicians in order to make a diagnosis, rather than identifying the positive attributes that being autistic can confer upon a person, as Asperger syndrome demonstrates.

2.1.2 Asperger syndrome as an identity

The acknowledgement of Asperger syndrome as separate to ASD recognised a population who shared the same diagnostic criteria, but without any developmental delay in language, often with extra abilities in memory, language or mathematics, and a higher IQ than the general population (Wing, 1981). Although still impaired by autism, Asperger syndrome was seen to be at the milder end of the spectrum, and previously harder to diagnose (Giles, 2014). With the expansion of diagnostic criteria and categories came an associated boom in diagnoses, sensationalised by some as an ‘autism epidemic’ (Arkowitz & Lilienfeld, 2012; Stevenson et al., 2011); and estimates vary slightly, but are reported as expanding from 4 in 10,000 or 0.04% in the 1970s, to 100 in 10,000 or 1% by 1990 (Howlin & Moss, 2012; Evans, 2013).

Disagreements as to the separation of Asperger syndrome from ASD, and the increasing belief that all are on a spectrum of abilities, precipitated a re-categorisation of all separate autism diagnoses back into one single autism spectrum disorder by the publication of version 5 of the DSM in 2013 (Verhoeff, 2013). This created much controversy, as by now, the separate diagnosis of Asperger syndrome was seen by many as not simply a diagnosis, but a cultural identity, integral to their sense of self, which had developed into a whole self-advocacy movement and community (Giles, 2014). Charities, organisations and online forums created by parents of autistic children throughout the 1990s slowly became aware of the presence of a population of adults with autism using online spaces to share their own experiences, challenge the information provided on autism websites, and meet other likeminded individuals with a shared diagnosis (Giles, 2014; Dekker, 2020). Asperger syndrome was essentially presented to clinicians as a milder form of autism, and allowed many who had not displayed as severe impairments or behaviours in childhood but were experiencing autistic difficulties as adults, to get a diagnosis and associated help and access to services (Lai & Baron-Cohen, 2015). The acknowledgement of a more subtle version of autism has also allowed for the recognition of autistic traits in those assigned female at birth, with an associated increase in diagnoses (Hull et al., 2020), challenging the previously held trope of autism as an intellectually disabled non-verbal white male child (Draaisma, 2009; Onaiwu, 2020; Pearson & Rose, 2021).

The concept of a ‘higher-functioning’ Asperger syndrome also refuted the previously held notion that autism is primarily a childhood condition, as it had been explained away as just improving with age and ‘growing out of it’ (Wolff, 2004; Lake et al., 2014). This is now understood to be the learnt ability to copy non-autistic behaviours while simultaneously masking undesirable autistic behaviours in order to fit in (Hull et al., 2020; Perry et al., 2022). The better the masking ability, the more invisible an invisible difference becomes, creating a vicious circle of camouflaging autistic behaviours making it harder to obtain a diagnosis or be taken seriously by professionals (Davidson & Henderson, 2010; Crane et al., 2019).

Masking is more likely to be employed as a coping mechanism in those considered to be higher functioning, attributed to an increased level of self-awareness, including awareness of undesirable autistic traits (Saxe, 2017). A recent systematic review has revealed that the level of masking is directly proportionate to the number or intensity of autistic traits experienced by the person, and that the greater the masking required, the poorer the mental health outcomes are (Cook et al., 2021). Masking creates cognitive dissonance, as there is a palpable discrepancy between the suppressed true self, and the social ideal that is presented; which cannot be maintained indefinitely as it draws significantly upon psychological resources, creating burnout in the long-term (Pearson & Rose, 2021; Perry et al., 2022). Prolonged management of autistic traits by masking internalises stigma and leads to a breakdown in the regulation of emotions, and alternative management strategies such as self-harm are resorted to (Pearson & Rose, 2021; Perry et al., 2022).

2.2 Mental illness in autism

Mental ill health is an extremely common comorbidity in autism, and many adults gaining an autism diagnosis later on in life have arrived there following a journey through the healthcare system primarily due to seeking help for mental illness (Pellicano et al., 2020). It is reported that up to 84% of people with autism also suffer from a diagnosable mental illness (Howlin & Moss, 2012; Cage et al., 2018), with anxiety, depression and obsessive-compulsive disorder being the most common (Howlin & Moss, 2012); but significant associations are also seen with post-traumatic stress disorder, eating disorders, and BPD (Au Yeung et al., 2019). Misdiagnoses are also common, with overlap of symptoms of autism confusing professionals into misdiagnosing schizophrenia due to emotional under-reactivity and social detachment, bipolar disorder if interests appear intense, or eating disorders when sensory sensitivities create food aversion (Au Yeung et al., 2019). Those with a normal or above average IQ are most likely to have mental illness (Howlin & Moss, 2012; Lake et al., 2014), believed to be due to an increased self-awareness of the dual stigma of autism and mental illness (Lake et al., 2014; Crane et al., 2019), and the ongoing effort of masking (Crane et al., 2019).

Loneliness and isolation feature heavily in the ability to manage mental wellness in autistic people. This is partly due to the social and communicative aspects creating barriers to seeking help, but also because although autism has hereditary genetic associations, autistic people are potentially more likely to be the only one in their family with a stigmatised invisible difference, and may be less supported and understood by family members than other marginalised identities such as racial background or social class (Davidson & Henderson, 2010; Brownlow & O'Dell, 2006). The duality of being autistic and suffering from mental illness also creates barriers when seeking help from healthcare professionals. Commonly reported criticisms include a lack of support into adulthood (Camm-Crosbie et al., 2019), a lack of knowledge or experience of autism in adults without intellectual disability (Lake et al., 2014), a paucity of suitable services and being passed repeatedly between disability or mental health clinics (Maddox et al., 2020), the need for autism-specific diagnostic tools and treatment plans (Camm-Crosbie et al., 2019), the belief that mental illness is part of autism and cannot be helped (Maddox et al., 2020; Camm-Crosbie et al., 2019), or that their problems are not severe enough to warrant help (Crane et al., 2019; Lake et al., 2014). The complex intersectionality of autism and mental illness and the subsequent lack of understanding and support from both family and professionals creates loneliness and isolation, and with no perceived way out, thoughts and behaviours can turn to self-harm and suicidal ideation.

2.2.1 Suicidality in autism

Recent studies into mental health in autism have focused upon suicide. A seminal study by Hirvikoski et al. (2016) on premature mortality in autism revealed that autistic people have an elevated premature mortality rate of 2.56 times the rate of the general population, in almost all diagnostic categories of causes of death, but particularly by suicide. The highest risk subgroup are those considered to be at the higher functioning end of the autism spectrum, and females with autism are at a greater risk of premature death by suicide than males with autism (Hirvikoski et al., 2016). Suicidal ideation and attempts were also the topic of a study by Cassidy et al. (2014), who focused upon a clinic specialising in adult Asperger syndrome diagnosis and discovered that 66% of their study population reported suicidal ideation, and 35% of them had actually planned or attempted suicide.

2.3 Self-harm

The urge to harm the self is considered a biological abnormality due to an inherent drive for self-preservation as a function of gene survival (Nock et al., 2019), and an associated avoidance of noxious stimuli in the form of pain sensation, which alerts us to potential tissue damage (Hooley & Franklin, 2018). As part of natural diversity, some individuals overcome these protective mechanisms and experience thoughts of self-injury, sometimes to the extent of ending their own life (Nock et al., 2019). Whether in the general population, or specific groups such as autism, self-harm is often considered to be inextricably linked to suicidality, with many researchers choosing to cover both topics within one study, and confusion surrounding the terminology used to describe self-harm further blurs the line between the two (McAllister, 2003; Oliphant et al., 2020). Self-harm was originally classified as a failed attempt at suicide until the 1960s, when clinicians began to realise that their patients did not necessarily intend to die (Skegg, 2005), and has been interchangeably referred to as self-injury, parasuicide, self-mutilation, deliberate self-harm, self-inflicted violence, and auto-aggression (Sadek, 2019; Skegg, 2005). Self-harm is on a spectrum of behaviours ranging from highly lethal methods such as shooting, poisoning, stabbing and jumping off buildings, through less lethal but severe cutting and burning, to violent behaviours like blunt tissue trauma, biting and scratching, and hair-pulling (Skegg, 2005).

The gateway theory suggests that self-harming behaviours and suicide are at opposite ends of a continuum, and that self-harm provides the starting point for a gradual desensitisation to pain and tissue damage and reduction in inhibitions that can end in the termination of life (Griep & MacKinnon, 2022; Harris & Ribeiro, 2021). The gateway theory was tested in a longitudinal study involving a large sample of college students, and reporting 20 or more lifetime incidents of self-injury was found to be a significant predictor in later suicidal thoughts and behaviours (Whitlock et al., 2013). Extending the gateway theory to provide more specific psychological reasoning for the transition from self-harming to suicidal behaviour is the interpersonal theory of suicide. The theory proposes that suicidal behaviour requires the presence of three elements, capability acquired by repeated exposure to pain which desensitises the individual, and two psychological constructs, thwarted belongingness, and perceived burdensomeness (Van Orden et al., 2010). Thwarted belongingness refers to feeling socially isolated, whether by family, friends, or a social group; and perceived burdensomeness describes having the perception of being a burden upon others, which creates the rationale for suicide to relieve this negative burden (Griep & MacKinnon, 2022; Moseley et al., 2022; Van Orden et al., 2010).

Further empirical evidence exists to support the relationship between self-harm and suicide, as self-harm was found to be a predictor in later suicide attempts, with the risk of death by suicide being highest within the first six months after attending hospital for treatment of self-harm (Cooper et al., 2005). Another study accessing data from a large survey of people considered to be at high-risk of suicidal behaviours discovered that self-harming behaviours were significantly associated with frequency of suicide attempt at 2-year follow up (Harris & Ribeiro, 2021). A meta-analysis of 172 studies discovered a significant but weak longitudinal association between self-injurious thoughts and behaviours and later suicide ideation, attempts or death (Ribeiro et al., 2016); and another review uncovered a reciprocal relationship between self-harm and suicide attempts, with 6-37% of self-injurers attempting suicide at some point, and 41-68% of those attempting suicide reporting a co-occurrence of self-injurious behaviours (Griep & MacKinnon, 2022). Sadek (2019) present the increased suicide risk from self-harming as being relatively low, with an estimate of 3-7% over a lifetime, and re-iterate that non-suicidal self-harm as a behaviour remains much more common than suicide attempts; and Nock et al. (2019) report a peak of suicidal thoughts and behaviours in 12% of the population at 18 years, with only 1/3 ever progressing onto suicide attempt, mostly within a year of onset of ideation.

2.3.1 Non-Suicidal Self-Injury

Nock et al. (2019) suggest that the most important distinction to make when evaluating self-injurious behaviours as suicidal is whether the intention to die is present. Sadek (2019) dichotomises the two behaviours in terms of non-suicidal self-harm providing a temporary relief from distress, whereas suicide offers a permanent relief. Suicidality can be broken down into three stages - ideation, planning and attempt, and likewise self-harming is also sub-categorised into three categories - suicide gesture regardless of intent, self-injurious thoughts, and self-injurious behaviours (Nock et al., 2019). Non-suicidal self-harming behaviours can unintentionally cross the line into suicidal behaviour if tissue damage is severe enough to cause death. To make a definition between harming with suicidal intent, or for other purposes, the term non-suicidal self-injury, or NSSI, has been created (Klonsky et al. 2014). The International Society for the Study of Self-Injury (ISSS) defines non-suicidal self-injury as “deliberate, self-directed damage of body tissue without suicidal intent and for purposes not socially sanctioned”. (ISSS, 2022). Due to prevalence in the general population without co-occurring mental illness diagnoses, NSSI disorder is now recognised by the APA in their DSM-5, where previously it existed solely as a symptom of BPD (Zetterqvist, 2015). Criteria for NSSI disorder include at least 5 separate engagements in self-injurious behaviours over a year, performed with the intention of relieving or altering psychological or social states, and experiencing urges or a preoccupation with self-harming that are hard to resist (Nock et al., 2019; Sadek, 2019).

General population pooled lifetime prevalence of NSSI is 13-23%, and peaks in adolescence, at an average age of 13 years (Kiekens et al., 2023; Kuehn et al., 2022;

Nock et al., 2019; Sadek, 2019; Swannell et al., 2014; Taylor et al., 2018; Zetterqvist, 2015). NSSI prevalence has been found to be significantly higher at 30-82% in clinical samples (Hooley & Franklin, 2018; Zetterqvist, 2015). Other proposed risk or contributary factors for engagement in self-harming behaviours include identifying as female (Griep & MacKinnon, 2022; Hooley & Franklin, 2018), identifying as non-heterosexual, transgender or nonbinary (Hooley & Franklin, 2018; Kiekens et al., 2023), growing up in a socioeconomically deprived background (Liu, 2023), experiencing childhood adverse events including abuse (McAllister, 2003; Liu, 2023; Sadek, 2019), living alone (Griep & MacKinnon, 2022), and having a co-occurring mental illness diagnosis (Griep & MacKinnon, 2022; Kiekens et al., 2023; Liu, 2023; McAllister, 2003; Nock, 2019; Sadek, 2019). Having an autism diagnosis shares some of these risk factors, including identifying as gender-diverse (Kallitsounaki & Williams, 2023; Mikulak, 2023), living alone or unsupported (Howlin & Moss, 2012; NHS, 2022), living in a socioeconomically deprived environment (Howlin, 2021; NHS, 2022) and experiencing mental illness (Howlin, 2021; NHS, 2022).

It remains unclear whether female over-representation in self-harm research is an accurate finding, as support for both increased NSSI prevalence in females, and no difference in NSSI prevalence between the sexes has been reported (Bresin & Schoenleber, 2015; Griep & MacKinnon, 2022; Miller & Smith, 2008; Liu, 2023; Sornberger et al., 2012; Victor et al., 2018). One study involving a large non-clinical sample found no significant difference in prevalence of NSSI between the sexes, and explain their findings in relation to the potential confounder of increased comorbid psychopathology in females, which may skew results in clinical samples (Liu, 2023). Another study accessing a large clinical population may confirm this assumption, as they report a female representation of 88% of their sample, with associations between females and higher rates of diagnoses of depressive or mood disorders or NSSI disorder (Victor et al., 2018). The authors rationalise their findings in respect to differences in gendered behavioural expectations and in treatment-seeking behaviours, as females are hypothesised to internalise any negative emotions, but be more forthcoming when seeking help, whereas males are expected to release negative emotions in the form of aggressive hitting/punching objects, which may not be considered as self-harm, and admitting emotional distress is viewed as a weakness (Victor et al., 2018). Plenty of support exists for the association between mental disorders and NSSI, as studies report high prevalence of co-occurring psychiatric disorders, and a positive correlation between number of comorbid diagnoses and odds of lifetime NSSI (Griep & MacKinnon, 2022; Kiekens et al., 2023; Liu, 2023; Miller & Smith, 2008). Directional causality between NSSI and mental disorders remains unclear, as NSSI has been found to be both caused by, and is a generator of, negative affect, depression, and related disorders such as BPD (Griep & MacKinnon, 2022; Kiekens et al., 2023).

Reasons given for NSSI are diverse and nuanced, with some describing intrapersonal difficulties managing emotional distress, to feel something when emotionally numb (Horne & Csipke, 2009), for avoidance of suicide, or due to psychological illness (McAllister, 2003); while others report harming due to interpersonal issues such as social and relationship difficulties, isolation, exposure to others who self-harm (Hetrick et al., 2020), to cope with memories of abuse (McAllister, 2003), or as a form of self-punishment for not fitting in (McDermott & Roen, 2016a). Any identified risk factors for NSSI rarely act in isolation, as intersections of gender identity, age, class, family dysfunction, and mental illness may simultaneously exist within individuals; and theories explaining why people engage in NSSI are also multi-factorial, combining biological, psychological and social factors that may co-occur in relatively unique ways to create similar outcomes.

2.3.2 Self-harm theories

A popular theory to explain the onset and maintenance of NSSI behaviours is the affect regulation hypothesis, reported to be the most endorsed function of NSSI (Kuehn et al., 2022). This theory proposes that it is a combination of increased negative affect that builds up prior to NSSI behaviour, the antecedent hypothesis, which subsequently reduces following an episode of NSSI behaviour, the consequence hypothesis (Hooley & Franklin, 2018; Kuehn et al., 2022). Affect or emotion regulation can be negatively reinforcing, reducing negative affect, but can also be positively reinforcing, increasing positive affect, using self-harm to create pain in order to feel emotions (Kuehn et al., 2022). One meta-analysis found support for both the antecedent and consequence functions, but the effect size was greater in support of the consequence model (Kuehn et al, 2022). Influencing psychological constructs within affect regulation are impulsivity, response latency, and urgency. Impulsivity is defined by poor planning and decision-making, difficulty maintaining attention, the need for immediate gratification, and increased risk-taking behaviour (Maxfield & Pepper, 2018). This feeds into urgency theory, where impulsive people are more likely to act without regard for future consequence, and the immediate negative reinforcement gained from the relief from distress caused by NSSI is likely to increase the frequency of NSSI as an effective affect-regulation strategy in the future (Maxfield & Pepper, 2018).

Affect regulation can be used to explain NSSI as a function to manage emotions when experiencing conditions such as depression, BPD, or other affect-related mental illnesses; but does not explain other well-described reasons for NSSI such as self-punishment, to communicate distress, or as an avoidance of suicide (Taylor et al., 2018). Affect regulation is part of a wider within-person or intrapersonal theory of self-harm, which also includes self-harm as self-punishment, generated by shame or low self-esteem (Kuehn et al., 2022; Taylor et al., 2018), which can be associated with identifying with marginalised communities such as the LGBTQ+ community (McDermott et al., 2013a); or originating from a history of childhood or sexual abuse (McAllister, 2003; Sadek, 2019). The intrapersonal theory of self-harm is also extended upon further to create a two-factor model, to incorporate between-person or interpersonal functions, which include communicating distress or seeking help from others, identifying as part of a social group or to feel belonging, to cope with dysfunctional or abusive relationships, or to hurt others (Hooley & Franklin, 2018; Taylor et al., 2018). Interpersonal functions are posited to have greater salience in adolescence, at a time when young adults are establishing an identity, creating relationships and finding a social group to belong to, while navigating physical and emotional changes (Heilbron & Prinstein, 2008; Kiekens et al., 2023). One study suggests that intra and interpersonal functions could be cyclically interlinked, directional causality has not been proven, but the authors hypothesise that interpersonal social difficulties may increase negative affect, which generates the need to self-harm in order to reduce the negative affect (Hooley & Franklin, 2018). This is supported by two other independent studies, as Muehlenkamp et al. (2013) discovered that interpersonal functions were more likely to initiate but not maintain NSSI behaviour in their large student sample, and in a meta-analysis of the affect regulation function, Kuehn et al. (2022) found greater support for intrapersonal functions as a consequence or maintenance factor of NSSI.

Nock's four-function model takes the intra and interpersonal theory the furthest, by expanding upon these two functions to create two sub-categories for each function, positive and negative reinforcement (Nock, 2008). Intrapersonal positive reinforcement describes the use of NSSI as a way of generating sensation or emotions, and intrapersonal negative reinforcement presents NSSI in order to relieve negative thoughts or feelings, e.g. affect regulation. Interpersonal positive reinforcement explains the use of NSSI to generate an affirmative social response, e.g. belonging to a community or eliciting care, and interpersonal negative reinforcement describes NSSI as a way of distracting the self from external undesirable events, e.g. family dysfunction or abuse (Nock, 2008).

2.3.3 Self-harm in autism – SIBs

Prevalence of self-harm in autism has been estimated to be much higher than general population estimates, with a recent systematic review meta-analysis pooled prevalence of 42% (Steenfeldt-Kristensen et al., 2020). Self-harming in autism is most often referred to as self-injurious behaviour (SIB), and is considered to be separate to NSSI in terms of intellectual function, age at which most affected, and in topography of harming (Steenfeldt-Kristensen et al., 2020; Matson & Turygin, 2012; Minshawi et al., 2014). SIBs are most commonly presented in children with autism, in those with more severe autism, and in those with impaired intellectual functioning (Licence et al., 2020; Matson & Turygin, 2012; Duerden et al., 2012; Rattaz et al., 2015). Classified as challenging behaviour, SIBs present as compulsive rhythmic and repetitive behaviours (RRBs) such as head banging, self-hitting, hair-pulling, self-biting and self-scratching (Steenfeldt-Kristensen et al., 2020; Matson & Turygin, 2012); with self-hitting being most prevalent in 60% of a study population of autistic children without intellectual disability (Licence et al., 2020). SIBs feature as part of all childhood development, but in non-autistic children, they diminish by the age of three (Vandewalle & Melia, 2021). Prevalence of SIBs in autistic children is much higher than typically developing peers at 30% (Shkedy et al., 2019), with one study reporting 52.3% of their population of autistic children displaying SIBs (Duerden et al., 2012), and a review estimating that 50% of autistic people experience SIBs at some point (Minshawi et al., 2014). Persistence of SIBs in both the short-term of 3 years in 77.8% of a study population (Richards et al., 2016), and follow-up long-term of 10 years at 44% of the same population (Laverty et al., 2020) has also been proven; suggesting a level of retention into adulthood.

SIBs are not exclusive to autism, as they are associated with intellectual disability, genetic disorders, neurological conditions and psychiatric illnesses (Bodfish et al., 2000); but autism can occur alongside all of these comorbidities, and the increased risk of SIBs in autism alone is significantly higher than for other presentations (Minshawi et al., 2014; Rattaz et al., 2015). SIBs are believed to be in response to aversive sensory stimuli, or to communicate a need (Karim & Baines, 2016; Duerden et al., 2012). Increased risk factors associated with SIBs have been found to be severity of autistic symptoms (Rattaz et al., 2015), presence of intellectual disability (Rattaz et al., 2015; Duerden et al., 2012; Richman et al., 2013; Bodfish et al., 2000), abnormal sensory processing (Duerden et al., 2012), insistence on sameness (Duerden et al., 2012), impulsivity (Richman et al., 2013; Laverty et al., 2020), hyperactivity (Richards et al., 2016; Laverty et al., 2020) stereotypy (Bodfish et al., 2000; Richards et al., 2016), and impaired social functioning or reduced communicative ability (Rattaz et al., 2015; Duerden et al., 2012).

Self-harming in a more neurotypical form may be overlooked in autism, due to it being attributed to SIBs, which are part of repetitive and restricted behaviours that are inherent to autism, and therefore harder to treat (Moseley et al., 2020; Oliphant et al., 2020; Shkedy et al., 2019). Treatments aimed at SIBs in neurotypical people such as talking therapies are ineffective if presentation of SIBs in autism is due to a non-verbal alternative communication strategy (Shkedy et al., 2019). Furthermore, the communicative difficulties experienced by many on the spectrum means that less effort may be made by professionals to engage with their clients to determine why they are self-harming, or the best way to help them (Shkedy et al., 2019).

In this chapter I have presented the negative associations between an autism diagnosis and poor mental health outcomes, highlighted the difficulty in defining both the methods and motivations for self-harming behaviours in autistic people, and the issues surrounding help-seeking in this population. Evidence is emerging in more recent studies to suggest that NSSI and SIBs can both occur in autistic people, and that it is not only seen within children or the intellectually disabled (Steenfeldt-Kristensen et al., 2020). In the next chapter, a systematic review is undertaken to determine the evidence base underpinning current knowledge about self-harming behaviours in autistic adults without intellectual disability.

Chapter 3 – Systematic Literature Review

In order to identify and evaluate the empirical evidence on self-harm in autistic adults without intellectual impairments, a review of the existing literature must be undertaken. In this chapter, I justify my review approach, define my search terms and inclusion and exclusion criteria, and describe my quality appraisal and data extraction method; before presenting my findings within a thematic synthesis. I then discuss my findings within the wider literature, acknowledge any limitations of my chosen review approach, and conclude by locating the gap in the knowledge that my study seeks to fill.

3.1 Review question & aim

Review Question

‘What evidence exists for self-harm in autistic adults without intellectual impairment?’

Aim

The aim of this review was to generate an overview of the current knowledge base on the topic of self-harm in autistic adults without intellectual impairment.

3.2 Method

3.2.1 Review approach

The systematic review method was selected to ensure that methodologically heterogeneous studies would be captured to answer the review question, while using a methodical, reproducible and rigorous strategy (Aveyard et al., 2016a). Autism research is historically rooted within the scientific discipline of psychology, which generates predominantly quantitative study designs (Pellicano et al., 2014a; Glynne-Owen, 2010); but mixed method and qualitative research in autism is increasing alongside the popularity of patient and public involvement in research (Pellicano et al., 2014b; Benevides et al., 2020). The research project driving this review uses a qualitative approach, but on initial scoping searches there were relevant quantitative and mixed studies that also answer the review question. Omitting relevant quantitative or mixed studies cannot be justified, as all studies that contribute to answering the question should be included, or it does not fall within the remit of a true systematic review (Lizarondo et al., 2017). In order to successfully synthesise such diverse studies, a mixed method review was selected.

Mixed methods reviews are less well described within the literature (Lizarondo et al., 2017), with few recognised frameworks for synthesising mixed studies specifically. Critical interpretative synthesis (Dixon-Woods et al., 2006) is suitable for a qualitative interpretation of findings, but focuses upon the development of theories and concepts. Meta-narrative reviews (Greenhalgh et al., 2005), realist reviews (Pawson et al., 2005), and narrative reviews (Popay et al., 2006) are suitable for mixed-methods, but are also theory-driven. Meta-narrative reviews aim to address philosophical assumptions within the literature, and realist reviews aim to explain complex interventions, all of which lie outside of the remit of this review. As this review was primarily descriptive of the existing knowledge base within the empirical literature, and did not necessarily either begin with, or develop any theories from the findings; the integrative mixed method review was selected as the most appropriate method.

The integrative mixed method review approach is a well described framework that can be applied to combine a wide range of evidence from methodologically diverse sources. Whittemore & Knafl (2005) describe the process as a reduction and relative homogenisation of data, followed by a visual display of the data in order to compare, contrast, find patterns and draw conclusions. The integrative review design is used to present a mixed methods review in which data from heterogeneous studies is easily converted to a comparable format (Sandelowski et al., 2006; Harden & Thomas, 2015; Whittemore & Knafl, 2005). The process as defined by Whittemore & Knafl (2005) is particularly suitable for this review as it allows for the answering of much broader questions, and can be merely descriptive, as opposed to having a more theoretical orientation.

Within an integrative review, there are different levels at which data can transformed and integrated (Hong et al., 2017). Sequential integration transforms and analyses qualitative, quantitative and mixed findings separately, and utilises the findings of one to inform the others (Hong et al., 2017). Convergent integration involves the homogenisation and synthesis of all studies at either data or results level (Lizarondo et al., 2017; Hong et al., 2017). Integration at results level keeps study types separate at analysis stage, and results are subsequently synthesised (Hong et al., 2017). Integration at data level transforms all data into a homogeneous format during data extraction, so that it can be analysed and synthesised collectively regardless of study type (Hong et al., 2017). As the overarching research project is entirely qualitative in nature, and as all the studies described their results in a narrative form, data was 'qualitised' or homogenised into narrative form during the extraction process (Lizarondo et al., 2017), analysed qualitatively and synthesised thematically to produce findings.

Thematic synthesis (Thomas & Harden, 2008) is an appropriate and widely used method to summarise and describe the findings of both qualitative and mixed methods reviews (Lizarondo et al., 2017; Noyes et al., 2019). Thomas & Harden (2008) describe thematic synthesis as being derived from thematic analysis, a commonly applied method of qualitative data analysis, presented by Braun & Clarke (2006). Thomas & Harden (2008) acknowledge that many studies are not so clear cut, containing aspects of both qualitative and quantitative designs, and so also advocate the use of thematic synthesis for mixed studies reviews. Thematic synthesis is a transparent and systematic method of undertaking a literature review, with the synthesis of data following a process of three stages (Thomas & Harden, 2008). Stage one concerns the inductive coding of data, and stage two organises these codes into descriptive themes. Stage three goes beyond description, developing a higher order of interpretation to generate concepts, hypotheses or frameworks to support the review question.

3.2.2 Search strategy

Key search terms were identified using the PICO tool, utilising the qualitative version from Lockwood et al. (2015) –

Population – Adults (over 18 years of age)

Issue – Self-harm

COntext – Without intellectual impairment, referred to in the literature as Higher-Functioning Autism or Asperger Syndrome

Table 3.1. Search terms

Search Set	Keywords
S1 – Autism	autism OR autistic OR asperger*
S2- Self-harm	"self-harm" OR "self-injury" OR "self-mutilation" OR "self-injurious behaviour" OR "deliberate self-harm" OR "non-suicidal self-harm" OR "non-suicidal self-injury" OR "self-mutilation" OR "self-cutting" OR "self-hitting"

These search terms were developed following a trial of more nuanced qualitative keywords, such as "cutting", "hitting", "skin-picking", "hurt myself", "cut myself"; which increased the number of studies returned, but reduced the relevance. Autism terms were kept to the three stated, as using abbreviations of ASD (Autism Spectrum Disorder) or HFA (High-Functioning Autism) only returned irrelevant items.

