Autism: Identity formation and experience of eye-contact

Study 1: Autistic Identity: A Qualitative Synthesis Exploring Autistic Peoples' Perceptions and Understandings of Autism Spectrum Disorder

Study 2: Deliberate and Self-conscious Adaptation of Eye-contact by People with Autism Spectrum Disorder (ASD)

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Declaration

This is to certify that the work I am submitting is my own and has not been submitted for another degree, either at University College Cork or elsewhere. All external references and sources are clearly acknowledged and identified within the contents. I have read and understood the regulations of University College Cork concerning plagiarism.

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Abbreviations and Terminology

ASD	Autism Spectrum Disorders
APA	American Psychiatric Association
DSM	Diagnostic Manual of Psychiatric Diseases
PDD	Pervasive developmental disorders
PDD-NOS	Pervasive developmental disorder- not otherwise specified
ID	Intellectual Disability
ToM	Theory of Mind
WCC	Weak Central Coherence
EF	Executive Function
SPIDER	Sample, Phenomenon of Interest, Design, Evaluation, Research type
CASP	Critical Appraisal Skills Programme
PABAK	Prevalence-adjusted and Bias-adjusted Kappa
TA	Thematic Analysis
IPA	Interpretative Phenomenological Analysis
WEIRD	White, Educated, Industrialized, Rich, Democratic
PICO	Population, Intervention, Comparison, Outcomes
MESH	Medical Subject Headings
EDD	Eye Direction Detector
ToMM	Theory of Mind Mechanism
SAM	Shared Attention Mechanism
PETs	Personal Experiential Themes
GETs	Group Experiential Themes

Chapter 1: Autism Spectrum Disorders- Overview of an evolving concept

Autism spectrum disorders (ASD) represents a diverse spectrum of neurocognitive conditions that include shared characteristics of impaired social interaction, communication, and repetitive behaviours or a narrow range of interests (American Psychiatric Association, 2013). Given the heterogeneous nature of the disorder, it is now recognised that there are some individuals with ASD who are able to lead independent and fulfilling lives, whereas for others, the impact of the condition is severe, and interfering significantly with their quality of life (Elsabbagh et al., 2012).

ASD as a concept has evolved over the years, informed by society's increased understanding of the condition, and its many manifestations. Major changes in the conception of ASD include its progression from a 'pure' to a complex condition, movement from a discrete entity to dimensional characterisation, and a shift from a 'neurodevelopmental disorder' to neurodivergence (Happé & Frith, 2020). Indeed, as our understanding of ASD continues to evolve, there has been a paradigm shift in ASD research towards obtaining an insider informed perspective that comes from autistic people themselves (Fletcher-Watson et al., 2019). Therefore, the following chapter presents an overview of ASD in order to review its progression as a concept across time, and highlights the movement towards qualitative frameworks in ASD research, in order to enable meaningful input from autistic individuals.

Prevalence

A recent systematic review estimated a global prevalence of ASD, that varied greatly within and across socio-economic groups, with a median prevalence of 100/10,000 (Zeidan et al., 2022). While there is no reliable method of estimating ASD prevalence rates in Ireland, a recent report by the Department of Health (2018) compiled data sources and epidemiological studies to estimate the prevalence of ASD in the Irish population. Based on the compiled data, an estimated prevalence rate of 1-1.5% was adopted for the purpose of planning policy and

services. The review also found a significant gender difference in the estimated prevalence rates of ASD across all studies, with males being four times more likely to be identified with ASD when compared to females (Department of Health, 2018). However, a review of gender differences in core symptomatology in ASD concluded that it was unclear to what degree the gender disparity in ASD reflects actual difference in prevalence and/or presentation of the condition, or to what degree the gender disparity is reflective of problems in the current diagnostic system (Rivet & Matson, 2011). For example, key instruments in ASD assessments are standardised on a predominantly male sample, thus suggesting a possible gender bias in diagnostic criteria. Moreover, there is emerging literature on a female ASD phenotype, which postulates that autistic females often display superficial social skills and internalise psychic distress, (Haney, 2016; Rivet & Matson, 2011) as well as evidence to suggest that autistic females display greater levels of social camouflaging when compared to males (Tubío-Fungueiriño et al., 2021).

A brief history of ASD

The term 'autism' was coined by Paul Bleuler, a Swiss psychiatrist, in 1912, to describe a specific symptom observed in patients with schizophrenia who withdrew into their own worlds (Evans, 2013). However, years later, a physician by the name of Leo Kanner (1943) published his seminal article 'Autistic Disturbances of Affective Contact' in the journal '*The Nervous Child'*. In his article, Kanner (1943) described a group of children who displayed an extreme preference for solitude from birth, had a marked need for sameness, repetitive behaviours, persistent interests, a lack of imagination and language difficulties. Based on his observations, Kanner (1943) distinguished autism from 'childhood schizophrenia' (Bender, 1947) into its own diagnostic category 'early infantile autism'.

A year after Kanner's (1943) report, Hans Asperger (1944), published a paper in which he described young boys presenting with similar features to the sample in Kanner's study.

Asperger (1944) used the term 'autistic psychopathy of childhood' to describe the young boys' presentation. His paper received considerable attention after it was published by Una Frith in her book 'Autism and Asperger syndrome' (Frith, 1991).

As psychoanalytic theory was highly influential during the 1940's, core impairments in ASD were explained by the 'refrigerator mother' style of parenting at this time (Lewis & Rudolph, 2014). Although Kanner stated that autism was likely an innate disturbance (Kanner, 1943), based on his observations, he also noted characteristics of his patients' parents, including a 'maternal lack of genuine warmth' (Kanner, 1949 p.422), and 'parents who were reared in emotional refrigerators' (Kanner, 1949, p.423). Following these observations, Bettleheim (1967) erroneously popularized the view that early infantile autism was a result of cold, detached and rigid parents. However, in the 1970's, mounting evidence suggested that this was incorrect, as cognitive and neurobiological approaches indicated that autism had biological underpinnings and was associated with impaired cognition (Hermelin & O'Connor, 1970; Rimland, 1964). As the neurological basis of autism gained interest, researchers began to investigate the genetic basis of the condition. The first twin study of autism was published (Folstein & Rutter, 1977), and the findings indicated a concordance rate of 82% among identical pair twins. While there are methodological critiques of this study, including a small sample size and the possible role of perinatal factors (Joseph, 2018), a recent meta-analysis of twin-studies published in 2016 reported that 74-93% of ASD is heritable (Tick et al., 2016), although non-genetic factors are also significant (Lord et al., 2018).

In the 1970's, Wing and Gould (1979) undertook the 'Camberwell study', in which they observed three areas of impairment that were most commonly identified among autistic children; social interaction, communication, and flexibility of thought or imagination. Following this study, the term 'triad of impairments' was coined, and subsequently became the basis of diagnosis. Wing is also credited with identifying autism as a 'spectrum disorder', rather

than a single entity (Nazeer et al., 2019). In a move from Wing's triad of impairments, the latest edition of the American Psychiatric Association's (APA; 2013) Diagnostic Manual of Psychiatric Diseases (DSM) conceptualises ASD as a dyad of impairments, including social interaction and communication difficulties, and unusually restricted, repetitive behaviours and interests.

ASD across diagnostic and statistical manuals

The first and second editions of the DSM (APA,1952;1968) categorised autism under 'childhood schizophrenia'. However, as research accumulated, there was strong evidence to include autism as a new condition in the DSM-III (APA, 1980), which had adopted an atheoretical research diagnostic criteria approach. Thus, autism was included in the DSM-III under a class of conditions called pervasive developmental disorders (PDD; Volkmar & Reichow, 2013). This included four subcategories; infantile autism, residual autism, childhood-onset pervasive developmental disorder and an atypical form. The edition was revised in 1987 in order to address the lack of developmental orientation. Thus, the DSM-III-R (APA, 1987), broadened the concept of autism by adding a diagnosis at the mild end of the spectrum; pervasive developmental disorder-not otherwise specified (PDD-NOS). The term 'infantile autism' was also replaced with 'autism disorder' to reflect an awareness of the need for a more flexible and developmentally-oriented approach that would be applicable across ages and developmental levels (Rosen et al., 2021). The DSM-III-R's (APA, 1987) criteria set was more extensive, and included a polythetic definition with symptoms chosen from social, communication, and resistance to change categories (Volkmar & Reichow, 2013).

In 1994, the DSM-IV was published, and Asperger's syndrome was included as a distinct subcategory under the umbrella term of PDD. Other distinct categorical subgroups included autistic disorder, childhood disintegrative disorder, and PDD-NOS (APA, 1994). The newest fifth edition of the DSM (DSM-5; APA, 2013) combines these categories into a single

umbrella term ‘Autism Spectrum Disorder’. The DSM-5 also includes levels of severity based on the need for support, thus capturing the ‘spectrum’ nature of the condition (Lord et al., 2018). The DSM-5 (APA, 2013) stipulates that although symptoms should present in early childhood, they may not fully manifest until social demands exceed limited capacities to cope with them. Moreover, the DSM-5 does not consider language delays to be a core feature of ASD, as level of language ability is highly variable in ASD (Grzadzinski et al., 2013). However, a striking feature about autistic language profiles is a universal impairment in pragmatic language (Paul & Norbury, 2012). ASD is frequently accompanied by co-occurring conditions and associated problems, one of which is intellectual disability (ID; APA, 2013). A wide range of intellectual functioning can be observed within this grouping, from individuals who also present with a severe learning disability, to those with average and above average intelligence (Department of Health, 2018).

Theoretical models of ASD

Several cognitive theories have been put forward in an attempt to explain the causes of specific behavioural signs in ASD, and to help develop a deeper understanding of how autistic people may experience the world and respond in the way that they do. Three primary cognitive theories of ASD are outlined below; the theory of mind deficit, weak central coherence, and executive dysfunction.

Theory of Mind

The theory of mind hypothesis (ToM) also known as ‘mindblindness’ and ‘mentalizing failure’, postulates that the social deficits observed in ASD stem from a failure to develop an intact ToM (Fletcher-Watson et al., 2014). ToM refers to the ability to ascribe mental states to oneself or others, and to explain and predict behaviour based on these underlying mental states (Baron-Cohen et al., 2000). This cognitive deficit was first demonstrated using the now classic ‘Sally-Ann’ paradigm, which assessed first-order false-belief ToM tasks (X falsely believes

that z is the case). In their original study, Baron-Cohen et al., (1985) found that almost 80% of a sample of autistic children (mean chronological age 11;11 years; mean verbal mental age 5;5 years) failed the Sally-Ann task, that typically developing children passed by approximately four years of age (Baron-Cohen et al., 1985; Boucher, 2012). In a follow up study, Baron-Cohen (1989) used a 2nd order belief task (X falsely believes that Y falsely believes that z is the case) to assess ToM in the sample of autistic children who had passed the false belief task in the original study. All of the autistic participants (mean chronological age 15;3 years; mean verbal mental age 7.8 years) failed the 2nd order belief task that typically developing children passed by approximately 8 years (Baron-Cohen, 1989; Boucher, 2012). Thus, it was concluded that 'mindblindness' is universal to all individuals on the autism spectrum. Over the next decade, the 'impaired ToM' hypothesis became the dominant focus of research exploring the behavioural precursors of ASD-associated behaviours (Boucher, 2012), and experimental research produced findings to support the claim that autistic individuals performed significantly lower on tasks designed to measure ToM, than typically developing comparison groups (Kimhi, 2014; Mathersul et al., 2013). However, the assertation that all autistic people lack a ToM has been critically disputed, as experimental evidence has demonstrated that many autistic children and adults pass ToM tasks, and therefore, 'mindblindness' cannot be a universal characteristic of ASD (Boucher, 2012; Gernsbacher & Yergeau, 2019; Ozonoff et al., 1991a). To explain these inconsistent findings, it has been reported that high verbal mental age is associated with enhanced ToM performance in autistic individuals, and one interpretation is that verbally able autistic individuals may have 'hacked' out solutions to ToM tasks when given time and structure in experimental settings (Happé, 1995; Jones et al., 2018). However, displaying an explicit ToM in artificial experimental tasks does not necessarily imply an intuitive mentalising capacity (Frith, 2004), and autistic participants have been found to perform significantly lower on implicit ToM tasks when compared to typically developing

comparison groups (Lozier et al., 2014; Schaller & Rauh, 2017; Zhou et al., 2019). Thus, ToM deficits may be more observable in complex, real life social challenges that autistic people face (Frith, 2004).

Weak Central Coherence

Weak central coherence (WCC) theory (Frith, 1989) was put forward to explain the non-social features of ASD, including a restricted repertoire of behaviours, rigidity and perseveration. Non-social features of ASD comprises both strengths and deficits. For example, an uneven pattern of intelligence is commonly observed in autistic individuals with no ID, in which tests examining factual knowledge, rote memory and focused attention to detail can lead to high performance; while tests that assess comprehension, working memory or strategic task planning can be remarkably poor. Central coherence describes an information processing style in which incoming information is processed in its context for higher level meaning (Frith et al., 2003). WCC postulates that autistic individuals tend to process information in a detail-oriented way, at the expense of global meaning (Frith & Happé, 1994). This detail-oriented processing style was evident in early research using visuospatial tasks, as autistic participants demonstrated superiority at disembedding (Shah & Frith, 1983), and a reduced inversion effect in face processing (Langdell, 1978). However, over time, research has produced negative and mixed results for the WCC theory (Rajendran & Mitchell, 2007). Thus, in response to empirical findings, the WCC hypothesis has evolved over time. For example, the conception of WCC as a global processing deficit has been reconceptualised as superior local processing. Furthermore, WCC is considered a processing bias, rather than a deficit. In this way, autistic individuals may be biased to attend to detail, but with effort, have the ability to extract overall meaning (Rajendran & Mitchell, 2007). Finally, the WCC theory is viewed as one part of cognition in ASD, rather than explaining all aspects of ASD (Happé & Frith, 2006).

Executive Function

Executive function (EF) is an umbrella term for a wide range of functions such as planning, impulse control, working memory, initiation and monitoring of action, cognitive flexibility, and the ability to sustain attention (Frith et al., 2003). The EF hypothesis was proposed as a theory to explain the repetitive behaviours and restricted interests observed in ASD, as a result of primary impairment in executive control (Hill, 2004). Difficulties in EF tasks have been demonstrated consistently among autistic participants across the lifespan (Hughes et al., 1994; Ozonoff et al., 1991b; Pellicano, 2012); however, given that some autistic participants do not present with these difficulties (Liss et al., 2001; Pellicano, 2010, 2012), a view has emerged in which the underlying cause of ASD is understood to encompass multiple cognitive atypicalities, rather than a single explanation for symptoms associated with ASD (Happé et al., 2006).

Models of disability

Different models of disability assume different interpretations of disability (Padilla-Petry & Saladrigas-Tuà, 2020) and ASD is commonly understood within medical and social models of disability.

The medical model of disability is currently the dominant model in autism studies (Woods, 2017), and aspires towards normalisation, and symptom reduction based on deficits assumed to cause functional impairment in major life activities (Kapp et al., 2012). As there are no reliable biomarkers of ASD (Lord et al., 2018), the DSM-5 (APA, 2013) sets forth the behavioural criteria necessary for receiving an ASD diagnosis, which primarily focuses on deficits on the basis of behavioural deviations from average. Thus, the medical model fails to acknowledge advantageous behaviours, the reasons behind behaviours, and society's role in establishing behaviours (Kapp et al., 2012).

In recent years, there has been a shift from a medical model towards a social model of disability (Happé & Frith, 2020; Shakespeare, 2016). The social model of disability posits that individuals with disabilities may be disadvantaged not only because of their own differences and challenges, but additionally because of societal structures, such as lack of accommodation, systemic barriers, and negative attitudes, that impeded optional functioning (Oliver, 1990; Sasson et al., 2017). Stemming from the social model of disability, is the neurodiversity approach, which understands ASD as a difference ('neurodivergence') that constitutes a disability in the context of the demands of a non-autistic world (Happé & Frith, 2020). From this perspective, 'curing' ASD itself is no longer acceptable. However, some believe that the neurodiversity movement is not appropriate for those with significant intellectual impairments and those who are minimally verbal (Happé & Frith, 2020). However, it has been emphasised that a neurodiversity stance does not preclude providing support to those in need, and does not deny the real challenges that autistic people face. Indeed, ASD is often accompanied by behavioural features, mental health difficulties, medical conditions, and ID. From a neurodiversity perspective, these issues are worthy of targeted support, but should not stigmatise ASD, or threaten its position as a difference rather than a deficit (Fletcher-Watson & Happé, 2019; Happé & Frith, 2020).

More recently, a 'predicament' model of ASD has been proposed to encompass the diverse autistic experience. From this perspective, ASD is reframed as an 'individualised' and 'highly variable' predicament, rather than a spectrum of low to high functioning (Anderson-Chavarria, 2021).

Cumulatively, it is evident from this review that ASD is transforming as a concept over time, and within this transformation, autistic individuals have, and continue to, adapt to new understandings and frameworks of ASD, as it relates to their identity. As such, there is increasing interest in gaining insights about the lived experience of being autistic, in order to

further our understanding and knowledge about ASD. In the context of ASD research and practice, the neurodiversity movement advocates for researchers to work closely with autistic people and their families to deliver research that matters to them (Fletcher-Watson & Happé, 2019).

'Nothing about us, without us': Including the voice of autistic people in autism research

In recent years, there has been an exponential rise in the amount of ASD research being undertaken (Milton, 2019). While earlier ASD research largely focused on the underlying biology and causes of ASD (Pellicano et al., 2014), there has been a call for a paradigm shift in how researchers approach ASD, to include research that will have an immediate and direct impact on autistic people and their families. This new era of ASD research has been characterised by increased participatory research methods, in which the voices of autistic people are included at all stages of the research process (Pellicano et al., 2018). It is asserted that autistic peoples' insights are crucial in understanding the many nuances associated with ASD, and for researchers to have access into autistic ways of thinking (Bertilsdotter Rosqvist et al., 2019; MacLeod et al., 2014).

Despite the need for increased participatory research, there is a tendency for researchers to neglect the specific expertise of autistic individuals. This is exacerbated by the widespread notion that autistic people lack the socialisation skills required for effective communication (Milton, 2014), as well as deficits in ToM and a lack of self-insight (Frith & Happé, 1999). However, it has been argued that this deficit in social insight is socially and biologically derived, while also being situated in social discourse, both culturally and historically (Milton, 2012). For example, the 'double empathy problem' asserts that communication difficulties between autistic and non-autistic individuals are due to bi-directional differences in communication style, and a reciprocal lack of understanding (Crompton et al., 2020b; Milton,

2012). In this sense, it is a 'double problem' because both people experience it as a problem, rather than a specific deficit on behalf of the autistic person (Milton, 2012). Indeed, there is a body of research evidence to suggest that non-autistic people contribute to interaction difficulties between autistic and non-autistic people (Crompton, et al., 2020a; Crompton et al., 2020b; Edey et al., 2016; Keating & Cook, 2020; Sasson et al., 2017). In response to this problem, autistic people often hide or camouflage their autistic traits and behaviours in an attempt to emulate the social interactional behaviours and style of neurotypicals (Hull et al., 2019; Mitchell et al., 2021), which can have negative implications for autistic peoples' mental health and well-being (Cassidy et al., 2020).

Autistic individuals have reported their experience of a lack of understanding about ASD from the general population (Griffith et al., 2011; Jones et al., 2013), and research has provided evidence to suggest that non-autistic people often misunderstand the behaviour of autistic individuals (Kapp et al., 2019; Sheppard et al., 2016). As an example, a recent online survey study assessed autism knowledge and stigma among autistic and non-autistic participants. In comparison to non-autistic participants, autistic participants exhibited more scientifically based knowledge, tended to describe autism experientially or as a difference, rather than deficit, and exhibited more knowledge about the internal and lived experience of ASD. Thus, the authors concluded that autistic people should be considered 'autistic experts' based on their lived experience (Gillespie-Lynch et al., 2017).

The research community has a great deal to learn from self-reported experiences of autistic individuals (Trevisan et al., 2017). Indeed, qualitative approaches can be employed to explore less known or underexplored topics or phenomenon to help generate unexpected knowledge (Tuffour, 2017). It has been suggested that ASD can significantly influence the construction of ones' identity (Moore et al., 2022). Given that ASD is a complex condition that has transformed as a concept over time, and manifests differently within different people

(MacLeod et al., 2013), there is a need to understand autistic identity through exploration of autistic peoples' understandings and perceptions of ASD. Furthermore, given the evidence to suggest that non-autistic people often misunderstand the behaviour of autistic individuals (Sheppard et al., 2016), there is also a need to gain insight into autistic peoples' experiences of particular behaviours that likely contribute to their socio-communication challenges (Kapp et al., 2019). The presence of atypical eye gaze is one of the most used diagnostic criteria for ASD from early infancy (Cañigueral & Hamilton, 2019; Zwaigenbaum et al., 2005). Therefore, in order to foreground the accounts of autistic people as experts on their own lives, the current thesis adopts a qualitative framework to explore the lived experience of being autistic. The thesis comprises two research papers. The first research paper is a systematic review of qualitative studies exploring how autistic people understand and perceive ASD, in order to inform autistic identity. The second research paper is an original empirical study exploring how autistic people experience eye-contact using an Interpretative Phenomenological Analysis (IPA) methodology.

Outline of Chapters

Chapter Two: Systematic Review

This chapter presents a systematic review on 'Autistic Identity: A Thematic Synthesis Exploring Autistic Peoples' Perceptions and Understandings of Autism Spectrum Disorder'. The review is written in the format of a journal article for '*Autism'*.

Chapter Three: Systematic Review: Extended Methodology

Information pertaining to the systematic review process is included in this chapter. This includes information related to the development of the review question, search strategy, and eligibility criteria. Additional information pertaining to the process of data extraction and synthesis is also included here.

Chapter Four: Major Research Project- Literature Review

This chapter presents a review of the literature on eye gaze in typical and atypical development. Rationale for the current research is also outlined.

Chapter Five: Major Research Project

In this chapter, the empirical paper explores the deliberate and self-conscious adaptation of eye-contact by autistic people. The paper is written in the format of a journal article for '*Autism'*.

Chapter Six: Supplementary Information for Major Research Project

In this chapter, additional information relating to the methodology of the major research project is presented. This included a detailed description of the Interpretative Phenomenological Analysis (IPA) process, information on sampling and recruitment, further information about data collection and analysis procedures, quality assurance procedures, researcher reflexivity, and the impact of COVID-19 on the research process.

Chapter Seven: Discussion and Conclusion

This chapter summarises the findings of the systematic review and the major research project, and discusses the limitations, clinical implications, and original contribution of the research findings.

Appendices

Appendices pertaining to the systematic review and major research project are presented in this section.

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Chapter Two: Systematic Review

Autistic Identity: A Thematic Synthesis Exploring Autistic Peoples' Perceptions and Understandings of Autism Spectrum Disorder

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This article is in the process of being formatted for the journal 'Autism'. The word limit for this journal is 6,000 words, including all elements (title page, abstract [200 words maximum], notes, tables, text), but excluding references. Publication guidelines for this journal can be found in Appendix A.

I declare that the content of this assignment is all my own work. It has not been submitted in respect of any other course/module. Where I have used the work of others it is acknowledged and referenced accordingly.

Abstract

'Autistic identity' describes a complex aspect of the experience of being autistic. The purpose of this systematic review was to explore autistic identity; through consideration of qualitative research on autistic peoples' perceptions and understandings of ASD. Thematic synthesis yielded four over-arching themes encapsulating understandings and perceptions of ASD that may inform autistic identity - terminology, being different, self-understanding, and autistic people as experts by experience. Findings may inform service planning and provision for individuals with an ASD diagnosis, thus promoting mental health and well-being in the context of their autistic identity.

Lay Abstract

There is evidence to suggest that an individual's identification with ASD can have mental health implications. Given the heterogenous nature of the condition, the purpose of this systematic review was to explore autistic identity, by integrating qualitative research on autistic people's perceptions and understandings of ASD. Themes identified included terminology, being different, self-understanding, and autistic people as experts by experience. The findings of this systematic review may inform mental health and well-being interventions for the autism community.

Keywords: autism spectrum disorder, identity, understanding, perspectives, systematic review, thematic synthesis

Autistic Identity: A Thematic Synthesis Exploring Autistic Peoples' Perceptions and Understandings of Autism Spectrum Disorder

Introduction

Autism Spectrum Disorder (ASD) describes a range of developmental disorders that primarily influence an individual's social functioning (Gates et al., 2017). Receiving an ASD diagnosis can cause an individual to reflect on their sense of self, and for some, adopt this label as an identity (Smith & Jones, 2020). 'Autistic identity' is a term used to describe a complex aspect of the experience of being autistic (Riccio, 2020). Autism is a stigmatised diagnosis and there is evidence to suggest that autistic identity and belonging to an autistic community is protective against that stigma. For example, cross-sectional research among autistic (n=272) and non-autistic (n=267) participants found that autistic individuals who did not strongly identify with other autistic people presented with lower self-esteem and higher levels of depression and anxiety than did the typically developing comparison group, while having high social identification with other autistic group members was protective against poor mental health (Cooper et al., 2017).

ASD has been described as an 'invisible disability' in that associated traits may not be discernible to others (Large & Serrano, 2018, p.1); despite this, autistic people often report a sense of being different (Lilley et al., 2021). Thus, many employ social camouflaging to make their autistic traits less visible. On the one hand, camouflaging has been linked to identity confusion and adverse effects on mental health (Cage et al., 2018; Cage & Troxell-Whitman, 2019; Hull et al., 2017). Conversely, autistic people who viewed ASD as a positive aspect of their identity expressed pride about being autistic (Jones et al., 2015; Mogensen & Mason, 2015). Given this diversity of responses to the experience of managing autistic traits in social settings, there is strong argument for further exploration of the factors influencing autistic identity.

Discourse about ASD in sociocultural contexts is another factor likely influencing autistic identity (Brownlow, 2010), with frameworks for understanding ASD shifting over time (Botha et al., 2020). The two primary representations of ASD that are predominant in the literature are that of the medical model of disability, and the neurodiversity paradigm (Angulo-Jiménez & DeThorne, 2019). The medical model of disability proposes that ASD is a neurological disorder, and therefore focuses intervention on the amelioration of autistic traits (Angulo-Jiménez & DeThorne, 2019; Mesa & Hamilton, 2021). However, some individuals may identify with ASD labels, but reject the notion of disability (Jones et al., 2015). Conversely, the neurodiversity paradigm portrays ASD as a neurological difference, in which ASD is a normal human variation that should be accommodated by an informed society (Angulo-Jiménez & DeThorne, 2019; Gobbo & Shmulsky, 2016) rather than treated. There is evidence that autistic people adopt a complex hybrid representation of autism, which integrates aspects of both discourses (Angulo-Jiménez & DeThorne, 2019). In addition to divergent frameworks for understanding ASD, descriptions and terms for the condition have changed over time, mostly in relation to person-first or identity-first language (Bury et al., 2020). Therefore, developing an autistic identity involves navigating these various, and often competing discourses (Mesa & Hamilton, 2021).

Current Review

Understanding more about the heterogenous experience of autistic identity could help inform mental health and well-being interventions for the autism community (Mesa & Hamilton, 2021). Qualitative research is particularly suited to this task, as it provides a richer perspective into the lived experience of participants (van Schalkwyk & Dewinter, 2020), and importantly, can reflect the diverse range of first-hand experiences. A synthesis of the existing qualitative literature aims to produce a ‘systematic logic’ in which diverse findings from a specific topic are drawn together and integrated systemically to produce more transferable and

reliable knowledge claims (Williams et al., 2019). Thus, the aim of the following study is to develop a better understanding of autistic identity by systematically searching for and reviewing qualitative research on autistic people's perceptions and understandings of ASD.

Methodology

A protocol for this review was registered with the PROSPERO database for systematic reviews (CRD42021264995). This systematic review was conducted in accordance with the PRISMA guidelines (Moher et al., 2009).

Eligibility Criteria

The *SPIDER* (Sample, Phenomenon of Interest, Design, Evaluation, Research Type) framework (Cooke et al., 2012) was used to develop eligibility criteria (Table 2.1) and as a means of informing and standardising the search strategy.

Table 2.1

Inclusion and Exclusion Criteria

	Inclusion Criteria	**Exclusion Criteria**
Sample	Adolescents (12 years +) and adults with a formal diagnosis of ASD and no intellectual disability (IQ<70). Data from first person perspective and not communicated by a third party.	Participants who self-identify as autistic, and where formal diagnosis is not confirmed.
Phenomenon	Qualitative papers where the primary aim of the study is to explore autistic adolescents'/adults' perceptions and understandings of ASD.	Papers not primarily addressing participants' perceptions and understandings of ASD.
Evaluation	Qualitative work that includes perceptions/ understandings/ descriptions/ views/ perspectives/ attitudes reflecting autistic peoples' perceptions and understandings of ASD.	Papers where themes/ findings combine quotes from mixed samples (e.g. parents, professionals, participants' with an ID). Papers that narrowly focus on the perception/ understanding or experience of being autistic in particular environments/ contexts e.g. school, relationships, LGBT, focus on female autistic phenotype, classification changes in DSM-5.
Design/ Research Type	Peer-reviewed primary qualitative data collection and analysis (including qualitative elements of mixed-methods studies if qualitative data are presented separately from quantitative results). English language.	Quantitative studies. Theses Non-empirical studies (book chapters, literature/book review, theoretical paper, commentaries or opinion piece, single case study, or autobiographies).

Search Strategy

The search strategy included keywords (Autis* OR ASD OR Asperger* OR 'Pervasive Developmental Disorder' AND Identit* OR 'Self*Concept' OR 'Self*Perception' OR Label* OR Insider* AND Perception* OR perspective* OR understand* OR view* OR feel* OR opinion* OR insight* OR belief* OR comprehen* OR experience* OR attitude* OR mean* OR narrative* OR interpretation* AND Qualitative OR Mixed Method* OR Interview* OR 'semi structured interview*' OR survey OR 'open*ended' OR 'open ended' OR 'semi-structured interview*' OR 'unstructured interview*' OR 'focus group*' OR 'thematic analysis' OR IPA OR 'interpretative phenomenological analysis' OR 'Grounded Theory' OR ethnograph*) with subject headings adapted and included for each database (Appendix B). Search terms were developed through consultation with the research supervisor, a subject librarian at University College Cork, a member of the autistic community as an expert by experience, and keywords from an initial scoping search. The following databases were searched for published literature on 29th October 2021; PsycINFO, CINAHL, MEDLINE, Web of Science and ERIC. Articles were filtered to include journal articles and those using the English language. Literature was also identified through the first 200 hits by relevance on Google Scholar (Haddaway et al., 2015) and forward and backward reference searching.

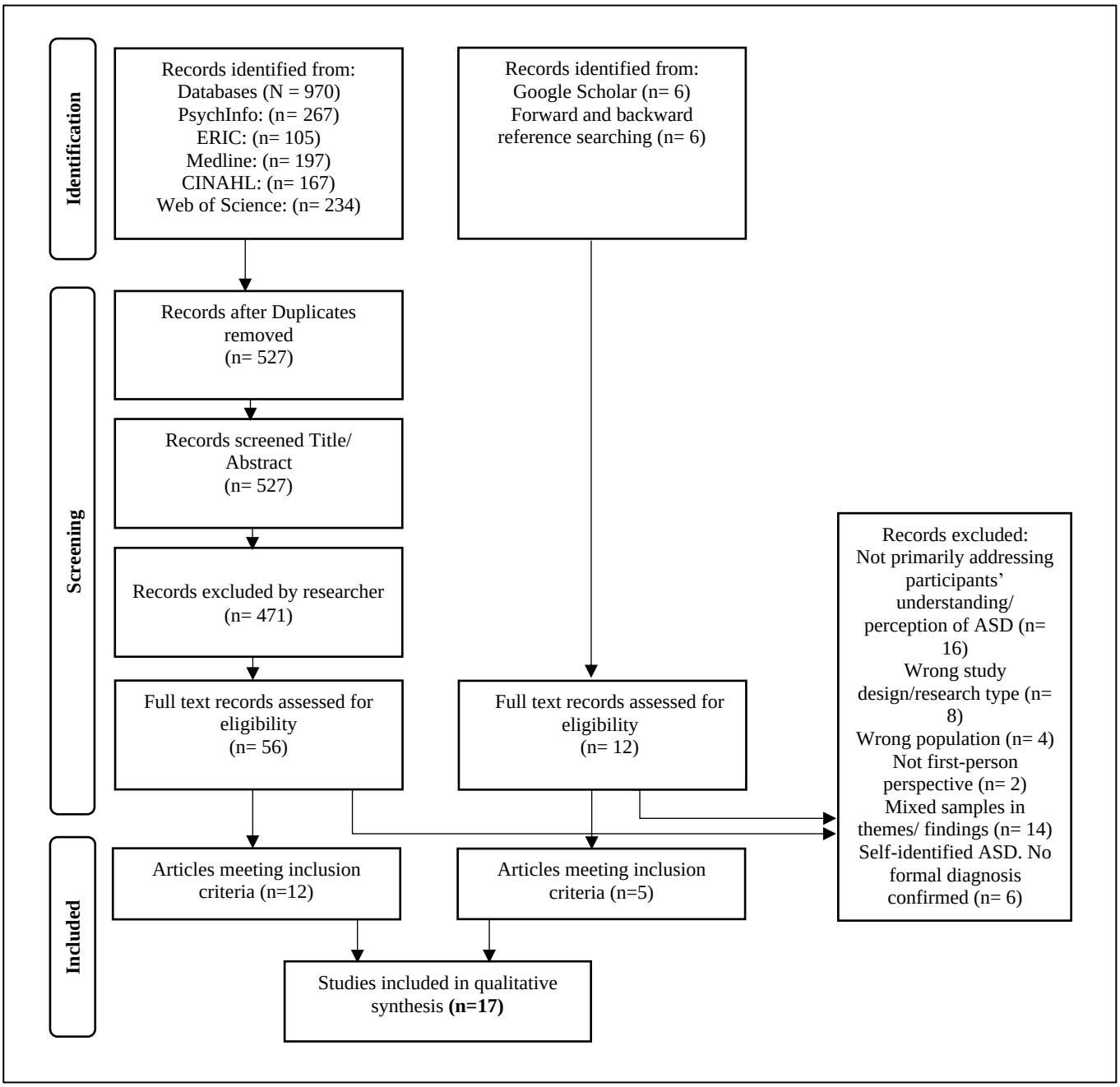
Data Screening

A total of 970 papers were identified through database searching. Following the removal of duplicates, 527 papers remained for title and abstract screening. A two-stage screening process was conducted to determine inclusion/ exclusion of identified studies. At stage one, the first author independently screened all titles and abstracts, and the third author independently rated more than 10% of titles and abstracts (n=60). There was substantial agreement between reviewers at this stage of the screening process (93.3%; Cohen's Kappa=0.79).

At stage two, a full text version of each paper was assessed independently against the inclusion/exclusion criteria by the first author. The third author independently screened over 10% of all full texts (n=8). There was substantial agreement between reviewers at this stage (87.5%; Cohen's Kappa= 0.80). At each stage of the screening process, discrepancies between reviewers were discussed and resolved by consensus. Papers identified through Google search and reference searching were screened by the first author, and any uncertainty was resolved through discussion with the second author. The full search strategy using PRISMA guidelines is outlined in Figure 2.1. Seventeen studies were deemed eligible for inclusion.

Figure 2.1

PRISMA Flow Chart



Data extraction

A data extraction tool was compiled based on the research question, and through consulting qualitative systematic review papers (Eccleston et al., 2019; Ringer, 2020; Williams et al., 2019). Extracted information included; author(s), year of publication, location, study aim(s), total sample, sample characteristics, recruitment, data collection method, data analysis

approach, overarching themes/ findings. Specific data on socioeconomic status and educational attainment levels were not recorded.