Where possible within the database filters, results were also sorted for relevance, to search within title and abstract only rather than full text, retrieve only published peer-reviewed journal articles, exclude articles not written in the English language, and retrieve articles from January 2000 onwards.

The search was undertaken in January 2021, and search alerts were set up in all databases to capture any new studies falling within the search remit during the review process.

The review protocol was registered with the systematic review database PROSPERO, under registration number CRD42021236966.

3.2.3 Databases and other sources searched

The ten databases consulted in the search were PubMed, Academic Search Ultimate, Web of Science, and Scopus, which provide a broad range of academic, scientific, medical, social and healthcare related publications; PsychInfo and PsychArticles for psychology-specific studies; SocIndex, Social Care Online and SAGE for sociological input; and CINAHL for nursing and allied healthcare.

The publications database within the Autism Research Centre was also searched to discover any published literature that was not included within the available databases. Journals not available via the selected databases, but that were accessible via Lancaster library to hand-search included *Advances in Autism,* and *Education and Training in Developmental Disabilities.*

The search strategy was extended to include citation tracking and reference list searching of key papers (Aveyard et al., 2016b).

Table 3.2. Inclusion and exclusion criteria

Criteria	**Include**	**Exclude**
Population	Adults over the age of 18 with either an official diagnosis of Autism Spectrum Disorder, or those who identify as being autistic, specifically at the high-functioning or Asperger end of the spectrum Studies including children or those under the age of 18 to be included as long as results for adults are easily separated Studies from the perspective of clinicians or other allied medical professionals	Studies solely concerning children or young adults under the age of 18 years Studies on non-autistic adult parents of autistic children Studies solely concerning intellectually impaired/low-functioning and non-verbal people with a diagnosis of Autism Spectrum Disorder Any studies where results for adults cannot be separated out from those under the age of 18
Phenomena of Interest	Studies concerning self-harm in high-functioning autism or Asperger syndrome Self-harm described as deliberately and directly damaging the tissues by blunt or sharp trauma with or without the use of implements, burning, or swallowing toxic or caustic substances	Studies concerning stereotypical and repetitive self-injurious behaviour within the intellectually impaired (low-functioning autism) Self-harm only described as being indirect, eg. in the form of an eating disorder Comorbid genetic syndromes associated with self-harm
Geographic location	Anywhere in the world	
Language	Studies written in the English language	Studies written in languages other than English due to time and cost of translation
Date	Studies between 2000 and 2020	Studies completed before 2000
Study design	Quantitative (with some specific exclusions), qualitative and mixed methods studies, and systematic reviews	Quantitative studies solely concerned with the effectiveness of biomedical interventions for self-harm in autism, single clinical case

		studies, and any animal models
Type of publication	Peer-reviewed published journal articles	Unpublished material – e.g., conference proceedings, letters, doctoral theses, information pamphlets

A date limit of the last 20 years was imposed, as although autism research is relatively recent in development, first defined just over 80 years ago, with dedicated journals only emerging in 1971 (Wolff, 2004); it was felt that relevance of studies has increased since 2000, along with a change in attitude and relative destigmatisation of the topics of mental health, autism and self-harm.

3.2.4 The selection process

Titles and abstracts were sifted within each database, and all results returned were exported to reference management software EndNote, where results were de-duplicated. Any studies meeting the inclusion criteria, or any ambiguity towards inclusion or exclusion during title and abstract sift, went to full-text read. A second reviewer was utilised to ensure consensus on all included papers.

3.2.5 Quality appraisal

The Mixed Method Appraisal Tool (MMAT) (Hong et al., 2018) was selected to appraise the mixed methods studies, as it provides an individual assessment of the separate qualitative and quantitative components first, before evaluating the design of the mixed method study as a whole. It is a comprehensive checklist developed via a review of existing critical appraisal tools, interviews with users, and an expert Delphi panel. The MMAT discourages the scoring or elimination of studies on quality alone. (Hong et al., 2018).

The Joanna Briggs Institute (JBI) critical appraisal tools were chosen to appraise the quantitative and qualitative studies, as their tools are individually tailored for different sub-types of quantitative designs, and allow for the evaluation of cross-sectional, cohort and prevalence studies separately. The JBI is an international organisation with a focus on systematic reviews within evidence-based healthcare, and develop all tools via extensive collaboration and peer-review (Moola et al., 2020). Studies are not scored, as the appraisal is intended to aid and inform interpretations at results and synthesis levels (Moola et al., 2020).

A second reviewer was used to check 20% of the studies appraised.

(Appendix 1- example of completed quality and data form).

3.2.6 Data extraction

The JBI Mixed Methods Data Extraction Form (Lizarondo et al., 2017) was adapted for use with this review. It contains author/year information, followed by study type, methodology, number and characteristics of participants, phenomena of interest, setting of study, outcomes significant to review objectives for both quantitative and qualitative studies, author’s conclusion, and reviewer’s comments. Adaptations to this basic form for this particular review included the title of the publication, the database and discipline the study is from, the research question and study aims, sampling method, how the data was presented, and any novel contribution to knowledge that the study makes. Topic-specific data extracted included documenting any methods used to assess autism spectrum diagnosis, methods used to assess self-harm, how the authors defined the self-harm in terms of SIB versus NSSI, and how they referred to the autistic population.

Data was extracted from within the results, findings, discussion and conclusion sections of each paper, and was copied verbatim when represented in narrative descriptive form to preserve the original context of the data (Thomas & Harden, 2008). A second reviewer was used to check 20% of the data extraction forms.

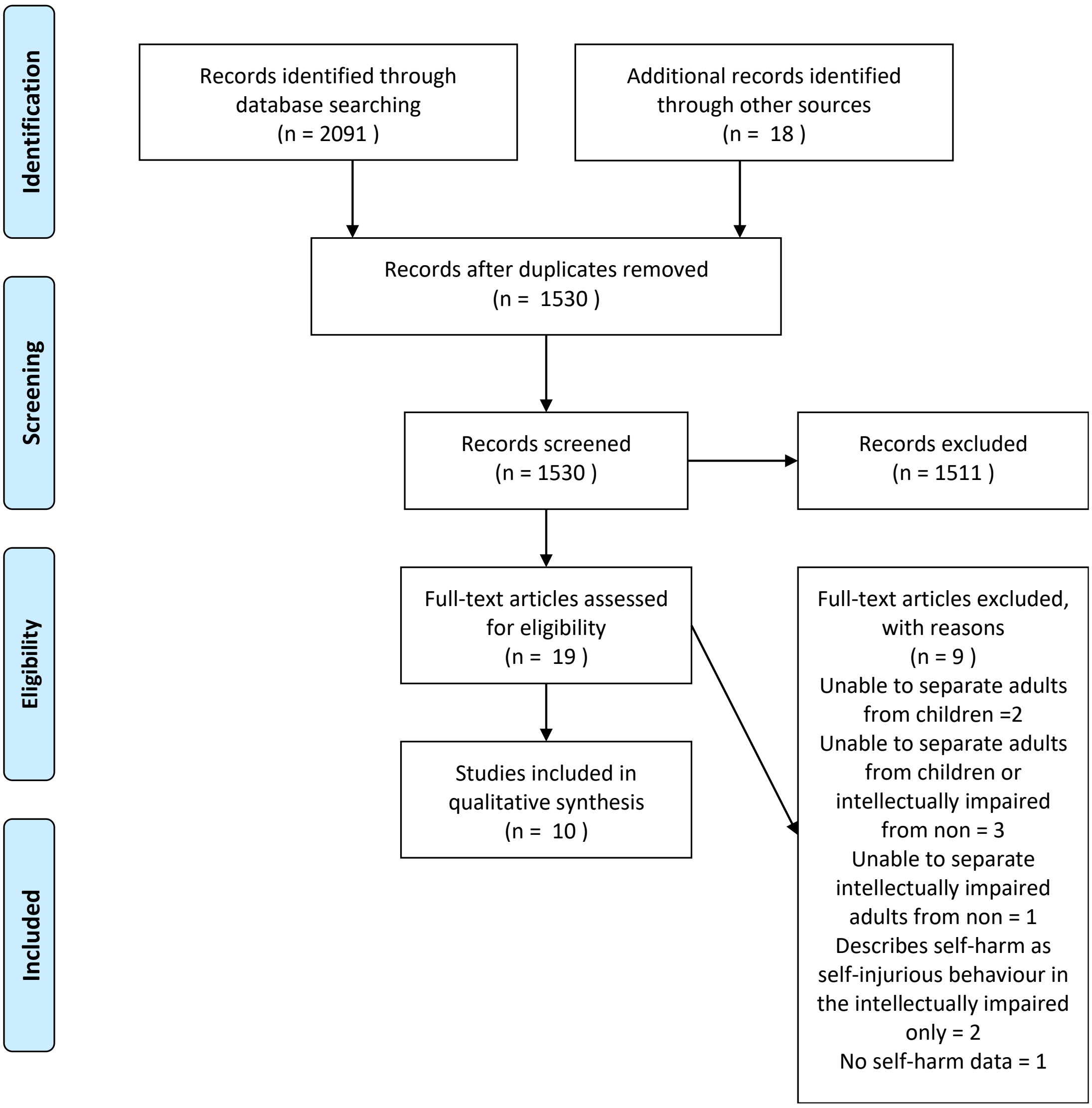
3.2.7 Data Synthesis

The data extraction forms were coded using NVivo 12. This generated 39 codes, some of which were collapsed together after re-reading the data extraction forms and full texts of the studies and identifying overlap, creating a total of 34 codes. Codes were then grouped into four overarching themes, and three were divided further into sub-themes to create a balance between losing salient points within the theme, versus describing every code in detail. A thematic map was generated in order to aid in the visualisation and comparison of the codes and themes (Appendix 2).

3.3. Results

Figure 3. 1 – PRISMA flow diagram (modified from Moher et al., 2009)

PRISMA Flow Diagram



(Appendix 3 – Database search results).

3.3.1 Study characteristics

The studies included in the review were all observational, and were dominantly quantitative in approach, with seven quantitative designs, two mixed method designs, and one qualitative design (Appendix 4). Within the quantitative studies, all followed an analytical cross-sectional approach, taking a snapshot of the populations studied. Gilmore et al. (2021) and Warrier & Baron-Cohen (2019), both utilised existing data from larger retrospective cohort studies to analyse relationships between variables. Gilmore et al. (2021) accessed Medicare records in the USA to compare health status between the intellectually disabled and non-intellectually disabled, with self-harm featuring as a small component, and not considered separately to suicidal ideation. Warrier & Baron-Cohen (2019) selected data from the UK BioBank to discover links between polygenic scores for autism and childhood trauma, lifetime self-harm and suicidal behaviour and ideation. Wilkinson (2015) used a within-subjects design to gauge attitudes from support workers in the UK to vignettes describing self-harming behaviour in people with and without autism.

Moseley et al. (2020) and Hedley et al. (2018) both measured relationships between variables in solely autistic populations using the survey method. Moseley et al. (2020) asked UK participants to complete a questionnaire to determine links between self-injurious behaviours and suicidality; and Hedley et al. (2018) explored the relationships between depression, loneliness and thoughts of self-harm in a specific population of autistic workers in Australia. Maddox et al. (2017) and Cassidy et al. (2018) both used general population control groups to compare specific characteristics. Maddox et al. (2017) determined prevalence, methods and functions of NSSI by surveying an American autistic population not all endorsing NSSI, in comparison with an American student control population who all endorsed NSSI. Cassidy et al. (2018) compared an adult autistic population with a general population in the UK to evaluate whether NSSI is a risk factor for suicidal ideation in autism.

Within the mixed methods studies, Moseley et al. (2019) used a convergent parallel design, surveying autistic adults in the UK to determine relationships between predictors of NSSI and frequency, functions and lifetime prevalence; with two open-ended questions to provide richer data to thematically analyse. Camm-Crosbie et al. (2019) adopted an embedded design in a survey format, evaluating autistic adults' experiences of accessing support and treatment for mental illness, self-injury and suicidality in the UK; with an emphasis upon the qualitative thematic analysis from open-ended questions, which was supported by quantitative descriptive data.

Both Camm-Crosbie et al. (2019) and Cassidy et al. (2018) use the same dataset to explore different avenues of enquiry; and Moseley et al. (2020) also accesses and expands upon their population studied in Moseley et al. (2019).

The single qualitative study (Goldfarb et al., 2021) adopted an interpretive phenomenological approach to thematically analyse interview transcripts from autistic adults in Israel, with a focus upon RRBs, combining acknowledgements of hoarding and self-injurious RRBs in adults without intellectual disability.

3.3.2 Theme 1 – Who is self-harming?

Considers the study participants and demographic results of significance.

Due to the dominance of quantitative study designs within this review, prevalence data is prominent. Although located within different contexts, all studies reporting on aspects of prevalence note that rates of self-harm in autistic adults without intellectual impairment are either significantly higher than previously described in the general population (Maddox et al., 2017; Moseley et al., 2019 & 2020), much higher than previously believed within autism (Goldfarb et al., 2021), over double the rate in comparison to their general population control

(Cassidy et al., 2018), or twice the rate found within their intellectually impaired comparison group (Gilmore et al., 2021).

Many of the studies report a higher response from autistic females, which is initially explained by Moseley et al. (2019) as response bias, a known general over-representation of females within voluntary survey participation. Other studies report a similar over-response from females (Camm-Crosbie et al., 2019, Cassidy et al., 2018; Goldfarb et al., 2021; Moseley et al., 2020) but also find significance within their responses. Proportionately, more females than males admit to self-harming (Cassidy et al., 2018; Maddox et al,. 2017; Moseley et al., 2020), and also admit needing support and treatment for self-injury (Camm-Crosbie et al., 2019). This may be partly explained by the reluctance of males to talk about stigmatised subjects generally (Moseley et al., 2020); but the genome-wide association study also found a significant positive association between females and higher levels of childhood trauma, self-harm, and suicidal behaviour and ideation, but not in males (Warrier & Baron-Cohen, 2019). Goldfarb et al. (2021) frame their high female response rate in respect of the gender balance in autism, which is currently believed to be 75% male. They cite that self-injurious behaviours are more prevalent in autistic females, and the over-representation in their study may have contributed towards highlighting behaviours that have previously not been considered.

3.3.3 Theme 2 – Why do autistic people self-harm?

The social and cultural motivations that may make autistic people turn to self-harm.

Sub-theme- Autism-specifics. These reasons for self-harm are believed to be behaviours identified as specific to autism.

Social and communicative difficulties are a shared feature of all on the autism spectrum, and so self-harm can be used as a way of expressing emotions or communicating distress to others when words are inadequate (Moseley et al., 2019). Alexithymia, the reduced capacity to verbalise emotions and distinguish between physical sensations and mental emotions is a feature of autism; and was shown to be a predictive variable between current and non-self-harmers, and had the greatest effect in the regulation of high-energy states (Moseley et al., 2019).

Another shared feature of those on the spectrum is altered sensory sensitivity, which may be either reduced or heightened. This presents a dichotomy of the use of self-harm for either mediating the effects of sensory over-stimulation, or because of a need for a form of stimulation where there is a lack of sensation. Goldfarb et al. (2021) present this phenomenon in the greatest detail, with participants describing this double-edged sword as their main motivation for self-injury in autism. Their first sub-theme is ‘sensory stimulation’ which represents the reduction or alteration in pain perception that can lead to self-harming to elicit bodily sensations, including the need for intense pressure that others around them would consider painful. Their second sub-theme is ‘self-regulation’, which includes the need to self-harm in order to control sensory overload, when an individual is feeling too much in terms of sensory input and needs to cancel out or over-write this with a singular distracting action of self-harm. Moseley et al. (2019) support this by suggesting that sensory stimulation may play a part in precipitating a self-harm episode, and their autistic participants scored above average for variables such as sensory sensitivity, sensory avoidance and low registration. Sensory sensitivity was also proven to be a distinguishing variable between current self-harmers and non-self-harmers, although not between current and historic self-harmers.

Sub-theme – Mental health. An obvious link between autism and self-harm, mental health features prominently in many of the studies.

Depression and anxiety have increased prevalence in studies quantifying specific diagnoses or proportion of their population on treatment (Camm-Crosbie et al., 2018; Cassidy et al., 2019; Moseley et al., 2019). Current and historic self-harmers scored moderately on the Beck Depression and Anxiety Inventories, compared to non-self-harmers scoring mildly, suggesting a link between self-harm, depression and anxiety (Moseley et al., 2019). Depression was found to have the greatest mediating affect between polygenic scores for autism, self-harm and suicidal behaviour and ideation (Warrier & Baron-Cohen, 2019); and was found to be the significant mediator between loneliness and thoughts of self-harm, supporting a model that loneliness increases depression which fosters thoughts of self-harm (Hedley et al., 2018). The only study contradicting the perceived relationship between depression and self-harm is Maddox et al. (2017), who discovered that self-harm in autism was not significantly linked to current depression or emotional dysregulation; but this is explained by a methodological anomaly created by comparing current depression with historical self-harm.

The use of the Non-Suicidal Self-Injury Assessment Tool (NSSI-AT) by three of the studies (Maddox et al., 2017; Moseley et al., 2019, 2020) introduces the concept of the function of self-harm to regulate affective states, as opposed to merely investigating the known comorbidities of depression and anxiety. Using this tool, the most commonly endorsed reason for self-harm was Affective Imbalance – Low Pressure, which describes dissociative or depressive emotional states, followed by Affective Imbalance -High Pressure, encompassing anxiety, agitation or high-energy states. (Moseley et al., 2019).

Suicidality is also strongly linked to self-harm, but the studies present an interesting dichotomy of function in relation to suicide. Lifetime self-harm has a significant association with suicidality (Moseley et al., 2020), and not just in the autistic population, but for those scoring high on self-reported autistic traits in the general population (Cassidy et al., 2018). Cutting as a modality has the greatest predictivity towards suicidality, explained by the severity of cutting causing a reduction in inhibitions and an increased tolerance over time (Moseley et al., 2020). Self-harmers can be distinguished from non-self-harmers by their responses to the suicidal ideation questions in the NSSI-AT, as for every point increase on the suicide item, participants are twice as likely to self-harm (Moseley et al., 2020). But this link to suicidality only correlates with the function of regulating low-energy states, and does not extend to the regulation of high-energy states (Moseley et al., 2020); suggesting that self-harm does serve other functions, supported by some participants disclosing the use of self-harm specifically as an avoidance of suicide (Maddox et al., 2017; Moseley et al., 2020).

Sub-theme – Genetics. A significant correlation was found between a small population identified as having an autism diagnosis within the UK Biobank, and self-harm and suicidal behaviour and ideation scores (Warrier & Baron-Cohen, 2019). This was confirmed by identifying autistic traits within the wider population of the Biobank and testing polygenic scores for autism within this population, which also correlated with higher scores on the self-harm and suicidal ideation measures. Furthermore, parents are significantly more likely to pass on polygenic scores for self-harm and suicidal ideation to any autistic children, but not to any neurotypical children. This supports a hypothesis of a bio-social or diathesis-stress model of self-harming and suicidal ideation in the autistic population (Warrier & Baron-Cohen, 2019).

3.3.4 Theme 3 – Defining self-harm

Presents the two forms of self-harming believed to exist within the autistic community, as both non-suicidal self-harm and self-injurious behaviour are used interchangeably as descriptive terms but are not necessarily talking about the same phenomena. Elements of both forms of self-harm are reflected in the studies.

Sub-theme – Non-Suicidal Self-Injury (NSSI). NSSI is the classic description of self-harm in neurotypical populations, with methods and topographies aligning with that of neurotypical self-harm. In terms of methods and topography of self-harm, there is a general agreement when responding to the NSSI-AT. The most popular methods were severely scratching or pinching with fingernails or other objects, or cutting wrists, arms, legs, torso, or other areas; and the top sites on the body for inflicting harm were arms and hands (Maddox et al., 2017; Moseley et al., 2019). These methods and sites are reflections of well-documented non-autistic forms of intentional self-harm, and with Maddox's student population in concurrence with the autistic populations, this does suggest an alignment between higher-functioning adult autistic populations and non-autistic patterns of self-harming.

Within the mixed method and qualitative study findings, the concept of self-harm either being a choice or a compulsion blurs the line between NSSI and SIBs. The notion of being able to choose whether to self-harm, how, and where, is rooted more within the non-autistic form of self-harm; whereas a compulsion to self-harm without premeditation in response to a trigger aligns more with repetitive self-injurious behaviours seen in autism with intellectual impairment. In the studies using the NSSI-AT (Maddox et al., 2017; Moseley et al., 2019), there are hints within the quantitative scale responses as to this interesting dichotomy. Agreeing with statements such as 'so I do not hurt myself in other ways', 'to avoid committing suicide' or 'I saw it on a movie/TV/on the internet/read it in a book' suggest a more carefully measured and planned use of self-harm; but equally, concurring with statements such as 'because I get the urge and cannot stop it', 'to relieve stress or pressure' or 'I accidentally discovered it' suggest a more immediate, visceral and uncontrollable response, either as a core feature of autism, or as a comorbidity. This phenomenon is discussed in the most depth in the qualitative findings - 'The question of choice' emerges in support of it being a conscious choice, with some participants describing the act of self-harm as being an acceptable strategy as long as it can be controlled and planned, and that they can also choose not to do it (Moseley et al., 2019).

Sub-theme – Self-injurious behaviours (SIBs). This accounts for acts of self-harm in terms of the more stereotypical RRBs classically described with intellectual impairment.

A small number of participants view self-harm solely as a compulsion, a lack of control even in the face of aversion towards the behaviour (Moseley et al., 2019). This is referred to in the context of repetitive, unpleasant acts undertaken habitually or stereotypically, describing self-harm more as a repetitive and restrictive behaviour that if interrupted, would make the person worse. Self-harming here is considered a part of their autism, and one participant uses the terms repetitive, stereotyped and ritualistic to describe a behaviour that has developed alongside them over time (Moseley et al., 2019).

Self-harm is portrayed as being a more compulsive, uncontrollable, and autism-specific phenomena located within the wider context of repetitive and restrictive behaviours in Goldfarb et al., (2021). Blunt trauma such as self-hitting or crushing pressure is used in response to sensory or emotional overload, or to self-stimulate due to altered sensation; but the study population all function at a high enough level to partake in qualitative interviews, so self-harm here crosses the divide between SIBs and NSSI.

Bodily-focused repetitive behaviours that support SIBs over NSSI from the NSSI-AT are ripping or tearing skin, hair-pulling, and preventing wounds from healing (Maddox et al., 2017; Moseley et al., 2019); all of which have double the autistic population participating in these methods in comparison to the student population control (Maddox et al., 2017). Blunt trauma such as punching or hitting the self with or without objects are less significantly different between the two populations, but still score highly, and may represent another blurring between the two types of autistic self-harm. Preferred sites on the body to self-harm that align with SIBs rather than NSSI are the head and face, due to the visibility of harming (Moseley et al., 2019); and which are twice as popular in autistic participants as in the student comparison population (Maddox et al., 2017).

3.3.5 Theme 4 – How to help/treat self-harm

Identifying problems and solutions that arise when seeking or providing help for self-harm within the autism spectrum.

Sub-theme – Problems. Autistic participants were asked what barriers and issues were raised in terms of accessing support for self-harm.

Access to services is a multifactorial issue. Treatment centres are not evenly distributed, and either co-occurring disabilities or an inability to drive or use public transport often prevent attendance. Problems arising at the early stage of accessing services include long waiting lists for appointments, self-funding in order to get a timely appointment, communication issues, a diminished capacity for self-advocacy, or belief that there is no support available (Camm-Crosbie et al., 2019). Support is available to children with autism, but disappears beyond school age, and adult services do not cover the dual diagnosis of autism and mental illness due to its complexity - the only services currently available are those concerning intellectual disability (Camm-Crosbie et al., 2019).

A lack of professional knowledge was raised by two studies (Camm-Crosbie et al., 2019; Moseley et al., 2019). Autistic people feel that therapists don’t know enough about autism, and even comment that autistic patients are expected to educate the professionals (Camm-Crosbie et al., 2019). Any knowledge of autism is often not worked into the therapy, and standard mental health therapies such as cognitive behavioural therapy are ineffective. Individual sessions or overall treatment duration is too brief, as autistic people need more time to develop a rapport with their therapist and process the content, and continuity of therapist is very important, due to an increased need for predictability (Camm-Crosbie et al., 2019). The inability to understand was found to be a two-way street, as autistic people may also not always understand what professionals are asking of them during therapies (Moseley et al., 2019).

One issue raised is the assumption by professionals that if an individual is seen to be higher functioning and navigating through life, then they are coping well enough to not require support for mental health issues (Camm-Crosbie et al., 2019). Participants also mentioned that they are not taken as seriously by professionals due to their reduction in emotional output (Camm-Crosbie et al., 2019). Another insensitive assumption made by professionals is a belief that all self-harmers enjoy pain and are harming to gain attention, and so do not require pain relief when being treated medically (Moseley et al., 2019). Professional beliefs and responses were the focus of Wilkinson (2015), who support all of the above issues by revealing that self-harm in autism is perceived to be less controllable by the person, and less likely to change; therefore healthcare workers are less likely to prioritise, offer more time to, or refer on for further support any patients with a dual diagnosis of autism and self-harm.

Negative associations that participants identified with their self-harming were the restrictions it imposed upon participating in either obligatory work or voluntary hobby activities, the types of clothes worn, and the ability to take care of the self effectively (Moseley et al., 2019). Participants described concealing pain caused by fresh harm, and anxiety in case anybody sees them harming in public, suggesting there is an immediate and uncontrollable aspect that differs slightly from neurotypical self-harm (Moseley et al., 2019).

Sub-theme – Solutions. Autistic participants describe what they had found to reduce or control their self-harm.

In reflection of the previously highlighted lack of professional knowledge, support and therapies, many participants identified that therapies tailored towards autism-specifics would be beneficial (Moseley et al., 2019). Even in the absence of tailored therapies, there is a need to treat any co-occurring mental illness, as this improves self-esteem, ability to function, manage emotions, and diminishes the requirement for self-harm (Camm-Crosbie et al., 2019; Moseley et al., 2019). Emotional awareness was identified as a significant trigger for self-harming, and having an increased awareness and understanding of emotions, and developing strategies to manage and master emotions reduces the need to turn to self-harm (Moseley et al., 2019). Several participants acknowledge that their self-harm was easier to both understand and control following their autism diagnosis, as it gave a perspective to understand it from, and increased their self-compassion (Moseley et al., 2019). Physical coping strategies included snapping an elastic band on the wrist, or finding alternative methods of sensory simulation to replace the need to self-harm (Moseley et al., 2019).

Some participants give self-harm a more positive spin, by describing it as a coping strategy to deal with overwhelming situations or emotions (Moseley et al., 2019). Other positive associations include viewing scars as battle wounds, feeling closer to those they care about, learning and growing emotionally and mentally, and ultimately, feeling able to help others who self-harm. Advice to others wanting to help an autistic person when self-harming was to remain calm and not get emotional, be patient and compassionate, and non-judgemental and understanding. Acknowledge the autism component, let them know they are not alone, and that they are loved, cared for and supported (Moseley et al., 2019).

3.4 Discussion

The increased prevalence of self-harm in autistic adults confirms not only that it exists, but also that it is a topic worthy of further research. A female over-representation aligns with findings in the non-autistic population (Bresin & Schoenleber, 2015; Sornberger et al., 2012; McAllister, 2003); but this has been suggested as being a self-fulfilling prophecy of self-harm as a predominantly adolescent white female concept perpetuated by research, media and popular culture in Western society (Chandler et al., 2011; Chandler & Simopoulou, 2021). Considering the male predominance in autism diagnosis is currently 3:1 (Zhang, 2020), combined with an increasing awareness of the existence of autism in females without intellectual impairment (Hull et al., 2020), the over-representation of self-harming autistic females is an interesting area of research that warrants further investigation.

Mental ill health comorbidities such as anxiety and depression have an increased prevalence in those on the autism spectrum (Hollocks et al., 2019), as well as featuring prominently alongside neurotypical self-harm (Klonsky et al., 2003). Suicidality is directly linked with self-harm in six out of ten of the studies, which raises the question of whether research is reinforcing this linkage, or whether this represents a real connection. Evidence suggests that there is an overlap between self-harm and suicide (McAllister, 2003), but there is also evidence for the clear separation of the functions of self-harm and suicide (Chandler et al., 2016). Research into autistic adults has shown that there is both a higher rate of suicidal ideation (Cassidy et al., 2014), and a higher rate of suicide particularly in females (Hirvikoski et al., 2016). This presents another potential focus for further research, considering the known gender paradox of suicide in the general population (Canetto & Sakinofsky, 1998).