Quality appraisal of included studies

Quality assessment was conducted using the appropriate tool for each research design (Nearchou et al., 2020; Appendix C). Qualitative studies were evaluated along 10 dimensions of research quality using the Critical Appraisal Skills Programme (CASP; CASP International Network, 2019). A score of 0 was given where the criterion was not met, 0.5 when it was partly met, and 1 where it was definitely met. Summed scores were assigned a quality classification from A-C, with 'A' denoting high quality work, 'B' for moderate quality, and 'C' denoting low quality studies (Fox et al., 2017).

Mixed-method studies were evaluated using the Mixed Methods Appraisal Tool (MMAT; 2018), which assesses the integration of qualitative and quantitative components (Huang et al., 2020). An overall quality score was presented using a five star system, where 5 stars indicated that 100% of the criteria were met (Hong et al., 2018).

The first author appraised all included articles. The third author independently reviewed a 10% sample of studies. Given the small number of mixed-method papers, no inter-rater reliability was calculated for the MMAT. The probability percent agreement between raters using the CASP tool was 95%. Given the high prevalence rate of positive scores on the CASP tool, inter-rater agreement was assessed using the Prevalence-adjusted bias-adjusted Kappa (PABAK)= 0.9. This statistic was calculated as the high quality of papers increased the rate of agreement between raters.

Data synthesis

Thematic synthesis is a commonly applied method within systematic reviews that addresses peoples' perceptions and experiences, with the aim of generating higher order themes and key messages (Thomas & Harden, 2008). Entire results or findings sections of included

papers were extracted. Thematic synthesis includes three stages; line-by-line coding, the generation of descriptive themes, and the development of analytical themes (Long et al., 2020). Articles were inductively coded using QSR NVivo (released in March 2020). The primary researcher independently coded each line of text according to its meaning and content. Descriptive themes were subsequently generated through 'translation' of concepts from one study into another, and a hierarchical structure was developed by grouping codes based on similarities and differences. New codes were created in order to encapsulate the meaning of groups of initial codes (Barnett-Page & Thomas, 2009; Thomas & Harden, 2008). Finally, descriptive themes that emerged from the inductive analysis were grouped into broader analytical themes.

Results

Description of included studies

Extracted data is presented in Table 2.2. Data from 583 participants were included in the review. Three papers drew from the same sample and so participants for these studies were counted once (Huws & Jones, 2015, 2008; Jones et al., 2013). Participants' ages ranged from 12 to 72 years. Just over half the sample were female (58.5%), which is a relatively high proportion compared with diagnostic rates of ASD in the population (Elsabbagh et al., 2012). Papers were published between 2002 and 2021. The majority were based in the United Kingdom (58.82%), followed by the United States (23.53%), and Australia (11.76%), and Sweden (5.88%). Semi-structured individual interviews were the most common method of data collection, which included oral or written responses (60%). Thematic analysis (35.29%) and variants of phenomenological analysis (29.41%) were the most common methods of data analysis.

Quality appraisal results

An overall moderate to high standard of qualitative articles was indicated by the CASP tool.

Mixed-method articles received a 4-star rating using the MMAT, indicating that 80% of the quality criteria were met .

Table 2.2

Data Extraction Table

Author(s), Year (Location)	Study Aim(s)	Total sample (N)	Sample characteristics (Gender, age)	Recruitment	Data Collection Method	Data analysis approach	Overarching Themes/ Findings	CASP / MMAT rating
Bertilsdotter Rosqvist, 2012 (Sweden)	To explore production of counter-hegemonic discourse of autistic normalcy among adults with high-functioning autism by analysing concepts of diagnosis.	12	Female (n=9) Male (n=3) Age: 20-50 (n = 10)	High school providing educational programmes for autistic adults.	Ethnography. Group interviews; field notes	Discursive psychological perspective	• Receiving the diagnosis • An ambivalent ideal of openness • Contesting holders of knowledge • Contesting the diagnostic criteria	A
Bury et al., 2020 (Australia)	To investigate autistic term preferences among autistic adults.	191 (responses to open-ended text)	Female= (67.2%)* Male = (31.3%) Age:18-71	Convenience sampling via universities, autism bodies, community groups, employers.	Online mixed methods survey design	Thematic Analysis (TA)	• Being autistic is core to my identity • Having autism is part of my identity • Diversity within the spectrum • I am different not disordered • Language can stereotype and stigmatise	****

							• Pragmatic: Terminology that serves a specific purpose	
Cooper et al., 2021 (United Kingdom)	To explore the attributes that autistic people perceive as positively and negatively impacting on their identity and well-being.	15	Female (n=5) Male (n=9) 'Other' (n=1) Mean age (students): 18.67 Mean age (community group): 35.5	University transition programme for autistic students; Community social group for autistic adults.	Focus groups; mixed methods study	TA	• Challenges due to autism • Diversity and adaptation • Navigating difference • Positive autism identity	****
Corden et al., 2021 (United Kingdom)	To examine aspects of personal identity for autistic adults diagnosed in adulthood.	54 (responded to open ended question)	Female (n=117) Male (n= 30) Non-binary/ Transgender (n= 4) Age: 18-25	Online using snowball sampling, including adverts on social media, relevant autism groups, organisations and charities.	Online mixed methods survey design	Content analysis	• Adjustment process • Self-exploration • Learning and support needs • Responses from others • Autism as positive difference • Challenges of the diagnosis	****
Lewis, 2016 (USA)	To explore the experience of realising a diagnosis of ASD in adulthood.	77	Female (n=32) Male (n=40) Other (n=4) Age:18-65	Online message boards, forums; Support groups for individuals with ASD.	Online open-ended survey design	Colaizzi's (1978) descriptive phenomenological method	• I always knew I was different • Riding the emotional roller coaster • Striving for self-acceptance • Strategizing towards a better life	A

							• Maintaining normalcy • Wandering into the future	
Hickey et al., 2018 (United Kingdom)	To explore the lived experience of ASD in later adulthood, what ASD had meant for individuals' lives, and perceptions regarding the helpfulness of diagnosis.	13	Female (n=3) Male (n=10) Age: 51-71	Adult autism diagnostic service; autism support and social groups.	Semi-structured interview	TA	• Difference • Life Review • Longing for connection	A
Hurlbutt & Chalmers, 2002 (USA)	To investigate the perceptions of adults with high-functioning autism.	3	Female (n=1) Male (n=2) Age: 31-61	Voluntary participation via autism conference.	Interviews; published and unpublished material written by participants	Open-coding procedure	• 'High functioning' adults with autism identify with their own unique culture • Support systems contributed to their feelings of self-worth • Strong opinions about what could make a difference in the lives of people with autism	B

							• 'High functioning' adults with autism want to be considered experts on, have opinions on, and be consulted on issues related to autism	
Huws & Jones, 2008 (United Kingdom)	To explore autistic young people's perceptions of autism and diagnosis experiences.	9	Female (n=3) Male (n=6) Age: 16-21	Specialist college for young people with ASD.	Semi-structured interview	Interpretative Phenomenological Analysis (IPA)	• Disclosure delay • Providing explanations • Potential effects of labelling • Disruptions and opportunities • Acceptance and avoidance	A
Huws & Jones, 2015 (United Kingdom)	To explore autistic young people's perceptions of autism, and their experiences of social comparisons.	9	Female (n= 3) Male (n= 6) Age: 16-21	Specialist college for young people with autism.	Semi-structured interview	IPA	• Changes over time: 'I'm really glad this is developmental' • Degrees of autism: 'They've got it really bad' • Degrees of ability: 'I'm not really disabled-disabled'	A

Jones et al., 2013 (United Kingdom)	To explore how people with ASD view the concept of autism and how they view society's reactions to ASD.	9	Female (n=3) Male (n=6) Age: 16-21	Specialist college for young people with ASD.	Semi-structured interview	IPA; Credibility check by autistic person	• The insider experience of autism • The outsider experience of autism	A
Jones et al., 2015 (USA)	To understand how adolescents with ASD identify with and make meaning of their diagnosis by examining how they construct narratives regarding their diagnosis.	10	Female (n=2) Male (n=8) Age:13-20	Non-profit agencies serving individuals with ASD and their families.	Semi-structured interview	Colaizzi's (1978) descriptive phenomenological method	• Formation of an ASD narrative • Social construction of the label • Confusion on whether ASD is a disability	A
Lilley et al., 2021 (Australia)	To explore the lived experience of autistic adults diagnosed in mid-late adulthood.	26	Female (n=14) Male (n=10) Non-binary (n=1) Prefer not to say (n=1) Age: 45-72	Convenience sampling with snowballing methods including social media campaign, video and flyer.	Oral history methodology, including semi-structured interviews or written communication	TA	• Being different • Exploring Identity • The suffering self • Being Autistic	A
MacLeod et al., 2013 (United Kingdom)	To explore how autistic students made meaning of	6	No sample characteristics identified	Self-selected sample of students from higher	Semi-structured interview	IPA	• Perceptions of others diagnosed with	B

	their Autism label.			education institution.			Asperger syndrome (AS) • Acquired knowledge of AS • Personal identifications with AS	
Punshon et al., 2009 (United Kingdom)	To examine the experiences of adults receiving ASD diagnosis.	10	Female (n=3) Male (n=7) Age: 22-45	Convenience sample at local service for adults with AS.	Semi-structured interview	IPA	• Negative life experiences • Experiences of services • Beliefs about symptoms of AS • Identity formation • Effects of diagnosis on beliefs • Effect of societal views of AS	A
Stagg & Belcher, 2019 (United Kingdom)	To explore the lived experience of older adults receiving an ASD diagnosis in later life and how they experienced their diagnosis.	9	Female (n=5) Male (n=4) Age: 52-54	Online ASD forums; Blog posts.	Individual interviews using free-associative narrative interview technique.	TA	• Early signs of ASC • Awareness of being different • Receiving a diagnosis • The usefulness of a diagnosis • Support and coping	A
Tan, 2018 (USA)	To describe the experiences of autistic adults	37	Female (n=16) Male (n=14)	Observations; Organization's email list;	Observation field notes, memos, semi-	Grounded theory approach	• Reinterpretation of self and identity	A

	who learned of the ASD diagnosis during teen years or adulthood, using biographical illumination.		Other (n=7) Age: 22-65	Snowball referrals.	structured interview.		• Adjustments to expectations of adaptation and intervention • ASD community entry and membership	
Winstone et al., 2014 (United Kingdom)	To explore the self-identity of autistic young people, through the use of an activity-oriented interviewing technique.	13	Male (n=13) Age: 12-14	School for special educational needs.	Standard interview and activity-oriented interview.	TA	• Self-perception and self-awareness • Description of the future self • Perception of self as a person with autism • Comparison of self to others	B

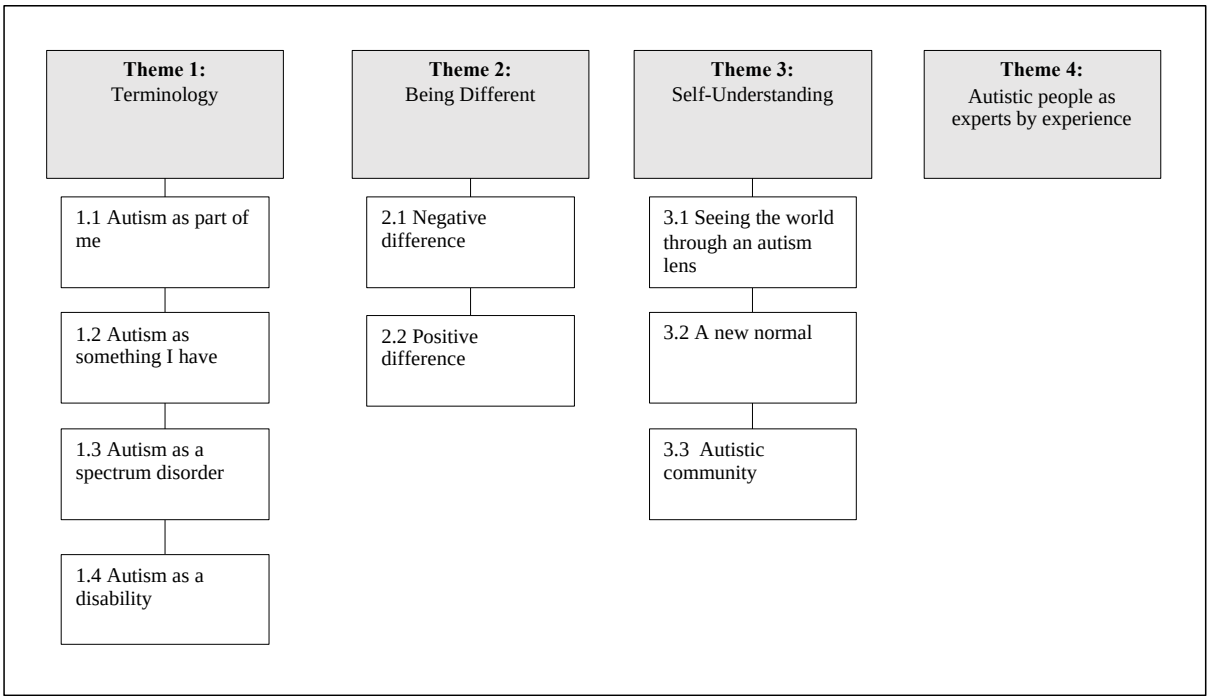
Note: *Bury et al., (2020) did not report gender ratio for open-ended text . Percentages represent overall sample who completed the survey.

Thematic Synthesis

Analysis of the synthesised findings identified four overarching themes and eight subthemes reflecting autistic peoples' understanding and perceptions of ASD (See Figure 2.2). Illustrative quotations for each theme are presented in Appendix D.

Figure 2.2

Themes and subthemes



Theme 1: Terminology

1.1 Autism as part of me. Some participants described ASD as an 'integral part' of the person (Bury et al., 2020), and a defining aspect of who they are (Bertilsdotter Rosqvist, 2012; Huws & Jones, 2015; Tan, 2018). From this perspective, autism could not be separated from the individual, as it was 'intertwined', and part of their 'identity' (Bury et al., 2020). Thus, some participants understood ASD to be part of their physical make-up (Tan, 2018), and spoke with pride about being autistic (Bertilsdotter Rosqvist, 2012; Bury et al., 2020; Corden et al., 2021; Huws & Jones, 2015; MacLeod et al., 2013).

1.2 Autism as something I have. Conversely, some participants understood ASD as a medical condition that they 'suffer from' (MacLeod et al., 2013), and was separate to who they are as individuals (Bury et al., 2020; Corden et al., 2021; Hickey et al., 2018; Lewis, 2016; MacLeod et al., 2013). Person first terminology, such as 'person with autism' was preferred, as it defined the person first, and autism second (Bury et al., 2020). Externalising language such as the term 'condition' was particularly helpful for adults diagnosed later in life, as they could consider ASD a behavioural feature that was separate to their true selves (Hickey et al., 2018).

1.3 Autism as a spectrum disorder. Many emphasised the importance of the autism spectrum in recognising ASD as a 'diverse and disparate diagnosis' (Lilley et al., 2021). From this perspective, ASD affects different people in different ways (Bury et al., 2020; Cooper et al., 2021; Hickey et al., 2018; Huws & Jones, 2015; Jones et al., 2013; Lilley et al., 2021; MacLeod et al., 2013). Participants recognised that autistic features can be impacted by factors, such as age, environmental factors, or time since diagnosis (Cooper et al., 2021). Furthermore, several statements indicated that participants engaged in social comparison with other autistic people, with the aim of understanding where they 'fit' on the 'autistic hierarchy' of mild to severe forms of ASD (Hickey et al., 2018; Huws & Jones, 2015; Macleod et al., 2013).

1.4 Autism as a disability. While some recognised ASD as a type of disability (Huws & Jones, 2015), many were 'not comfortable with disability' (Lilley et al., 2021) as they felt that the term did not 'fit' (Bertilsdotter Rosqvist, 2012; Huws & Jones, 2015; Lewis, 2016; Lilley et al., 2021; MacLeod et al., 2013). Similar to the autism spectrum itself, some described disability in terms of a hierarchy, with ASD perceived as a mental disability, that is positioned more favourably than physical disability (Huws & Jones, 2015; MacLeod et al., 2013).

Theme 2: Being Different

2.1 Negative difference: Across studies, participants described a sense of negative difference and challenges associated with ASD. Problems due to employment (Hickey et al., 2018; Hurlbutt & Chalmers, 2002) emotional (Cooper et al., 2021; Corden et al., 2021) and social difficulties (Cooper et al., 2021; Hickey et al., 2018; Hurlbutt & Chalmers, 2002; Lewis, 2016; Punshon et al., 2009; Stagg & Belcher, 2019) were reported. Fear of stereotypes and stigma associated with ASD were also identified (Cooper et al., 2021), and some found it difficult to portray their 'true self' (Hickey et al., 2018). Thus, camouflaging was employed with the aim of 'fitting in' or 'appearing normal' (Hickey et al., 2018; Huws & Jones, 2015; Lewis, 2016; Lilley et al., 2021). The emotional cost of camouflaging was evident, as one participant described being different 'characters' and consequently did not have a clear sense of self (Lilley et al., 2021). Some also masked their differences with alcohol (Punshon et al., 2009) or social withdrawal (Hickey et al., 2018).

2.3 Positive difference: This subtheme highlights the positive sense of identity many participants experienced in relation to their differences, as being different signified that autistic people were 'unique' (Cooper et al., 2021). Statements reflected participants' pride in their autistic qualities; for example, a high IQ, remarkable memory abilities, and passionate interests (Hickey et al., 2018; Jones et al., 2015; Lilley et al., 2021; Punshon et al., 2009; Tan, 2018). Autistic differences were viewed positively, and for some, autistic characteristics were perceived as 'superior' relative to non-autistic others (Lewis, 2016).

Theme 3: Self-understanding

3.1 Seeing the world through an autism lens: Across studies, ASD provided a sense of self-understanding, as experiences, behaviours and challenges of past and present were attributed new meaning and appreciation through the lens of ASD (Cooper et al., 2021; Corden et al., 2021; Hickey et al., 2018; Huws & Jones, 2008; Lilley et al., 2021; Punshon et al., 2009;

Stagg & Belcher, 2019; Tan, 2018). Participants recognised that they were not 'faulty' (Lilley et al., 2021), and described how their experiences 'made sense' (Stagg & Belcher, 2019) in the context of ASD. This appeared to be particularly relevant to adults diagnosed later in life, as one adult explained 'finding out I was an Aspie was a light in the darkness' (Lewis, 2016). Conversely, some young people viewed the label as stigmatising and disruptive to future plans (Huws & Jones, 2008). Mental health difficulties such as depression (Stagg & Belcher, 2019) and self-harm (Punshon et al., 2009) were also understood in the context of ASD.

3.2 A new normal: Many described a transformation from being an 'abnormal neurotypical' to a 'normal autistic person' following diagnosis (Tan, 2018), and reported enhanced self-acceptance and self-compassion (Bertilsdotter Rosqvist, 2012). Participants could embrace their 'real' self (Corden et al., 2021), and some felt more 'confident and comfortable' in their own identity, as 'the stress of having to 'fake it'' was gone (Lewis, 2016). Several statements emphasised that the onus was on society to change their views (Jones et al., 2015; Lilley et al., 2021; Punshon et al., 2009).

3.3 Autistic community: Several participants reported a sense of collective identity with other autistic people. Sharing a diagnosis with others helped to normalise that 'other people go through the same' (Corden et al., 2021), and there was a sense of hope that there were other people who shared similar experiences (Corden et al., 2021; Jones et al., 2013, 2015; Lewis, 2016; MacLeod et al., 2013; Tan, 2018). Those without autism were referred to as 'neurotypicals' (Hurlbutt & Chalmers, 2002) or 'normal people' (Punshon et al., 2009). By identifying as autistic, individuals gained membership of autistic communities that offered social relationships and networks (Tan, 2018). Some reported using online chat forums with the specific function of acceptance and universality (MacLeod et al., 2013).

Theme 4: Autistic people as experts by experience

Participants from several studies researched ASD in order to make sense of their experience. Many researched online, read books, and attended conferences in order to educate themselves on the topic (Cooper et al., 2021; Corden et al., 2021; Hurlbutt & Chalmers, 2002; Jones et al., 2015; MacLeod et al., 2013; Punshon et al., 2009). Some felt that the information available to them did not adequately describe their experience, and noted that those without autism could never come from a 'bottom-up perspective' in contrast to those living with ASD (Bertilsdotter Rosqvist, 2012; MacLeod et al., 2013). Therefore, some participants were 'committed to the cause of autism' (Hurlbutt & Chalmers, 2002), and identified their desire to educate the public based on their knowledge and experience (Hurlbutt & Chalmers, 2002; Jones et al., 2013). Others avoided seeking information related to ASD, as it would 'probably get [them] upset' (Huws & Jones, 2008).

Discussion

Overview of findings

Thematic synthesis identified four over-arching themes that reflect autistic peoples' understandings and perceptions of ASD, which in turn may influence their autistic identity: terminology; being different; self-understanding; and autistic people as experts by experience. A number of theories related to identity may be drawn on to further elucidate these findings. For example, the first theme 'Terminology' related to the diverse perspectives underlying term preferences to understand ASD. There was no consensus on a single preferred term. Rather, there was considerable diversity, as some felt that ASD was a core part of their identity; others preferred terms that reflected a medical condition; while others emphasised the diversity of the spectrum. Research on well-being among autistic adults identified narratives describing participants' personal journey, ranging from their perception of themselves as a 'person with ASD', to an 'autistic person' (Milton & Sims, 2016). These findings may be understood in light

of Marcia's (1980) identity status theory, whereby an established sense of identity is achieved when individuals explore various roles, before committing to identity defining domains (Årseth et al., 2009; Cresswell & Cage, 2019). Therefore, terminology preferences may reflect exploration and commitment processes towards a more satisfied autistic identity. Overall, this theme suggests that preferred terminology reflects how individuals perceive themselves, and how they choose to express their autistic identity to others (Bury et al., 2020). Thus, where possible, autistic people should be given the opportunity to express their preferred terminology to honour their sense of identity.

Social identity theory (SIT; Tajfel & Turner, 2010) posits that as humans, we have a propensity to form ourselves into social groups, and self-identity is partly formed through group memberships (Cooper et al., 2021). In the current review, participants' self-understanding was established through connection with an extended autistic community. Autistic community was often accessed through online platforms, which fostered a positive sense of autistic identity, as individuals could interact with like-minded others and experience a sense of connectedness (Bertilsdotter Rosqvist et al., 2013). Evidence suggests that autistic people who associate positive attributes with ASD affiliate strongly with their autistic identity (Cooper et al., 2021). Indeed, autistic traits that participants had positive attitudes towards were identified throughout studies.

On the other hand, themes relating to feeling 'different' were also reported across studies. Cooley's (1983) 'looking glass theory' posits that we view ourselves through the evaluations and judgements that others make of us (Jones et al., 2013). Across studies, 'differences' largely reflected negative experiences of stigma and marginalization. Social camouflaging was consequently employed to try and conform to non-autistic behavioural expectations. The impact of camouflaging on mental health is widely recognised (Beck et al., 2020; Mandy, 2019), and the deleterious effects on participants' identity was evident, as many

described their experience of hiding their 'true self' (Lilley et al., 2021). Furthermore, some participants described potentially maladaptive coping responses to deal with feelings of difference, such as alcohol consumption. These findings are consistent with research from other disability groups (Hartley et al., 2008; Lindsay, 2014), and emphasise the importance of developing adequate stress management skills (DePape & Lindsay, 2016). Many reported researching and learning about ASD in order to develop a more holistic conception of the condition, whilst others avoided seeking ASD related information. This is comparable to the way in which people with chronic illness seek health information, with some actively seeking and using information in order to cope, while others avoid seeking information about the long term implications of their illness (Huws & Jones, 2008; Pinder, 1990). Many participants did not feel adequately represented in the literature, and acknowledged a lack of support and services. Given their insider perspective, autistic advocates have argued for increased consultation on issues relating to ASD in research and practice, with the goal of educating professionals and society about autistic experiences (Hurlbutt & Chalmers, 2002). Collectively, these findings indicate the adverse implications associated with a negative identification with ASD, while also highlighting the importance of fostering an in-group sense of identity. There is a growing body of research advocating for the use of peer support within the autistic community (Crane et al., 2021). Thus, including the voice of autistic service users may help foster a positive autistic identity and help protect against stigma and mitigate attempts to conform to non-autistic behavioural expectations.

Following diagnosis of autism, evidence from the thematic synthesis suggest that several participants underwent some degree of identity transformation (Huws & Jones, 2008). According to the results, developmental stage may influence reactions to diagnosis. For example, young people considered the impact of the diagnoses on their future, as awareness of being different and a desire to 'fit in' are characteristic of this age group (Jones et al., 2013).

Conversely, adults diagnosed later in life were afforded a framework to understand their differences and past experiences (Hickey et al., 2018). Socioemotional selectivity theory may illuminate these findings, as it maintains that goals are always set in temporal contexts. Thus, when time is perceived as expansive as it often is in youth, individuals tend to focus on the future. In contrast, when people perceive time as limited, they tend to focus on emotionally meaningful aspects of their life (Carstensen & Mikels, 2005). Pre-existing mental health difficulties were also understood in the context of ASD, and helped some participants make sense of their past experiences. This supports evidence that co-occurring mental health difficulties may be precipitated by the emotional impact of masking (Hull et al., 2021), and ASD related stigma (Pearson & Rose, 2021). Given the emotional and personal experiences that may arise during the diagnostic process (Crane et al., 2021), the findings from the review collectively point to the potential benefit of autistic-led peer support groups, or post-diagnostic groups in order to help create a positive autistic identity through service provision.

Methodological limitations

Findings from the thematic synthesis provide more credible and potentially transferable claims to knowledge than is possible in any one qualitative study (Flemming & Noyes, 2021). However, given that autism is a spectrum disorder, it is important to consider the level of functioning of participants. Across studies, participants tended to be educated and cognitively and verbally able to engage in research. In addition, the articles largely represented sampling from WEIRD (Western, educated, industrialised, rich, democratic) populations (Rad et al., 2018). Thus, the findings are likely to represent a subset of autistic individuals, highlighting gaps in the research (Williams et al., 2019).

While all articles were assessed to be of moderate to high quality, many of the articles did not provide sufficient information pertaining to participants' intellectual ability, and how diagnosis was verified. Therefore, formal ASD and IQ assessment measures, and official ASD

reports may be useful in future studies to enhance interpretation of the participants' experiences.

Another methodological aspect to consider is that of research bias. The slightly higher percentage of overall female participants is not indicative of a gender bias in the general population (58.5%); however, this gender ratio is not representative of the sample population. The higher number of female participants was mostly observed in online survey studies, which has also been reported in other online autism research (Arnold et al., 2019; Bury et al., 2020; Kenny et al., 2016). Autistic females have reported a preference for communicating via online platforms given the social and communication benefits (Bargiela et al., 2016); however, future research should further examine autistic females' motivation to engage in online research. In the current review, papers focusing on the female autistic phenotype, and changing classification systems were excluded, as they were evaluated as focusing narrowly on one aspect of autistic identity, rather than capturing the understanding and perceptions of autism more generally. Therefore, future reviews may explore autistic identity from these perspectives.

Finally, given the wide age range and the developmental nature of ASD, it is possible that participants who are diagnosed later in life construct their identities differently to those who are diagnosed younger (Cooper et al., 2021). Future reviews may conduct separate analysis to compare autistic identity at different developmental stages. Nonetheless, statements across studies reflected common themes that were relevant across age groups.

Conclusion

Collectively, the findings suggest that autistic identity is not one defined entity, given the diversity inherent within the spectrum (Huws & Jones, 2015; MacLeod et al., 2013). However, the findings inform our understanding of factors influencing autistic identity, including terminology, awareness of differences, society's role of defining 'normal', and the

importance of identifying with other autistic community members. Professionals working with autistic individuals may consider these factors in service planning and provision to promote mental health and well-being in the context of autistic identity.

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Chapter 3: Systematic Review Extended Methodology

Development of research question

My interest in the review question stemmed from my clinical experience of working with autistic people, who often struggled with issues related to their identity in the context of their ASD. I was therefore interested in the concept of autistic identity. In order to define and formulate the research question, a scoping review was completed between February and March 2021 to gain an overview of research evidence available for synthesis. A mind map was produced in order to summarise the results of the scoping searches, and to refine the scope of my review (Boland et al., 2017). The SPIDER framework (Cooke et al., 2012) was then used to develop and refine the research question (Table 3.1). This tool adapts components of the more frequently applied PICO (Population, Intervention, Comparison, Outcome) tool to better accommodate qualitative research papers (Cooke et al., 2012). Given the broad nature of the topic area of interest, the research question was refined continuously in order to establish a focused, and well defined research question and objectives (Soilemezi & Linceviciute, 2018). Prior to undertaking the systematic review, a protocol was submitted for review in April 2021 (Appendix E).

Table 3.1

Development of research question using the SPIDER framework

Sample	Autistic adolescents and adults, with no intellectual disability
Phenomenon of Interest	Perceptions and understandings of Autism Spectrum Disorder
Design	Any qualitative data collection and analysis
Evaluation	Perceptions, understandings, descriptions, views, perspectives, attitudes
Research Type	Qualitative or mixed-methods

Methodological Framework

Systematic Reviews

Systematic reviews are considered the 'gold standard' way to synthesis the results of a number of empirical studies investigating the same research questions (Boland et al., 2017, p.2). Thus, the advantage of a systematic review, is that they examine and combine empirical evidence related to a specific phenomenon, and reveal new explanations or deeper insights that would not be possible with a single study (Soilemezi & Linceviciute, 2018). As the name suggests, researchers are required to follow a transparent and systematic methodology when conducting a systematic review. Four elements are typically common; defining the research question, determining the eligibility criteria, formulating a search strategy, and screening the literature. When conduced rigorously, systematic reviews allow for an unbiased summary and critical synthesis of the cumulative literature on a given topic (Laher & Hassem, 2020). Thus, Synthesised findings from a systematic review can be used to guide decision-making in health care settings, and have implications for theoretical developments, and policy and practice (Cajal et al., 2020; Laher & Hassem, 2020).

In recent years, there has been an increasing interest in qualitative synthesis to inform health related policy and practice (Barnett-Page & Thomas, 2009; Mays et al., 2005). Qualitative synthesis aims to draw together findings from qualitative research, that can often lead to the emergence of new understandings of the data (Seers, 2012). Given my interest in including autistic peoples' voice in research, a qualitative synthesis was conducted to explore autistic identity; through consideration of qualitative research on autistic peoples' perceptions and understandings of ASD.

Rationale for Thematic Synthesis

When choosing an appropriate qualitative data analysis method, there were a number of factors I had to consider, including the research question, the availability and type of data,

resources available, and how the results could be used in a meaningful way (Laher & Hassem, 2020). Thematic synthesis was selected as it is primarily concerned with peoples' perspectives and experiences (Eccleston et al., 2019; Griffith et al., 2013; Leeuwen et al., 2019). Thematic synthesis provides a systematic and transparent approach which enables the creation of rich and interpretative themes, that are grounded in data, in order to expand on our conceptual understandings of a particular phenomenon (Heath et al., 2017). It is also considered an appropriate method to aggregate findings from a large number of qualitative studies (France et al., 2014; Leeuwen et al., 2019; Thomas & Harden, 2008). The synthesis component of thematic synthesis involves an iterative process of inductively grouping descriptive themes into higher order themes, and allows for the generation of hypothesis of the phenomenon under investigation (Hannes & Lockwood, 2011). Thus, thematic synthesis goes beyond the cumulative studies to offer novel interpretations not found in any single study (Lipworth et al., 2010). In addition, thematic synthesis involves a line-by-line coding of text from primary studies, which allowed me to stay as close as possible to the accounts of autistic participants, or the authors' interpretations (Thomas & Harden, 2008). I was interested in exploring autistic peoples' understandings and perceptions of ASD, with the aim of generating new insights into this phenomenon that may inform mental health and well-being interventions for the autism community. Therefore, thematic synthesis was considered a suitable approach.

Identifying Studies for Inclusion

Development of Eligibility Criteria

Defining the eligibility criteria was an important step of the systematic review process, as it served as a reference point when developing the search terms (Laher & Hassem, 2020). As previously mentioned, the SPIDER framework (Cooke et al., 2012) was used to define the inclusion and exclusion criteria for the current systematic review. Autistic adolescents and adults were the specified population for the current systematic review as the developmental

task of identity development becomes particularly salient during adolescence. The review included adolescents and adults with a formal diagnosis. In the current review, a formal diagnosis was established by assessment and measures included in the research study; validated by an external service; or the researchers or participants confirmed a formal diagnosis. Data had to be from the first-person perspective and not communicated by a third party.

Defining the eligibility criteria is recognised as a cyclical process, that evolves as the study progresses (Laher & Hassem, 2020). Based on a scoping review of the literature, it was apparent that there were a number of studies specifically exploring subthemes in relation to autistic identity. In particular, studies that focused on the removal of Asperger's syndrome as a discrete category in classification systems, as well as studies that specifically focused on the female autistic phenotype, which reportedly manifests differently to the male based conceptualisation of ASD (Bargiela et al., 2016). Furthermore, some papers narrowly focused on the perceptions, understanding, or experience of being autistic in particular environments or contexts. Thus, it was decided that papers primarily exploring these areas would be excluded, as they were evaluated as focusing narrowly on one aspect of autistic identity, rather than capturing the understanding and perceptions of ASD more generally.

Non-empirical studies were excluded due to them not having been subject to the scrutiny of peer review. Furthermore, papers where themes or findings combined quotes from mixed samples, for example, parents, professionals, participants' with an ID, participants outside age-range, as it would have been impossible to identify to what degree themes reflected autistic peoples' understandings and perceptions of ASD.

Search Strategy

The development of the search strategy involved two main steps; the identification of appropriate search terms; and the selection of appropriate databases (Laher & Hassem, 2020). As described in chapter two, search terms were developed through consultation with my

research supervisor, a subject librarian at University College Cork, a member of the autistic community as an expert by experience, and keywords from an initial scoping search. The SPIDER framework (Cooke et al., 2012) was utilised in order to segment the research question into individual concepts (Laher & Hassem, 2020). Boolean operators, with truncations and wild cards were included where appropriate.

Based on the consultations and scoping searches, I developed an excel sheet to document keywords, synonyms, and alternative concepts for each segment of the research question. My initial search strategy included concepts related to the population, including 'adolescen*' or 'young adult', as well as alternative concepts related to identity, including 'camouflag*', 'social identity', and 'diagnos*'. However, I piloted my search string, and received a large number of hits that were irrelevant to my research question. In order to ensure sensitivity and specificity, I refined and narrowed my search string by including key terms, alternative concepts, and synonyms related to the research question, and truncated words to include various word endings and spellings.

Appropriate databases were identified in consultation with a subject librarian at University College Cork, and selected based on their relevance to the research question. Multiple specialist databases were used in order to minimize bias. The search strategy was refined for each database, using a combination of keywords, and subject headings or Medical Subject Heading (MESH).

Record Management

Open access software, including Zotero and Rayyan, were used for reference management, database searches, duplication removal, and screening purposes.

Data synthesis

Data was analysed thematically following Thomas and Harden's (2008) method. Entire results or findings section of included papers were extracted for data analysis. This included

direct quotations or the authors' interpretations. As previously mentioned, thematic synthesis involves three key stages; line-by-line coding, developing descriptive themes, and generating analytical themes (Thomas & Harden, 2008). The process of grouping descriptive themes into broader analytical themes involved consideration of how the descriptive themes answered the research question relating to autistic peoples' perceptions and understandings of ASD. Codes and themes were reviewed by the third author, and any disagreements were discussed until consensus was reached.

Dissemination of findings

This systematic review was submitted for review for publication in the journal '*Autism'* on 2nd April 2022.