All of the studies investigating motivations, methods and topographies, blur the distinctions between stereotypical SIBs and neurotypical NSSI. This suggests that there is a third more nuanced and autism-specific form of self-harm that can only be revealed by qualitative methods. Goldfarb et al. (2021) describe a more SIB-oriented behaviour pattern, but in a population of adults without intellectual impairment. They acknowledge the limitations of their small sample, and suggest that as RRBs are so prominent in the autistic population, that a larger study is warranted. They go on to discuss the taboo nature of the topic, which may not be shared within either research or clinical investigations, and also the need for reflection within autism that is made difficult within face-face interviews. My thesis seeks to address these shortcomings, as larger populations can be accessed via online forums, and the forums also provide an anonymous place to present personal representations that have been written without time pressure.

The majority of studies in this review focus through the lens of positivism, reducing both self-harm and autism to medical disorders operationalised by scores. Self-harm is also not the main focus in seven of the studies, either represented as a mediating factor, or an accessory to suicidality, or measured by a single item on a scale, so many of the studies bring little to this review. The medical models of both autism and self-harm remain at the forefront of this under-researched topic, and when medicalised, prevent us from asking the reasons why, or exploring the wider socio-cultural contributions and influences (McDermott & Roen, 2016b). The wider literature presents a continued neurologisation of autism (O’Dell et al., 2016) and pathologisation of self-harm (Chandler et al., 2011); reflecting a normalisation agenda whereby anything outside of ‘normal’ is seen as negative (Milton & Moon, 2012). Reducing emotional states into diagnosable conditions such as depression and anxiety reinforces the psychomedical paradigm of abnormality, prescribing interventions and treatments in order to fit in with society (McDermott & Roen, 2016b). This medical ontology presents both autism and self-harm as being internal factors, placing the responsibility solely upon the individual for their mental wellbeing (McDermott & Roen, 2016b). Self-harm continues to be passed off as a repetitive restricted behaviour inherent to autism that cannot be helped, as reflected by the lack of professional knowledge highlighted in this review.

A wider conversation involving the adult autistic voice needs to be held, opening the discourse to include the self-advocacy movement empowered by the advent of online communication, whose multiple voices of autism reframe both self-harm and autism as part of natural neurodiversity. My study aims to investigate how autistic people present their experiences of self-harm to the online community, and how the community responds to these experiences, using intersectionality and the neurodiversity paradigm as theoretical lenses. This will be the first study to apply these frameworks to self-harm in autism, refocusing the concept of ‘normality’, and discovering whether self-harm on the spectrum is represented as a purely pathological phenomenon.

3.5 Limitations

Although a systematic approach was taken, it is never possible to capture all available studies on the topic, due to accessibility of databases and other restrictions placed upon the review by the inclusion and exclusion criteria. The systematic approach, although intended to enable maximum inclusion of all relevant studies, in this case served to eliminate some potentially interesting studies. This can be attributed to either the inability to separate out data between adults and children, level of intellectual ability, or both, as well as studies involving SIBs only.

The research project underpinning this review takes a qualitative approach, and so an integrative review where any quantitative data would be transformed into qualitative narrative form was selected. This may not be considered as the most intuitive way of analysing the data considering that the majority of the included studies had a quantitative methodology; but as a meta-analysis of quantitative data was not possible due to heterogeneity of topics covered, it was felt that an integration at data level of all homogenised data was the clearest way to synthesise the findings.

The thematic synthesis itself is subjective, and even though an inductive approach was taken, acknowledgement has to be made of some prior assumptions and knowledge by myself as a researcher, especially as I identify as part of the autistic community. The thematic nature of the analysis also splintered the studies into separate fragments, which may have lost some of the original context in which it was presented, particularly where the self-harm data was either a small piece of a much larger study, or where other topics that were not related to self-harm were also interwoven within the original results.

3.6 Conclusion

This systematic review evaluating the current knowledge base on the topic of self-harm in autistic adults without intellectual impairment discovered that there is an increased rate of self-harming within autism in comparison to the general population; and that it contains autism-specific elements which require a deeper understanding in order to successfully help and support autistic adults who self-harm. Questions raised by this review include whether there is a greater prevalence of autistic females self-harming, and the extent to which suicidality and mental health are linked to self-harm in autism, as well as the influence that autism has on the form and function of self-harm. My online approach collects data without demographic information such as sex or gender, so this cannot be investigated further within this PhD thesis. My study focuses upon the form and function of self-harm as described in online autism forums, and how this triangulates with aspects of autism, and mental health. Research into self-harm in autistic adults has so far remained mainly in the domain of quantitative study designs, which can offer statistically accurate insights into specific aspects of this phenomena, but too many studies still focus upon children and those with intellectual impairments. No study to date has applied an entirely qualitative approach specifically to how autistic adults without intellectual impairment describe and define their lived experience of self-harming. In order to present these nuanced experiences outside of the constraints of a positivist paradigm, an alternative theoretical viewpoint needs to be considered. In the next chapter, I introduce the theoretical framework that underpins my online qualitative approach.

Chapter 4 – Theoretical Frameworks

In this chapter, I begin by discussing the well-established psychological and cognitive theories of autism and self-harm, and critique these assumptions for placing negative labelling and personal responsibility upon the individual. I then propose an alternative sociological lens through which to view self-harm and autism, by presenting the neurodiversity paradigm and supporting theoretical frameworks which situate the problem as residing within society, to gain a more holistic overview of this complex topic.

4.1 Biomedical theories

Both autism and non-suicidal self-injury are categorised as mental health disorders within the APA's DSM 5 (2013). (Zetterqvist, 2015; Lai et al., 2013; Smith et al., 2020). As both fall under the remit of the scientific discipline of psychology, research to date has predominantly concentrated upon generating psychological or medical theories for the underlying causes, or trying to discover whether there are genetic susceptibilities or specific neurological connections as determined by brain imaging technology (O'Dell et al., 2016).

The neuro-culture of autism research has generated multiple cognitive theories, including weak central coherence (Frith & Happé, 1994), executive dysfunction (Pennington & Ozonoff, 1996), theory of mind (Baron-Cohen et al., 1985), the empathising-systemising theory (Baron-Cohen, 2009), hyper-systemising theory (Baron-Cohen, 2006), the extreme male brain theory (Baron-Cohen, 2002), the amygdala theory of autism (Baron-Cohen et al., 2020), and the neurophysiological theory of mirror neuron dysfunction (Williams et al., 2001). All theories share the assumption that there is something inherently wrong that needs to be corrected (Jaarsma & Welin, 2012), but so far, there has been no single unifying 'theory of everything' that can explain autism. Harmful behavioural and medical 'cures' such as electric shock therapy (Neumeier & Brown, 2020), chelation therapy (James et al., 2015), antipsychotic drugs (Murray, 2020) and applied behavioural analysis (Milton, 2014; Taylor, 2022), are still in use today in Western society.

Self-harm has also experienced a predominantly medicalised narrative. Medical models of self-harm comprise the endogenous opioid theory describing a reduced sensitivity to pain; or a dysfunction of the dopaminergic or serotonergic systems (Jacobson & Batejan, 2014; Chandler et al., 2011). Underlying psychiatric comorbidities attributed to self-harm include borderline personality disorder, bipolar disorder, psychosis, and post-traumatic stress disorder (McAllister, 2003). Psychological profiling of the classic self-harmer is of the young, White, middle-class girl, participating in taboo behaviours for the purpose of either attention-seeking, or copying others (Chandler et al., 2011; Chandler, 2018; Chandler & Simopoulou, 2021). This psychologisation of self-harm has created imagery that pervades popular culture, generating misconceptions by medical professionals, including the belief that because it is self-induced there is no need for pain relief, that they are wasting time that could be used for more deserving patients at Accident & Emergency, or that self-harm is purely a mental health problem that requires medication (Chandler et al., 2020; Harris, 2000).

4.2 Critique of biomedical theories and alternative sociological theories

This biomedical focus reduces both conditions to purely medical disorders, suggesting that they could and should be treated or cured; using pathological language with a negative prefix of ‘dis’ – ‘disease’, ‘disorder’, and in the case of autism, ‘disability’. The use of negative labelling is the first step towards stigmatisation (Inckle, 2020; Botha & Frost, 2020), and creates an us/them divide between those considered ‘normal’, and those considered outside of normal, a sub-population who become marginalised (Milton & Moon, 2012). A completely successful treatment or cure for either self-harm or autism remains to be discovered, and so those considered to be suffering from either condition are left feeling in a state of learned helplessness, and ultimately unable to function normally or fit in with society (Milton & Moon, 2012).

4.2.1 Neoliberalism and the sick role

Medicalisation creates an internal psychological focus for any abnormality, placing the responsibility solely upon the individual – the ‘neoliberal selfhood’; without asking whether there are wider sociological influences that have contributed to either conditions, or asking the individual their reasons why they may feel the need to behave ‘abnormally’ (Chandler, 2012; McDermott & Roen, 2016b). Neoliberalism is essentially the belief system of capitalism, with individual wealth, the privatisation of services in society, and a power imbalance of oppression by the richer few over the poorer majority, all being upheld as ideologies (Clarke, 2005). Privatisation of services widens the privilege gap, economically restricting access to those who can afford it, which further isolates and marginalises the autistic population. Within disability research, the autistic population have the lowest proportional representation within employment (GOV.UK, 2022; Grant & Kara, 2021), putting them at the lowest end of the economic scale in terms of ability to afford and access services. In Western neoliberal society, a medical diagnosis allows a version of citizenship to those who can either contribute in some way to the market economy, or to those who accept their disability diagnosis and occupy the ‘state of exception’ or ‘sick role’ (Runswick-Cole, 2014; Milton & Moon, 2012). Individuals considered to be autistic or self-harmers either have to cover up their behavioural abnormalities and strive to fit in with society, or accept the label of disorder and be treated as second-rate citizens surviving on the margins of society within the welfare state (Runswick-Cole, 2014). The phenomenon of ‘masking’ or ‘camouflaging’ behaviours in order to appear ‘normal’ can actually be more harmful, as it creates an extra dimension of pressure upon the individual (Cook et al., 2021; McDermott & Roen, 2016a); generating a vicious cycle of behaviour that is harder to break, and driving those attempting to fit in with society to ultimately occupy the ‘sick role’ (Milton & Moon, 2012).

4.2.2 Social theories of self-harm

Alternative explanations for non-suicidal self-harm have also been given consideration in the wake of the social model, acknowledging that mental distress is not purely an internally generated condition, rather that it is a complex socio-cultural phenomenon that requires a more nuanced understanding. The harm is still there on the surface, but beneath this, there are multiple explanations and reasons that go beyond simply seeking attention or copying trends. The skin is used as a communicative billboard in some cultures, extending the natural emotional expressions of blanching or blushing with make-up, or by the more permanent representation of tattoos, or ritual scarification (McAllister, 2003). Scarring from self-harm provides a permanent reminder of life events, proof of survival against the odds, a sense of belonging to a ‘tribe’ (Edmonson et al., 2016). As a physical representation of the self, the body can be punished by self-harm for shame felt for not conforming to the neoliberal societal ideal, whether physically or mentally (McDermott & Roen, 2016a). Viewed through a social lens, self-harming can be observed as a form of self-control in a world of unpredictable social pressure (Chandler, 2012; Brossard & Steggals, 2020); or a coping mechanism for inner distress when words are not enough, turning emotional pain into physical pain, adopting emotional labour theory and taking a sociological approach to affect regulation theory (Chandler, 2012, 2013; Brossard & Steggals 2020). Self-harming here is given a positive spin in the form of self-care, giving the individual control, purpose, a way of self-soothing, even an existential affirmation (Chandler & Simopoulou, 2020).

4.3 Intersectionality

Emerging from within Black feminist activism in the late 1980s, intersectionality has only relatively recently been considered within disability and autism research (Saxe, 2017; Botha & Gilespie-Lynch, 2022). Intersectionality posits that the cumulative effects of having more than one marginalised identity are greater than the sum of the individual components, and that no single identity should be considered in isolation (Crenshaw, 1989). Identifying with more than one marginalisation will create more barriers to seeking help for problems and being accepted by society, and understanding how these identities intersect can shed light upon how societal barriers can be overcome (Saxe, 2017). Diagnosis, support and legal protection rely upon clear boundaries between identities, and these naturally blur in the centre of the Venn diagram of autism, self-harm and mental illness, creating an under-represented and under-served population (Botha & Gillespie-Lynch, 2022). The interaction between these multiple marginalised identities within each individual creates a unique experience of being ‘othered’ (Saxe, 2017), and with each additional difference it becomes harder to be accepted and understood, which is where the online autism community steps in to provide a space to find yourself among similar others (Moore et al., 2022). My research focuses upon the intersection between autism, self-harming and mental health, and although I acknowledge that there are other identities that exist alongside being autistic, such as gender, race and class, these are outside of the scope of this thesis.

4.4 The social model of disability and the neurodiversity paradigm

Although the medical model still retains dominance today within all spheres of health research, a counter-model has developed alongside it in the last 60 years (Hogan, 2019). The social model of disability criticises the medical positioning of the problem directly upon the individual; and argues that forms of disability or mental illness are stigmatised by this negative labelling, and that society is unaccommodating of any perceived difference from ‘normal’ (Hogan, 2019). The medical model suggests that treatment or cure eradicates discrimination, but the social model posits that discrimination is created by socially and politically generated systemic obstacles, and that these barriers need to be confronted and reduced in order to eliminate discrimination (Petasis, 2019). This paradigm shift from internal to external causal attribution has become a manifesto for disability activists fighting to secure civil rights for those existing on the margins of society (Petasis, 2019).

Civil rights movements and laws protecting the rights of disabled groups have arisen from the social model of disability (Petasis, 2019). This includes the autism self-advocacy and neurodiversity movement, which takes a further step away from the medical model by acknowledging that the only true experts on autism (or any disability or medicalised neurodivergence) are those who identify personally with the community, and that they should be actively involved in any research undertaken about them (O’Dell et al., 2016; McWade et al., 2015). Research for the purpose of discovering a ‘cure’ for autism is directly opposed, as it perpetuates the cycle of attracting funding and fuelling medical research, when funding could be put to better use by improving services and opportunities for marginalised people, or focusing upon treating comorbidities to increase quality of life (Robison, 2020; Runswick-Cole, 2014). The neurodiversity paradigm focuses instead upon the positives that each individual brings to society, and accepts that we are all on a spectrum of natural variance or biodiversity that is not necessarily pathological, turning what were originally believed to be weaknesses into strengths by focusing through a new lens of advocacy (O’Dell et al., 2016; Leadbitter et al., 2021). Questions such as ‘what is normal?’ are asked, to argue against the normalisation agenda, challenge the outsider perspective, and alter the power imbalance (Milton & Moon, 2012). Behaviours that are seen as abnormal to outsiders but comforting to the individual are encouraged or left alone if not detrimental, as preventing any repetitive or self-soothing behaviours can do more harm than good to an autistic person (Milton & Moon, 2012; Leadbitter et al., 2021).

4.4.1 Critiques of the neurodiversity paradigm

The neurodiversity movement is often criticised for being completely anti-medicalisation of autism, and although on the surface this appears true, there is an underlying acknowledgement by the community that autism and its comorbidities can be disabling on an individual basis (Russell, 2020). Disability is context-specific, and co-existing medical conditions do not define autism, but can be disabling and legitimately benefit from treatment or cure (Baron-Cohen, 2017). The use of scientific terminology is also not completely disregarded, as autistic advocates have successfully adopted medical language and used it to their advantage when fighting for access to services, or within the political arena as a form of 'strategic medicalisation' (O'Dell et al., 2016; Russell, 2020). Because autistic advocates are usually at the intellectually able end of the autism spectrum due to the necessity of articulate communication, the neurodiversity movement is also criticised for speaking for all on the spectrum, when they may not necessarily consider themselves to be disabled (Gillespie-Lynch et al., 2017; Jaarsma & Welin, 2012). One counter-argument to this is that there should be no labelling of higher versus lower functioning, as each individual experiences differences in ability both in relation to others on the spectrum, and also in the form of daily fluctuations in abilities (Den Houting, 2019; Bottema-Beutel et al., 2021). The belief that we should all be considered part of natural biological diversity and abolish diagnostic labels is further criticised as it may make it harder to access help for those who need it (Jaarsma & Welin, 2012; Runswick-Cole, 2014). The establishment of the neurodiversity community is also believed by some to be creating an us/them divide, as belonging to any community requires some level of labelling, which in the case of autism, perpetuates the requirement for a medical diagnosis in order to belong (Russell, 2020). The concept of neurodiversity itself is also by definition hard to clarify, as in its most literal interpretation, it has to include non-neurodiverse people too, creating an existential paradox for the community (Russell, 2020; Runswick-Cole, 2014).

Criticisms aside, the neurodiversity paradigm creates a fresh lens through which to view the topic of self-harm within the autism spectrum. The neurodiversity movement owes its existence to the birth of online communication via the internet (Dekker, 2020), due to the social and communicative differences experienced by individuals and their preference for written communication and time for reflection (Jaarsma & Welin, 2012); and so it is fitting to apply this theoretical paradigm to the online autistic community. Autism is seen as an identity that is constructed differently, dependant on specific sociocultural contexts (O'Dell et al., 2016; Stenning & Rosqvist, 2021), and the neurodiversity paradigm holds the ontological assumption that everybody on the spectrum experiences their own reality of autism, disability and self-harm (O'Dell et al., 2016; Woods et al., 2018). This belief is extended to include the acceptance of autistic behaviours such as stimming and meltdowns that may precipitate self-harm as a coping mechanism, rather than trying to stop or change the behaviours (Milton & Moon, 2012), which may shed new perspective on a previously under-researched topic.

In this chapter, I have argued for an alternative theoretical framework through which to interpret the subjective and intersecting experience of self-harm in non-intellectually impaired autistic adults. In the following chapter, I present my methodological choices that are supported by this framework, and ethically justify my selection of an online qualitative methodology.

Chapter 5 - Methodology

As I have articulated within the preceding chapters, much of self-harming behaviour within autism remains hidden, due to a combination of the taboo nature of self-harm, added to the specific barriers to help-seeking that autistic people experience, and augmented by a predominantly quantitative approach to inquiry. In order to uncover the subtleties of the subjective experience of autistic self-harm in an uncensored way, without causing undue distress to participants, I adopted an online qualitative approach. In this chapter, I present my rationale for selecting this particular methodology, taking into account the philosophical assumptions and ethical considerations that underpin this topic and approach.

This is an exploratory qualitative study (Hunter et al., 2019; Bradshaw et al., 2017; Salmons, 2016), utilising online qualitative research methods (Hine, 2016; Kozinets, 2017; McDermott et al., 2013a). The exploratory design is suitable for an inductive approach to data collection, where there is little prior knowledge to guide the researcher towards a more circumscribed methodology (Hunter et al., 2019; Bradshaw et al., 2017). Self-harming within the adult autistic population without intellectual impairments has not previously been approached using online qualitative methods, and the research questions, aim and objectives also reflect the exploratory nature of the study.

5.1 Philosophical paradigm

The philosophical assumptions underpinning this study are encompassed within a naturalistic philosophy (Guba & Lincoln, 1982; Bradshaw et al., 2017), which upholds that the phenomena under investigation should be studied in its natural setting. This is congruent with the unprompted online forum discussions that comprise the data for this study, which are not intruded upon or affected by the presence of the researcher (McDermott et al., 2013a); and represent natural expressions of experiences and beliefs between members of a community with a shared identity and preference for online communication (Dekker, 2020).

Naturalistic inquiry has evolved over time to become what is now known as the constructivist paradigm (Guba & Lincoln, 1994). Within the constructivist paradigm, the ontological position is that of relativism, which upholds multiple realities, as no singular reality exists due to each person's individual interpretation and experiences (Guba & Lincoln, 1982, 1994; Braun & Clarke, 2013a). This is congruent with the reality of living with either an autism diagnosis, or identifying as autistic, as it is a reality experienced as an autistic person, outside of 'normal' or 'neurotypical' society, guided by individual sensory sensitivities and reactions to this reality. Epistemologically, the constructivist paradigm assumes a subjective approach to the creation of knowledge, which accepts that a reality of objects does exist, but that we all have a subjective understanding of this reality (Guba & Lincoln, 1982, 1994; Braun & Clarke, 2013a). The constructivist approach also holds the belief that meaning and experience are socially produced (Byrne, 2021). In an exploratory design, this is augmented by the perceptions of the participants, and the interpretation made of these perceptions by the researcher (Bradshaw et al., 2017). Reflexive thematic analysis (RTA) is located within an interpretivist/constructivist paradigm (Byrne, 2021); and there is an acknowledgement of the researcher's position within the research, and the preconceptions the researcher brings to the study (Hunter et al., 2019; Bradshaw et al., 2017), which is reflected in my personal involvement in the autism community due to having a diagnosis of Asperger syndrome.

5.2 Rationale for a qualitative approach

Returning to the evidence base evaluated within the background and systematic review chapters, both autism and self-harm remain predominantly within the domain of quantitative research, specifically psychological and neuroscientific research. A quantitative approach allows for an appraisal of how many autistic people are experiencing self-harm, and what methods they may employ; but this medicalised representation presents a limited view of self-harm in autism as an interiorised disorder that the individual is directly responsible for, and does not consider the wider social and cultural factors that may influence this phenomenon (Chandler, 2012; McDermott & Roen, 2016a). A qualitative methodology was selected in order to gain a deeper and more nuanced understanding of how those identifying as autistic understand and experience self-harm, and explain it within the context of existing social and cultural theories intersecting with self-harm and neurodiversity. A systematic review of the literature discovered only one qualitative study concerning expressions of self-harm in autism (Goldfarb et al., 2021), which thematically analysed interviews with autistic adults on self-injurious behaviours as part of a wider study into repetitive and restricted behaviours. The topics of self-harm and autism have both been separately explored within a qualitative paradigm, and also using online methodologies; but no study to date has focused entirely upon representations of self-harm in autistic adults as reported directly by themselves to each other within online discussion forums.

5.2.1 Online qualitative methodology

Qualitative research involving online data is relatively recent and growing in line with the expansion of the internet and increasing access to technology globally (Illingworth, 2001). It allows access to a wider population and a larger sample than with traditional qualitative research, as those who are geographically isolated or physically housebound are able to connect with others within the virtual space (Wilkinson & Thelwall, 2011; Giles, 2017). This method has been highlighted as potentially excluding those who are either economically marginalised or technologically illiterate (Illingworth, 2001); but Wilkerson et al. (2014) argue that access to technology and the internet is now so widespread that this should no longer be considered as a practical limitation. Online data collection also provides the advantage of instantly available transcripts that are free of transcription errors (Paechter, 2012), and is useful for researchers limited in both time and funding (Wilkerson et al., 2014; Hewson et al., 2017).

Using online interactions qualitatively allows a unique level of access to an otherwise hard-to-reach population, as the social and communicative differences that the autistic community experience can limit their active participation in conventional qualitative research (Botha et al., 2021). Face-face interactions present many communicative difficulties, including maintaining eye contact, interpreting body language and voice tone, and having to respond immediately; and there is a known preference for written communication because it avoids these issues (Davidson & Henderson, 2010; Jaarsma & Welin, 2012). The neurodiversity movement began online for these reasons (Dekker, 2020; Hughes, 2021), and some studies have gone so far as stating that online communication for autistic people is as important as sign language for hearing-impairments, or braille for sight-impairments (Brownlow & O'Dell, 2002, 2006; Jordan, 2010); and represents a form of self-advocacy that is otherwise not available to this marginalised community (Brownlow & O'Dell, 2006; Giles, 2014).This is compounded by mistrust felt by some autistic people when talking to professionals, as many have travelled through the mental health system on the way to an autism diagnosis (Lai & Baron-Cohen, 2015); and there is a belief held by the autistic community that they are the real experts on autism (Brownlow & O'Dell, 2006; Gillespie-Lynch et al., 2017).

Within the context of researching sensitive topics such as self-harm, an online methodology has a distinct advantage over conventional qualitative methods. It can be argued that interviews or focus groups create fresh distress by recalling memories or emotions, and the presence of a researcher or the nature of the questions asked may limit the truthfulness or extent of response (McDermott et al., 2013a). When recruiting for traditional qualitative methods, participants are limited to those who are comfortable talking to researchers or strangers, and in the case of sensitive topics, those who feel able to open up about a personal subject (McDermott et al., 2013a; Wilkerson et al., 2014). Self-harm is often hidden, and may not be brought to medical attention, so recruitment by traditional means may end up excluding the majority of the population of self-harmers (McDermott, 2015). An online qualitative approach to self-harm has been explored within the context of identifying as part of the LGBTQ+ community (McDermott et al., 2013a; 2013b); and it was felt that there was a rawness and immediacy to the posts, reflecting the moment the participant made contact with the forum, which was not adulterated or shaped by the presence of the researcher. It was also noted that due to the relative anonymity provided by an avatar, that there is greater disclosure when posting online, augmented by a feeling of community that is created by accessing online spaces dedicated to specific groups with similar experiences (Hetrick et al., 2020; McDermott et al., 2013a; Wilkerson et al., 2014).

5.2.2 Online qualitative methodology limitations

The benefits of disclosure online cannot be discussed without an acknowledgement of the potential drawbacks that it may present. Although the online forum contributors are not self-selecting for research, as is the case for other research participants (Bethlehem, 2010), they do arrive at the forums with individual personal agendas and motivations to disclose or conceal parts of their identities as they see fit. Self-selection may appear in the form of identifying with the neurodiversity community online and sharing an anti-medicalisation standpoint; or as a need to disclose experiences of stigmatisation by others or misdiagnoses by medical professionals, for personal validation. Although the ability to use an avatar to create and online persona can be argued as providing for a certain freedom of anonymity, which may allow for greater disclosure to relative strangers; there is also a counter-argument which posits that by creating an alternative online persona, people can pretend to be a different and not necessarily accurate representation of themselves (Hollenbaugh & Everett, 2013). Within all types of research involving collecting people’s responses to questions, there is a phenomenon known as the socially desirable response bias. This is described as presenting aspects of the self in more favourable terms to meet social norms when responding in self-report questionnaires

(Tracey, 2015), and can be extended to altering one’s behaviours or conversational responses to align with the majority consensus in social situations (Lalwani et al., 2006). This relates to social identity theory, where self-esteem is boosted when identifying with a community that you feel an affinity with (Tajfel & Turner, 2004). Sharing accounts of self-harm provides a way of affiliating with others, and is described as a socially positive reinforcer within the four-function model of NSSI (Nock, 2008); and although self-harming is considered to be a taboo and socially unacceptable behaviour in the general population, contributors to self-harming discussions online may feel the need to distort their truth in order be accepted within this secretive and outcast social group. The individualist nature of many on the autism spectrum may paradoxically draw them towards fellow individualists for self-validation, creating a social group of outcasts. The taboo nature of self-harming can create a further sub-group of outcasts who are doubly removed from acceptable society by virtue of their self-harming as autistic people, and harder to infiltrate as an outsider unless in total agreement with group values, creating the potential for participants to stretch their truth in order to gain acceptance.

The social distancing created by the online platforms and asynchronous mode of communication can bring out the worst as well as the best in people, as evidenced by the ‘keyboard warrior’ phenomenon (Polipo & Willemsen, 2023). A ‘keyboard warrior’ is an intentionally provocative person who takes advantage of the relative anonymity of online participation by causing offence or creating controversy with their unconventional or rude comments that are socially unacceptable and would not be made in a face-to-face situation (Handy, 2023; Polipo & Willemsen, 2023). The taboo nature of the topic of self-harm makes it a controversial topic, and therefore has the potential to attract the keyboard warrior persona to these discussion threads. It has been suggested that keyboard warriors may struggle with face-to-face interactions and feel more in-control when using written communication (Handy, 2023), which resonates with autistic preferences. Furthermore, one analysis of ten key features of keyboard warrior behaviour (Polipo & Willemsen, 2023) presents a black and white mentality, a commitment to the truth, a ‘know it all’ attitude, moral high ground, intellectual antagonism, and systematic misunderstanding as six features that can also be argued as recognisable traits within Asperger syndrome (Wing, 1997).

5.3 Methods

5.3.1 Sampling strategy

Two contrasting but prominent autism online forums were selected for data collection. The first forum accessed was a charity in the UK, the National Autistic Society (NAS), which was created initially by parents of autistic children to provide support and a point of contact for information, but does have an active community of autistic adults. The second forum accessed was AutismForums, a public forum with no charitable affiliations, based in the USA with global contributions. Giles (2017) recommends selecting well-known and active online communities to study, in order to ensure adequate diversity of viewpoints and richness of data. The use of only two forums provided a way of setting a boundary on data collection, as it can be difficult to decide when to stop collecting data from online sources due to the vast amount of available and relevant material out there (Hine, 2016; Giles, 2017).