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Chapter 4: Major Research Project- Literature Review

Eye Gaze in typical and atypical development

Eye gaze is a central element in human communication. During a social interaction, eye gaze cues can indicate social engagement, reflect the speaker, and listener's goals and feelings, reflect a desire to communicate, and directs the listener's attention to objects in the environment (Çetinçelik et al., 2021). Direct eye-contact is an aspect of eye gaze behaviour, which describes mutual gaze with another person (Farroni et al., 2002). Research exploring eye-contact in autistic participants has largely measured the amount of eye-directed gaze as a proxy for eye-contact (Jongerius et al., 2020). Therefore, the current chapter begins with an overview of the eye gaze literature in typical and atypical development in order to provide an overview of the existing knowledge base. Throughout this thesis, eye-contact will refer to the specific act of mutual eye gaze, in which one individual gazes at the other simultaneously (Jongerius et al., 2020).

Eye Gaze in Typical Development

While spoken language constitutes a salient form of communication, an abundance of information can also be conveyed non-verbally in social interactions. Non-verbal communication, including gestures, facial expressions, posture, body language and eye gaze reportedly accounts for up to 65% of overall interaction (Gatica-Perez, 2009). Indeed, eye gaze is recognised as one of the most crucial modalities of non-verbal communication, given that human social interaction is typically facilitated by information conveyed through the eyes (Csibra & Gergely, 2006; Hanley et al., 2014; Klin, 2008). The use of eye gaze has been identified as an extremely adaptive behaviour. In contrast to other primates, it has been argued that the exposed white sclera and the darker iris unique to humans, have evolved for effective social communication by making it easy to discern eye gaze direction (Kobayashi & Kohshima, 1997; Senju & Johnson, 2009a). As such, the human visual system is hyper-sensitive to eye

gaze cues, and humans have been found to detect and discriminate eye movements as small as 1° visual angle (Anderson et al., 2011).

The social information conveyed by eye gaze has two major components; direct and averted eye gaze (Senju & Hasegawa, 2005). Indeed, gaze direction serves several important functions during social interactions, such as indicating a desire to communicate (Çetinçelik et al., 2021), facilitating cognitive processing when answering questions of moderate difficulty (Glenberg et al., 1998), establishing joint attention (Farroni et al., 2002), and signalling turn-taking during conversation (Laskowitz et al., 2022).

In typical development, eye gaze behaviour and social preferences and attention emerge spontaneously during infancy (Nation & Penny, 2008). A common methodology for studying eye gaze behaviours is that of eye-tracking technology, which allows researchers to measure how the observer distributes gaze, and provides an insight into cognitive processes via a rapid, accurate, and largely automatic motor response (Bush & Kennedy, 2015; Falck-Ytter et al., 2013). Indeed, extensive lines of eye-tracking research have found that neonates preferentially orient to facial configurations (Farroni et al., 2005), have a preference for direct gaze rather than averted gaze (Farroni et al., 2002), and faces with eyes open rather than closed (Batki et al., 2000). By at least four months of age, infants have demonstrated enhanced neural processing of mutual gaze (Farroni et al., 2002), and from the age of 9 months, infants start to use eye gaze direction as an indicator of another person's interest or attention, which is termed 'joint attention' (Bertenthal & Boyer, 2015; Scaife & Bruner, 1975). Experimental research found that six month old infants followed adults' eye gaze, only when it was preceded by a period of direct eye-contact, suggesting that direct eye-contact engages an infant whose attention can be subsequently directed, and implies that an infants' preferential attention to others establishes new opportunities for social interaction and learning (Senju & Csibra, 2008). Thus, based on this cumulative evidence, it can be concluded that typically developing infants

have a predisposition to engage with the social aspects of the world around them (Shultz et al., 2015).

In typically developing adults, experimental research has also indicated the salience of social information, as adult participants demonstrated a preference to fixate on the eyes and faces of people rather than inanimate stimuli when viewing real-world social scenes (Birmingham et al., 2009). Eye gaze direction also serves important cognitive functions. For example, a review by Senju and Johnson (2009a) found that perceived direct gaze with another face modulates certain aspects of concurrent, and/or immediately following, cognitive processing. This has been termed 'the eye-contact effect'. For example, eye-tracking experimental research has found that direct gaze enhances the detection of faces (Senju & Hasegawa, 2005), potentiates gender categorisation (Macrae et al., 2002), and promotes implicit memory for faces (Mason et al., 2004). In contrast, averted eye gaze shifts an individual's visual attention to the area around the gaze direction (Cui et al., 2019; Hietanen, 1999). Neuroimaging research also supports the idea that humans have a particular sensitivity to the eye region as a source of social communicative information. For example, cortical and subcortical regions of the brain that are involved in the processing of social information have been identified and termed the 'social brain network'. Specifically, brain areas that become activated when exposed to direct gaze include the prefrontal cortex, the superior temporal gyrus, the fusiform gyrus, the cingulated gyrus, and the amygdala (Baars & Gage, 2013; Senju & Johnson, 2009a).

The weight of evidence supports the view that there is a sensitivity to eye gaze from birth, which serves a vital foundation for subsequent social development (Farroni et al., 2004). Social attention and interpretation of another's face, eyes, and behaviours is foundational to how humans communicate, learn about the social and physical world, regulate emotions, and develop relational attachments (Bertenthal & Boyer, 2015). However, atypical eye gaze may

precede behaviours that are commonly observed in ASD, such as unusual eye-contact, impaired joint attention and theory of mind deficits, and therefore has received much research attention (Nyström et al., 2017). Given the eyes are a major source of communicative information, avoiding or failing to pay attention to the eyes may result in repeated missed opportunities for social and emotional learning that can subsequently have an adverse impact on social-cognitive development, and impact face-to-face interactions (Trevisan et al., 2017).

Atypical Eye Gaze in ASD

While social preferences and attention emerge early in typical development, autistic individuals exhibit significant impairments in social attention, which appear to persist over the lifespan (Bush & Kennedy, 2015).

Numerous studies have demonstrated the early onset of social attentional abnormalities in autistic children, particularly atypical eye-contact. Although ASD is rarely diagnosed before two years of age (Nyström et al., 2017), retrospective studies using home video analysis (Osterling et al., 2002), and retrospective semi-structured interviews administered to parents (Wimpory et al., 2000), found that children who subsequently received an ASD diagnosis demonstrated atypical eye-contact before the age of two. Although the retrospective methodology of these studies must be interpreted with caution owing to a lack of experimental manipulation, experimental research on early atypical eye gaze in ASD has also reported similar characteristics, as reviewed below.

While typically developing infants demonstrate an increase in preferential attention to the eye region between two and six months, a prospective longitudinal study using eye-tracking methodology found that children who were later diagnosed with ASD exhibited a mean decline in eye fixation from that of their peers during this early developmental period, and a continuous decline thereafter. This finding that autistic children's' eye contact appeared to begin at 'normative levels' suggested the developmental onset of reduced eye-contact, rather than a

congenital absence of social adaptive orientation (Jones & Klin, 2013). However, closer inspection of the data revealed that the underlying rate-of-change in eye-looking differed between autistic infants and typically developing comparisons; and autistic infants' magnitude of eye-looking was slightly, but significantly, higher at two months of age in autistic infants. Therefore, it could be concluded, that while eye fixation may appear superficially similar to typical development in early months, the underlying developmental processes may already be distinctly different (Shultz et al., 2015).

This atypical eye-contact processing in early infancy may also contribute to atypical gaze following behaviour. For example, joint attention deficits were observed in infants at familial risk for ASD, in which they demonstrated reduced rates of initiating joint attention when compared to infants who are at low risk of ASD (Nyström et al., 2019). However, in this study, there was a contrast in initiating and responding to social communication, as differences in gaze following were not observed (Nyström et al., 2019). A more recent study by the authors found that, although autistic children followed gaze to the same extent as a typically developing comparison group, the autistic children looked back to the model faster when a peripheral object was absent. Thus, the authors concluded, that while gaze following was largely typical in autistic children, there may be subtle atypicalities in gaze behaviours directly after gaze following (Thorup et al., 2021).

While eye-tracking research exploring eye gaze in ASD has identified some general patterns, it has also yielded some inconsistent findings. For example, some eye-tracking studies have found that autistic participants spend less time attending to the eyes when compared to a typically developing comparison group (Auyeung et al., 2015; Jones et al., 2008; Klin et al., 2002), while other studies have found typical patterns of attention allocation to the eyes in ASD (Asberg Johnels et al., 2014; Grossman et al., 2015; Tenenbaum et al., 2014).

It is noteworthy that most research studying eye gaze behaviours used controlled static images, or videos of social stimuli, with no scope for real social interaction (von dem Hagen & Bright, 2017). Thus, these inconsistent findings may be a consequence of the lack of experimental paradigms to research eye gaze in real world social interactions (Cañigueral & Hamilton, 2019). Recent research has therefore used live social interaction paradigms to explore social attention in autistic individuals. For example, an eye-tracking study explored the influence of gaze direction and conversational phase (speaking or listening) on the social attention of autistic and typically developing participants during a face-to-face interaction (Freeth & Bugembe, 2019). Autistic participants showed significantly reduced fixations and demonstrated reduced social attention in response to direct eye gaze, compared to a typically developing comparison group. In terms of conversational phase, both autistic and typically developing participants tended to look more at the experimenter's face while listening compared to speaking, indicating that autistic individuals could modulate their social attention depending on the conversational phase.

In another study, Cañigueral and colleagues (2021) explored how autistic peoples' eye gaze behaviours were modulated by the belief that they were being watched by another person. The level of social engagement was adjusted across three conditions; video (pre-recorded video of the confederate), videocall, and live face-to-face interaction with the confederate. These different social contexts varied the participants' belief in being watched, and potential to demonstrate true gaze direction. The findings revealed that gaze patterns were similar across autistic and typically developing groups, as both groups demonstrated reduced eye fixation to the confederate when being watched and when speaking. The study also found that the autistic participants gazed more at the confederates' eyes at the start of the face-to-face interaction, compared to the comparison group. The authors concluded that autistic people are able to adjust their eye contact to the demands of a structured conversation. However, the authors also

suggested that their findings could reflect compensation strategies, in which autistic participants had learned to make more frequent eye-contact in social interactions (Cañigueral et al., 2021).

Despite methodological heterogeneity making the exact nature of eye-contact abnormalities in ASD unclear (Frazier et al., 2017), overall, eye-tracking research has provided ample evidence to suggest atypical eye-contact and social attention behaviours in autistic individuals. However, these differences appear to emerge under certain conditions, and are influenced by other factors. Moreover, in some cases, compensatory strategies may be playing a role in participants' performance on social attention tasks (Bush & Kennedy, 2015). Given the critical role of eye-contact in social interactions and communication, further research is necessary to better understand autistic peoples' experience of this phenomenon.

Models to explain atypical eye-contact in ASD

Four models have been proposed to help ground our understanding of atypical eye-contact in ASD; the hyperarousal model, the hypoarousal model, the mindblindness model, and the fast-track modulator model. Definitions of these models are provided in the main paper. Therefore, additional information pertaining to these models is described below.

Within the hyperarousal model, hyperactivation of the amygdala and the sympathetic nervous system is the cause of atypical eye-contact in ASD, and autistic individuals demonstrate a deliberate avoidance of eye-contact in order to prevent negatively-valanced, over-stimulating hyper-arousal (Moriuchi et al., 2017). Research in support of this hypothesis has found that looking at the eye region of the face elicited increased autonomic arousal (Kaartinen et al., 2012; Kylliäinen & Hietanen, 2006) and amygdala activation (Dalton et al., 2005; Hadjikhani et al., 2017) in autistic participants, compared to a typically developing comparison group.

Conversely, the hypoarousal model postulates that autistic individuals are insensitive to underlying social signals from another person, leading to passive omission of eye-contact, as the eyes are not perceived as engaging or socially informative (Moriuchi et al., 2017). In typical development, it is reported that eye-contact has intrinsic reward value, as repeated experiences of attaching eye-contact to positive social experiences will lead to a conditioned motivation to seek out eye-contact (Trevisan et al., 2017). However, it is postulated that hypoactivation of the amygdala in ASD interferes with attaching positive reward value, and thus autistic individuals are ambivalent towards others' eyes (Dawson et al., 2005; Senju & Johnson, 2009b; Trevisan et al., 2017). In support of this hypothesis, areas of the social brain system in autistic individuals, including the amygdala, have demonstrated hypoactivation to social stimuli, and a diminished degree of responsiveness to gaze cues (Moriuchi et al., 2017; Pelphrey et al., 2005, 2011). Furthermore, an eye-tracking study of two year old children found that when cued to look at the eyes, the autistic children did not look away faster than their typically developing peers, and the effects of direct cueing were stronger for autistic children. Thus, these results were inconsistent with the hyperarousal hypothesis, and indicated passive insensitivity to social information in the eyes. The findings also concluded that given the young age of participants, it is possible the atypical affective response to eye gaze observed in older autistic children and adults, may be a consequence, rather than cause, of atypical eye gaze behaviours (Moriuchi et al., 2017).

The 'mindblindness' model is consistent with the ToM hypothesis, which claims that autistic individuals demonstrate atypical eye-contact based on their difficulty in inferring others' mental states from their eyes (Baron-Cohen et al., 2001; Senju & Johnson, 2009b). Due to the adaptive importance of detecting eye-contact early in life, Baron-Cohen (1994) proposed the eye direction detector (EDD) module, that is dedicated to perceiving another person's eyes, and the direction in which they are gazing. The EDD functions to detect eyes, and then

subsequently inputs to the theory of mind mechanism (ToMM) that then calculates others' mental states. Based on this model, ASD involves impairment in a shared attention mechanism (SAM), which relays the input from the EED to ToMM (Senju & Johnson, 2009b). As this is a difficult model to test directly, evidence in support of this theory is primarily indirect, based on atypical performance on ToM tasks (Hanley et al., 2014) or reduced joint attention (Caruana et al., 2018) in autistic individuals.

Finally, the fast-track modulator model was proposed by Senju and Johnson (2009b). This model proposes a rapid and early developing pathway for the detection of faces in the peripheral visual field (Nyström et al., 2017) and is reportedly responsible for an attentional bias to respond to faces and eye gaze in infants, prior to the development of cortical face processing (Johnson, 2005). Based on this model, 'the eye-contact effect' involves a rapid subcortical visual processing network, that involves interactions of the superior colliculus, pulvinar, and amygdala (Cañigueral & Hamilton, 2019), and is subsequently modulated by higher cortical regions that depend on social context and task demands (Senju & Johnson, 2009b). Thus, from this perspective, alterations or delays in the development of social cognition and social brain networks are associated with difficulties observed in ASD (Akechi et al., 2014; Senju & Johnson, 2009b).

The Current Study

While experimental and neuroimaging research has made important contributions to our knowledge of eye gaze behaviours and direct eye-contact in typical and atypical development, there is a dearth of research exploring the first-person experience of eye-contact by autistic individuals. Recent research has advocated for a qualitative phenomenological approach to research on ASD, in order to gain further insight into autistic peoples' subjective experiences, and a greater understanding of autistic social cognition (Nilsson et al., 2019). Only one qualitative study exploring the experience of eye-contact for autistic individuals has been

published in the research literature. The authors analysed secondary data and identified themes related to adverse emotional and physiological reactions, feelings of being ‘invaded’, sensory overload, difficulties understanding social nuances, and difficulties receiving and communicating information via eye gaze (Trevisan et al., 2017).

The current study is interested in understanding the phenomenology of eye-contact from the perspective of autistic people. Therefore, in order to gain insight into autistic peoples’ experiences of eye-contact, this study will conduct qualitative interviews with autistic adults using an Interpretative Phenomenological Analysis (IPA) methodology.

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Chapter 5: Major Research Project

Deliberate and self-conscious adaptation of eye-contact by people with Autism Spectrum Disorder (ASD)

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Abstract

One of the characteristic hallmarks of Autism Spectrum Disorder (ASD) includes an atypical response to eye-contact. Experimental research has contributed significantly to the extant literature on eye-contact in ASD; however, there is a dearth of qualitative research exploring the phenomenological experience of eye-contact for autistic individuals. The current study aimed to explore the subjective experience of deliberate and self-conscious adaptation of eye-contact by autistic participants using Interpretative Phenomenological Analysis (IPA). Nine autistic adults were interviewed. Group experiential themes included; (1) Eye-contact: Awareness and motivation, (2) Phenomenology of eye-contact, and (3) Strategies to make eye-contact. This study makes an important and novel contribution to understanding the experience of eye-contact for autistic individuals, and highlights factors influencing effective eye-contact, which may have implications for psychological intervention.

Lay Abstract

Autistic people often experience difficulties making and maintaining eye-contact, but there is no qualitative interview studies exploring how autistic people experience eye-contact. In this study, we interviewed nine autistic adults about their experience of eye-contact. Participants are motivated to make eye-contact for different reasons, and many employ camouflaging strategies to mask or compensate for their atypical eye-contact. Participants experience difficulty processing information when they are making eye-contact, particularly managing competing demands during social interaction, and reading social information. We conclude that autistic people have different experiences of eye-contact, but underlying processing difficulties may influence their attempts to make eye-contact.

Keywords: autism spectrum disorder, eye-contact, eye gaze, qualitative, interpretative phenomenological analysis

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Introduction

Eye gaze is widely recognised as a powerful tool for social interaction that has multiple functions in the modulation of social processes (Hietanen, 2018). Eye gaze serves a dual purpose, as we can both perceive information from others, and use our gaze to communicate information (Cañigueral & Hamilton, 2019). For example, eye gaze allows us to gather information about what other people are looking at (Cañigueral & Hamilton, 2019), infer how others think and feel (Baron-Cohen et al., 1997; Cañigueral & Hamilton, 2019), and strategically cue another person's attention (Kuhn et al., 2009; Cañigueral & Hamilton, 2019). Furthermore, eye gaze regulates and organises social interactions. For example, during conversation, the speaker ends their turn by shifting their gaze to the person listening, who in turn begins to speak with an averted gaze (Ho et al., 2015; Laskowitz et al., 2022). Thus, eye gaze is a significant factor in facilitating social interaction, and signalling turn-taking in conversations (Laskowitz et al., 2022).

In typical development, direct mutual eye-contact is often experienced positively (Hietanen, 2018). Indeed, a preference for eye-contact has been demonstrated through research that has found that typically developing adults (Senju & Hasegawa, 2005) and infants (Farroni et al., 2002) shift their attention preferentially and reflexively towards others' direct gaze to establish mutual eye-contact. Conversely, one of the characteristic hallmarks of Autism Spectrum Disorder (ASD) includes an atypical response to eye-contact (Madipakkam et al., 2017). In his seminal article on 'infantile autism', Kanner (1943) described children who presented with 'markedly unusual' eye-contact and eye-gaze, including atypical eye-contact patterns and looking at irrelevant stimuli, and subsequent research has supported these observations (Frazier et al., 2017). Since that time, abnormalities in eye-contact has been

included as a common feature of ASD in classification systems (American Psychiatric Association, 2013) and diagnostic instruments (Lord et al., 2000).

Autistic speakers, such as Robison (2009), have described how alien eye-contact may feel to autistic people '[we] are just not comfortable doing it. In fact, I don't really understand why it's considered normal to stare at someone's eyeballs.' Eye-tracking research has also contributed to our knowledge of atypical attention processes in ASD, and has provided evidence to suggest that differences in social attention are key features of ASD. For example, in contrast to typically developing comparison groups, social attention differences have been observed in autistic participants across studies, ranging from decreased fixation to others' eyes and social stimuli in infancy (Chawarska et al., 2013; Jones & Klin, 2013), to aberrant attention allocation to faces in autistic adults (Moore et al., 2012). Furthermore, recent meta-analyses of eye-tracking studies have found mixed results regarding social attention in ASD, but identified overall atypical gaze patterns in autistic individuals, characterised by reduced time attending to social stimuli, and difficulties selecting socially relevant information for attention (Chita-Tegmark, 2016; Frazier et al., 2017).

Despite evidence suggesting that autistic people exhibit atypical eye-contact, the underlying cause of this deficit remains unclear. Four models make different predications in an attempt to explain why autistic people might demonstrate reduced eye-contact. For example, the hyperarousal model proposes that eye-contact during mutual gaze directly activates brain arousal systems and/or an emotional response. Thus, from this perspective, autistic individuals purposefully avoid looking at others' eyes, because the eyes are perceived as having negative valence (Moriuchi et al., 2017). Conversely, the hypoarousal model postulates that autistic people demonstrate reduced eye-contact as the amygdala fails to prioritise social information in the environment, and consequently, autistic individuals do not preferentially attend to social

stimuli such as faces and eyes. Therefore, based on this model, social information has less intrinsic reward (Trevisan et al., 2017).

Baron-Cohen's (1994) 'mindblindness' model proposes that aspects of gaze perception are influenced by innate modules, including an 'eye direction detector', 'shared attention mechanism', and the 'theory of mind mechanism' (Frischen et al., 2007). Therefore, the lack of optimal functioning from one or more of these modules may reduce the degree to which autistic people attend to others' eyes to determine their intentions and mental states (Trevisan et al., 2017). Finally, the fast-track modulator model reportedly involves a fast subcortical face detection pathway, that modulates neural processing in cortical areas (Akechi et al., 2014; Senju & Johnson, 2009). From this perspective, it has been suggested that autistic people are impaired in the fast sub-cortical processing of information from other peoples' eyes, which may subsequently alter the development of social cognition and 'social brain' networks, which are both related to difficulties associated with ASD (Akechi et al., 2014; Falck-Ytter et al., 2013; Senju & Johnson, 2009).

Although eye-tracking research has contributed important information about eye-contact in ASD, experimental research must focus on behaviour during tightly controlled, and primarily contrived, scenarios, giving us limited insight into real-world social attention. To date, only one qualitative study carried out a secondary analysis of accounts of people with self-declared ASD describing their experience of eye-contact (Trevisan et al., 2017). However, there is no qualitative interview studies exploring autistic peoples' experience of eye-contact. Atypical eye-contact can lead to significant barriers and challenges for autistic people when attempting to regulate real-world social interactions (Trevisan et al., 2017). Therefore, by including the voice of autistic people in research, we can develop an understanding of how autistic people experience eye-contact, and how this may inform psychological supports and intervention.

The Present Study:

In order to better understand the experience of eye-contact the current study aims to explore the subjective experience of deliberate and self-conscious adaptation of eye-contact by autistic individuals. In order to gain a richer understanding of participants' experiences of eye-contact, factors such as strategies to make eye-contact and experience of eye-contact during social interactions will also be explored.

Method

Methodological Approach and Study Design

A qualitative design using Interpretative Phenomenological Analysis (IPA; Smith et al., 2021) and semi-structured interviews was the chosen method of data collection and analysis. IPA focuses on specific phenomenon, such as eye-contact, and aims to distil the essence of this experience (Cooper et al., 2021). IPA is rooted in three philosophies; phenomenology, hermeneutics, and idiography. It is a phenomenological approach as it is interested in the participants' experience of living through a common phenomenon. Research based in IPA adopts a double hermeneutic process, in which there is a dual process of interpretation; firstly at the level of the participant who is making meaning of their own lived experience, and secondly at the level of the researcher who is making sense of the participants' sense making (Smith et al., 2021; Chen, 2022). Finally, a core feature of IPA is its idiographic emphasis which aims to generate rich and detailed descriptions of how each individual participant makes meaning of the phenomena under question (Cooper et al., 2021). IPA has been deemed an effective qualitative approach in autism research, due to its reflexive engagement, and attempt to equalise the power between autistic participants and non-autistic researchers (Howard et al., 2019).

Participants

Inclusion criteria specified that participants must be eighteen years of age or over and have no intellectual disability (ID). In line with theoretical underpinnings of IPA, a small purposeful sample of participants was recruited in order to identify a specific group for whom the research focus had relevance and personal significance (Pietkiewicz & Smith, 2014).

Nine participants with an ASD diagnosis were interviewed. Participants' diagnosis was verified while accessing support services in which recruitment took place, as participants were required to have a diagnosis of ASD to access services. Participants were also asked to confirm their ASD diagnosis in the consent form. Participants ranged in age from 20-56 years, and seven were male, which is relatively reflective of the gender ratio typically observed in those with an ASD diagnosis (Elsabbagh et al., 2012). Demographic information for participants is presented in Table 5.1. Specific data on educational attainment levels and socioeconomic status was not recorded.

Table 5.1

Demographic information

Pseudonym	Sex (M/F)	Age (in years)
Maria	F	20
John	M	56
Sam	M	28
Kevin	M	44
Ryan	M	27
Jason	M	20
Lauren	F	21
Shane	M	20
Jack	M	28

Procedure

Ethical approval was granted by the appropriate institutional ethical review panel at the local university (Appendix F). Participants were recruited from an ASD support service and a

disability support service in Ireland. The services circulated an email to clients on their database, who consented to receive emails in relation to research projects, and prospective participants were emailed the study information sheet and consent form (Appendix G & H). Participants were invited to keep a diary of their experience of eye-contact for one week before the scheduled interview, to enrich the recall of the phenomenological aspects of eye-contact experienced immediately prior to the interviews.

Recruitment took place during the COVID-19 pandemic, and so data collection was conducted online using a live video interview. The interview schedule was uniquely developed by the researchers for the sole purpose of this study (Appendix I). Adaptations for conducting semi-structured interviews with autistic participants included piloting the interview schedule (Maloret & Scott, 2018; Tierney et al., 2016), and providing participants with an outline of topics to be discussed prior to the interview (Griffith et al., 2012; Huws & Jones, 2015; MacLeod et al., 2018; Petalas et al., 2015). Information on how to access the meeting was included in the information sheet, and participants received an email with a link to the meeting prior to attending. The interview was video recorded using the online software and transcribed by the first author. Interviews lasted an average of 51 minutes, with a range of 37-66 minutes.

Data Analysis

Data analysis was completed by the first author, and followed the seven sequential steps recommended by Smith et al. (2021). This involved reading and re-reading the transcripts, and then making ‘exploratory notes’ to capture descriptive, linguistic and conceptual aspects of the data. Experiential statements were then generated by analysing the exploratory notes of discrete chunks of transcript. The next step involved searching for connections across experiential statements, and producing a structure of the most interesting and important aspects of the participants’ account. Each cluster of experiential statements were then labelled as ‘personal experiential themes’ (PETs), and consolidated and organised in a table. This systematic process

of individual analysis was continued for all other participants. Finally, patterns of convergence and divergence were searched for across PETs to develop a set of 'Group Experiential Themes' (GETs), to highlight the shared and unique characteristics of the experience of eye-contact across all participants (Smith et al., 2021; Chen, 2022).

Validity and Quality Assurance

Nizza et al.'s (2021) guidance for researchers to produce excellence in IPA research was applied to ensure credibility and trustworthiness of the analysis.

Credibility of analysis was also ensured through a coding audit, which was completed by the second author in order to ensure that the exploratory notes, experiential statements and themes were grounded in the transcripts and the participants' reported experiences (Smith et al., 2021). Finally, the first author attended IPA meetings with the second author to discuss the methodology, and critically evaluate the analysis of a sample of transcripts.

Researcher Reflexivity

The first author kept a reflexive diary throughout the research process, and aimed to stay close to the meaning-making of each individual in order to offer insights into the participants' experience, while remaining aware of her identity as a non-autistic researcher.

Community Involvement statement

A member of the ASD community was consulted as an expert by experience to discuss the nature of the research and design of the interview.

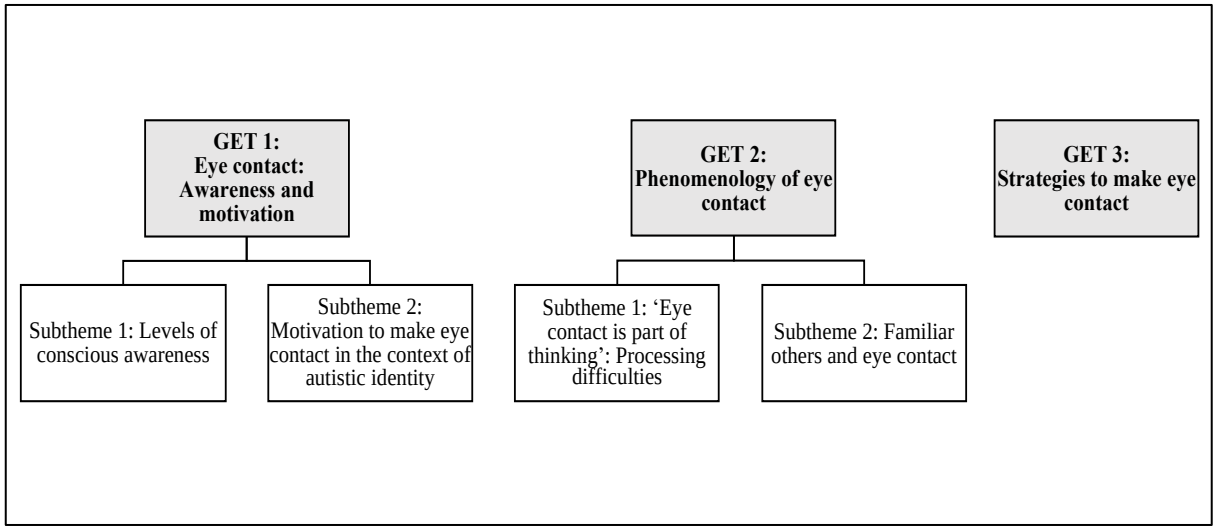
The outcomes of this study will be disseminated to the autistic participants who took part in this study.

Results

Analysis of the data produced three interrelated group experiential themes (See Figure 5.1). A table of GETs is presented in Appendix J.

Figure 5.1

Group Experiential Themes and Subthemes



GET 1: Eye-contact: Awareness and motivation

This GET reflects participants' levels of conscious awareness of the atypicality of their eye-contact, as well as their motivations to make eye-contact in the context of their autistic identity.

Subtheme 1: Levels of conscious awareness

For most participants, atypical eye-contact was experienced outside of conscious awareness, and entered into conscious awareness through feedback, discovery, or reflection. For example, Maria emphasised her lack of conscious awareness of eye-contact in the following statement 'for my personal case, we don't realise that we're not making eye-contact directly.' Maria's pronoun shift from the first person singular to plural, indicates an internal shift from focusing on oneself, towards a concern for autistic people as a collective group, suggesting that a lack of conscious awareness of eye-contact is understood by Maria to be a shared phenomenon. For Maria, atypical eye-contact is not something that she is typically cognisant of during social interactions, but it is brought into her awareness through her father's frequent feedback:

'I might not be looking directly in their eyes. But I don't realise that. I think,
if I'm looking at the person, I'm kind of looking up and down, or it's hard,
so I think my dad will always notice it.' (Maria)

Maria's ambivalent feelings towards feedback regarding her atypical behaviours was evident in her statement 'I'm quite glad he said it, but it is sometimes a bit hard to hear.'

Conversely, Shane and Lauren described their increased awareness of eye-contact following their ASD diagnosis: 'she just took out the form of traits, and what not, of Asperger's and I thought 'That sounds like that makes sense' [laugh]. And I guess that it wasn't until that that I thought 'Hold on, eye-contact!'' (Shane)

In his utterance, Shane exclaims his surprise in his words 'hold on, eye-contact!', suggesting that past experiences of eye-contact entered conscious awareness, and made 'sense' under the diagnosis of ASD. An increased awareness of eye-contact led to different internalised beliefs and emotional reactions. For example, following her diagnosis, Lauren felt that she would have to 'make sure that [she] was making some eye-contact'. Her assertation that she would have to 'make sure' indicates her belief that eye-contact is necessary in social interactions, while her use of the quantifier 'some' suggests that, despite its importance, eye-contact is experienced as an effortful task. Similarly, John experienced ambivalent emotions about his increased awareness of eye-contact after it was 'pointed out to him', as it provided him with both a framework of understanding, and also an internal pressure to conform; 'In some ways it was a revelation, and in some ways it was inconvenient [laugh].' (John)

On the other hand, Jason 'eliminated dairy' from his diet and became cognisant that he had not been making eye-contact up to that point. Jason understood the 'casein in dairy' as influencing his autistic traits, particularly his eye-contact, and described how he 'started to look people in the eyes' following his dietary changes. Jason's developmental understanding of eye-contact, and his sense of excitement about his new initiation of eye-contact was evident in his

use of simile, as he described this experience as akin to a 'child waking up to some sort of experience.'

Subtheme 2: Motivation to make eye-contact in the context of autistic identity

Participants' motivations to make eye-contact appeared to be influenced by their perceptions about ASD, and society's expectations regarding social communication. Participants spoke about intrinsic and extrinsic motivating factors. For example, for both Ryan and Jason, eye-contact was understood as a means of 'connecting' with others, in the context of their social difficulties associated with ASD. Using exercise as a simile, Ryan highlights the absence of his natural motivation to establish eye-contact, while also identifying the social reward that serves as a positive reinforcement: 'It's kind of like doing exercise, you never really want to do it but when you actually do it you feel better after doing it.' (Ryan)

While Jason also experiences a sense of 'connection' with others, he described an inner conflict between his desire to make eye-contact and his persistent struggle to maintain eye-contact on a multisensory level: ''If I look at people then I'm connecting more' and then another epiphany of like 'I can't look at people and talk to them meaningfully at the same time.'' (Jason)

Other participants were motivated to make eye-contact by a desire to 'fit in' and be 'normal'. This appeared to be influenced by their perception of ASD as a diverse spectrum of ability, in which autistic traits may differ according to where people exist on the spectrum. For example, Maria feels that her autism is not 'very bad', and does not want being autistic to 'define' her. She therefore attempts to camouflage her autistic traits in order to 'make friends'. Similarly, Jack described his social skills as 'stronger' in comparison to other autistic people he knows. His assertion that eye-contact is a 'required skill as a human' depicts his belief that eye-contact is expected from others during social interactions.

Conversely, three participants do not have an intrinsic motivation to make eye-contact, but rather engage in compensatory behaviours for external purposes, such as avoiding negative social outcomes. For example, Shane 'never saw much use' for eye-contact, and expressed his belief that it was unnecessary for communication, as he doesn't 'need to' make eye-contact with his autistic friends. Similarly, John perceives eye-contact to be for the 'benefit of neurotypicals', and highlighted that bi-directional differences in autistic and non-autistic behaviours can influence interpretations of reduced eye-contact, as it 'doesn't necessarily mean anything' if autistic people are not making eye-contact.

GET 2: Phenomenology of eye-contact

This GET describes participants' phenomenological experience of making eye-contact, including their processing difficulties and the experience of eye-contact with familiar and unfamiliar others.

Subtheme 1: 'Eye-contact is part of thinking': Processing difficulties

One of the most striking aspects of participants' accounts was their description of processing while trying to maintain eye-contact. All participants spoke about difficulties related to cognitive and social processing during social interaction. For example, Jason conceptualises social interaction as a 'multifaceted task', which echoes John's experience of 'decision work'. In general, participants referred to the challenge of 'multi-tasking' during conversation and difficulties processing multi-sensory components simultaneously: 'I might look at someone in the eyes for a few seconds but be able to say absolutely nothing, but then when I look away I can say it.' (Shane)

> 'being so focused on the other person takes a lot of effort. It's kind of- to just stay in conversation and not drift off into your own thoughts. Particularly when you are in conversation; you kind of think of something

you want to say- it's trying to focus on the person, and what they're saying, and maintain dialogue and be present, I think is something hard.' (Maria)

In these quotes, both Shane and Maria's description of competing cognitive demands during a social interaction implies that conscious eye-contact depletes their cognitive capacity to attend to other aspects of the conversation, such as thinking about what to say and focusing on the dialogue of their conversation partner. In her statement, Maria highlights the effort of not 'drifting off' into her thoughts, which indicates her natural tendency to focus on her own consciousness during social interactions. Ryan echoes this point, as he described eye-contact often feeling 'unnecessary' given he has 'thoughts in [his] mind that [he] like[s] to think about'. Shane's tendency to 'look away', implies that averting his gaze allows him to focus on his own thought process and preserve attentional and cognitive resources to maintain a social interaction. Indeed, many participants described averting their gaze in order to feel 'embodied' (Jason), 'tap into feelings and thoughts' (Jason), 'think of what to say' (John), and 'process what to do next' (Jack).