No active recruitment of individual participants was required, as data consisted of existing and freely available forum posts online. A purposive sampling strategy was used as data was collected specifically from online spaces dedicated to autism, and within this, only those who were discussing aspects of self-harm. The purposive strategy is especially useful with studies of such narrow focus, where rich and specific data is sought (Braun & Clarke, 2013b). A purposive sampling strategy is also congruent with an exploratory approach, as it aims to represent the phenomena of interest with the widest variety of viewpoints (Hunter et al., 2019).

An inductive approach to data collection was selected due to the unknown quality and quantity of available data (Braun & Clarke, 2013b). The sample size of the data was limited by both available data, and my decision that the research questions had been adequately answered by the richness of data collected. Braun and Clarke (2021a) advise that limiting data collection by saturation is not appropriate for an inductive reflexive thematic analysis, as this suggests that there is a finite and predetermined amount of meaning within the data, with nothing new to discover; so saturation was not utilised as a stopping point for data collection. Autistic adults and young adults were the target population, and contributors to both communities were restricted to over 16 years old, but it was not clear how either forum would effectively control this. Due to the necessary requirement of access to technology, and the ability to communicate by written word, this limited the contributors to those with little or no intellectual impairment, but did include those considered to be minimally verbal.

5.3.2 Data collection

Data was collected over a period of three months, from October to the end of December 2021, with data being collected and coded from the NAS forum first, before visiting AutismForums after an initial round of coding. Data collected was in the form of threads containing a whole discussion involving multiple participants, which were copied and pasted into a word-processing document ready for analysis, and deidentified and anonymised at this point, before being imported into NVivo12 (Appendices 5 & 6 – examples of discussion threads). Data was originally to be collected from 2013 onwards, coinciding with the reclassification of all separate autism spectrum diagnoses into ASD in version five of the APA’s DSM, the most common guidance manual used by clinicians in the diagnosis of autism. This limitation was not implemented during data collection, as no relevant data was found before this cut-off date, with much of it being within the last five years.

Both forums had a search bar which enabled terms to be searched for within the threads, and the terms ‘self-harm’, ‘self-injury’ and ‘hurt myself’ were initially used to generate relevant material. The use of medical or research-oriented terminology such as ‘non-suicidal self-injury’ was not appropriate here, as the forum contributors use lay language only. The NAS forum was searched first, and after searching for the first three terms above, the content indicated that a lot of what the participants were considering to be self-harm was actually in the context of meltdowns and self-stimulatory behaviours, or stimming; so search terms ‘meltdown’ and ‘stimming’ were also used. All searches were ordered for relevance, which diminished with each new page, until pages 10 and above held nothing new or of any relevance. This search strategy was repeated within AutismForums, but as a larger forum, was harder to search for relevance, as searching for ‘meltdown’ returned over 5,000 threads, but not in the context of self-harm; and combining ‘self-harm’ with ‘meltdown’ returned the same results as with searching for ‘self-harm’ alone. A slight difference in language used within AutismForums created a new search term ‘harmful stim’ as a more specific search to ‘stimming’, which was then used to search within the NAS forums and revealed two new threads not found with the previous terms. Any threads concerning children were rejected, as self-reported adult experiences were the focus of the study, and especially on the NAS forums it is often parents talking about their autistic child’s behaviour.

5.3.3 Data analysis

Data was analysed using the reflexive thematic analysis (RTA) method as described by Braun and Clarke (2006; 2019). Thematic analysis is a suitable analysis method as it seeks to identify common themes across a dataset, without any specific epistemological or theoretical bindings (Campbell et al., 2021); and this flexibility is congruent with the exploratory nature of the study (Hunter et al., 2019). Thematic analysis is less complex and prescriptive than other qualitative methodologies, which is useful for a novice qualitative researcher (Braun & Clarke, 2021b); but the inherent flexibility of RTA should not be confused with an absence of theoretical assumptions (Byrne, 2021). Braun & Clarke (2021c) highlight the importance of locating epistemological underpinnings, orientation to data, and level of analysis, justifying your individual approach to thematic analysis. Within this study, the analysis and interpretation sought to move beyond the experiential and consider the social structures underpinning self-harm in autism, taking a constructivist and critical approach, coding at a semantic level, but interpreting at a latent level. The unique nature of the forum data and how it can be ethically used means that other qualitative methodologies such as interpretative phenomenological analysis, grounded theory, or discourse analysis were not as suitable; as the researcher had no interaction with the participants, individual participants could not be identified, and the data could not be reproduced as verbatim quotes to illustrate the findings (Braun & Clarke, 2021b).

Braun & Clarke describe their RTA following a six-step process, although not strictly in a linear fashion, with some movement back and forth between steps as the analysis develops (Braun & Clarke, 2021c). Stage one involves familiarisation with the data by repeated reading and making notes, before moving into stage two, coding the data. Stage three reviews the codes in order to develop initial themes, which blends into stages four and five, where themes are refined, defined and named in an iterative and reflexive process, before the analysis is written up in stage six. There is a strong emphasis upon the researcher's reflexive engagement with the data, interpretation and wider theory, and an acknowledgement of researcher subjectivity as an analytic tool (Braun & Clarke, 2021c).

The dataset from the NAS was analysed first before moving on to AutismForums, to ensure that data was sufficiently rich to allow for coding and themes to develop. Data was initially read on collection, and was subsequently re-read on multiple occasions to enable familiarity. The data was then considered on three levels - as single statements, part of the whole thread conversation, and within the context of the wider dataset. Hand-written notes were made upon reading each thread, including my thoughts and feelings as an autistic person, before coding was undertaken within NVivo. The theoretical literature was revisited during coding to aid in the organisation and mapping of the data. Line-by-line coding was not undertaken, as some posts were irrelevant to the subject, for example, moderator comments, or unrelated observations and asides; and it is also not a requirement of RTA (Braun & Clarke, 2021b). Coding was initially data-driven and inductive in the first phase of NAS data analysis, but it soon became apparent that because threads had been selected due to their relevance to answering the research questions, coding was actually following the themes of the research questions, and so became deductive by the time the AutismForums data was analysed. Concern about losing context and fragmenting the data meant that blocks of text or paragraphs were coded to multiple codes rather than coding each line separately if it had a different meaning. Decisions as to where the text was best represented were made later on in the process, in the theme identification and writing stages. A revisit of each dataset following initial coding was made, and more text was coded on subsequent rounds; but only one new code was created from the AutismForums dataset, and both datasets supported each other well in terms of experiential richness.

46 initial codes were created from the two datasets, which were then compared, contrasted, and reduced to a final 35 codes. Codes with only one piece of text were considered first, to ensure they were representing a unique aspect, and not just another way of saying the same thing; and this extended to other codes with less than ten coded items within. Codes that were named with similar labels were also compared, and were collapsed together if too similar, for example, ‘meltdown’ and ‘overload’ were actually describing the same experiences. Coding was undertaken within NVivo, as multiple codes could be applied to the same data with visual separation of codes by colour, and software also facilitated the comparison and collapsing of similar codes. Coding was at semantic level only, as analysis progressed to latent level during

thematic discussion. Themes were identified as answering the research questions, and sub-themes developed within these three themes. Thematic definition returned to paper again, as it was easier to visualise the grouping of codes together, as well as link any associations between codes and themes together by drawing lines. The first two research questions were combined as one theme, as it was felt that reasons people give for self-harm were inextricably linked to the methods they described, and one could not be discussed without the other. Once the themes, sub-themes and codes supporting these were determined, the themes were reviewed by returning to the codes, and were also considered within the context of the whole dataset and the research questions. Themes were finalised during the writing of the findings, and linked to the wider literature and theory during the discussion.

5.4 Ethical issues

Self-harm is a sensitive issue, and this study was also located at the stigmatised intersection of mental health and autism, and so required significant consideration in order to minimise any distress caused by the subject matter. Guidance was sought from both the British Psychological Society (BPS) (Hewson et al., 2017) and the Association of Internet Researchers (AoIR) (Franzke et al., 2020) with regard to the specific concerns raised by the use of internet content within a research project. Both groups recognise the diversity of content available online, and advocate taking a bottom-up individualised approach to ethics by taking into consideration the context, methodology, and research questions posed. The AoIR advocate a more utilitarian approach taken by both the United States of America and the United Kingdom, which is where much of the online content is expected to originate from, and acknowledge that risks to subjects are allowed provided that the anticipated benefits are greater (Franzke et al., 2020). Ethical approval for this study was obtained from the Lancaster University Faculty of Health & Medicine Research Ethics Committee (Appendix 7).

5.4.1 Participant safety

The sensitive subject of self-harm has the potential to create distress in participants when undertaking traditional qualitative research by face-face interviews (Wilkinson & Thelwall, 2011), and this study directly addressed this by only using existing online material that is not prompted in any way by the researcher. Existing material posted online is potentially generated by emotional distress at the immediate time of the experience, but should not generate any further distress if handled carefully during the research process (Wilkinson & Thelwall, 2011). I did not interact with the online community, reflecting the naturalistic underpinnings of this study, and negating any Hawthorne effect that may otherwise distort data (Brownlow & O'Dell, 2002). The Hawthorne effect is a known phenomenon likened as the social research equivalent to the placebo effect, whereby participants alter their behaviour or response to questions to please the researcher when they are aware that they are being observed or evaluated in some way (Wickstrom & Bendix, 2000). Lack of direct involvement avoids other potential ethical concerns such as unwanted intrusion in social groups, and also the issue of interacting with and safeguarding vulnerable groups such as autistic people, who are considered to be more open to manipulation or coercion. (Hewson et al., 2017). Covert non-participatory research is justifiable when protecting vulnerable populations, to avoid the Hawthorne effect, and when unable to practically obtain consent from each individual when researching larger groups (Marzano, 2018).

5.4.2 Researcher safety

The research design avoided any physical personal risk to myself as a researcher, such as lone working; but had the potential to adversely affect mental health due to the subject matter (Roberts, 2015). The retrospective aspect of the data provides an emotional distance from a sensitive topic that cannot be emulated by traditional qualitative methods (Paechter, 2012). My dual identity as both researcher and autistic person added another personal layer of involvement to the study; but the underlying drive to truthfully represent mental health issues in the autistic community overcame any temporary distress that content may have created.

5.4.3 Informed consent, anonymity and confidentiality

Another significant ethical debate within online research is the public versus private issue, and any associated harm that publishing identifiable material may cause to the contributor (Roberts, 2015). There is no single consensus over what constitutes public material, as even if there is an assumption that by posting to an open forum it becomes public access, the contributor may not have held this intention at time of posting (Hewson et al., 2017). Private material is determined by forums that require membership with password-protected access (Roberts, 2015), and these were not accessed by this study.

Both the BPS and the AoIR believe that unless it is justifiably impossible, or because it is undeniably public data, informed consent should be obtained from any participants within a study (Hewson et al., 2017; Franzke et al., 2020). There is a difficulty with obtaining consent for the use of individual posts within a forum, as there is a general use of pseudonyms, and so contributors cannot be identified or contacted directly. The posts used were historical, and so some of the contributors may no longer be part of the online community, and therefore not contactable (Brownlow & O’Dell, 2002).

To moderate the issue of personal consent, there are different levels of steps that can be taken. The NAS had a set of community rules and site terms and conditions (NAS, 2020), in which it states that posts are public, and warns contributors against posting any personal or identifying information. By posting content within the forums, users grant the NAS intellectual property and copyright rights to content. Research was mentioned only within the context of using the forums to advertise for participants in surveys, but the research office of the NAS was contacted directly by the researcher for permission to use material from the forums prior to any data collection. AutismForums terms of service (AutismForums, 2021), states that the site owners reserved license to use or re-use any content posted, and that content should not be submitted if considered to be private or confidential; but there were no rules regarding use of the forums for research purposes, or any contact details provided to request permission, so permission was not requested for this forum.

To avoid any distress caused by the usage of material from the forums, anonymity of individuals and their posts were preserved by the use of alternative identifiers, and also by the removal of any identifying features during data processing (Hewson et al., 2017). It can be argued that to anonymise individuals is to further silence an already marginalised population (Franzke et al., 2020; Macleod & Mnyake, 2018), and the voice of autism has historically been represented by professionals, carers and parents (Brownlow & O'Dell, 2006); but I did not have the ability to contact individuals directly to confirm or remove their anonymity.

Verbatim quotes were not used when writing the findings, so that these cannot be entered into a search engine and traced back to source. The use of verbatim quotations from participants to support the researcher's interpretation of the findings is considered by many to be the gold standard in qualitative research, and an expected component of qualitative reporting (Eldh et al., 2020; Thorne, 2020). Used wisely, quotations can bring the findings alive to the reader, and reinforce the message that the researcher aims to convey, as well as give a direct voice to the participants (Corden & Sainsbury, 2006). Quotations can also be viewed as a measure of quality, aligning qualitative research with quantitative research quality values such as internal validity, reliability and objectivity; namely, that the researcher representation accurately represents the participant's words, and the data is grounded in the events and not just an individual interpretation of the events (Eldh et al., 2020; Thorne, 2020).

However, criticisms of the use of verbatim quotes include the over-use and reliance upon quotations in place of researcher interpretations, selecting unsuitable quotes in terms of either length or content, and the inevitable editing of quotes that renders them no longer verbatim, or outside of their original context (Eldh et al., 2020; Thorne, 2020). The verbatim quotation argument essentially reduces down to a data validity versus confidentiality of participant debate (Giles, 2017). One study incorporated participants' views on verbatim representation within their qualitative study, and found that not being able to be identified by others via their quotes was just as important as being given voice (Corden & Sainsbury, 2006).

For my study, the focus is upon a sensitive topic within a marginalised population, so confidentiality has been prioritised over the use of verbatim quotes, and I have presented my findings as my own interpretation of the written forum posts. Due to the historical nature of the posts, and the existing relative anonymity of the forum participants, I also could not utilise member-checking to confirm the accuracy of my interpretations; but the nuanced tension between giving voice versus preserving confidentiality meant that I had to strike a balance between the two. A transparent and rigorous process was used to keep participant views as close to the data as possible without risking revealing their identities, but an inability to obtain individual consent meant that participants had to remain anonymous.

This lack of agency that my chosen method confers upon my participants could be viewed as creating a power differential between myself as a researcher, and the population that I seek to represent. A power imbalance always exists to some extent between the researcher and the researched population, which becomes greater when investigating sensitive or taboo topics such as self-harm or autistic behaviours, or when working with vulnerable groups such as autism, disability or mental illness (Brownlow & O'Dell, 2002). Covert non-participation within online forums can also create a form of power imbalance between researcher and researched, as there is a greater potential for exploitation of populations who have not been informed about or consented to their involvement (Brownlow & O’Dell, 2002). Conversely, Hewson et al. (2017) argue that online non-participation can actually reduce the power imbalance because there is no active involvement or manipulation of participants by the researcher.

The power differential created by my choice of topics, study population and covert non-participation methods is mitigated somewhat by my identification as part of the community that I am researching, softening the ‘voyeuristic gaze’. Insider researchers are able to provide a more authentic representation of the views and experiences of the populations being studied than an outsider, as there is a level of prior knowledge, understanding and subjectivity that cannot be achieved by outsiders (Greene, 2014). The neurodiversity movement is underpinned by a belief that the true experts on autism are those who are themselves autistic (Brownlow & O’Dell, 2002). As an adult with Asperger syndrome, I feel qualified and justified in my interpretation and representation of the experiences of the adult online autistic communities that I have studied. Furthermore, I consider myself to be both an autistic self-advocate, and an advocate for the autistic community, which further reduces the power imbalance (Greene, 2014). The intersection of my dual identity as both researcher and autistic person was considered throughout the research, as an insider position can create inherent bias, and make it easy to make assumptions based upon prior knowledge (Greene, 2014). Maintaining a reflexive journal, and taking regular breaks to return with fresh eyes was an essential component of this qualitative methodology.

As I have described and justified within this chapter, selection of an online methodology presents an appropriate and novel way of addressing the qualitative gap in the literature, without causing fresh distress to participants when researching a sensitive topic. In the following chapter, I present the findings from this chosen method.

Chapter 6 – Findings

This empirical chapter reveals the results of my reflexive thematic analysis of online forum discussion threads pertaining to self-harming behaviours in autistic adults. I present my findings within three identified themes, which naturally reflect my research questions. The convention within qualitative research is to support the researcher's interpretations with the use of verbatim quotations, but due to the methodological and ethical constraints outlined in the previous chapter, I was unable to use verbatim quotations to illustrate direct examples within my thematic descriptions. In lieu of quotations, where I directly present the participant's representations, I have highlighted this in *italics,* to delineate as clearly as possible between what are my interpretations, and what are the participant's representations.

The numbers of participants from each forum were comparable, but there were less threads found within the more international AutismForums, and more participants per thread (Table 6.1). Due to the de-identification process, I was unable to determine whether some of the participants appeared in more than one chat thread, so the absolute total of participants may not be as high.

Table 6.1 Number of threads, participants per thread, and totals per forum

Website	**Search term**	**Number of threads**	**Number of participants**
NAS	Self-harm	5	23
	Self-injury	1	5
	Hurt myself	5	16
	Meltdown	2	6
	Harmful stims	2	12
	Stimming	4	21
Total		*19*	*83*
AutismForums	Self-harm	5	55
	Hurt myself	1	5
	Harmful stims	2	19
Total		*8*	*79*

Sum-Total		*27*	*162*

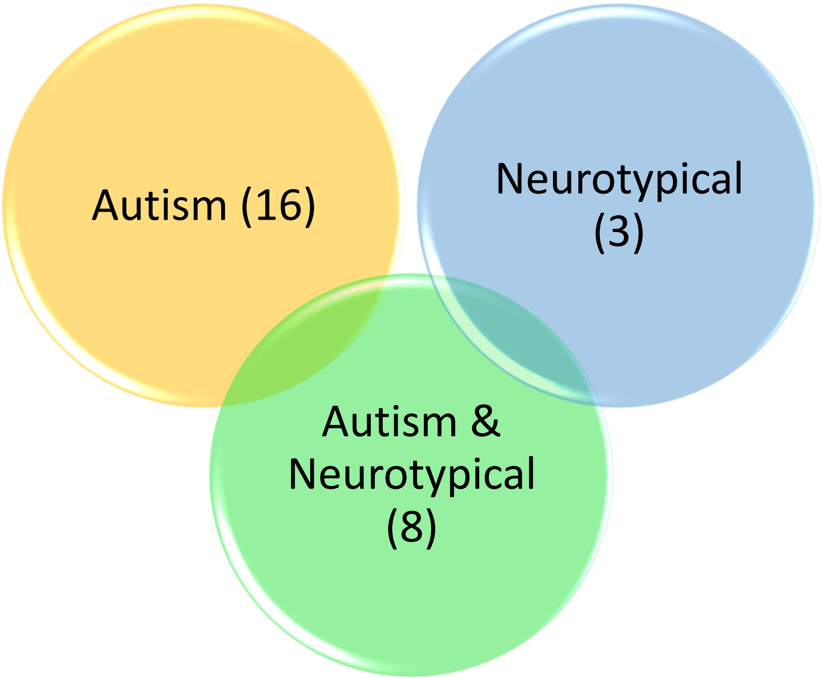


Figure 6.1. Types of self-harm as represented over the 27 forum threads analysed. A predominance of autistic or autistic plus neurotypical self-harming behaviours was found.

6.1 Theme 1 - Reasons and forms of self-harm

The first theme presents both reasons why those on the autism spectrum self-harm, and the forms of self-harm that they describe; as although this answers the first two of the research questions together, the reasons and the forms are inextricably linked, and one cannot be discussed without mentioning the other. Many reasons given for self-harm are in some way related to or influenced by characteristics that are inherent to autism. Maybe this is not surprising considering the specificity of the forums, but even within threads describing what are considered to be more neurotypical forms and reasons for self-harm, there are nuanced aspects of autism that reveal themselves as the narratives unfold (Fig. 6.1).

Table 6.2 Sub-themes and codes described within Theme 1

Theme	Reasons and forms of self-harm		
Sub-theme	Part of autism		Mental health
Sub-sub-theme	Too much information	Not enough information	
Codes	Compulsive behaviour Overload Rumination Shutdown or dissociation Stimming To stop from hurting others	Comforting Sensation-seeking	Anxiety Controlled self-harm Coping mechanism History of abuse or childhood trauma Low mood Low self-esteem Personal & private Physical pain to express emotional pain Self-punishment Suicidality

6.1.1 Part of autism

Much of the self-harm described on the forums can be attributed directly to autistic traits, and is essentially about management of information, whether it be too much, or not enough. One of the cardinal criteria for an autism diagnosis and experienced by all on the spectrum to some extent, is altered sensory perception, in the form of some senses being heightened and others diminished, in comparison to those considered non-autistic (Pellicano, 2013). Cognitive processing can also take longer, so the brain and senses can quickly become overloaded, manifesting in a build-up of tension which needs to be released in the form of a meltdown (Belek, 2019). If not released, it may be channelled into management techniques such as self-harm; or via stimming, a more compulsive, repetitive, unconscious way of dissipating an accumulation of anxiety and negative energy, which can also be destructive if it involves physical harm.

Overload or meltdown features strongly in reasons given for acts of self-harm, with participants describing no specific trigger every time, just a build-up of multiple smaller things until it becomes too much to process. Rumination over issues can also become too much, with the cycle of thought and worry needing to be broken somehow; with one participant feeling as if they had no ability to use their inner or 'gut' feelings as a way of assessing problems, creating the need for over-thinking to solve worries. Meltdowns are described as a loss of physical and mental control, with lashing out at others, inanimate objects, or the self. Some participants report memory loss around the event, as if they left their mind and body as part of the loss of control - a dissociative event. *One participant refers to it as a black-out, as if they experienced a total loss of consciousness, returning to reality with no recollection of what happened.* Self-harm here is unpremeditated, and *participants mention a compulsive urge to hurt themselves as part of the meltdown even if they know it is wrong,* a reflex behaviour, which can also be hard to stop until the pain becomes too intense. The pain created shuts off the overloaded channels within the brain by creating a new over-riding physical sensation to process, like a reset switch – *participants liken the meltdown to blowing a fuse in the brain, flipping a switch, or a circuit-breaker*. Hitting is the most prevalent form of self-harm during overload events, which is *revealed by participants as hitting the self on blunt objects repeatedly, or hitting themself with their hands, most commonly targeting the head, sometimes until bruised or teeth are damaged.* This can also become worse over time, with *some relating a progression from hitting objects to hitting the self, and using more visible areas such as the head and face. Biting is also mentioned by a few participants, most often the hands, sometimes until blood is drawn, or at least visible toothmarks are left as a reminder.*

Public displays of these harmful meltdowns are common, highlighting this difference between autistic and neurotypical forms of self-harm, although *some mention an ability to control the urge to meltdown until alone and in private.* More commonly, anecdotes contain *members of the family who may have triggered the overload, having to witness, restrain, or even sustain injury from the ensuing physical release of stress. Restraint is noted as always making the situation worse,* as it generates more sensory over-stimulation. Family members are also not the most tactful here, sometimes mocking the individual due to misunderstanding. *One participant reports being videoed during the meltdown and having it replayed back to them afterwards to show them how it appears to onlookers, as an attempt to shame them into stopping the behaviour. Some self-harm during a meltdown is justified as a redirection of aggression towards others, turning the anger in on themselves in order to avoid hurting others*, suggesting a certain level of consciousness around the event. *Others describe turning it upon themselves in an effort to avoid the full-on meltdown, cutting it off before it escalates, so the experience of uncontrolled meltdown is considered to be worse than the more controlled act of self-harm;* and it is often in these cases that cutting and burning, as more 'traditional' neurotypical methods of self-harm are used. There is an interesting dichotomy here between the uncontrolled and impulsive nature of using the body directly against the body, fists upon face, the violent blunt trauma deployed in the act of meltdown self-harm; versus the use of implements such as blades or lighters which creates a separation between the mind and the body in conscious and controlled acts of self-harm. It is almost as if it is easier to use something other than the hands to do the harm when there is an element of conscious control.

The use of the words 'self-harm' to describe the damage caused by these autism-specific behaviours is deliberately used by all the participants. This is acknowledged within the threads, as *participants feel that they are detrimentally harming themselves*, and are reaching out to other autists to ask if this is 'normal' for autism, and also to discover what self-harming behaviours others do, and what they do to stop it. *Some participants feel that it is simply a part of autism,* invoking their medical diagnosis as a way of absolving personal responsibility, or as a reason to continue harming. *Others use medicalised discourse to explain what is happening* *during a meltdown, with a common reduction of this phenomenon to an accumulation of chemicals within the brain and body that are dissipated by the act of self-harm.*

Stimming is another autism-specific behaviour that is mentioned significantly within threads on the topic of self-harm. Self-stimulatory behaviour, or stimming/stims as it is described by the autistic community (Charlton et al., 2021), is another unconscious physical repetitive way of reducing the build-up of anxiety and stress before it reaches meltdown levels; but it also exists as a completely harmless activity recognised throughout the neurodiverse spectrum into neurotypicality. The most commonly discussed autistic stims within psychology are hand-flapping, rocking, and echolalia (repeating or singing words used by others); but there are other more harmful stims such as skin-picking - scratching, biting, chewing and peeling until it bleeds, and hair-pulling (Charlton et al., 2021). Non-autistic stims accepted by society include knuckle-cracking, hair twiddling, humming, whistling, leg or foot jiggling, nail-biting, finger-tapping, or general fiddling with objects; which has generated a need for fidget toys (Biswas et al., 2022).

The harmful stims are again labelled as 'self-harm' by participants within the forum threads, although care is taken to acknowledge that alongside meltdown self-harm, this form of harm is not to be considered a concern, and others should not worry about them, as they are not suicidal. Biting of the lips, or inside the mouth, as well as biting skin on fingers or nails, is commonly described, as well as generally picking the skin. Skin picking is either only done in private locations on the body, where it cannot be viewed by others, such as the scalp under the hair, or the feet; or is entirely public, involving the face and hands, sometimes to the point where no nails remain, and scars are left. Re-opening of scabs is described as a compulsion, worrying at something that doesn't feel right until it has been removed, reducing the accompanying anxiety. Skin damage often continues until bleeding, and even then, it is hard to stop. The sensations of bleeding and pain create a sensory overload that can be useful if a *meltdown is building up, as these new sensations can function as an over-ride switch. One participant justifies their scalp-picking as a localised way of shutting off more distant sensory stimulation coming from the rest of the body.*

Once in this pattern of stimming, *it is felt by some to be comforting or soothing* - physically because of the repetitive action, and mentally because it resets the brain. This form of stimulation blurs into sensation-seeking, where altered sensory sensitivity is reduced rather than heightened, and pain is described as bearable, even pleasurable, feeling something physically in order to feel present mentally, or a way of connecting with the senses. *One participant describes a relaxation of the body when having skin picked by someone else, a pleasurable loss of control, and feeling a connection with a loved one.*

6.1.2 Mental health

Some of the reasons given for self-harm can be directly attributed to aspects of poor mental health, all of which have some connection to the experience of being on the autism spectrum but are not solely related to autism, and are also well-known reasons for self-harm within the neurotypical literature on the subject. *The act of harming is often presented by participants as a way of processing emotional pain,* a physical expression of overwhelming feelings or memories. Although alexithymia is only explicitly mentioned once, *some describe classic symptoms of not being able to describe their feelings adequately and use physical methods of displaying how they feel instead, including using the scars as a reminder. One participant relates a time when they wanted to demonstrate to a loved one that they could empathise with their emotional pain by cutting and causing physical pain. Emotions described here are often anger or frustration towards the self or others, building up towards a meltdown, and turning it upon the self to avoid a public display or hurting others. Self-punishment for not being 'normal', not conforming to society, not being good at being human, being a* *disappointment to relatives, or getting in trouble with the authorities* are all given as reasons for this more premeditated and controlled form of self-harm. Low self-esteem contributes here, with *autistic people experiencing bullying from non-autistic people for not conforming to the 'norm', and generally expressing low self-worth in comparison to the majority of society*. The knowledge that autism has no cure or treatment compounds these feelings into helplessness, and combining with the belief that they don't deserve to be here can further translate into suicidality.

Self-harm alongside suicide attempts is discussed in the context of low self-esteem and feelings of worthlessness, commonly in conjunction with narratives of childhood trauma or historical abuse from family members. One participant describes an overly-strict upbringing with daily beatings for minor misdoings, which developed the habit as an adult for punishing themself with a variety of methods, and feelings of worthlessness that led them to regularly contemplate suicide. Another reveals unpredictable parents and sexual abuse from a relative left them a long-term self-harmer to cope with the memories, which led to multiple hospitalisations after cutting went too far. A third participant attributes their self-harm to feeling unable to self-advocate in situations of mental abuse from family members, turning it upon themselves as a way of coping when there was no-one to help.

Anxiety and depression are the most common co-morbid mental health diagnoses with autism (Hollocks et al., 2019; Sedgewick et al., 2021), and are frequently mentioned by participants as a reason for self-harm. Anxiety is always present at low levels, and builds up with stressful experiences until it needs releasing in some way, via a meltdown as previously described; or by a more premeditated, controlled and private self-harm, usually in the form of cutting. *Participants describe the pain and adrenaline rush, as well as the sight and sensation of the blood providing a temporary relief from the constant background noise of anxiety,* and have made self-harm into a coping mechanism for this kind of overload. In contrast to this, *self-harming to relieve depression is related to more as using the physical pain to exteriorize emotional pain,* which may have a sensation-seeking aspect if using the pain of harming in order to feel something.

Cutting as a form of self-harm is most frequently mentioned alongside mental health diagnoses, and is also described as being controlled, premeditated, and private, with the term 'conventional' or 'non-autism-related' self-harm used by some to define and differentiate it from autistic self-harm. The knowledge that it may upset those close to them means that cutting is undertaken in private, and most often in places on the body that are easily concealed, as it leaves scars. One participant mentions having a first aid kit prepared in order to avoid the embarrassing trip to hospital, after accidentally cutting too deeply; and another agrees with not cutting too deeply, and also the importance of keeping the wounds clean afterwards, revealing a hidden depth of self-care woven beneath the harm (Chandler & Simopoulou, 2020).

6.2 Theme 2 - Barriers to seeking help

The second theme presents perceived barriers to seeking help for self-harm as an autistic person.

Table 6.3 Sub-themes and codes described within Theme 2

Theme	Barriers to seeking help	
Sub-theme	Unprofessional experiences	Communication issues
Codes	Misdiagnoses Negative experiences with professionals No appropriate help available	Alone Taboo subject Unable to self-advocate Unable to verbalise Vulnerability of autistic people

6.2.1 Unprofessional experiences

Negative experiences are related by forum posters when interacting with qualified medical or social care professionals, mostly due to a lack of knowledge and resources. Misdiagnoses are felt to be common, as participants interacting within these threads describe themselves as at the intellectually able end of the spectrum with less obvious characteristics, and the ability to mask their autism in order to fit in with society. Their autism flies under the radar when being assessed for self-harm and other related mental health issues, and they are often diagnosed with another disorder with similar or overlapping symptoms. Misdiagnoses or co-morbid diagnoses mentioned within the threads are borderline personality disorder /emotionally unstable personality disorder, post-traumatic stress disorder, attention-deficit hyperactivity disorder, sensory processing disorder, and obsessive compulsive disorder. All of these conditions feature either high anxiety levels, emotional dysregulation, or both; and are therefore hard to separate from the contribution that their autism diagnosis makes to either overall mental health state, or tendency to self-harm (Lai et al., 2019; Au-Yeung et al., 2019).

Participants attribute their misdiagnoses to professionals having greater knowledge and experience of other related disorders and so latch onto particular symptoms they have seen in other conditions, and are satisfied as long as their patient gets a diagnosis. Consideration into whether it is the correct diagnosis, or whether there may be multiple diagnosable problems in one person, was felt by participants to not be a concern for professionals. Once a diagnosis is given, it is then much harder to return and contest this or ask for a second opinion. One participant describes visiting a psychiatrist who was experienced in psychosis, and so focused in on their auditory hallucinations and wrongly prescribed an antipsychotic medication. This was later revoked by a psychologist who re-diagnosed the participant as having autism with synaesthesia. All of the above points are echoed in Au-Yeung et al. (2019), who used a mixed-methods approach to discover the issues surrounding mental health diagnoses and misdiagnoses in autistic participants. *The general feeling by many in the forum discussions was that professionals are simply not as well trained in spotting any of the more subtle features of autism, especially presentations in intellectually able adults, focusing instead upon the classic childhood extremes of meltdowns and stimming in non-verbal boys. One participant is incredulous when told by a professional that they couldn't be autistic because they didn't look or behave like an autistic person, using rocking and hand-flapping as the diagnostic criteria. Another was not taken seriously because they could correctly determine emotions when presented with a range of emojis.*

Even if an autism diagnosis is eventually given, this experience is often bad enough in itself to ensure that when the autistic person starts to self-harm, they do not feel comfortable enough to return to mental health services and go through the distressing process again; which is why the participants reach out for help via the online forums instead. High turnover of staff in health and social care leads to mistrust of professionals, as autistic people prefer continuity (Camm-Crosbie et al., 2019), and change of staff inevitably leads to difference of opinion and contradiction of previous instructions. There is a belief held by some professionals that if autistic people are higher-functioning and articulate, they are coping and have capacity to self-advocate, and therefore do not need help (Camm-Crosbie et al., 2019). *One participant describes being refused help for mental health and self-harm because they did not appear visibly distressed due to differences in communication and expression; and another got told they did not look depressed because they smiled on greeting.*

This ignorance extends to other related social care professionals, *as in one thread an anxious participant was told to stop stimming or the professional would not help them. This precipitated the need to self-harm once the participant returned home, due to the frustration, anger, humiliation and helplessness they felt. Where individuals attended Accident &*

Emergency, some relate negative experiences including feeling that they are wasting time that could be spent on 'real' patients, with one participant even being made to believe that they had inadequately self-harmed, so they subsequently returned home and harmed themselves in a much more severe way. One participant turns this around by suggesting that autistic people are 'wasting time' within the mental health services channels that they are being sent down, as none of the services are appropriate for someone who has autism. Attendance at social meetings and therapy groups were prescribed for a participant experiencing low mood, but they explain that this increases their distress by having to go out and interact with strangers and overload their senses. Even when multiple counselling services were prescribed for one respondent, none of them had any experience of autism, and their psychiatrist resorted to calling an inappropriate helpline. Another participant mentions that help is available as a child, but then abruptly stops on reaching 25, even though the autism doesn't. Multiple participants reveal having to educate professionals, including sending information to them on the subject of autism; and feel their diagnosis is an important part of getting help, as professionals seem to require written proof as evidence before they will make efforts to help autistic people with mental health issues. One participant did finally get to see a professional who was educated in autism, but was told that there were no local services available, and that they could not refer elsewhere.

On the NAS forums, moderators intervene when a participant appears to be in distress, but any help offered from forum moderators is surprisingly generic, citing well-known phone helplines to call, or websites to visit, highlighting the lack of any autism-specific national support services in the UK.

6.2.2 Communication issues

One of the difficulties that all autistic people have in common to some degree is communication, which can include an inability to read body language or make eye contact, taking what is said literally or misunderstanding content of conversations, a dislike of social interactions because it overloads the sensory system, or difficulties in deciding when to take turns in speaking (Benford & Standen, 2009). This can lead to feeling alienated from others, and feeling alone is one of the reasons that self-harmers make contact with online forums. *One participant posted to the forum after attempting to contact neurotypical friends by text message, as although they replied, it was on a superficial level, and seemed as if they didn't want to engage with such a complex situation*. The combination of being on the autism spectrum and self-harming creates a feeling that they cannot speak to anyone close to them for fear of upsetting others, or that they will not be understood as well as non-autistic people in the same position. *Some participants mention their experience of friends and family actively avoiding the double-taboo of both the autism and the self-harm* – even if someone has experience of one of the issues, they are unlikely to have experience of both, which forces autistic self-harmers to connect with the wider online community in order to find someone else with similar experiences. The anonymity of online interactions means that posters can be open and honest without revealing their identity, and there is always someone online to connect with, which is vital in the immediacy of self-harm. Even so, *participants often apologise for and acknowledge the sensitive nature of their posts, feeling that they shouldn't be talking about this taboo subject in public forums, using headings such as TRIGGER WARNING; and moderators sometimes intervene by removing content or warning users to change the language used to avoid upsetting others.*

The vulnerability of being autistic is palpable in many threads. Differences in communication style, and the requirement for more time to process information, may cause neurotypical family and friends to speak for the autistic person, either in a well-meaning but unhelpful way, or in a more controlling and deliberately manipulative way. Due to their own need for honesty, autistic people can be naïve and overly trusting; and impairments in reading facial expressions and body language combined with a literal interpretation of words means that they are less able to determine the true intentions of others, and so can be easily taken advantage of (Griffiths et al., 2019). *Some participants contact the forum for outside opinions on whether they are being abused or controlled by family members, including being sent for professional help against their will, and being spoken for by family when meeting with professionals as if they weren't there,* suggesting that the neurotypical perspective on their self-harm and autism is the only valid one. *Others describe being taken advantage of by others, which leads to low self-esteem and subsequent self-harm. One participant was treated badly by a social care professional, and lodged an official complaint, but the professional's account was believed over the autistic person's word,* suggesting that an autistic person has less worth in society. If family and professionals cannot be trusted, there is nowhere else to go, leaving a sense of helplessness, feeling trapped and alone, with self-harm being the only outlet.

Many participants mention feeling unable to stand up for themselves in confrontational situations with others, not knowing what to say or do, attributing this directly to their autism, as their brains fill up with too much information, and they end up withdrawing into silence and self-harm. Alexithymia is touched upon again here, as *participants are unable to adequately tell others face-face how they are feeling in the moment; but given time to process, and space to write it down, they are more able to communicate thoughts and feelings* via the online forum interactions. The preference for written communication, whether by texting others, or by posting in online forums, is tangible; and *one participant goes as far as blaming their alexithymia for reducing their options down to meltdown, shutdown or self-harm. Contradictions from professionals is highlighted by one participant, as they are told they won't* *get help unless they ask for it, but when subsequently asking for help, they are told that they are not helping themselves enough, so they retreat into silence as a learned behaviour.*

6.3 Theme 3 - Responses from the online community

The third theme presents the ways in which the online autistic community responds to posts describing self-harm.

Table 6.4 Sub-themes and codes described within Theme 3

Theme	Responses from the online community	
Sub-theme	Emotional	Practical
Codes	Empathy from others Reassurance of self-worth	Professional help Redirection strategies

6.3.1 Emotional

This sub-theme summarises emotional support offered by fellow forum posters, most commonly when a participant admits to low mood, low self-esteem, distress or suicidal ideation. Contrary to historical belief within psychology that autistic people have limited or no empathetic abilities (Milton, 2012), *responders to posts on self-harm reply with admissions of similar situations, and openly relate their own experiences of harming to help the person feel that they are not alone. Understanding and feeling the same things that are described within the posts are common and instant responses from the online community, as well as stating that they care, and wishing the person well. Empathy is offered rather than helpful strategies when self-harm is described as being an addiction, also when understanding the relief that it can bring from overload*. There is also an acknowledgement that autistic people will not deal with situations in the same way as neurotypical people. *A common complaint by posters is that non-autistic people will never understand autistic people, so one participant extends their empathy to others outside of the community by reminding the community that this is a two-way thing, as* *autistic people will also never be able to see things from a non-autistic perspective, and that friends and family will usually act with best interests at heart, even though sometimes misguided. Participants that are posting because they are asking for help are encouraged to return to the community, because there are likeminded people there.* Much support comes from *those stating that they are older and have had more time to come to terms with their autism, providing reassurance that others will love their autistic self more as they learn to accept their differences.*

Reassurance of self-worth also features strongly within the threads, with *reminders that everyone is flawed, not just because they are autistic, and that they should value their life and contributions made to society, however small*. There is a focus on strengths gained from being autistic here, and how these can be used in a positive way, *including the ability to think logically and view situations from a unique perspective, and channel the self-control and focus required to self-harm into other less harmful behaviours or strategies.*

6.3.2 Practical

This sub-theme offers practical suggestions from the online community as to how those who are currently self-harming can help improve their situations, as it is common for participants to contact the community to ask for help from others who have experienced self-harm as an autistic person. Many respondents reply with not only their experiences of self-harm, but also with successful strategies that they have discovered to reduce or stop self-harming.

Redirection of the urge to self-harm, specifically by conventional/neurotypical means such as cutting, is focused upon activities such as snapping an elastic band on the wrist, or applying an ice cube or pack to an area that would normally be cut to substitute the pain, or dripping hot wax rather than burning in a naked flame. Occupying the mind, keeping busy, and meditation are also successful strategies suggested by community members, both for *conventional and autistic forms of self-harm, with immersion in computer games one suggestion to induce a flow-state of hyper-focus that calms the mind. For meltdowns and overload-induced self-harm, knowing what is happening and learning the triggers is considered key, so that the full meltdown can be averted, walking away and giving the self some time out. Common triggers for a meltdown cited by participants are hunger, fatigue, being somewhere with lots of sensory stimulation, and unexpected change of plans; so being prepared in advance by taking snacks and naps can reduce the build-up of multiple triggers. Sensory over-stimulation can be short-circuited by refocusing the senses with a favourite piece of music or nature sounds, a calming scent sprayed on a handkerchief, eating a spicy snack or chewing gum, or carrying a smooth pebble or fidget spinner to occupy the hands.*

For reducing harmful stims, *switching to a less harmful stim such as rocking or hand-flapping was suggested by one participant, but this is likely to carry the same stigma as harmful stims if used in public as a management strategy. Practising the less harmful stim when not overloaded was also well-considered advice, so that it becomes an automatic behaviour when losing control in the throes of a meltdown. In the privacy of familiar surroundings, banging the head or hitting the self with soft furnishings, or using weighted blankets to apply pressure and refocus the senses can avoid the need to hurt the self when alone. One participant describes being told by a professional to buy objects specifically to be smashed in anger when feeling a meltdown coming on. Pets are non-judgemental, and stroking them is soothing, so seeking solace in animals at home is also discussed by participants, including one person having an autism-assistance dog to take out with them, which reduced anxiety and meltdowns significantly. To burn off the excess anxiety that can build up before a meltdown, exercise is the most popular suggestion by the community. This can be in the form of running and cycling, or more violent forms such as using a punchbag, or martial arts training. One person suggests that if self-punishment is required, doing repetitions of a difficult exercise every time they feel* *the need to harm can be effective.*

Although many arrive at the forums through negative experiences with medical and allied professionals, there are also *some who advocate adherence to any drugs prescribed, as it has helped them deal with comorbid mental health issues or diagnoses. One participant reduces their difficulties down to an imbalance of chemicals in the brain, which medications have successfully corrected, and they go on to reassure sceptics that drugs are improved now, with reduced side-effects, and that their personality has not been altered or diminished by them. Of all medical professionals, seeing your own family doctor is most often recommended by one person, as they have the greatest personal knowledge of your autism and health history,* representing continuity of care, which is appreciated by autistic people. *Attending counselling or therapy is also suggested, with the caveat that they must have some official training or experience of autism. One participant suggests that if family members are part of the problem, then they should also attend counselling, as sometimes hearing it from a third party with professional qualifications will validate the experiences and difficulties faced as an autistic person, and increase their understanding and support.*

Those who describe being able to self-advocate and navigate the complex system of healthcare and mental health are more positive here, with *specific advice being to get the professional to always write everything down so that it can be taken away and presented to other professionals in future appointments, as this makes the path smoother. Knowledge of the legalities of support and disability is also advised, with more than one participant quoting that professionals have a 'duty of care' to their patients, that service users are legally customers, and that sections of specific acts are being broken by being refused care or treated badly by professionals.* If participants contact the online community because they feel they cannot self-advocate, *contacting specific charities or advocacy services are recommended by some, and a few even offer to advocate on behalf of the original poster if necessary.*

This chapter has presented the findings of my thematic analysis on forum posts at a semantic level of interpretation. I discovered that self-harm in autistic adults without intellectual impairments often takes the form of self-injurious or self-stimulatory behaviours, resulting from sensory or cognitive overload, or increased anxiety. Because these behaviours are misunderstood and stigmatised by others, this can create poor mental health and can generate a vicious cycle of self-harm as a form of self-punishment for not being ‘normal’. A perceived lack of understanding and support from non-autistic family and professionals means that many autistic adults turn to the online autistic community, who support each other emotionally and practically. In the following discussion I take this interpretation to a theoretical level. I critically analyse how self-harm and autism are currently problematised within society as unacceptable ways of being, and negative medicalised illnesses that should be fixed, placing the responsibility upon the individual; all of which create further mental ill health. I then open up the discourse to consider alternative sociological theories which provide a more holistic lens through which to interpret this topic.

Chapter 7 - Discussion

By taking an alternative methodological approach to reveal the lived experience behind the predominant biomedical quantification of self-harm in autistic adults, my study unites literature and theory on autism and self-harm which have not been previously combined in this way, making a novel contribution to research in this area. Parallels can be drawn between the literature on autism and self-harm, as both are medicalised as disorders that are stigmatised for being abnormal; but they also both contain sociological causes and functions that reveal the complex and nuanced social contexts that underpin these behaviours, which can help shed light on new ways to help autistic people, and those who self-harm. Sharing origins from within activism, the neurodiversity paradigm and intersectionality speak well to each other, as both seek to reveal hierarchies of power within society and turn the spotlight upon socially constructed and maintained marginalised populations (Strand, 2017). The notion within intersectionality that each separate facet of an individual's identity holds a different social value, and no individual is neither fully privileged nor oppressed at any one time (Strand, 2017; Windsong, 2018), rings true with the concept of the 'spiky profile' of autism, where the differences experienced can be both disabling or advantageous, dependant on the context (Bottema-Beutel et al., 2021; Russell et al., 2019). An intersectional lens has recently been employed to examine the development of the neurodiversity movement and autistic identity (Botha & Gillespie-Lynch, 2022), and intersectionality has previously been considered in the context of gender and autistic identity (Moore et al., 2022; Saxe, 2017); but this thesis combines both intersectionality and the neurodiversity paradigm in a unique way in order to gain a deeper understanding of how autism interacts with self-harm.

7.1 Thinking intersectionally about self-harm and autism

The self-harm discussed in the autism online forum threads is a combination of what could be described as neurotypical or classical self-harm, and autism-influenced SIBs; but what is important is that all of the acts are described by the participants as self-harm, whether they conform to the stereotype or expected behaviour pattern. Mental health issues and diagnoses are believed to underpin much neurotypical self-harm (Klonsky et al., 2003), but these are not mutually exclusive with an autism diagnosis or identity, as it is well known that poor mental health also features strongly alongside being autistic (Hollocks et al., 2019; Lai et al., 2019). Intersectionality helps shed light upon this complex topic, as no single factor is considered in isolation, rather that it is a combination of influencing factors that create issues for individuals within specified communities or social categories (Atewologun, 2018); in this case, autism, mental health, and self-harming behaviours. The essentialist reduction of humans to their labels, such as an autism or mental health diagnosis, creates an assumption that this is their sole defining characteristic, without taking into consideration the wider social and political influences that also shape life choices and behaviours (Atewologun, 2018; Saxe, 2017). Furthermore, the accumulation of multiple stigmatising labels creates a problem that is greater than the sum of its individual components; and the more labels you have, the more marginalised you become and the lower you feature within societal hierarchy (Crenshaw, 1989).

One critique of intersectionality is that there is a tendency for it to be applied at a granular level, with the focus remaining upon the individual and their unique additive experiences of oppression and marginalisation (Bowleg & Bauer, 2016). Informed by my understanding that these experiences operate across multiple levels, I incorporated a macro viewpoint, with how autism and self-harm are portrayed within society at a systems level, as stigmatised and stereotyped medicalised mental health disorders that require fixing. This naturally trickles down through to an interpersonal level, where power is wielded by clinicians when attempting to obtain an autism diagnosis, and adults without intellectual impairments are not considered to be autistic enough. If presenting with combinations of autism, self-harming behaviours and mental ill health, where these intersect, there is less understanding and help available, rendering the individual marginalised and othered. At an intrapersonal level, because there is no specific help or understanding of the combined effects of autism without intellectual impairments, mental ill health and self-harming behaviours, the individual is left to cope alone, having to mask unacceptable behaviours in public even if they represent coping mechanisms. This creates a build-up of stress and anxiety over time, creating a vicious cycle of having to release this pressure in public via a meltdown when it cannot be contained, producing stigma and shame, which can then generate further self-harm in private to self-punish for not conforming to the societal ideal. Multiply marginalised individuals can even find themselves excluded from their own community (Strand, 2017), and so the only help and support available is found from within communities of people experiencing the same intersecting phenomena, the online adult autistic community.

7.2 Separation by medicalisation

Autism and self-harm have historically received a predominantly medicalised narrative, as both fall under the remit of psychology, and are categorised as mental health disorders within the APA’s DSM-5 (2013). (Zetterqvist, 2015; Lai et al., 2013; Smith & Jones, 2020). Much of the self-harm described within the forums is autism-specific, but does not fall neatly inside the categorisation as described within psychology, so is under-researched and under-represented within the literature. Unpremeditated blunt repetitive trauma in response to sensory overload in the form of a meltdown is considered to be classic self-injurious behaviour, which is a form of self-harming that is believed to be only experienced by children with autism, or autistic adults with intellectual impairment; and not autistic adults without intellectual impairment (Matson & Turygin, 2012; Karim & Baines, 2016). In the process of screening studies for the systematic review, many studies had to be eliminated because they either had a focus on childhood presentations of autistic harming (License et al., 2020; Minshawi, 2014; Oliphant et al., 2020; Shkedy et al., 2019), or of adults with intellectual impairment (Vanderwalle & Melia, 2021), or both (Richards et al., 2016, 2017; Laverty et al., 2020; Jokiranta-Olkoniemi et al., 2021). Only one single qualitative study considering self-harm in autistic adults without intellectual impairment suggested that there could be SIBs as self-harm within this population (Goldfarb et al., 2021).

There remains no clear distinction, both in descriptions presented within the forums and in medical definition, in terms of self-harm/self-injurious behaviours within the autistic community. The interchangeable use of language and multiple definitions of NSSI and SIB within research made the systematic review searches, inclusion/exclusion criteria and analysis difficult; and the forum posts reveal that the online community have themselves selected the vernacular and all-encompassing ‘self-harm’ to describe both SIBs and NSSI behaviours rather than attempting to define and differentiate. This suggests that clinicians and researchers should not concentrate further on the demarcation of these forms of harm, or whether they feature in the intellectually impaired or children only, as all self-inflicted harm should be taken equally seriously as a sign of distress regardless of the presentation. Instead, the focus should be upon trying to understand these experiences from an autistic point of view, learning how to help autistic people manage their distress, and accept and celebrate the differences that autism confers upon a person. As a minority and marginalised population, with intersections of mental illness and other visible and invisible differences, the autistic community will be treated as less important than the majority in a utilitarian society.

7.3 Sociological self-harm

Reasons for non-autistic self-harm still resonate and apply to autistic self-harm, regardless of the method used. Explanations presented in the sociological literature for self-harm include emotional pain being channelled into physical pain (McAllister, 2003; Chandler, 2013; Edmonson et al., 2016), a way to regain control from chaos (Chandler, 2013 & 2014), a history of mental or physical abuse from family and others (McAllister, 2003; Chandler, 2012), self-punishment for not conforming to an ideal (Edmonson et al., 2020; McDermott & Roen, 2016a), not being taken seriously by professionals (Chandler et al., 2020; Harris, 2000), being marginalised by society (McAllister, 2003; McDermott & Roen, 2016b), and the pathologisation of social deviance (McDermott & Roen, 2016b); all of which feature within the online forums where autistic adults are communicating their difficulties. In my findings, participants describe self-harming as a physical release of sensory or emotional overload in the form of a meltdown, or as part of socially unacceptable self-stimulatory behaviours. These can develop into more conventional forms of self-harm if they also experience mental ill health, or are made to feel abnormal by family or professionals. This can exacerbate the harming behaviour, as it becomes a form of self-punishment for not being ‘normal’, or to transform the emotional pain into physical pain in order to process the experience.

The interpersonal element of Nock’s four function model of self-harm (Nock, 2008) considers the effect of social influences on self-harm, acknowledging that self-harm is not just an intrapersonal construct originating from within the self. Focusing specifically on adolescents, Heilbron & Prinstein (2008) hypothesise that young adults are developing their identity at this time, spending more time with peers, learning social roles and establishing behaviours. If experiencing negative affect, they may be introduced to NSSI as a coping strategy by peers, which is reinforced by social media, websites and forums dedicated to self-harm (Heilbron & Prinstein, 2008). When developing an identity, individuals may engage in behaviours that their desired peer group are advocating in order to gain acceptance or status, even if the behaviours are considered socially deviant (Heilbron & Prinstein, 2008). Nock (2008) presents this as a physical display of strength, as harming the self is biologically costly, but can be a way of protecting the self from victimisation from others. Using the example of goth subculture, tattoos, piercings and scarification are used to present a tough exterior and the ability to withstand pain, as well as a visual display of identification with a specific social group (Nock, 2008).

The second social function of NSSI is as a way of communicating distress. Invalidating or dysfunctional family environments, poor social skills, avoiding demands from others, or eliciting caregiving responses from others, are all reasons for using NSSI as a physical distress signal (Nock, 2008). Physical signals are believed to be clearer, as verbal communication can be dishonest, and physical injury is also taken more seriously as a sign of needing help from others, including medical professionals (Nock, 2008). There is a trade-off by resorting to a physical display of distress, as it is biologically more costly than using verbal communication, but is more likely to elicit a response (Nock, 2008). Autistic people may escalate their meltdown SIBs to NSSI as a secondary behaviour if their distress is passed off as part of their autism that cannot be helped.

7.4 Overload and meltdowns

Parallels can be drawn between transforming emotional pain into physical pain and overload/meltdowns when considering the interactions between autistic sensory sensitivities and inherent and constant low-grade anxiety, depression and other co-morbid mental health diagnoses. The shame and stigma of having an uncontrollable autistic meltdown in public is palpable within the threads, with both close family members and qualified professionals treating the autistic person poorly during and after the event, making them stop by restraint, or ridiculing them afterwards in the hope that they will be shamed into not repeating the behaviour. These physical manifestations of mental overload and distress are coping mechanisms, often described as a last resort when there is no other escape, and self-harm emerges as a way of dealing with stress. Within the sociological self-harm literature, Brossard describes this as a ‘pressure-cooker’ situation, where self-harm is used as a release for overload of emotions; taking the affect-regulation theory of self-harm in psychology further by positing that it is pressure applied by society to appear or behave in a certain way that creates the need to self-harm and release this pressure (Brossard & Steggals, 2020).

7.5 Harmful stimming

A disproportionate amount of autistic self-harm discussed within the forum is linked to stimming. These repetitive and compulsive behaviours are often performed unconsciously in order to alleviate the build-up of anxiety or overload, and are described as self-soothing, therefore even if considered by outsiders to be physically harmful, they provide a protective mechanism against distress. Linked mainly to autistic children in psychology literature, these behaviours are stigmatised if experienced as adults (Kapp et al., 2019), as the behaviours fall outside of what is considered to be normal or acceptable, creating minority stress. A direct example of this within my findings is when the participants in the forums acknowledge that their behaviours are considered unacceptable by others, as they relate experiences of being filmed and ridiculed by family and professionals in efforts to stop them from stimming. These activities are acknowledged by participants on the forums as being socially unacceptable, displaying a level of self-awareness and social understanding that autistic people are not believed to be capable of (Baron-Cohen et al., 1985); and they advise each other to either suppress these habits until alone, or develop more socially acceptable stims in order to avoid confrontations. One participant suggests that professionals concentrate upon exterior autistic behaviours too much, which then turn into a focus for treatment. If successfully stopped, they are considered cured, when really, the behaviours are merely being suppressed. Self-stimulatory unconscious behaviours such as hair twiddling or leg jiggling are considered acceptable within the non-autistic population, being neutrally attributed to restlessness or boredom, and are only viewed negatively when associated with autism (Pearson & Rose, 2021).

One qualitative study asked autistic adults how they understood stimming, why they stim, and the value of this behaviour; and it was confirmed overwhelmingly as a self-regulatory behaviour for excess sensory over-stimulation, or intense emotional overload, even if considered harmful (Kapp et al., 2019). This population also described the negative reactions received from others when publicly stimming, even if mild or inoffensive, and the shame, belittlement and frustration they felt, having to wait until alone, change the stims to more acceptable ones, or suppressing the urges altogether, which generates anxiety. Modifying their environment to reduce the sensory input, and increasing awareness and social acceptance were key points from this study; with the neurodiversity movement adopting the word stimming to take back power, teaching fellow autists to learn to use stimming as a positive behaviour by watching online videos (Kapp et al., 2019). Framed by the neurodiversity paradigm, this form of self-harm can be viewed in a more positive light, and there is an argument for such behaviours to be left alone if they serve a purpose (Leadbitter et al., 2016; Milton & Moon, 2012).