For some, eye-contact was also related to difficulties managing sensory input, as expressed by Shane 'looking someone in the eyes while speaking to them or listening to them cuts off my mental imagery as well as my ability to take in their words.' In his statement, Shane understands eye-contact as impeding his ability to engage meaningfully in conversation, as it 'cuts off' his ability to speak and listen to others.

All participants spoke about attempts to process social information during social interactions. This appeared to be a conscious attention to social information, which contrasts to the neurotypical experience in which this social information would be absorbed effortlessly and without conscious thought. For example, some participants looked towards the face in an attempt to gauge information about how they are performing socially, or make a social decision: 'You will look at that person to sort of, how much should I say? I might look at them

and try and gauge that.' (Maria). 'You're trying to get a hint of are they interested, or maybe facial expressions.' (Jack)

However, despite their efforts, some reported difficulties reading social information, such as body language (Kevin, John) facial expressions (Shane, Lauren, John), and inferring others' mental states (Kevin, John, Lauren), as expressed by John: 'But when I'm looking at somebody's face though, I'm thinking, I'm sort of thinking that a normal person could read a whole load of things by doing this, but I can't [laugh].' (John)

John demonstrates a self-reflexive process in which he considers his experience of eye-contact in relation to a 'normal person', which implies John's felt sense of being abnormal in struggling to interpret social information from the face.

In addition, three participants spoke about difficulties maintaining eye-contact in group situations given the increased cognitive demands of trying to manage interactions with multiple people, as highlighted by Kevin who feels that he 'gets lost' and 'can't keep [eye-contact] going.'

Subtheme 2: Familiar others mediating affective arousal and eye-contact

Many participants found that their experience of making eye-contact was dependent on 'how relaxed or stressed' they are (John). In particular, affective arousal levels appeared to be influenced by their familiarity with their conversation partner: 'I find…the more you know a person the easier it is to do eye-contact with them.' (Ryan)

Participants distinguished between their experience of making eye-contact with familiar and unfamiliar others. For most participants, eye-contact with familiar others was perceived to be easier due to a number of factors, including predictable emotional reactions (John, Maria), familiar others 'get' them (Maria; Sam), familiar others have no 'expectations' regarding eye-contact (Shane, John), and some participants identified the importance of close relationships (Shane, Jack), and having 'nothing to hide' (Kevin) with familiar others. The

conscious process of making eye-contact was experienced as being 'hard' (Maria), and a lot of 'work' (John). As such, John's sense making of eye-contact with familiar others is that he can 'turn the conscious bit off' and feel more 'relaxed', which denotes that reduced cognitive effort and decreased affective arousal positively influence his felt experience of eye-contact.

On the other hand, eye-contact with unfamiliar others increased levels of affective arousal in the context of being unable to read 'ambiguous' behaviour (John, Kevin), felt pressure to perform socially (Lauren, Kevin), and concerns of 'giving off a bad impression' (Maria). This experience of increased self-consciousness was echoed by Lauren and Jason who felt 'hyper-aware' when interacting with unfamiliar others, as illustrated in the following quote: 'I'd be looking at them, and then when they look at me it's like a reflex to just look away. Like I wouldn't continue looking at them.' (Lauren)

Lauren's description of her automatic reaction to 'look away' implies that she equates direct eye-contact with increased concern about how she is perceived by others, as she is 'worried what they would think' of her. For Jason, his felt experience of eye-contact is 'exponentially less laborious' following reductions in his 'social anxiety', implying the negative impact of heightened affective arousal on autistic peoples' efforts to maintain eye-contact.

GET 3: Strategies to make eye-contact

Participants demonstrated an awareness of the social function of eye-contact, such as conversational turn-taking, signalling an intention to communicate, and inferring how others are thinking and feeling. Thus, strategies were developed to try and cope in a social world.

Eye-contact required conscious thought and effort, and some participants described their attempts to manage appropriate eye-contact so that they were not 'staring', as highlighted by Maria: 'You just sort of look away 'cause you don't want to be seen as staring.'

By referring to herself in the second person, Maria creates an emotional distance from the content of her statement, in a possible attempt to relieve some of the shame that she experiences as a result of failing to meet the standards set by neurotypicals. Other participants employed compensatory behaviours in order to pass as 'normal' or benefit their conversation partner; for example, 'practicing' (Ryan), 'looking away occasionally to avoid staring' (John), looking in the 'general direction' of the eyes (Shane), and sitting at a 'perpendicular angle' to avoid direct eye-contact (Lauren). Shane described strategic use of eye-contact:

> 'I say in my core sentence whatever I have to say and then for a brief second, I slightly look them in the eye or I totally do. And that's not comfortable either but at least I've said what I needed to say.' (Shane)

In this excerpt, the negative impact that compensatory behaviours can have on autistic people is evident in Shane's experience of discomfort while trying to behave in line with societal expectations regarding eye-contact.

Conversely, both Ryan and Jason experienced adaptation following conscious attempts to establish eye-contact:

> **'**Before when I tried to make eye-contact I could do it almost too hard in a sense. But I can do it more, I can do it better now like. At first I was being kind of surgical with practicing it. Now it comes a bit more naturally to me.' (Ryan)

Both Ryan and Jason reported increased frequency of eye-contact over time, and described their awareness of 'eye colours' when establishing a direct gaze, which would suggest an intense fixation on the eyeball itself. Thus, while the frequency and their felt experience of eye-contact has changed over time, their descriptions suggest an atypical quality to their attempts at eye-contact.

While many described their attempts to make eye-contact, John believes that autistic people should have a 'choice' to attempt eye-contact, or receive intervention input: 'As long as it means having the option, I think [it] is good, right? I think it should be a choice, rather than something mandatory or drummed into people.' (John)

John's use of the phrase 'drummed into people' depicts a lack of agency for autistic people in making decisions for themselves, and his wish for autistic people to initiate and control their own actions relating to eye-contact is expressed through his words 'option' and 'choice'.

Discussion

The aim of this study was to explore autistic people's experiences of eye-contact, using an IPA qualitative methodology. The analysis revealed three interrelated GETs: Eye-contact: Awareness and motivation, Phenomenology of eye-contact, and Strategies to make eye-contact. The GETs are discussed below to consider how the current findings relate to, and expand upon existing knowledge.

Consistent with experimental eye-tracking research (Chita-Tegmark, 2016; Frazier et al., 2017), participants in this study experienced atypical eye-contact, characterised by unusual eye-contact patterns, and reduced attention to the eyes. Participants experienced various levels of conscious awareness of eye-contact, and most participants became aware of their differences in eye-contact over time, either through feedback, prior to diagnosis, or through the process of increased self-awareness, suggesting that avoidance of direct gaze was not initially occurring on a conscious level. This finding is consistent with eye-tracking research, in which an absence of preferential unconscious processing of direct gaze has been observed (Akechi et al., 2014; Madipakkam et al., 2017). The emotional valence associated with increased awareness of eye-contact is important, as it provided some participants with a framework for understanding and

a sense of determination in developing this skill, while others felt a heightened pressure to conform, indicating their awareness of societal expectations regarding mutual eye-contact.

The findings from this IPA study also contribute to existing qualitative research exploring the way in which autistic people experience and manage social interactions. For example, a recent study exploring autistic people's experience of speech perception identified contributing factors to speech perception difficulties, including acoustic and non-acoustic factors such as multi-sensory processing and social cognition. The study also reported the social, emotional, and practical impact of speech perception difficulties on participants, and identified deliberate and reflexive coping mechanisms that were employed, such as self-awareness and self-advocacy, communication tactics, and developing auditory skills (Sturrock et al., 2022). Furthermore, another qualitative study identified camouflaging behaviours used by autistic adults in everyday social interactions, including masking, superficial social engagement, communicating in line with non-autistic norms, and active self-presentation (Cook et al., 2021). Thus, the current study contributes to the growing body of qualitative research exploring autistic people's first-hand experience of social interaction.

In the current study, participants reported motivations to make eye-contact, that appeared to be largely influenced by their perceptions of autism, and a social expectation from the general population. While most participants held an understanding of non-autistic peoples' value of eye-contact, some felt that eye-contact was 'unnecessary', and was 'not need[ed]' in order to communicate with other autistic people. This is consistent with previous qualitative literature highlighting that autistic peoples' interactions with each other are fundamentally different to interactions with non-autistic others (Crompton et al., 2020). However, despite these beliefs and consistent with previous research, many participants reported camouflaging their atypical eye-contact, by masking, or adopting compensatory strategies. The tendency for autistic people to modify their social behaviours and autistic traits in order to adapt or cope

within a social world has been found in other studies (Cook et al., 2021; Hull et al., 2017). In the current study, some participants were internally driven to make eye-contact in order to establish specific goals, such as friendships, or to appear 'normal', particularly those participants who perceived autism as a spectrum of varying ability. However, others felt resigned to engage in camouflaging behaviours due to external demands of how a person should behave in society, despite their autistic identity. This is important, as the negative impact of continuous camouflaging on autistic peoples' well-being has been widely documented (Hull et al., 2017; Tierney et al., 2016).

Consistent with previous qualitative findings, some participants reported an awareness of 'staring' during social interactions (Trevisan et al., 2017). Participants employed conscious masking strategies, such as looking away, in order to avoid engaging in this behaviour. A tendency to stare during social interactions may support the hypoarousal model, as some participants do not naturally gauge when to look away from the eyes, but instead rely on conscious thought and effort (Trevisan et al., 2017).

Several participants also engaged in compensatory strategies to appear neurotypical in certain contexts. However, there is ample evidence to suggest that autistic people who engage in compensatory behaviours remain autistic at the cognitive level (Livingston et al., 2020). Indeed, many participants reported the psychological and emotional impact of employing compensatory strategies, including on the ability to process information, and some described the process of making direct eye-contact as effortful. Conversely, some participants described remediation of their difficulties with eye-contact, in which they experienced more frequent and comfortable eye-contact. However, their descriptions of mutual eye gaze suggest an unusual quality to their eye-contact persisted. It is plausible that with repeated efforts to establish direct eye-contact, these participants experienced a reduction in physiological arousal, and increased social rewards over time. Therefore, this improvement in the participants' felt experience of

eye-contact may not reflect alterations or alleviations of underlying cognitive deficits, but rather, the participants' enhanced experience of making eye-contact (Livingston et al., 2019).

During conversation, the participants used eye-contact to monitor the other person's availability, interest, reactions and emotions. However, participants experienced specific cognitive activity that influenced their phenomenological experience of eye-contact during social interactions. Consistent with other qualitative reports (Trevisan et al., 2017), participants described difficulties multi-tasking, and processing information from multiple sensory modalities at one time, particularly maintaining eye-contact, while listening or speaking to others. Indeed, multisensory integration difficulties, particularly pertaining to audio-visual integration, have been identified in ASD (Feldman et al., 2018). In the current study, participants reported their tendency to 'look away' in order to process information or think about what they will say. This is consistent with experimental research in which both autistic and non-autistic people showed increased attention to their conversation partner's eyes when listening, rather than speaking, suggesting that autistic and non-autistic participants could modulate their social attention depending on conversational phase (Freeth & Bugembe, 2019). Averted gaze during conversation may be explained by the 'cognitive load hypothesis', in which gaze aversion is understood as a cognitive control strategy that is used by both typical and atypical populations in complex interactions (Doherty-Sneddon et al., 2013). Therefore, in the current study, participants' tendency to avert their gaze during conversation may serve a cognitive and social function, as they can focus on their internal processing, and reduce the cognitive load of attending to each aspect of the social interaction.

In addition to more general cognitive processing, social processing differences have also been identified as a reliable feature of ASD (Frazier et al., 2017). Indeed, some participants experienced difficulties mentalising and gauging social information from the face, suggesting that social processing difficulties may influence their experience of eye-contact. This was

experienced as distressing and frustrating by most participants, and echoed findings from previous qualitative work, in which autistic people understood that social information could be obtained from the eyes, but they personally could not detect (Trevisan et al., 2017). This finding is consistent with the mindblindness model (Baron-Cohen, 1994), which postulates that a difficulty with inferring mental states of others is associated with atypical eye-contact.

Participants also described a distinct phenomenological difference when making eye-contact with familiar and unfamiliar others. Some participants felt it was more 'comfortable' to make eye-contact with familiar others, as they could predict their emotional responses, as opposed to the 'ambiguous' behaviours of unfamiliar others. Thus, eye-contact with unfamiliar others was experienced as more cognitively effortful, but appeared to be mitigated when interacting with a familiar social partner. Previous research has found that emotional processing difficulties observed in ASD may be mediated by familiarity (Nuske et al., 2014). Therefore differences in participants' felt experience of making eye-contact with familiar and unfamiliar others may be a result of more frequent emotional learning opportunities that comes from familiar others, that may not generalise to unfamiliar people.

Heightened self-consciousness and increased awareness of autistic traits was another factor influencing the felt experience of eye-contact with unfamiliar others. Self-consciousness requires an understanding of the self in relation to external standards, as well as an appraisal of how one's behaviour is evaluated by others (Davidson et al., 2017). Recent qualitative research found that autistic people became aware of their minority status when interacting with non-autistic peers (Crompton et al., 2020), and autistic people have been found to resemble non-autistic people in their susceptibility to social desirability and self-enhancement (Gernsbacher et al., 2020). Therefore, while some participants described increased physiological activity in response to direct eye-contact, it is plausible that interacting with unfamiliar others induces

feelings of shame, and anxiety, which ultimately influences levels of affective arousal in response to direct gaze.

Limitations and directions for future research

Several limitations should be considered in the interpretation of this study's results. Here, we included participants with no ID to ensure relative homogeneity of the sample as is required in IPA studies. Therefore, future research may consider using more flexible methodologies in order to consider the experiences of less cognitively able autistic individuals (Leedham et al., 2020).

In the context of COVID-19, the interviews were conducted online, which had implications for the researcher forming an impression of participants' use of eye-contact during the interview.

Although meaningful and rich data was obtained from participants using IPA methodology, challenges with language difficulties were noted, and some participants demonstrated limited capacity to introspect on their thoughts and feelings, and articulate their emotional or physiological experiences. Therefore, future research may consider interviewing both autistic participants and a close relative or partner, in order to integrate a first and third person perspective on eye-contact. Future research may also gather additional demographic information, including socioeconomic status and educational attainment level, in order to consider individual factors that may influence participants' experience of eye-contact.

Conclusion

The findings of this study reflect the heterogenous phenomenological experiences of eye-contact among a sample of autistic adults. Based on the findings, eye-contact is often a conscious process, and many employ camouflaging strategies to mask or compensate for their atypical eye-contact. However, despite their best efforts to make eye-contact, factors such as cognitive and social processing difficulties appear to inhibit effective eye-contact. This has

implications for psychological intervention, as it suggests that other cognitive processes may need to be targeted concurrently. Additionally, autistic individuals should be afforded the 'choice' to make eye-contact. This is consistent with the neurodiversity movement, which advocates the development of a diversity-valuing society (Cage & Troxell-Whitman, 2020) in which autistic people feel safe to express their autistic traits, and not a pressure to conform.

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Chapter 6: Supplementary Information for Major Research Project

Research Design

Qualitative methodology Frameworks

Qualitative research methodologies aim to explore and understand the meanings people assign to their experiences (Tuffour, 2017). That is, qualitative paradigms allow researchers to develop an idiographic understanding of participants, and what it means to them, within their social world, to live with a particular situation or be in a specific situation (Bryman, 1988). In this way, qualitative research affords participants the opportunity to 'speak in their own voices', and consequently present their experiences from their own perspective (Grypdonck, 2006; O'Day & Killeen, 2002, p.10)

Qualitative methodologies tend to be concerned with the 'what', 'why' and 'how' questions, as opposed to the questions of 'how much' and 'how many' preferred by quantitative approaches. Thus, the objective of qualitative research is to provide rich descriptive accounts of the phenomena under investigation, rather than predict (Pietkiewicz & Smith, 2014; Tuffour, 2017; Willig, 2008). The research questions determine the data collection method, and data is subsequently analysed inductively to explore meanings that participants assign to their experiences. Furthermore, a qualitative approach is suitable when an in depth view of a phenomenon is required to explore a complex process, and to elucidate the multifaceted nature of human experience (Tuffour, 2017).

Interpretative Phenomenological Analysis

Interpretative Phenomenological Analysis (IPA) is a qualitative research approach that examines how individuals make meaning of their life experiences (Pietkiewicz & Smith, 2014). As previously mentioned, IPA draws upon concepts from three key areas of philosophy of knowledge: phenomenology, hermeneutics and ideography (Smith et al., 2021).

Phenomenology is a philosophical approach to the study of experience (Smith et al., 2009). Hence, IPA aims to identify the essential component of phenomena or experiences that make them unique or distinguishable from others (Pietkiewicz & Smith, 2014). In order to disengage from activity, and become focused on the experience, Husserl (1927), founder of phenomenology, stated that individuals must step outside of their 'natural attitude' and adopt a 'phenomenological attitude'. In this way, one must avert their gaze from objects in the world, and direct it inwards, towards one's perception of those objects (Smith et al., 2009, p.12). Phenomenological studies therefore focus on how individuals perceive or talk about experiences or events, rather than describing phenomena according to a predetermined categorical system, and scientific criteria (Pietkiewicz & Smith, 2014). Husserl (1927) asserted that in order to achieve a 'phenomenological attitude', the researcher must 'bracket' or put to one side, their presuppositions and judgements, and allow the phenomena to speak for themselves (Pietkiewicz & Smith, 2014). While bracketing is an attempt to assess the data in its purest form, it is acknowledged that bracketing can never be fully achieved (Morrell-Scott, 2018).