7.6 The price of masking

Having to behave ‘normally’ and appear happy in order to appease family members is presented as a form of emotional labour by Chandler (2012) and McDermott & Roen (2016a), and the effort required to suppress either natural behaviours or negative feelings creates a need for a release in the form of self-harm, turning it upon the self when there is no other option. ‘Passing’ as normal is a known phenomenon within many hidden differences, most prominently within the LGBTQ+ community (Shippee, 2011), and has its own label within the autistic community as masking or camouflaging (Hull et al., 2020; Pearson & Rose, 2021). Masking requires an ability to accurately perceive how the self is received by others, and adjust behaviours accordingly, rendering psychological assumptions of autistic antisociality and the theory of mindblindness (the inability to understand what others are thinking) obsolete (Pearson & Rose, 2021). With 8/10 of traits associated with autism carrying negative associations (Botha et al., 2020), masking is a daily necessity in order to avoid stigmatisation and disadvantage, but it is known that levels of stress and autistic burnout are directly proportional to the amount of masking required (Cook et al., 2021; Pearson & Rose, 2021). Changing the external presentation only internalises the problem (Hull et al., 2020; Pearson & Rose, 2021), and self-harm releases the pressure that builds up from this.

7.7 Neoliberal normality

The dominance of medicalised discourse within both self-harm and autism creates the belief within society that ‘normal’ is the ideal, and that once diagnosed, treatment or cure is the goal. Any responsibility for illness or deviation from the norm is placed upon the individual, as the problem is seen to come solely from within. This is described as the neoliberal selfhood within sociological self-harm literature (Inckle, 2020; McDermott & Roen, 2016b), and appears as the normalisation agenda within critical autism studies (Milton & Moon, 2012; Runswick-Cole, 2014). The ‘norm’ in society that all are expected to aspire towards is to be successful, wealthy, happy, physically and mentally well, and a contributor to society; which is represented best in Western society by the middle-class white male (McDermott & Roen, 2016b). For those on the spectrum, neurotypicality is the normaliser to aspire towards. Any who cannot achieve this ideal are relatively marginalised, the degree of which is directly proportionate to the level of deviance from this ideal (Crenshaw, 1989). Runswick-Cole (2014) argues that if a diagnosis renders you unable to perform as a productive citizen in society, then medical experts are appointed in order to make you more productive by attempting to treat or cure. If unsuccessful, the individual adopts the ‘sick role’, a theory developed by Parsons and elaborated upon by Milton & Moon (2012), who suggest that the sick role allows those who cannot conform to the societal ideal of productivity, to instead reside within society as a marginalised sub-class of citizens, but citizens nonetheless. If unable to either conform to society, or adopt the ‘state of exception’/’sick role’, you are othered, and effectively excluded from society (Runswick-Cole, 2014). Society is beginning to accept autism in some specific situations, described by autistic researchers as a temporary personhood (Botha, 2021), dependant on whether the person can contribute beneficially to society; for example, celebrity Aspergians such as Elon Musk or Greta Thunberg portraying the intellectually able, eccentric but socially acceptable face of ‘autism-lite’ (Gabarron et al., 2022; Skafle et al., 2021).

The normalisation agenda represents a form of oppression at a systems level, within society itself, whereby ableism pigeonholes anyone not conforming to ‘normal’ into the disabled sick role. The neurodiversity paradigm challenges this ableist thinking, as autism is not perceived to be a disability when viewed through a neurodiverse lens, and all have something to contribute to society (Pellicano & den Houting, 2021). At an interpersonal level, many autistic adults without intellectual impairments are ‘othered’ by professionals when not believed to fall within the remit of a classic autistic diagnosis. The participants within my study are unable to conform to society by merit of their autism diagnosis, but also struggle to meet the standards of the sick role, as they present as intelligent and articulate, and so are often not taken seriously enough by professionals, when either obtaining a diagnosis, or seeking help.

7.8 Minority stress

Underpinning the normalisation agenda, understanding can be translated from the minority-stress framework (McDermott & Roen, 2016b; Botha & Frost, 2020), as stress is caused by the stigma of being ‘othered’, where both autists and self-harmers are made to feel inadequate and wrong in comparison to ‘normal’ society for their deviant behaviours. This reduces mental wellbeing, creating a vicious cycle of needing to self-harm in order to punish the self for being abnormal, or alleviate the build-up of negative thoughts and emotions. The intersection of being both autistic and self-harming, and the associated stigma of both of these marginalised identities, compounds any negative effect further, making it even more impossible to seek help, or feel accepted by society. Many of the forum posts regarding mental health diagnoses also reflect an inability by professionals to take into consideration the overlap between autism and many symptoms of mental illness diagnoses, often settling for a mental illness diagnosis over an autism diagnosis due to the siloed categorisation of disorders within the DSM-5, and the associated monolithic thinking of psychology as a science.

7.9 Diagnosis

Obtaining a diagnosis presents a double-edged sword, as diagnosis holds the power to both repress and liberate. Diagnosis is underpinned by certain shared characteristics, but autism as a concept is partially a social construct, which changes over time as language, attitudes and meanings evolve (Botha & Gillespie-Lynch, 2022). Normality is also a social construct, linked to the eugenics movement, and historically used to justify the elimination of undesirables from society (Botha & Gillespie-Lynch, 2022). Prior to diagnosis, many autistic adults have already internalised a notion of being abnormal, derived from societal messages surrounding acceptable behaviour (Botha & Gillespie-Lynch, 2022). Diagnosis is traditionally sought when experiencing the negative effects of a condition, so necessarily carries negative connotations. No-one thinks to seek confirmation that they have autism if they have noticed positive traits such as an extraordinary memory, a higher IQ than the general population, acute sensory perception, or an ability to intensely focus on a task for a long period of time. Some positives that autism bestows are even portrayed as abnormal, as ‘super-powers’ can be intimidating to those who do not possess them (Pellicano & den Houting, 2021).

Poor professional knowledge of autistic traits was a strong theme within the forum discussions, with some describing having to educate healthcare professionals about aspects of their identity or on the more subtle presentations, or even being told that they couldn’t be autistic because they were not showing the more stereotyped behaviours. This also arises within the systematic review and is echoed in Botha et al. (2020), where participants discussing stigmatisation through stereotypes of autism felt that if not conforming to the classic depiction of autism, they were dismissed, creating a barrier to seeking help. If presenting with subtle or ‘mild’ traits, masking, or considered to be higher-functioning and capable of self-advocacy; there is a general misconception that the person is not needing help (Gillespie-Lynch et al., 2017; Milton & Moon, 2012). It is argued that being considered high-functioning or having an Asperger syndrome diagnosis represents a marginalised identity in itself, for not being autistic enough (Saxe, 2017); creating yet another point of intersection between mental illness, autism and self-harm that this thesis serves to highlight.

Within the neurodiversity movement and critical autism studies, there is a standpoint epistemology theory stating that those who have lived experience are the true experts (Gillespie-Lynch et al., 2017; Russell, 2020); but the dominance of the medical model and general deferment to the superiority of doctors and psychiatrists’ opinions creates a power imbalance, so the autistic voice remains silent (Milton, 2012). Due to the historical portrayal of autistic people as having no empathy, unable to comprehend or communicate with others, or even being incapable of morality, people with autism are still considered to be unreliable in their ability to tell their own truths (Botha et al., 2020; Milton, 2012). Autism continues to be represented mainly by the medical profession, or by neurotypical parents of autistic children who cannot self-advocate; perpetuating the prevailing stereotypes and the ‘infantilisation’ of autism (Stevenson et al., 2011).

7.10 Strategic medicalisation

Although the neurodiversity framework appears to be against the medicalisation of autism on the surface, it is underpinned by the belief that in order to self-advocate and demedicalise autism, biomedical language has to be engaged with and understood, and used positively where needed (Russell, 2020). To make significant changes to the medical approach to autism, the neurodiverse community must adopt clinical discourse in order to be respected and listened to by medical professionals (Russell, 2020). Many of the forum participants admit to making autism their specialist subject, and use knowledge to their advantage when negotiating with medical professionals, some being so confident as to offer advocacy on behalf of others. Within the neoliberal or normalisation agenda, this affords a version of ‘biological citizenship’, and this use of ‘strategic medicalisation’ can be found within the wider literature of other marginalised communities, such as the trans community, when articulating medical needs or validating beliefs (Johnson, 2019).

This adoption of medicalised language also provides a way of reducing the power differential between professionals and autistic people (Goethals et al., 2015). It has been suggested that extra effort is made by marginalised groups in order to find medical professionals who will be understanding of their condition, and get them the help that they require (Newman et al., 2021). This is reflected in the advice given by some of the community, who do not reject medical help outright, but do highlight the need for the right help from the right people. The neurodiverse movement does not specify a need for a diagnosis in order to identify with the community; but there is an argument for the use of a diagnosis to relieve personal responsibility from an individual for deviant behaviours, which can be seen to reduce stigma, and it affords access to services or reasonable adjustments (Russell, 2020).

7.11 The double-empathy problem

A classic misunderstanding and stereotype of autistic people that has been psychologised and therefore considered an absolute truth, is the reduced ability to empathise with others, coined the empathising-systemising theory by Baron-Cohen (2009). Milton (2012), autistic academic and self-advocate, adds a new twist to this theory by arguing that this problem is actually a two-way thing, as non-autistics (including medical professionals) also have difficulties empathising with autistic people. This double-empathy theory may explain why autistic people find it hard to seek help from professionals, either when getting a diagnosis, or seeking help for mental health or self-harm. Prior research has revealed that non-autistic people judge autistic people less socially favourably based upon brief interactions (Alkhadi et al., 2019; Sasson et al., 2017), which can be presumed to extend to medical professionals. It is also well-documented that some medical professionals have little empathy for self-harm because it is considered to be self-inflicted, wasting time in Accident & Emergency which could be used for ‘real’ emergencies (Chandler et al., 2020; Harris, 2000). This is reflected within my findings, where one individual is made to feel like they haven’t even harmed themself enough to justify their presence in the hospital, which creates feelings of inadequacy, and makes them return home to harm themself further.

The other side of the double-empathy theory arises within the third theme of how the online community responds to admissions of self-harm, as it is further theorised that autistic people not only possess empathy, but also have greater empathy for fellow autists than for non-autists (Milton, 2012). This is confirmed within the threads, as there is a real sense of community and support from fellow people with their own lived experience. There is a known preference for written communication and a need for reflection within autism (Hughes, 2021; Jaarsma & Welin, 2012), presented within both the systematic review findings, and within the forum posts when articulating difficulties in seeking help or feeling unable to self-advocate.

This has been facilitated further by the development of online communications, which has enabled autistic self-advocates from around the world to get together and share experiences, opinions, and empower each other; in the form of the neurodiverse community (Dekker, 2020).

7.12 The power of community

The neurodiversity paradigm provides an alternative viewpoint on being autistic from an insider perspective, with a focus upon differences and strengths rather than disabilities and weaknesses, acknowledging that each person is unique in their abilities, and that this should be celebrated regardless of whether neurodiverse or neurotypical. Social identity theory (Tajfel & Turner, 2004) proposes that self-esteem and pride are greatly increased when identifying positively with a group of likeminded individuals; and belonging to the neurodiverse community may go a long way to reverse the negative psychological state about being autistic that is created by minority stress and stigmatisation. The neurodiverse community argues that autistic behaviours are adaptive coping strategies that should be destigmatised and left alone if not causing direct harm or distress to an individual, which includes harmful stimming behaviours used to avert a more serious meltdown or self-harm episode (Leadbitter et al., 2021; Milton & Moon, 2012). Furthermore, Perry et al. (2022) call for a targeting of stigma by reduction programmes and changing the external environment to reduce autistic coping behaviours rather than attempting to change the autistic person.

Real change can only come about from within the community itself, as it is education of those within the community, and this spread of knowledge from the community to the rest of society, that can affect real change. Knowledge empowers people to challenge authority, and stand up for minority rights; and the neurodiverse movement allows those able to self-advocate to speak for a whole community, and bring geographically isolated people together within a shared identity. Two recent studies with a focus upon the importance of autistic social identity reveal that autistic people feel more at ease with fellow autists, can be their authentic self, feel better understood and have to explain less, feel more equal in conversations with no pressures to talk, have a sense of belonging, and have a more positive social and political identity (Botha et al., 2020; Crompton et al., 2020). Both studies go on to conclude that spending time with other autists means the mask can be dropped, reducing or eliminating stigma, which reduces minority stress, and therefore also reducing the need to self-harm.

7.13 Reflexive account

I have to acknowledge that my positioning as a member of the non-intellectually impaired autistic community will have affected the choices that I have made throughout this thesis.

My decision to take a qualitative approach was influenced not only by the gap in the literature and dominance of quantitative and mixed method studies, but also by my philosophical alignment with the beliefs of critical autism scholars and the neurodiversity movement, who state a need for inclusive research and representation of the lived experience of autistic people in a predominantly non-autistic society.

My selection of the online non-participatory methodology was justified by the limitations imposed upon face-to-face qualitative research at the onset of the Coronavirus pandemic; but was also in sympathy with my own heightened discomfort induced by the additional communicative pressures of face-to-face interactions, associated eye contact and body language interpretation distractions, reinforced by my relative lack of confidence in participant interactions as a novice qualitative researcher. Although I identify as part of the autistic community, I do not take part in online forums, so do not consider myself to be immersed in the specific culture of online autism forums.

Although the subject matter of self-harm was influenced by prior online research undertaken within Lancaster University, I have lived experience of autistic meltdown and stimming behaviours, and so regardless of the autistic forum discussions being weighted more towards the autistic self-injurious behaviours, I may have been subconsciously drawn towards those accounts that resonated with my own experiences, as well as accounts of later diagnosed and less obviously autistic adults not being taken seriously by non-autistic others.

My choice of philosophical paradigm, theoretical lens and frameworks used to interpret my findings was directly influenced by my identification with the neurodiverse community and non-intellectually impaired autistic self-advocates and scholars. I wanted to present my findings through an alternative social lens as an insider researcher, to counter the dominance of the medical model of autism as a disability, and present autistic people’s experiences of stigmatised behaviours as being partly created and maintained by society.

This chapter has expanded upon the empirical findings of my research by providing alternative sociological explanations for self-harming behaviours in autism, suggesting ways in which self-harm should be viewed and treated by non-autistic people, and highlighting the power of community. In the final concluding chapter, I summarise my research by presenting the empirical, theoretical and methodological contributions that it has made to the topic of self-harming in autism. I then identify where my findings fit within wider policy and strategy, acknowledge limitations of the study, and finally suggest directions for future research.

Chapter 8 - Conclusion

The aim of this thesis was to explore and represent experiences of self-harm as described by autistic people within online forums, including reasons for self-harm, forms and methods of self-harm, barriers to seeking help for self-harm, and support offered by the online community. This was achieved by thematically analysing forum posts from two different online autistic communities, and in doing so, has made unique contributions to autism research in the following ways.

8.1 Empirical

Empirically, the systematic review presented the increased prevalence of self-harm within the autism community, in comparison to the general public or non-autistic control populations. The review also highlighted the dominance of quantitative research and lack of qualitative research, revealing the gap in the research that the project sought to fill. A further finding was the blurring of definitions and descriptions of self-harm versus self-injurious behaviour used within the literature, making self-harm in autism elusive to both comprehension and treatment. SIBs in autism have been historically considered as a separate phenomenon to conventional self-harming behaviours in the non-autistic population (Matson & Turygin, 2012; Vandewalle & Melia, 2021). Even within SIBs in autism, this has been observed as existing in children and the intellectually impaired only (Minshawi et al., 2014; Rattaz et al., 2015), and as an inherent part of autism, and therefore considered almost impossible to help (Shkedy et al., 2019).

My findings from the online forums present a nuanced blend of what is considered to be conventional non-suicidal self-harm, in combination with more autism-specific SIBs; and as such, cannot be separated out or clearly defined. The participants referred to all of their behaviours as self-harm regardless of method used, whether compulsive and public, or controlled and private. Much of the harming behaviours described were of the more compulsive, repetitive blunt trauma associated with SIBs, triggered by sensory or cognitive overload which precipitates a meltdown. This could be in any situation, the important factors were the amount of overload experienced, and whether it could be managed by the person or not. Meltdown self-harm is unconscious and uncontrollable, often halting only when pain or blood triggers the brain out of the primal response mode, and is stigmatised if experienced in a public place (Lewis & Stevens, 2023). My findings confirm that autistic adults without intellectual impairment do experience SIBs and meltdown-related harming behaviours, challenging the previously held tropes of meltdowns and SIBs as solely presenting within the domain of children, the intellectually impaired, or both.

An interesting finding was that of stimming as a form of self-harm, reflected in the popularity of harmful stims discussions on the forums, supported by use of the descriptor ‘harmful’ by the participants, directly acknowledging these behaviours as such. My findings presenting self-stimulatory behaviours as a form of self-harming add an avenue of research to explore within the fields of both autism and self-harm research; as non-autistic people also experience stims to a lesser extent as habitual fidget behaviours, but without any stigma attached. Participants described the use of stimming behaviours as either conscious or unconscious methods of averting a full meltdown by relieving the build-up of anxiety with these smaller scale but no less stigmatised repetitive behaviours. Many were contacting the forums to check if their stims were acceptable, to reassure others by sharing similar stims, and also by providing alternative less harmful stimming behaviours.

Conventional self-harming in the form of private and controlled behaviours, such as cutting, were more often described alongside mental ill health, low mood, and low self-esteem; but also occurred in combination with meltdowns and SIBs. For example, some participants described self-harming in a private and controlled way following a meltdown to alleviate the shame or punish the self; while others mentioned that their self-harm created negative experiences with others, subsequently precipitating a meltdown.

Negative experiences with professionals, whether via poor understanding of the subtler presentation of Asperger syndrome, receiving a misdiagnosis of another mental health condition, or not receiving effective support; were all reasons that participants sought help from others on the forum. Support from fellow forum participants was both empathetic and practical, refuting prior psychological theories of reduced empathy in autism, and putting a positive spin on the abilities that autism can confer, as well as encouraging engagement with the medical and legal worlds in order to effectively self-advocate. This peer support is important on more than one level. It is mutually empowering, both for the person seeking help and knowing that there are others living with similar intersections, and for those providing the advice as experts by experience. This helps redress the power imbalance and negative labelling created by the medicalisation of autism and self-harm. It also provides a way to seek help and support that is not otherwise available, using a preferred written and asynchronous method of communication, where there is always someone online available to talk to who understands the autistic experience.

8.2 Theoretical

Theoretically, this thesis has taken the subject of self-harm in autism beyond the realms of the purely objective observational and scientific studies within psychology and neuroscience; into the more interpretative and experiential, but no less valid, field of social research. This study is the first to consider self-harm in autism, and autism-specific socially unacceptable or taboo behaviours, within the context of how society treats and views autistic people, using the neurodiversity paradigm as a fresh lens. Grounded in the social model of disability, the neurodiversity paradigm allowed me to draw parallels between autism and self-harm as predominantly medicalised and stigmatised ways of being. I challenge the dominance of the medical model and add to increasing calls for a paradigm shift from medical to social (Pellicano & den Houting, 2021), which will change how we support autistic people, and our approach to knowledge production, going forward. My sociological approach to self-harm in autism argues against a purely biomedical explanation or solution, especially as self-harming is described by the participants as being at least partly created by their interactions within society. The medical model of disability is criticised for placing sole responsibility for any ‘abnormalities’ onto the person, without considering the wider social and environmental aspects that contribute to a person’s experience (Jaarsma & Welin, 2012); and a more nuanced version of the social model of disability, the neurodiversity paradigm, is used as a lens through which to view the autistic experience of self-harm. The neurodiversity paradigm refocuses upon the positives that autism can bestow upon a person, alongside acknowledging that stigmatised coping behaviours such as stimming should be left alone, as it can do more harm than good when suppressed (Milton & Moon, 2012; Leadbitter et al., 2021). The neurodiversity movement also highlights that both the general public and professionals should be better educated to help reduce stigma and stereotypes held around autism, and that autistic people are the best experts on their neurodifference, encouraging engagement with self-advocacy (O’Dell et al., 2016; Kapp, 2020).

Intersectionality is an emerging standpoint within autism research, originating from within Black feminist studies (Crenshaw, 1989). It is only very recently that the combination of autism and other aspects such as mental illness have been identified as compounding factors contributing to the marginalisation of this population (Botha & Gillespie-Lynch, 2022). Much of the self-harm within my findings was autism-specific, but because it is not so neatly pigeonholed into any of the psychological categories or descriptions, it has remained an under-researched topic. Intersectionality presented a way for me to consider the combined effects of living with multiple marginalised identities, such as being an adult with an autism diagnosis without intellectual impairments, who are taken less seriously by professionals, and who experience mental health comorbidities alongside compulsive harming behaviours that are unacceptable in society. Thinking intersectionally also allowed me to draw together two separate bodies of literature on autism and self-harm, and apply a range of theories in support of my findings which have not been considered together before.

The forums revealed that a lot of adult autistic self-harm was in the form of SIBs and stims - taboo, uncontrolled and sometimes public behaviours believed to be experienced only by children or the intellectually impaired (Minshawi et al., 2014; Rattaz et al., 2015). These stigmatised behaviours act as physical coping mechanisms for overload in all autistic people (Kapp et al., 2019), but because they are considered shameful, they are hidden as part of masking/camouflaging behaviour in the intellectually able (Pearson & Rose, 2021). This creates a build-up of stress which then needs to be released by other more harmful behaviours, either as an uncontrolled meltdown or as a more controlled act of self-harm, theorised by Brossard as a sociological ‘pressure cooker’ (Brossard & Steggals, 2020). Emotional labour theory accounts for the extra stress caused by masking, having to present ‘normally’ to appease family, or assimilate themselves in public (Pearson & Rose, 2020). Minority stress theory, another emerging theory within autism research (Botha & Frost, 2020), underpins emotional labour and intersectionality in the explanation of marginalisation and stigmatisation that creates the vicious cycle of harming, shame and mental ill health. To help break this cycle, the neurodiversity movement has reclaimed stigmatised labels such as stimming, and proudly promotes stimming as a positive anxiety-reducing behaviour (Kapp et al., 2019), encouraging acceptance of stims as part of a spectrum of normal displacement behaviours, labelled as fidgeting in non-autistics.

The normalisation agenda within neoliberal society allows for acceptance via either contributing to society by work, or accepting your disability and adopting the sick role, with the only remaining option being othered and marginalised as a sub-human (Runswick-Cole, 2014). The struggle to be understood by professionals when negotiating the sick role is a form of inclusivity labour, where non-neurotypicals work harder to get a diagnosis, help or support for their difficulties than neurotypicals, to the point where they are effectively educating the professionals (Newman et al., 2021).

The neurodiversity movement promotes active involvement in the medical sphere by self-education and advocacy, using medicalised terminology to obtain a diagnosis, and legal knowledge to access support (Russell, 2020). This is augmented by the online community sharing information and experiences, with social identity theory underpinning the positive connections that are made by meeting others with similar differences (Tajfel & Turner, 2004). This study also provides direct support for Milton's double empathy theory (2012), which argues against the cognitive theory of mind (Baron-Cohen et al., 1985), and later empathising-systemising theory (Baron-Cohen, 2009). Both theories suggest that autistic people lack the ability to understand or imagine what other people may be thinking, and therefore are unable to empathise with others. My findings revealed that within the online autistic community, empathy was shown both for fellow autists, and for non-autistic people; and some explain their disagreements with family and professionals over harming behaviours as a mutual misunderstanding, providing more support for the double-empathy theory.

8.3 Methodological

Methodologically, this is the first study to adopt an online qualitative methodology to explore the hidden world of self-harm in non-intellectually impaired autistic adults. A qualitative approach allows for a deeper and more nuanced understanding of self-harm, which both expands upon and supports the dominantly quantitative studies within the systematic review reporting high prevalence, but unclear forms, methods or motivations for self-harm in autism. The single qualitative study in the review interviewed a small population as part of a wider project on RRBs in non-intellectually impaired adults (Goldfarb et al., 2021); which suggested that SIBs as self-harm in autistic adults does exist, something that I have been able to both confirm, and explore further within my larger online population. The online methodology captures a wider population than those volunteering to talk face-face with a researcher, and includes those unable to leave the house, or who cannot participate in conventional research (Illingworth, 2001; Wilkerson et al., 2014). This allows direct access to an epistemic population able to describe their own experiences from a personal viewpoint, without prompting from a researcher (McDermott et al., 2013a). The forum posts represent real-time conversations despite their historical nature, playing out between people with similar experiences, allowing a level of disclosure permitted by the sense of community that the online forums provide (McDermott et al., 2013a). Online communication allows for greater reflection, and represents a form of self-advocacy, as written posts can be carefully composed with no instant face-face pressure, something that impairs social communications in the physical world (Brownlow & O'Dell, 2006; Jordan, 2010). Some participants expressed a preference for written and online communication, which supports a body of literature on autistic communication (Brownlow & O'Dell, 2006; Davidson & Henderson, 2010; Jordan, 2010), and emphasises the need for a greater variety of communication methods to be offered within health and social care service provision.

As an insider researcher, I have been privileged to be able to represent this community as a fellow adult autist, and the reflexive nature of qualitative research allows for a reality that is otherwise disenfranchised by the belief held by some non-autistic researchers and professionals that autistic people are not able to accurately represent themselves (Botha, 2021). My insider researcher status somewhat mitigates the outsider gaze and power differential created by not presenting experiences directly as verbatim quotes, as the sensitive nature of the topic required a carefully considered ethical approach to my chosen methodology.

8.4 Contributions to current policy and strategy

Since the creation of the Autism Act (2009) - the first condition-specific piece of disability-based legislation acknowledging a legal requirement for the provision of adult autism services; autistic charities, the UK Government, and the NHS, have all undertaken surveys and reports in order to create strategies, policies and recommendations for services and research going forward. In 2016, Autistica collaborated with the James Lind Alliance to produce their top ten research priorities (JLA, 2022), of which this thesis directly contributes to five : informing the improvement of mental health, understanding and reducing anxiety, education of family members to better understand an autistic relative, a greater understanding of sensory processing, and improvement of service delivery for autistic people. Within the top 25, my findings also shed light upon : improving the training of professionals to better recognise autism, understanding the lived experience of autism, improving public understanding of autism, and understanding common mental health conditions in autism. The NAS commissioned a survey of 11,000 participants in 2019 to evaluate improvements made ten years on from the Autism Act, and revealed that 71% are still not getting the support needed within mental health, and professional understanding is still considered poor (NAS, 2019). 99.5% of people are now aware of autism, but only 16% of autistic people feel that this awareness translates into understanding (NAS, 2019). The five things that autistic people would most like the public to be aware about in order to reduce stigma and stereotypy are-

1. They need extra time to process information
2. They experience anxiety in social situations
3. They experience anxiety when experiencing unexpected change
4. They experience sensory overload
5. They experience meltdowns and shutdowns (NAS, 2019).

All of the above points are emphasised within the findings of this thesis, hopefully increasing awareness and understanding while simultaneously presenting the human side of autism, reducing stigma and shame through increased empathy. The UK Governmental 5-year strategy from 2021 has six main themes to focus upon, of which this thesis contributes towards two : improving understanding and acceptance within society, and tackling health and social care inequalities (GOV.UK, 2021).

8.5 Limitations

Although this study accesses more participants than usually stated within qualitative research, it is still not considered to be generalisable to the autistic population for multiple reasons. The online nature of this study limited the participants to those who were not only computer literate, but also that had access to technology, although online methods do allow access for those who may be geographically isolated or unable to travel to physical meetings (Wilkerson et al., 2014). The relative anonymity of creating an avatar online means that demographic information was variable and incomplete, so although female over-representation was highlighted as an area for further investigation during the systematic review, I was not able to take this point further during this project. There is also an argument to suggest that people are not their true self when contributing online (Brownlow & O'Dell, 2016), which has been refuted by more than one researcher who suggest that anonymity actually allows for greater disclosure (McDermott et al., 2013a; Wilkerson et al., 2014; Hewson et al., 2017). Due to the inability to obtain individual consent for the use of forum posts, I was unable to illustrate my findings with verbatim quotes, which is considered by some to be an essential component of a qualitative study (Hewson et al., 2017; Franzke et al., 2020).

My identity as an insider researcher allows for some credibility, but as the neurodiversity movement clearly states, one person does not represent the entire autistic community. My insider involvement as an autistic person will have influenced what I focused upon and how I represented the findings; reflected in my own experiences of autistic harmful behaviours, but not non-autistic self-harm. As the sole researcher on this PhD project, these are entirely my representations, and due to the historical aspect of the postings and anonymity online, I was unable to use participants to member-check my findings; but a reflexive journal was maintained throughout to record my thoughts and decisions.

8.6 Recommendations for future research

Recommendations for research going forward include an expansion of this study to include in-depth interviews, or the inclusion of other forms of online communications, including blogs, and vlogs. Interviews would allow for a selection of the population to ensure all demographics are included, which could not be determined in this anonymous online study. Interviews would also allow for the exploration of the female experience of autistic self-harm, as well as other overlapping intersections of marginalisation. The intersection of gender and autism creates a sub-population of marginalised individuals in autistic females, as milder symptoms and behaviours in comparison to autistic males leads to later diagnosis and a reduced credibility, a form of ‘autism-lite’ which is a prejudice in itself surrounding not being autistic enough (Pearson & Rose, 2021). Historically, the male presentation of autism has dominated diagnosis and research, supported by psychological theories such as the extreme male brain; and all within a male-privileged patriarchal society and from an over-representation of White, middle-aged, middle-class males within research (Saxe, 2017; Botha & Gillespie-Lynch, 2022). Further qualitative research into topics such as meltdowns and stimming would also be beneficial in order to gain a deeper understanding of how autistic adults experience and manage these behaviours.

More qualitative research is needed generally within autism, as society and professionals alike are beginning to realise that all autistic children grow up to become adults with autism (NAS, 2019); and that they are able to self-advocate and articulate their experiences and needs directly, rather than through a third party (Stevenson et al., 2011). It is increasingly becoming a necessity for the inclusion of representatives of the study population as co-producers in all areas of participation-based research, including autism (Pellicano et al., 2014b), although some autistic researchers feel that this is tokenistic (Milton, 2012). In the UK, research often fails to have any impact on those who should be most affected by it, as there is no over-arching systematic process for coordinating autism research (Pellicano et al., 2014a). Priorities are often determined by individual interests and existing projects, and funders, including parent-funded charities; and researchers are still too cause-focused, with genetic and neuroscientific discoveries making no difference to those already living with autism (Pellicano et al., 2014a).

A paradigm shift is required in terms of research focus in the future : listening to and involving more autistic people, concentrating upon real social and environmental changes that can improve the lives of those already living with autism, increasing awareness and acceptance through education of professionals and the public, making diagnostic services more widely available and accessible, and having appropriate post-diagnostic support. These changes will help to improve associated mental health conditions such as anxiety, depression, self-harm and suicidality. Autism needs to be removed from official diagnostic categories such as the Mental Health Act in the UK, or the APA's DSM in terms of being labelled a mental illness or disorder (NAS, 2019). We need to re-write the 'disorder' narrative to become a positive 'difference', located within a spectrum of neurodiversity that we all exist upon. It is not autistic people that need to become more 'normal', it is society and the wider environment that needs to adapt to accommodate this difference, and then autistic people would not appear to be so different after all. As one anonymous autistic person is quoted as saying, ‘We are fresh water fish in salt water. Put us in fresh water and we are fine. Put us in salt water and we struggle to survive’ (Baron-Cohen, 2017).

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Appendix 1 – Example of a completed quality and data extraction form.

JBI CRITICAL APPRAISAL FORM FOR ANALYTICAL CROSS-SECTIONAL STUDIES

Reviewer: SM.

Date: 30.03.21

Author/Title/Year : Cassidy, S., Bradley, L., Shaw, R., & Baron-Cohen, S. (2018). Risk markers for suicidality in autistic adults.

Record Number: 9

Y/N/unclear/NA

1. Were the criteria for inclusion in the sample clearly defined? Yes

2. Were the study subjects and the setting described in detail? Yes

3. Was the exposure measured in a valid and reliable way? Yes

4. Were objective, standard criteria used for measurement of the condition? Yes

5. Were confounding factors identified? Yes

6. Were strategies to deal with confounding factors stated? Yes, some variables controlled for within the statistical analysis

7. Were the outcomes measured in a valid and reliable way? Yes

8. Was appropriate statistical analysis used? Yes

Overall appraisal: Include/Exclude/Seek further info Include

Comments (Including reason for exclusion) Also note that the questions were developed in consultation with an autistic population who have experienced suicidal ideation – overall seems a very thorough and clearly thought out study.

DATA EXTRACTION SHEET

Reviewer: SM **Date:** 30.03.21

Record Number: 9

Author/Title/Year: Cassidy, S., Bradley, L., Shaw, R., & Baron-Cohen, S. (2018). Risk markers for suicidality in autistic adults.

Journal: *Molecular Autism*

Database and discipline: Academic Search Ultimate, Scopus, PubMed, Web of Science.

Type of study (quant/qual/mixed): Quantitative

Research question and aims: Aim : to better understand suicidality in autistic adults, and associated risk markers, using instruments with evidence of validity (albeit not yet in autistic adults). Questions : Whether autistic adults are at increased risk of suicidality compared to the general population, while controlling for known common risk factors for suicidality (e.g. age, sex, mental health problems, employment, living situation). Exploring risk markers such as camouflaging, age of diagnosis, and unmet support needs. Also to explore whether NSSI is an independent risk marker for suicidality in those with and without autism spectrum condition (ASC), and whether autistic traits are an independent risk marker for suicidality in the general population without ASC diagnosis.

Methodology: Analytical Cross-Sectional online questionnaire

Sampling Method: Purposive - Participants were recruited from research volunteers databases located in the Autism Research Centre at the University of Cambridge. (CARD database).

Number of participants: The ASC group comprised 164 adults (65 males; 99 females) who self-reported a diagnosis of ASC from a trained clinician, and a majority (81.1%) confirmed the clinic where this diagnosis was obtained. The general population (GP) group comprised 169 adults (54 males; 115 females).

Characteristics of participants: Participants were aged between 20 and 60 years old. There were no significant differences in age ($t(331) = .657$, $p = .511$) or sex ratio ($\chi 2$ (1) = 2.14, $p = .14$) between the ASC and general population group. The ASC group scored significantly higher on the Autism-Spectrum Quotient (AQ) (36.42) than the GP group (19.87) ($t(331) = .657$, $p < .001$).

Phenomena of interest: Autism as a risk factor for suicidality or self-harm, both in autistic people, and those with autistic traits in the general population. Also, NSSI as a risk factor for suicidality in ASC population and general population; and autism-related items such as camouflaging, late diagnosis and unmet support needs.

Setting and other context-related information (e.g. cultural, geographical): UK participants. Questionnaire developed by an autistic steering group with suicidal ideation experience.

Methods used to assess autism : AQ- Autism Spectrum Quotient, also specified had to be professionally diagnosed (but couldn't prove this).

Methods used to assess self-harm : NSSI-AT – Non-Suicidal Self-Injury Assessment Tool. (SBQ-R – Suicidal Behaviour Questionnaire, Revised used for the suicide aspects).

Author's terminology used for autism or self-harm : ASC- autism spectrum condition (as in, those diagnosed with an ASC)

Presentation of data: Within text, and Table 1 – Demographics, Table 2 – Inter-correlations between variables, tables 3,4,5 & 6 are hierarchical regressions for various items, table 7 is inter-correlations for all variables in the GP group, table 8 is another hierarchical regression.

Results: *Group comparisons- suicidality***.** There was no significant difference in total SBQ-R scores between autistic males and autistic females, so results were pooled. A one sample t test showed that autistic adults SBQ-R total scores were significantly higher than the recommended cut-off for the general population, and psychiatric populations. A majority (72%) of autistic adults scored at or above the cut-off for psychiatric populations. There was a significant difference in total SBQ-R scores between GP males and females, so data from males and females were analysed separately. One sample t tests showed that GP males SBQ-R scores were not significantly different from the recommended cut-off for the general or psychiatric population. GP females scored significantly lower than the recommended cut off for the general and psychiatric population. Autistic adults scored significantly higher on the SBQ-R than GP adults and were significantly more likely to score above the psychiatric cut-off for suicide risk (72%) than GP adults (33.7%).

NSSI- Significantly more autistic females (74%) reported NSSI than autistic males (53.8%). There was no significant sex difference in NSSI in the GP group, autistic adults were significantly more likely to report lifetime NSSI (65%) than GP adults (29.8%).

Demographics - Compared to the general population, autistic adults reported significantly lower satisfaction with their living arrangements, were significantly more likely to be unemployed, be diagnosed with at least one co-occurring developmental condition, at least one mental health or other condition, depression, anxiety, and report higher unmet support needs.

Camouflaging- There was no significant difference between autistic males (89.2%) and autistic females (90.9%) in terms of whether they attempted to camouflage their ASC in order to fit in in social situations. However, autistic females scored significantly higher on the camouflaging questionnaire overall (14.7, SD 3.61) than autistic males (12.9, SD 4.06)

Correlations within the ASC group for suicidality – In the ASC group, lifetime NSSI, camouflaging, ADHD, depression, anxiety, unmet support needs, and satisfaction with living arrangements all significantly correlated with suicidality (total SBQ-R scores). However, age of diagnosis was not significantly correlated with any other variables

ASC diagnosis- In step one, the regression model containing sex and age significantly predicted SBQ-R scores, accounting for 4.1% of the variance. In step two, employment, satisfaction with living arrangements, presence of at least one developmental condition, depression, and anxiety accounted for significantly more of the variance (33.4%) in SBQ-R scores. In step three, autism diagnosis accounted for significantly more of the variance (4.5%) in SBQ-R scores.

NSSI- In step one, the regression model containing sex and age did not significantly predict SBQ-R scores, accounting for only 2.5% of the variance. In step two, employment, satisfaction with living arrangements, presence of at least one developmental condition, depression, and anxiety accounted for significantly more of the variance (19.9%) in SBQ-R scores. In step three, NSSI accounted for significantly more of the variance (4%) in SBQ-R scores.

Camouflaging- In step one, the regression model containing sex and age did not significantly predict SBQ-R scores, accounting for only 0.7% of the variance. In step two, employment, satisfaction with living arrangements, at least one developmental condition, depression, and anxiety accounted for significantly more of the variance (20.7%) in SBQ-R scores. In step three, camouflaging total scores accounted for significantly more of the variance (3.5%) in SBQ-R scores.

Unmet support needs- In step one, the regression model containing sex and age did not significantly predict SBQ-R scores, accounting for only 0.4% of the variance. In step two, employment, satisfaction with living arrangements, at least one developmental condition, depression, and anxiety accounted for significantly more of the variance (13.5%) in SBQ-R scores. In step three, unmet support needs accounted for significantly more of the variance (3.1%) in SBQ-R scores.

Correlations for suicidality within the GP- In the GP group, self-reported autistic traits (AQ total scores), lifetime NSSI, depression, anxiety, satisfaction with living arrangements and employment all significantly correlated with suicidality (total SBQ-R scores).

Autistic traits- In step one, the regression model containing sex and age significantly predicted SBQ-R scores, accounting for 8.4% of the variance. In step two, employment, satisfaction with living arrangements, presence of at least one developmental condition, depression, and anxiety accounted for significantly more of the variance (31.5%) in SBQ-R scores. In step three, self-reported autistic traits accounted for significantly more of the variance (3.2%) in SBQ-R scores

From the discussion - Results are consistent with previous findings that autistic adults are at significantly increased risk of suicidality compared to the general population. A majority (72%) of autistic adults scored significantly above the recommended cut-off for suicide risk in psychiatric populations, significantly higher than general population adults (33%) with similar age and gender composition, which remained significant when controlled for using different potentially confounding variables, and also for autistic traits in the GP. Autism or traits in the GP is an independent risk factor for suicidality. Camouflaging is a new variable to be studied, results from the current study showed subtle differences in camouflaging behaviour between autistic males and females: there was no sex difference in reporting whether one engages in camouflaging behaviour, but autistic females tended to report that they camouflaged across more situations, more frequently and more of the time than autistic males.

Contrary to expectations, and discussions with our autistic steering group, age of ASC diagnosis was not significantly correlated with any other variables, such as mental health problems, suicidality, or NSSI. However, this may have been due to the fact that the mean age of ASC diagnosis was 34 years, and therefore, participants represent autistic people diagnosed in adulthood. Unmet support needs significantly predicted suicidality in the ASC group when controlling for the aforementioned variables. Hence, a clear recommendation for policy and practice to reduce suicide risk in autistic adults, a high-risk group for dying by suicide, is to urgently identify and address unmet support needs in this group. The rate of NSSI in the ASC group (63.6%) was significantly higher than the general population group (29.8%), and similar to the rate reported in previous research (50%), which also utilised the NSSI-AT in autistic adults. NSSI also significantly predicted suicidality in autistic adults, after controlling for a range of known risk factors. Hence, NSSI should not continue to be overlooked, or seen as part of ASC, and rather must be addressed in its own right.

Lifetime suicide attempts in the general population (8%) and ASC group (38%) are similar to previous studies, which suggests that the sample was not biased in this respect. However, lifetime experience of depression in the general population (44.9%) and ASC group (80%) were much higher than previous estimates, despite participants not being recruited because of experience with mental health problems.

Outcomes or findings of significance to the review objectives: Significantly more autistic females (74%) reported NSSI than autistic males (53.8%). There was no significant sex difference in NSSI in the GP group, autistic adults were significantly more likely to report lifetime NSSI (65%) than GP adults (29.8%). Compared to GP, autistic adults significantly more likely to be diagnosed with at least 1 mental health or other condition- depression or anxiety, and report higher unmet support needs.

In the ASC group, lifetime NSSI, camouflaging, ADHD, depression, anxiety, unmet support needs, and satisfaction with living arrangements all significantly correlated with suicidality (total SBQ-R scores). However, age of diagnosis was not significantly correlated with any other variables. In the GP group, Self-reported autistic traits (AQ total scores), lifetime NSSI, depression, anxiety, satisfaction with living arrangements and employment all significantly correlated with suicidality (total SBQ-R scores).

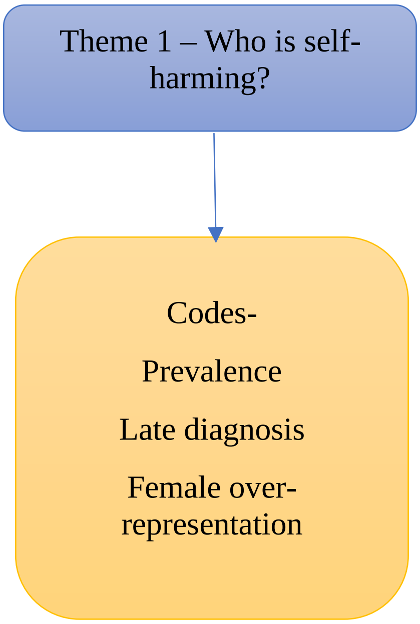
The rate of NSSI in the ASC group (63.6%) was significantly higher than the GP group (29.8%), and similar to the rate reported in previous research (50%), which also utilised the NSSI-AT in autistic adults. NSSI also significantly predicted suicidality in autistic adults, after controlling for a range of known risk factors. Hence, NSSI should not continue to be overlooked, or seen as part of ASC, and rather must be addressed in its own right. Our findings are therefore an important call to action for the research community and clinicians to increase understanding and support for those with ASC experiencing NSSI. However, future studies will need to explore whether this rate of NSSI in ASC adults remains stable, and explore the measurement properties of NSSI assessment tools in ASC.

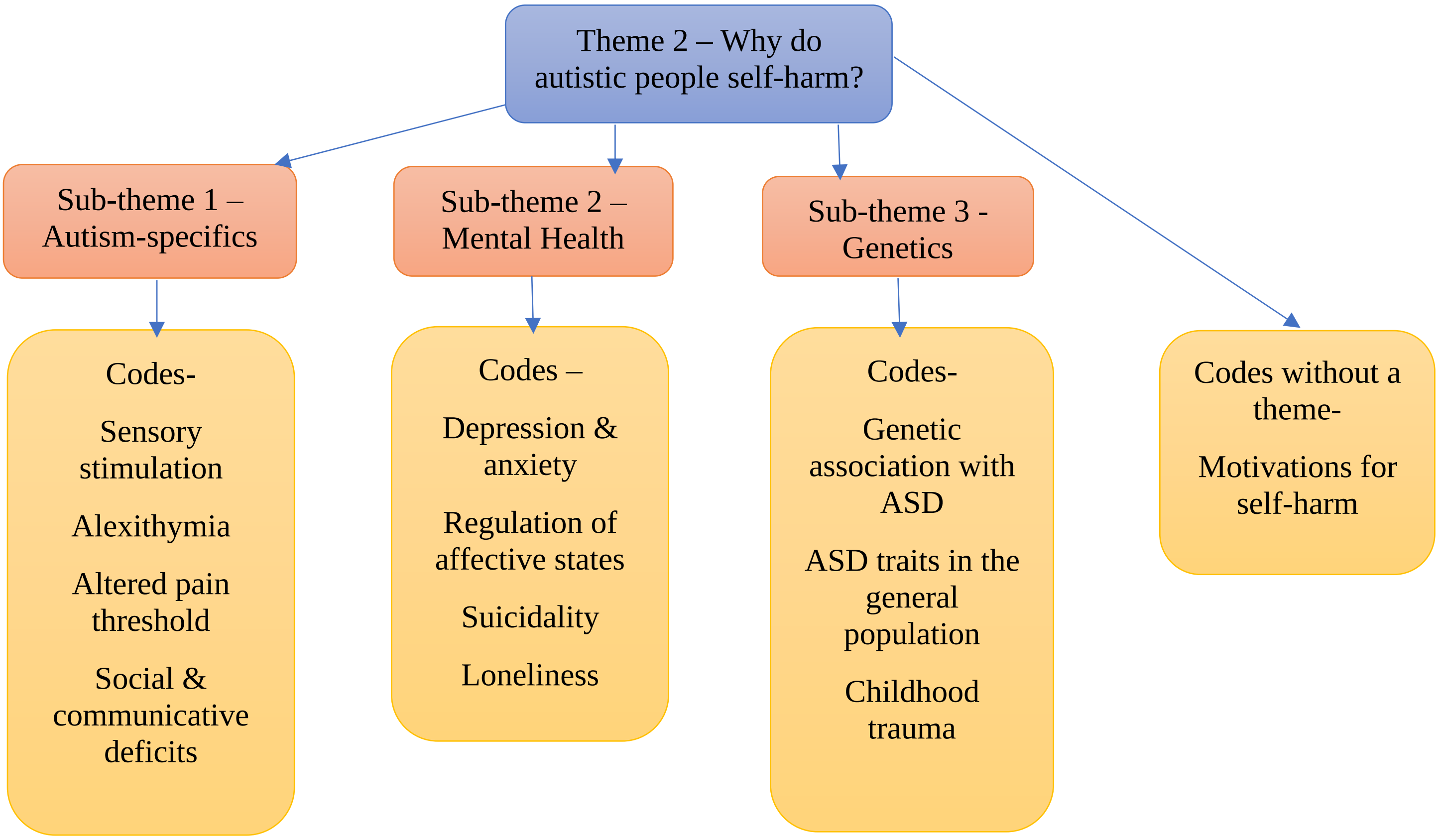
Novel contribution to knowledge: Study used both a review of the available literature, and consultation with a steering group of autistic adults who have experienced suicidality, to ensure that we identified a range of high priority risk markers for suicidality in autism, some of which may be unique to this group. Also, it was the first to utilise a well-validated suicidality assessment tool in autistic adults, and NSSI assessment tool previously utilised in autistic adults. It also included a general population comparison group. Hence, the study was able to explore whether autistic adults are at increased risk of suicidality compared to the general population, while controlling for known common risk factors for suicidality (e.g. age, sex, mental health problems, employment, living situation). The study also explored for the first time a potentially unique risk marker for suicidality and NSSI in ASC males and ASC females—camouflaging ASC in order to cope in social situations

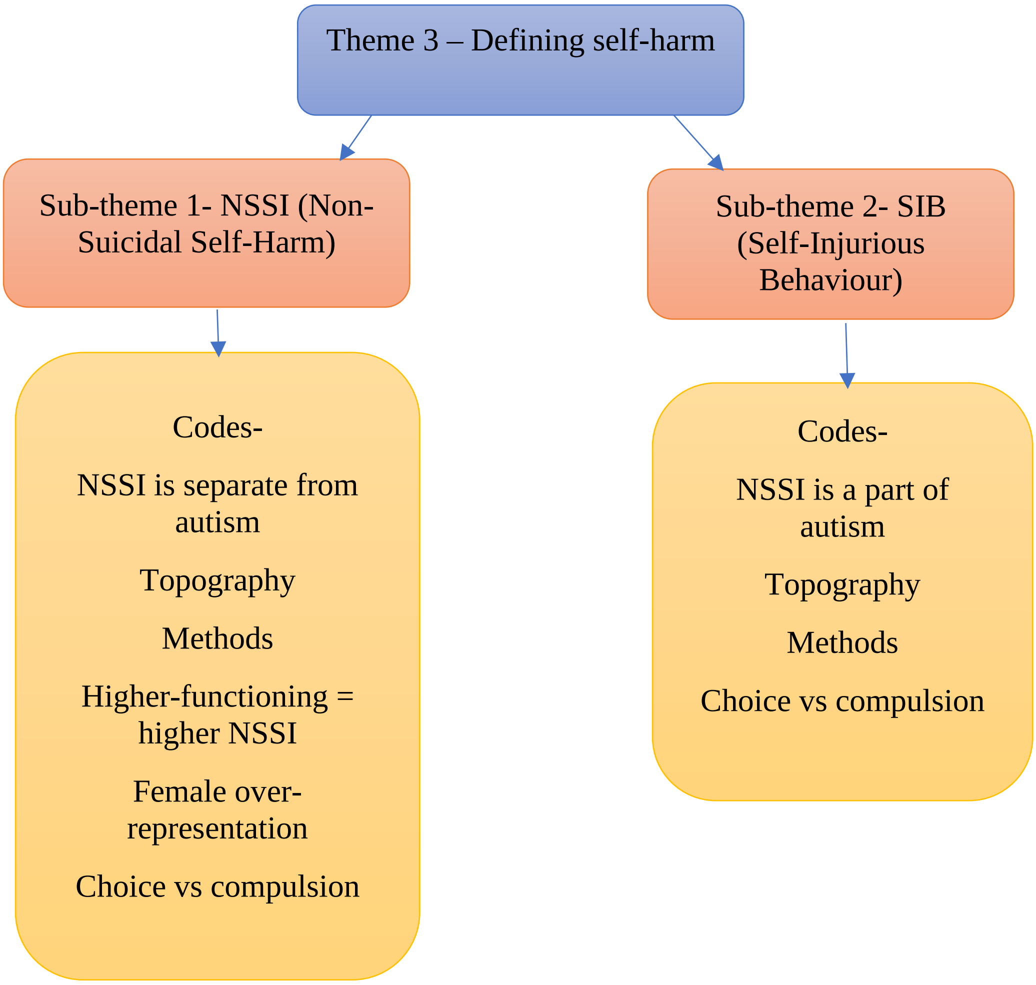
Author's conclusion: The current study is the first to use validated assessment tools, and survey co-designed with autistic people, to explore unique risk factors for suicidality in this group. Results reiterate that rates of suicidality in autistic adults are higher than the general population, and ASC diagnosis and autistic traits are independent risk markers for suicidality. Importantly, unique risk markers for suicidality in ASC include camouflaging one's ASC in order to fit in in social situations and number of unmet support needs. These explain small but significant additional variance in suicidality in ASC, above a range of known risk factors common with the general population. Future research must further explore these and identify other unique mechanisms driving suicidality in ASC to develop new effective suicide prevention strategies for this group.

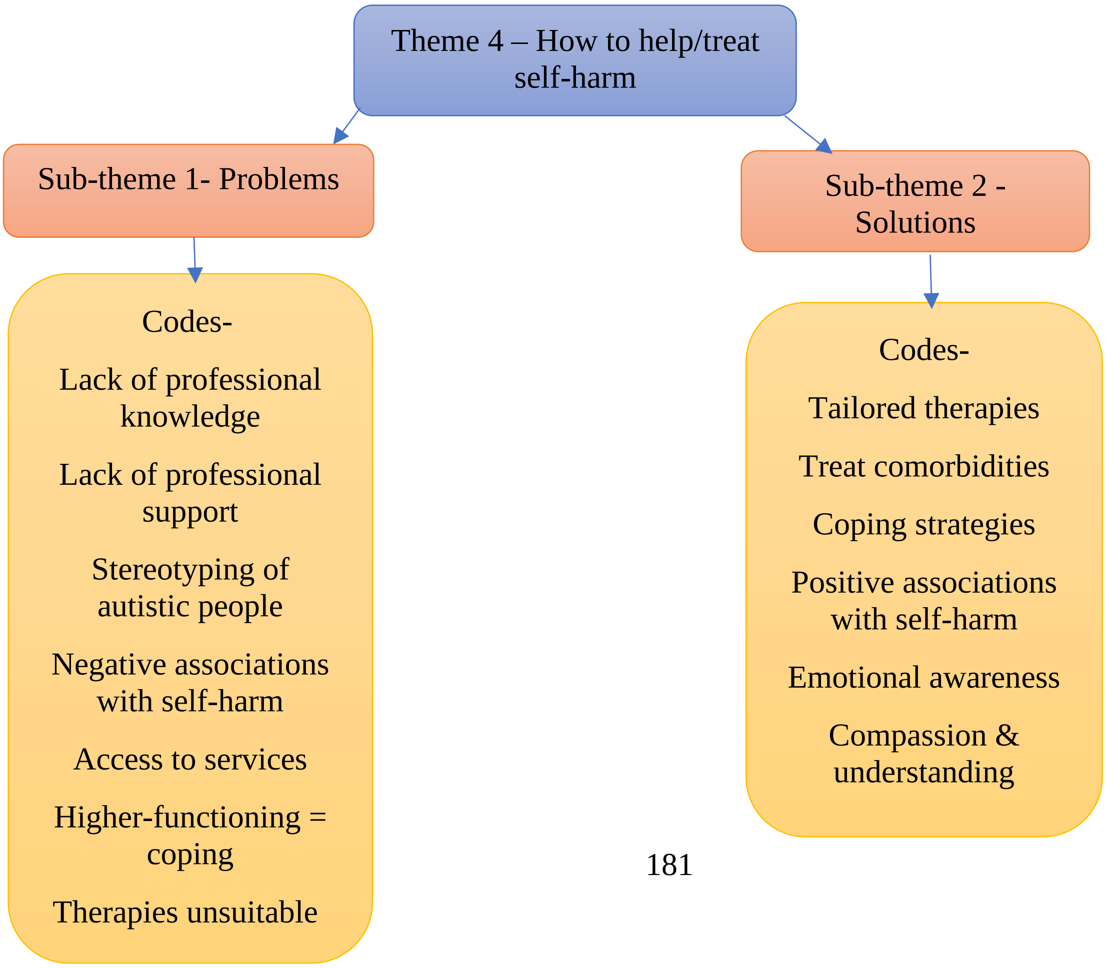
Reviewer's Comments: Study focus is on suicidality rather than NSSI, but has some useful and novel findings, and has involved autistic people with experience of the phenomena to guide the questionnaire. Themes are prevalence, suicidality, mental health, adult diagnosis, camouflaging, females with autism (both higher NSSI and camouflaging), and lack of support.

Appendix 2 – Systematic Review Thematic Map






Theme 3 – Defining self-harm
Sub-theme 1- NSSI (Non-Suicidal Self-Harm)
Sub-theme 2- SIB (Self-Injurious Behaviour)
Codes-
NSSI is separate from autism
Topography
Methods
Higher-functioning = higher NSSI
Female over-representation
Choice vs compulsion
Codes-
NSSI is a part of autism
Topography
Methods
Choice vs compulsion


Theme 4 – How to help/treat self-harm
Sub-theme 1- Problems
Sub-theme 2 - Solutions
Codes-
Lack of professional knowledge
Lack of professional support
Stereotyping of autistic people
Negative associations with self-harm
Access to services
Higher-functioning = coping
Therapies unsuitable
Codes-
Tailored therapies
Treat comorbidities
Coping strategies
Positive associations with self-harm
Emotional awareness
Compassion & understanding

Appendix 3 – Database search results

Date	Database	Search Strategy	Field Searched	No. of hits	No. for full text	Excluded	Included
06/01/21	Social Care Online	(autism OR autistic OR asperger) AND (“self-harm” OR “self-injury” OR “self-mutilation” OR “self-injurious behaviour” OR “deliberate self-harm” OR “non-suicidal self-harm” OR “non-suicidal self-injury” OR “self-mutilation” OR “self-cutting” OR “self-hitting”)	abstract only, title keywords are automatically highlighted, and title search reduces returns. Dates set as 'publication year' as 3rd category in search, 2000-2020, and format type 'journal article' as 4th category.	205	1	0	1 - Wilkinson (2015)
06/01/21	SAGE Journals	[[Abstract autism] OR [Abstract autistic] OR [Abstract asperger*]] AND [[Abstract "self-harm"] OR [Abstract	abstract only, title keywords are automatically highlighted	46	3	0	3 - Maddox (2017), Camm-Crosbie (2019), & Gilmore (2020)

		"self-injury"] OR [Abstract "non-suicidal self-injury"] OR [Abstract "non-suicidal self-harm"] OR [Abstract "deliberate self-harm"] OR [Abstract "self-injurious behaviour"] OR [Abstract "self-mutilation"] OR [Abstract "self-cutting"] OR [Abstract "self-hitting"]	and title search reduces returns to 14. 2000-2020				
06/01/21	PsychInfo	AB (autism OR autistic OR asperger *) AND AB (("self-harm" OR "self-injury" OR "non-suicidal self-harm" OR "non-suicidal self-injury" OR "self-injurious behaviour" OR "deliberate self-harm" OR "self-mutilation" OR "self-hitting" OR "self-cutting"))	abstract only, title keywords are automatically highlighted, and title search reduces returns to 39. Filtered by academic journal only to remove books and dissertations. 2000-2020	272	9	5- Jokiranta (2020), Richards (2016), & Licence (2019) all not able to separate child results from adult; Steenfeldt-Kristensen (2020) review unable to separate out results; & Richards (2017) unable to separate	4 - Hedley (2018), Warrier (2019), Camm-Crosbie (2019), Maddox (2017)

						adult results out from ID versus non-ID.	
06/01/21	PsychArticles	AB (autism OR autistic OR asperger*) AND AB (("self-harm" OR "self-injury" OR "non-suicidal self-harm" OR "non-suicidal self-injury" OR "self-injurious behaviour" OR "deliberate self-harm" OR "self-mutilation" OR "self-hitting" OR "self-cutting"))	abstract only, title keywords are automatically highlighted. Filtered by academic journal only. 2000-2020	5	0	0	0
06/01/21	CINAHL	AB (autism OR autistic OR asperger) AND AB (("self-harm" OR "self-injury" OR "non-suicidal self-harm" OR "non-suicidal self-injury" OR "self-injurious behaviour" OR "deliberate self-harm" OR "self-mutilation" OR "self-hitting" OR "self-cutting"))	abstract only, title keywords are automatically highlighted. Filtered by English language, if filter by journal article at initial search it removes relevant records-refined results	139	2	0	2 - Camm-Crosbie (2019), Maddox (2017)

			afterwards. 2000-2020				
08/01/21	Academic Search Ultimate	AB (autism OR autistic OR asperger*) AND AB (("self-harm" OR "self-injury" OR "non-suicidal self-harm" OR "non-suicidal self-injury" OR "self-injurious behaviour" OR "deliberate self-harm" OR "self-mutilation" OR "self-hitting" OR "self-cutting"))	abstract only, title keywords are automatically highlighted. Filtered by academic journal, & English only (this still gave foreign language papers). 2000-2020. Wildcard or not, no difference.	225	7	2- Shkedy (2019)was SIB only, and Laverty (2020) unable to separate children from adults or intellectual disability status	5- Camm-Crosbie (2019), Maddox (2017), Moseley (2020), Moseley (2019), Cassidy (2018)
08/01/21	SocIndex	AB (autism OR autistic OR asperger) AND AB (("self-harm" OR "self-injury" OR "non-suicidal self-harm" OR "non-suicidal self-injury" OR "self-injurious behaviour" OR "deliberate self-harm" OR "self-mutilation" OR "self-hitting" OR "self-cutting"))	abstract only, title keywords are automatically highlighted. Filtered by academic journal only. 2000-2020	7	0	0	0
08/01/21	Scopus	(TITLE-ABS-KEY (autism OR autistic OR	Abstract, Title &	745	8	1- Vanderwalle	7- Gilmore (2020), Hedley (2018), Camm-Crosbie (2019), Cassidy

		asperger*) AND TITLE-ABS-KEY ("self-harm" OR "self-injury" OR "non-suicidal self-harm" OR "non-suicidal self-injury" OR "self-injurious behaviour" OR "deliberate self-harm" OR "self-mutilation" OR "self-hitting" OR "self-cutting")) AND DOCTYPE (ar OR re) AND PUBYEAR > 1999 AND (LIMIT-TO (LANGUAGE , "English"))	Keyword search, also selected document type Article or Review only, dates 2000-2020. Wildcard works, so left it (in doesn't make a difference). Filtered by English language.			(2020) defined SIB as repetitive and restricted behaviour	(2018), Moseley (2019), Moseley (2020), Maddox (2017)
12/01/21	PubMed	(autism[Title/Abstract] OR autistic[Title/Abstract] OR asperger*[Title/Abstract]) AND ("self-harm"[Title/Abstract] OR "self-injury"[Title/Abstract] OR "non-suicidal self-harm"[Title/Abstract] OR "non-suicidal self-injury"[Title/Abstract] OR "self-injurious behaviour"[Title/Abstract] OR "deliberate self-	Abstract and title, dates 2000+, wildcard left in.	298	6	1 - Zahid (2017)was solely on suicide and although the words self-harm were in the article, there was nothing about it	5 - Gilmore (2020), Camm-Crosbie (2019), Warrier (2019), Cassidy (2018), Moseley (2020)

		harm"[Title/Abstract] OR "self-mutilation"[Title/Abstract] OR "self-hitting"[Title/Abstract] OR "self-cutting"[Title/Abstract])					
12/01/21	Web of Science	((AB autism OR autistic OR asperger*) AND (AB "self-harm" OR "self-injury" OR "non-suicidal self-harm" OR "non-suicidal self-injury" OR "self-injurious behaviour" OR "deliberate self-harm" OR "self-mutilation" OR "self-hitting" OR "self-cutting"))	Abstract only as title keywords highlighted. 2000-2020, English language, excluded proceeding papers and meeting abstracts.	112	5	0	5 - Cassidy (2018), Moseley (2020), Moseley (2019), Camm-Crosbie (2019), Gilmore (2020)
18/01/21	Autism Research Centre Publications Database (Cambridge University)	“self-harm” OR “self-injury” OR “self-mutilation” OR “self-injurious behaviour” OR “deliberate self-harm” OR “non-suicidal self-harm” OR “non-suicidal self-injury” OR “self-mutilation” OR “self-cutting” OR “self-hitting"	No need for autism search set S1 as this is an autism specific site. Specified journal article only, unable to refine by date.	2	2	0	2 - Warrier (2019), Moseley (2020)

22/01/21	Emerald Insight- single journal search within Advances in Autism	Self-harm, self-injury	no need for autism search set S1 as this is an autism specific journal. Full search set S2 gets nothing, either at Emerald level or at journal level. Unable to refine by date.	3	0	0	0
22/01/21	JSTOR- single journal search within iterations of Education & Training in Autism & Developmental Disabilities	Self-harm, self-injury	no need for autism search set S1 as autism specific journal. JSTOR unable to compute full S2, and also unable to compute " so left off. Dates 2000-2018 last issue	13	0	0	0

Appendix 4 – Study characteristics

Author & Year	Title	Country	Participants	Methodology	Focus of Study	Measures/tools used	How is self-harm conceptualised?
Camm-Crosbie, L., Bradley, L., Shaw, R., Baron-Cohen, S., & Cassidy, S. (2019)	'People like me don't get support': Autistic adults' experiences of support and treatment for mental health difficulties, self-injury and suicidality.	UK	122 female, 77 male, 1 unknown; autistic diagnosis, all without ID	Mixed method embedded design, online survey with emphasis on qualitative findings	autistic adults' experiences of receiving treatment and support for mental health problems, self-injury and suicidality	None	As a mental health issue, linked to suicidality, & not the main focus of the study, as is mental health services-oriented. Represented as the neurotypical form of self-harm, with no mention of Self-Injurious Behaviours (SIBs) as Repetitive and Restrictive Behaviours (RRBs).
Cassidy, S., Bradley, L., Shaw, R., & Baron-Cohen, S. (2018).	Risk markers for suicidality in autistic adults	UK	164 autistic adults without ID (65 male, 99 female); 169 adults from the general population (54 male, 115 female).	Quantitative analytical cross-sectional online questionnaire	Autism or autistic traits in the general population being a risk marker for self-harm or suicidality; & NSSI as a risk marker for suicidality; & camouflaging, late diagnosis and unmet needs	AQ (Autism Spectrum Quotient) & NSSI-AT (Non-Suicidal Self-Injury Assessment Tool). Also SBQ-R (Suicide Behaviours Questionnaire-Revised)	As a risk factor for suicidality, & not the main focus of the study. Represented as the neurotypical form of self-harm, with no mention of SIBs as RRBs.

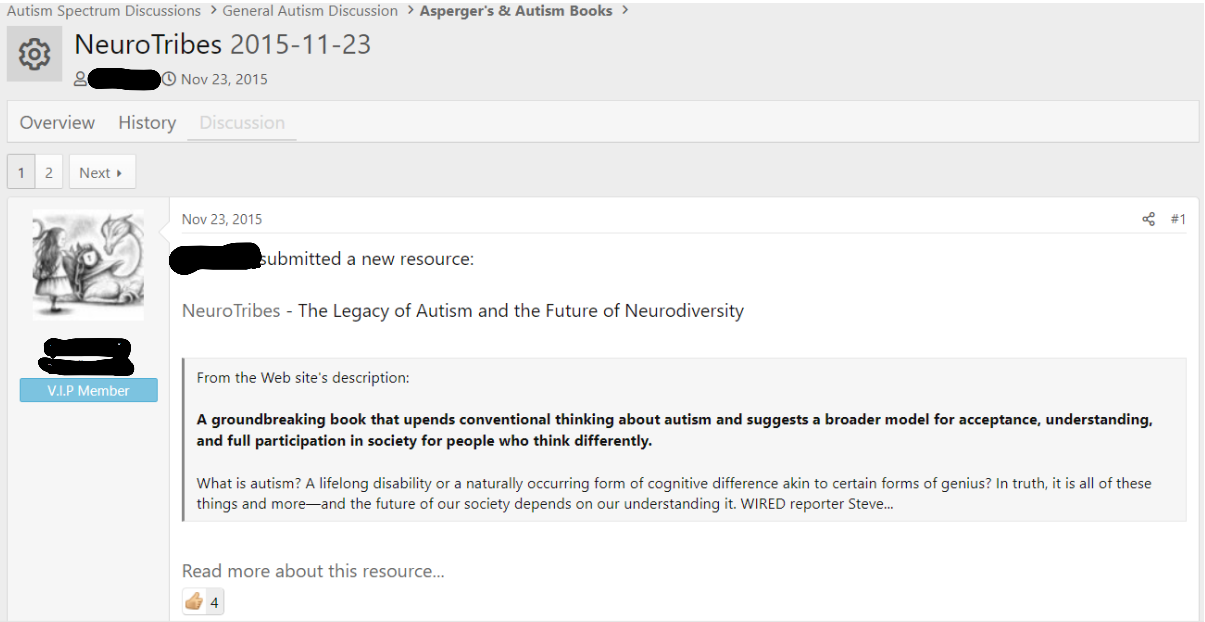
Gilmore, D., Harris, L., Longo, A., & Hand, B.N. (2021).	Health status of Medicare-enrolled autistic older adults with and without co-occurring intellectual disability: An analysis of inpatient and institutional outpatient medical claims.	USA	4685 autistic adults, 2054 with ID, 2631 without ID	Quantitative cross-sectional retrospective cohort prevalence study	Prevalence of mental and physical health conditions in autistic adults with and without ID	No tools used, ICD-10 categories used to identify various diagnoses/conditions within the data	As a mental health issue, and not separated from suicidality by the authors, as not separated within the primary data being accessed for this study.
Goldfarb, Y., Zafrani, O., Hedley, D., Yaari, M., & Gal, E. (2021)	Autistic adults' subjective experiences of hoarding and self-injurious behaviours.	Israel	10 autistic adults without ID, 5 female	Qualitative, IPA, interviews	Subjective experiences of hoarding and self-harm behaviours, and how they make sense of them	RBS-R (Repetitive Behaviour Scale-Revised)	As a repetitive and restrictive behaviour determined by autism, but occuring in cognitively able adults.
Hedley, D., Uljarevic, M., Richdale, A., & Dissanyake, C. (2018).	Understanding depression and thoughts of self-harm in autism : A potential mechanism involving loneliness.	Australia	71 autistic adults, 63 male, applicants to a workplace support programme	Quantitative analytical cross-sectional questionnaire	Examine associations between ASD symptoms, loneliness, depression, and thoughts of self-harm; and test two mediatory theories	PHQ-9 (Patient Health Questionnaire-9 - Item 9 used for identification of self-harm), UCLA Loneliness Scale, AQ-short (Autism Spectrum Quotient-short version).	As a mental health issue, and not separated from suicidality by the authors, as item 9 on the PHQ used as a proxy measure, which involves suicidality and self-harm.

Maddox, B.B., Trubanova, A., & White, S.W. (2017).	Untended wounds: Non-suicidal self-injury in adults with autism spectrum disorder.	USA	42 autistic adults, and a gender-matched NSSI-endorsing sub-sample of 42 from a larger group of university students as a comparison.	Quantitative cross-sectional descriptive and analytical online survey	NSSI in non-intellectually disabled adults with autism, including topography, functions, frequency, motivations, prevalence, association with depression and emotion regulation, and comparison with non-autistic people.	Non-Suicidal Self-Injury Assessment Tool (NSSI-AT); Severity Measure for Depression - Adult; & Difficulties in Emotion Regulation Scale (DERS).	As a mental health issue, and specifically described as damage to tissues deliberately caused without suicidal intent.

Moseley, R.L., Gregory, N.J., Smith, P., Allison, C., & Baron-Cohen, S. (2019)	A ‘choice’, an ‘addiction’, a way ‘out of the lost’: exploring self-injury in autistic people without intellectual disability.	UK	103 - 70 female, 33 male, all autistic without ID	Mixed method convergent parallel design, cross-sectional survey descriptive and anlaytical, thematic analysis of 2 questions.	Variables of interest in relation to NSSI included alexithymia, autistic traits, sensory processing differences, mentalising abilities, depression and anxiety.Exploration of responses to open-ended questions.	Non-Suicidal Self-Injury Assessment Tool (NSSI-AT); Autism Spectrum Quotient (AQ); Toronto Alexithymia Scale (TAS-20); Adolescent-Adult Sensory Profile; Reading the Mind in the Eyes Test (RMET); Beck Depression Inventory (BDI); Beck Anxiety Inventory (BAI).	As a mental health issue, and specifically described as damage to tissues deliberately caused without suicidal intent.
Moseley, R.L., Gregory, N.J., Smith, P., Allison, C., & Baron-Cohen, S. (2020).	Links between self-injury and suicidality in autism.	UK	102 - 29 male, 73 female, all autistic without ID	Quantitative, analytical cross-sectional questionnaire	Explore the relationship between self-harm and suicidality	Non-Suicidal Self-Injury Assessment Tool (NSSI-AT); Suicide Behaviors Questionniare-Revised (SBQ-R); Interpersonal Support Evaluation List 12 (ISEL-12).	As a mental health issue, with a link to suicidality.

Warrier, V., & Baron-Cohen, S. (2019).	Childhood trauma, life-time self-harm, and suicidal behaviour and ideation are associated with polygenic scores for autism	UK	105,638 total qualifying participants; 150 autistic individuals, 44% male	Quantitative, cohort data used in an analytical cross-sectional correlational study	Determining associations between autism, or genetic propensity for autism, childhood trauma, & lifetime suicidality and self-harm	No tools used, the authors self-selected items from the 10 self-harm related questions in the UK Biobank, which they reduced to just 4 items, measured on different scales.	As a mental health issue, use terms self-harm (with or without suicidal intent) and suicidal behaviour and ideation (SSBI)
Wilkinson, J. (2015).	Supporting individuals with autism who self-harm: attributions, emotional response and willingness to help	UK	16, 7 male, 9 female, all support workers with experience of autism or self-harm	Quantitative, within-subjects design, vignettes in a questionnaire used to assess response	Attitude towards autistic patients who self-harm, versus mental health patients who self-harm.	Attributional Style Questionnaire; Emotional Response Rating Scale; Optimism/Pessimism Scale; Helping Behaviour Scale.	Not clear how self-harm is conceptualised.

Appendix 5 – AutismForums example chat thread



Autism Spectrum Discussions > General Autism Discussion > **Asperger's & Autism Books** >

NeuroTribes 2015-11-23

[redacted] Nov 23, 2015

[redacted]

V.I.P Member

Nov 23, 2015 #1

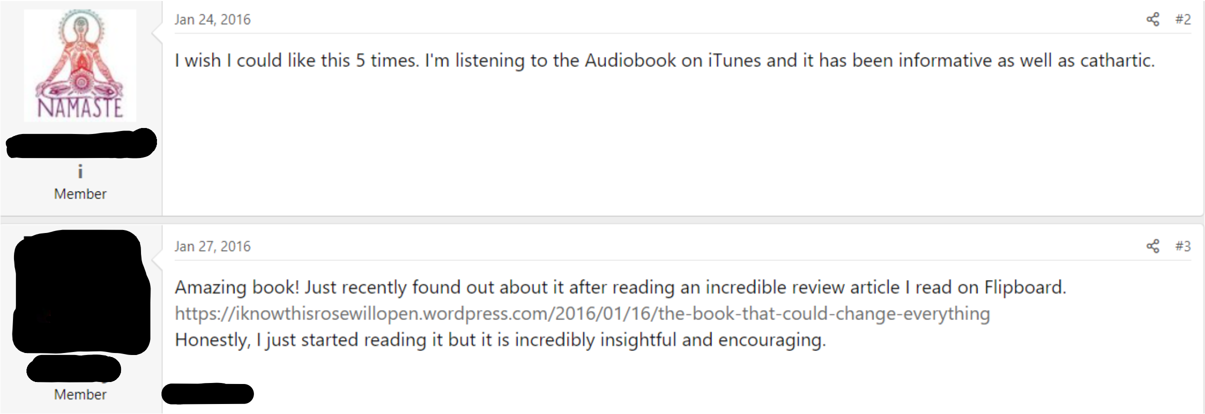
[redacted] submitted a new resource:

NeuroTribes - The Legacy of Autism and the Future of Neurodiversity

> From the Web site's description:
>
> **A groundbreaking book that upends conventional thinking about autism and suggests a broader model for acceptance, understanding, and full participation in society for people who think differently.**
>
> What is autism? A lifelong disability or a naturally occurring form of cognitive difference akin to certain forms of genius? In truth, it is all of these things and more—and the future of our society depends on our understanding it. WIRED reporter Steve...

Read more about this resource...

👍 4



[redacted]

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Member

Jan 24, 2016 #2

I wish I could like this 5 times. I'm listening to the Audiobook on iTunes and it has been informative as well as cathartic.

[redacted]

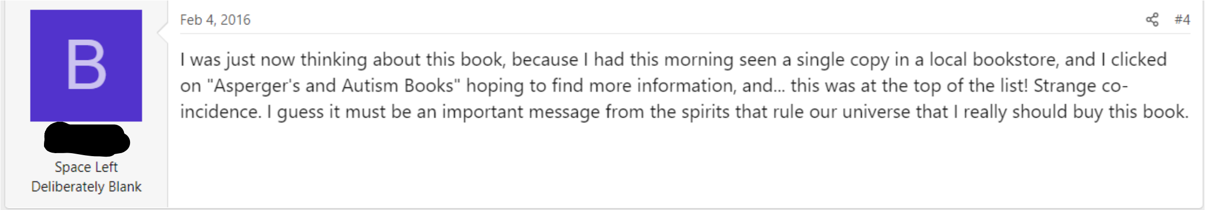
[redacted]

Member

Jan 27, 2016 #3

Amazing book! Just recently found out about it after reading an incredible review article I read on Flipboard.
https://iknowthisrosewillopen.wordpress.com/2016/01/16/the-book-that-could-change-everything
Honestly, I just started reading it but it is incredibly insightful and encouraging.

[redacted]



[redacted]

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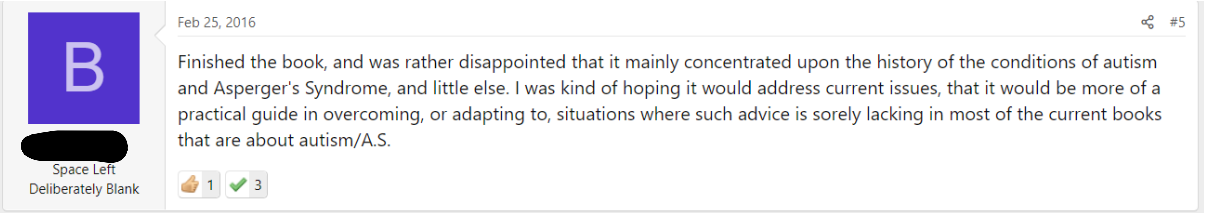
Feb 4, 2016 #4

I was just now thinking about this book, because I had this morning seen a single copy in a local bookstore, and I clicked on "Asperger's and Autism Books" hoping to find more information, and... this was at the top of the list! Strange co-incidence. I guess it must be an important message from the spirits that rule our universe that I really should buy this book.



[redacted]

Space Left Deliberately Blank

Feb 25, 2016 #5

Finished the book, and was rather disappointed that it mainly concentrated upon the history of the conditions of autism and Asperger's Syndrome, and little else. I was kind of hoping it would address current issues, that it would be more of a practical guide in overcoming, or adapting to, situations where such advice is sorely lacking in most of the current books that are about autism/A.S.

👍 1 ✓ 3

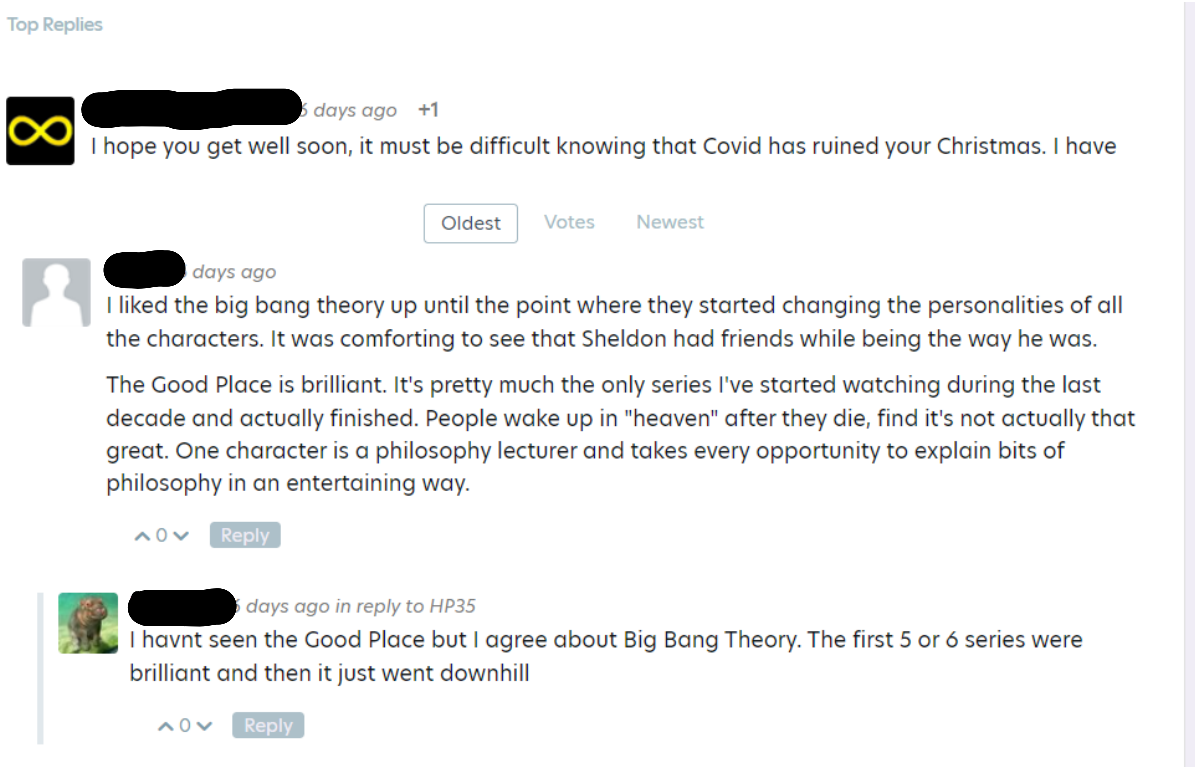
Appendix 6 – NAS example chat thread

Friends and other comfort comedies

[redacted] 6 days ago

So while being ill with covid and tooth infection I have gone through 7 series of Friends on Netflix since Christmas eve. When I was at my most ill having it rolling all day and night was the only thing that would get me through. Especially at night when I couldnt sleep from the pain.

Does anyone else have any comedy shows that are like comfort blankets or safe places to them? Mine are Friends, The Office US, New Girl, How I Met Your Mother



Top Replies

[redacted] 5 days ago +1

I hope you get well soon, it must be difficult knowing that Covid has ruined your Christmas. I have

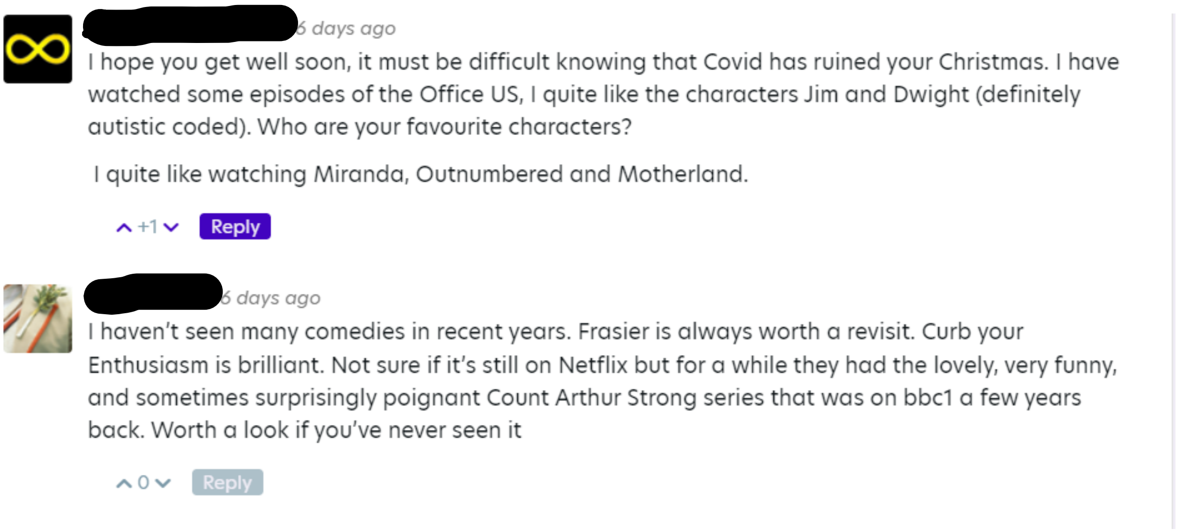
[redacted] days ago

I liked the big bang theory up until the point where they started changing the personalities of all the characters. It was comforting to see that Sheldon had friends while being the way he was.

The Good Place is brilliant. It's pretty much the only series I've started watching during the last decade and actually finished. People wake up in "heaven" after they die, find it's not actually that great. One character is a philosophy lecturer and takes every opportunity to explain bits of philosophy in an entertaining way.

[redacted] 5 days ago in reply to HP35

I havnt seen the Good Place but I agree about Big Bang Theory. The first 5 or 6 series were brilliant and then it just went downhill



[redacted] 6 days ago

I hope you get well soon, it must be difficult knowing that Covid has ruined your Christmas. I have watched some episodes of the Office US, I quite like the characters Jim and Dwight (definitely autistic coded). Who are your favourite characters?

I quite like watching Miranda, Outnumbered and Motherland.

[redacted] 6 days ago

I haven't seen many comedies in recent years. Frasier is always worth a revisit. Curb your Enthusiasm is brilliant. Not sure if it's still on Netflix but for a while they had the lovely, very funny, and sometimes surprisingly poignant Count Arthur Strong series that was on bbc1 a few years back. Worth a look if you've never seen it

Appendix 7 – REC Approval letter

Applicant: Sarah Marsden

Supervisor: Professor E. McDermott; Dr. R. Eastham.

Department: DHR

FHMREC Reference: FHMREC20159

08 July 2021

FHMREC20159
'The Truth Hurts' – An Online Qualitative Study of Self-Harm on the Autism Spectrum

Dear Sarah,

Thank you for submitting your research ethics application for the above project for review by the **Faculty of Health and Medicine Research Ethics Committee (FHMREC)**. The application was recommended for approval by FHMREC, and on behalf of the Chair of the Committee, I can confirm that approval has been granted for this research project.

As principal investigator your responsibilities include:

- ensuring that (where applicable) all the necessary legal and regulatory requirements in order to conduct the research are met, and the necessary licenses and approvals have been obtained;
- reporting any ethics-related issues that occur during the course of the research or arising from the research to the Research Ethics Officer at the email address below (e.g. unforeseen ethical issues, complaints about the conduct of the research, adverse reactions such as extreme distress);
- submitting details of proposed substantive amendments to the protocol to the Research Ethics Officer for approval.

Please contact me if you have any queries or require further information.

Email: fhmresearchsupport@lancaster.ac.uk

Yours sincerely,

T. Morley

Tom Morley,

Research Ethics Officer, Secretary to FHMREC.