IPA is also underpinned by hermeneutics, which refers to the theory of interpretation. In contrast to the descriptive phenomenology of Husserl; Heidegger, a hermeneutic phenomenologist, asserted that the worldly and embodied nature of our existence, shapes our interpretation of the world. In this way, phenomenology is a 'situated enterprise' (Larkin & Thompson, 2011, p.103). Therefore, consistent with Heidegger's views, IPA considers phenomenological inquiry as an interpretative process (Shinebourne, 2011). Thus, hermeneutics does not subscribe to a straightforward bracketing process, but rather considers bracketing as a cyclical process between the interpretative work and the researcher's fore-conception (Smith et al., 2009).

The hermeneutic circle is another resonant idea within hermeneutic theory. The hermeneutic circle implies that understanding the text as a whole, requires an understanding of the parts of the text; and similarly, to understand the parts of the text, one must look to the whole text. In this way, the process of IPA analysis is iterative, as the researcher moves back and forth through a number of different ways of thinking about the data, rather than following a linear process (Smith et al., 2009). The IPA analytic process is also often described as a 'double hermeneutic', as the participants attempt to make sense of their world, and the researcher attempts to make sense of the participants' attempts to make sense of their world (Pietkiewicz & Smith, 2014; Smith et al., 2009). There are two primary interpretative stances; the hermeneutic of empathy, and the hermeneutic of suspicion. Hermeneutics of empathy attempt to reconstruct the original experience in its own terms, while the hermeneutics of suspicion adopt a questioning approach, that involves a move away from representing what the participant would say themselves, and move towards the interpretative work of the researcher. IPA adopts a centre-ground position, that aims to combine an empathic stance with a hermeneutic of suspicion (Smith et al., 2009).

Finally, IPA is idiographic in its approach. In this way, IPA aims to elucidate in-depth, nuanced analyses of individual instances of lived experience (Pietkiewicz & Smith, 2014; Smith et al., 2009). The fundamental principle behind an idiographic approach is to complete a detailed analysis of one case, until a degree of gestalt has been achieved, and then move to an equally attentive exploration of the second case, and so on (Pietkiewicz & Smith, 2014; Smith, 2004). Therefore, a small purposive small sample is required in order to complete a detailed analysis associated with IPA (Smith, 2004). The design of this study was consistent with IPAs' philosophical foundations (Chen, 2022).

IPA in Autism Research

In addition to exploration of the individual experience, IPA also encourages exploration of how this experience is contextualised by society, historical influences, and dominant cultural forces. This would appear relevant to autistic individuals, whose difficulties are often defined within a social context, and the impact of these difficulties are often assessed from the outside, in terms of how their behaviours influence the environment, rather than exploring how the environment affects the individual (MacLeod, 2019). IPA views participants as experts of their own personal and social worlds (Howard et al., 2019). Thus, IPA has been deemed an appropriate mechanism to gain insight into autistic people's experiences (MacLeod, 2019).

As mentioned in the empirical paper, a recent review validated the use of IPA in autism research, as it emphasised features of the methodology that help to illuminate the experiences of autistic participants, including researcher reflexivity, and its treatment of participants as experts (Howard et al., 2019). The double-hermeneutic in IPA was understood as a methodological strength, that was compared to the 'double empathy problem' (MacLeod, 2019; Milton, 2012). While the double-hermeneutic acknowledges the participant's and researcher's different perspectives and experiences of the world in general, the 'double empathy' paradigm asserts that any fundamental differences between the autistic participant and non-autistic researcher can be best understood as a mutual problem, rather than being entirely located within the autistic individual (MacLeod, 2019).

A recent systematic review also deemed IPA a useful and appropriate participatory method to consult with autistic participants. Participatory elements included co-construction of the interview schedule, credibility checking with participants, and offering alternative forms of participation and help to prepare for research interviews (MacLeod, 2019). Howard and colleagues (2019) found that semi-structured interviews were the most common method of data collection employed when using IPA with autistic participants, and identified adaptations made

for autistic participants, such as using concrete examples (Howard et al., 2019; Tierney et al., 2016).

Rich data is often required for phenomenological research as it allows for encompassing true thoughts and perspectives of participants. In the current study, participants were invited to keep a diary of their experience of eye-contact for one week before the scheduled interview. Diaries have been supported as an effective tool in phenomenological research, as they allow for self-expressed thoughts that the participant feels are pertinent to note in relation to their experience of the phenomenon and improve peoples' ability to recall the phenomenon of interest in detail (Tierney et al., 2016). During interviews, recall or memory of retrospective events can inhibit accessing accurate data. Thus, diaries have been claimed to facilitate hard to observe phenomena (Alaszewski, 2006, 2011; Morrell-Scott, 2018). The use of diaries as a complementary tool alongside interview has been reported in another IPA study with autistic participants. The researchers stated that the use of diaries afforded the participants greater time for reflection, as well as facilitating access to personal information, that may not emerge in an interview context (Humphrey & Lewis, 2008).

While IPA was recognised as offering valuable insights into the lived experiences of participants, IPA's focus on language as a medium of expression can pose a challenge among autistic participants (Howard et al., 2019). For example, Dewinter and colleagues (2017) reported that limited expressive language and overly formal language of some of their participants' limited the richness of their data. Therefore, it is likely that IPA's methodological framework may not be appropriate for some autistic participants, given the reliance on spoken language. As such, other creative and visual methods may be considered, in order to capture the experience of autistic individuals with language difficulties (Howard et al., 2019).

Rationale for Methodology

Critical realism is the theoretical stance that reflects my own epistemological stance in relation to this research project. A critical realist stance assumes that while there is one reality, there are many different interpretations of that reality (Botha, 2021). Thus, from this perspective, no person can have a complete understanding of reality; rather, one's understanding of the world is interpretative, rather than representational (Maxwell, 2012). In this way, one only has access to events that exist in reality through a particular lens, that is, through the particular perspective of the individual describing the event, and at a particular place and time (Forrester & Sullivan , 2018). Thus, the research question was formulated to reflect this epistemological position.

The aim of this study was to explore how autistic participants experience and make sense of their use of eye-contact. Thus, a qualitative in-depth account of people's phenomenological experience of eye-contact was sought in order to answer this research question. In light of the present study's aims, IPA was selected as the most appropriate methodology, as it engages with individuals' reflections of their unique lived experiences and explores how people make sense of them (Larkin & Thompson, 2011; Smith et al., 2009). Given the dearth of qualitative research exploring autistic people's experience of eye-contact, including the individual voice of autistic participants was considered important, to gain a nuanced and detailed account of their experience.

When selecting a qualitative method, thematic analysis (Braun & Clarke, 2006) was also considered, as it was found to be the primary qualitative method in a meta-synthesis of the lived experience of autistic people (DePape & Lindsay, 2016). However, IPA's focus on phenomenology allowed for exploration of autistic participants' sense-making in relation to eye-contact. Furthermore, IPA's idiographic approach allows a detailed focus on the particular, and ensures that any generalisations are grounded in this (Willig & Stainton-Rogers, 2017).

Sampling

In line with IPA methodology, purposive sampling was utilised in the current study. Purposive sampling involves selection of a defined group of participants, for whom the research question has personal significance and relevance (Pietkiewicz & Smith, 2014; Smith et al., 2009). This was established through inclusion and exclusion criteria, in order to achieve a specific and fairly homogenous sample. The degree of specificity of the sample is dependent on the phenomena under investigation. Research questions that are less specific, may draw samples from a population with similar demographics (Noon, 2018). In the current study, inclusion criteria specified that participants had to be over eighteen years of age or older and have no intellectual disability (ID).

Qualitative researchers typically use a small selective sample, because the focus should be on the depth rather than breadth of the study (Smith et al., 2009). Smith and colleagues (2009) assert that a sample size between four and ten is optimal for doctoral level. The current study recruited a sample of nine participants.

Recruitment

As previously mentioned, participants were recruited from an ASD support service and a disability support service in Ireland. Participants' date of birth was confirmed before commencing the interview, and participants were asked to sign an electronic consent form that confirmed they have a diagnosis of ASD and that they were eighteen years old or older. Recruitment took place between September and October 2021. In keeping with the IPA methodological framework, recruitment stopped once a degree of saturation was achieved.

Data Collection

Method

According to Smith and colleagues (2009), IPA is best suited to a data collection method that will encourage participants to provide a rich and elaborate, first-person account of

their experiences. Semi-structured interviews were selected as an appropriate method of data collection for the current study, as they elicit 'stories, thoughts, and feelings' about the phenomenon in question (Smith et al., 2009, p.56), and have been utilised in other IPA studies with autistic participants (Howard et al., 2019). Participants were also invited to keep a diary of their experience of eye-contact prior to attending the interview, which was not subject to data analysis.

Interview Schedule

The semi-structured interview comprised of eight open-ended questions that were formulated to answer the research question pertaining to the participants' experience of eye-contact. IPA requires richness and depth of individual experience (Noon, 2018). Therefore, prompts were prepared to further elicit information if the participants' response to initial questions were insufficient. While constructing my schedule, one interview technique I drew upon was 'funnelling'. Funnelling requires that the interview schedule begins with more broad questions, to enhance memory recall and obtain as much information as possible, and then gradually moves towards a more specific line of questioning (Noon, 2018). The interview schedule was piloted with my research supervisor and re-drafted as appropriate. According to Smith et al., (2009), the range of topics selected should serve as a navigating tool throughout the interview. However, the primary role of the researcher during the interview is that of an 'active listener', which may involve moving away from the research schedule and following the concerns of the participant (Smith et al., 2009).

Procedure

Interviews were conducted on Microsoft Teams, which is University College Cork's preferred online secure platform. Microsoft Teams includes a video recording feature that was used in order to record the interview. Prompts related to the interview questions were provided on the information sheet to assist with the reflective experience. Prior to commencing the

interview, I reviewed the information sheet and confirmed participants' consent to proceed with the research. Participants were invited to ask any questions pertaining to the study both before and after the interview. Participants were asked whether they had decided to keep a diary of their experiences, and if so, were invited to share any observations or notes that they had. In order to avoid disrupting the flow of participants' narratives during the interview, I made a short note of key words or topics to return to, in order to explore particular experiences in greater detail. Following each interview, I recorded my observations and impression of each participants' eye-contact to aid with the data analysis.

COVID-19 Impact Statement

In light of the COVID-19 pandemic, interviews were conducted online. In October 2020, I initially applied for ethical approval for both online and face-to-face data collection methods, depending on COVID-19 guidelines at the time of data collection. I hoped to conduct face-to-face interviews to build rapport, and to gain an impression of participants' eye-contact and other non-verbal behaviours during the interview. However, as COVID-19 restrictions continued, I amended my ethics form in June 2021 to seek approval for online data collection only, in line with UCC, HSE, and National guidelines at the time.

I opted for video-calls in place of telephone calls, as this method provided both me and the participant a synchronised experience of both seeing and hearing one another (Krouwel et al., 2019). At the time of data collection, I had experience of using video software to deliver tele-health interventions to clients in the context of a secondary mental health service. This allowed me to use the mode comfortably, and possibly aided in developing rapport with participants, particularly with those participants who were not familiar with video-platforms. The online method made it difficult to form an accurate impression of participants' eye-contact, as making eye-contact on screen requires the user to look off centre to appear to be making eye-contact, as a result of the positioning of the camera (Krouwel et al., 2019).

While most participants' reported that they had previous experience of using video platforms in the context of COVID-19, I was concerned about technical difficulties causing disruption to the interview process. Kevin found it stressful to connect to the on-line platform, and so took some time to settle into the interview process as a result. Jack's interview was disrupted by poor connection, and I had to ask him to repeat himself on several occasions in order to capture what he was saying. Despite these minor technical difficulties, they did not appear to excessively disturb the interview process, and no interviews were aborted due to technical issues. Several participants commented that they were happy to contribute to autism research, and were satisfied with the online interview method.

Data Analysis

IPA analysis has been described as an 'iterative and inductive cycle' (Smith et al., 2021, p.65). Below, I outline the analytic process I followed, as recommended by Smith et al, 2021. An example transcript with exploratory notes, and developed PETs are presented in Appendix K and L respectively.

Step 1

I immersed myself in the data by reading and re-reading the transcripts and listening to the video recordings of participants' interviews while reading the transcripts, in order to imagine the voice of the participant in subsequent readings of the transcript.

Step 2

The next step involved exploratory notes, and examination of participants' semantic content and language use. At this stage of analysis, I endeavoured to maintain an open mind, in order to produce a comprehensive set of notes about each transcript (Smith et al., 2009). Commenting occurs at three levels; descriptive, linguistic, and conceptual. Descriptive comments describe the content of what the participant said, and includes key words, phrases, emotional responses, and idiosyncratic figures of speech that reflect the participants'

understanding of things that matter to them (Smith et al., 2021). Linguistic comments explore the participants' language use, that may contribute to the researcher's overall understanding of the participants' experience. Language features include metaphor, pronoun use, repetition, tone and degree of fluency. Finally, the third level of annotation involves conceptual comments that are interpretative. This involves a shift away from the explicit claims of the participant, and towards a more questioning stance. An element of personal reflection was involved at this stage of coding, as I drew on my own experience and knowledge to inform my line of questioning (Smith et al., 2021). Throughout this stage of the analysis, I used a paper copy of the transcript and colour coded the various levels of commenting, including descriptive content (black pen), linguistic features (blue pen), and conceptual content (red pen).

Step 3

Using a paper copy of the transcript, I developed experiential statements to reflect the participants' experiences, or their experience of making sense of things that have happened to them (Smith et al., 2021). This step involved a shift towards working primarily with the comprehensive exploratory notes, which remained closely related to the original transcript. Construction of experiential statements involved focus on discrete chunks of transcript and exploratory notes, and transforming these notes into a 'concise and pithy summary' of what was crucial at particular points in the text. Experiential statements were expressed as brief phrases, that reflected the experiential core of the piece of text, and indicated both the participants' words, and my interpretation. This stage of the analysis represented the hermeneutic circle, as my knowledge of the whole transcript, influenced my interpretation of specific parts (Smith et al., 2021).

Step 4

The next step involved the identification of connections across experiential statements. For the first participant, I cut up each experiential statement onto a separate piece of paper, and

included the transcript page after each statement. I randomly distributed all of the experiential statements on the floor, in order to facilitate a search for a more conceptual ordering (Smith et al., 2021). I looked across the statements, and moved them around so that statements that were related were clustered together. I explored different possibilities of arranging clusters of statements, in order to keep an open mind, and view clusters in novel ways. Experiential statements were clustered using different organising devices, including similarity, in which sub-themes comprised highly related experiential statements, and polarisation, where contradictory or contrasting statements were brought together to highlight contrasting aspects of the experience. I also stacked experiential statements that had an identical meaning on top of the other, to highlight the recurrence of the experience by the items in the stack. Through this process, I constructed a pattern of experiential statements that produced a structure of the most intriguing and important aspects of the participants' experiences (Smith et al., 2021). An example of this manual process of searching for connections across experiential statements is demonstrated in Appendix M.

Step 5

Following the clustering of experiential statements, I labelled these connections as 'Personal Experiential Statements' (PETs). The themes are 'personal' as they relate to the individual, and 'experiential' as they relate directly to the participant's experience, or their experience of sense-making (Smith et al., 2021). This organisation of themes is recognised as a creative process, and shifts the analysis to a higher level (Smith et al., 2021). Inter-related clusters were brought together into larger groupings, and named as a 'PET'. Each of the smaller clusters was then labelled as a sub-theme of the PET. I presented these PETs in a table for each participant. The PETs were presented in bold upper case, and the PET's were divided into sub-themes, whose titles were presented in lower case bold. Under each sub-theme, the set of

experiential statements that were brought together to develop the theme were presented (Smith et al., 2021).

Step 6

This step involved moving to the next participant's transcript to continue the process above, and so on (Smith et al., 2021). In keeping with IPA's idiographic commitment, I was cautious about treating each case in its own terms at this stage of the analysis, and allowing new 'analytic entities' to emerge in each case (Smith et al., 2021, p.99). I was aware that my fore-structures had changed following completion of my first transcript, and therefore attempted to bracket my ideas, assumptions, understandings, and themes based on what I had already found. Given my sample size and the limited time frame to conduct the analysis, the manual method of organising experiential statements and PETs was deemed to be a time consuming task. Therefore, for subsequent cases after the first participant, I used QSR NVivo software for the process of clustering and compiling experiential statements and PETs. This software closely mimicked the manual process, as I could move the material flexibility into different folders.

Step 7

The final step involved searching for patterns of divergence and convergence across the PETs, to create a set of 'Group Experiential Themes' (Chen, 2022; Smith et al., 2021). Rather than attempting to present a 'group norm' of the experience of eye-contact, I aimed to highlight both the unique and shared experiences of eye-contact across participants. In order to do this, I looked across the PETs, to identify connections across cases. This was a dynamic process involving different levels of comparison, as I moved back and forth between PETs, sub-themes, and experiential statements. Each GET was supported by experiential statements, reflecting the participants' experiences. GETs were labelled and I developed a table of GETs in order to demonstrate relevant experiential statements from contributing participants. Smith et al.,

(2021) suggest that for professional doctoral theses involving larger samples, a GET may be considered if it is present in at least half of the participants' interviews. They also assert that larger samples may make it difficult to reflect as much idiographic detail and divergence within the data set. Thus, they emphasise that there may be an emphasis on the shared elements in GETs in this case. The analysis remains true to IPA methodology, as the GETs and sub-themes are still illustrated by specific examples from the participants (Smith et al., 2021).

Reflections on Methodology

While rich and meaningful data was obtained through IPA methods, I reflected on my experience of the research process from an IPA perspective.

While the use of diaries was a methodological strength in the current study, only two participants prepared notes prior to the interview. Rich data is required for phenomenological research. However, some participants demonstrated difficulty identifying emotions and specific thoughts, and responding to open-ended questions that they had not prepared for. Furthermore, a number of participants were observed to speak in the second-person, with frequent use of the pronoun 'you', and provided general rather than specific examples of their experiences.

As previously mentioned, language difficulties have been identified as a challenge to IPA research. In the current study, some participants demonstrated expressive and pragmatic language difficulties. I was therefore cautious in how I inferred meaning from language use, and wondered whether the participants' language difficulties made it more challenging to access their experiential worlds. In particular, Sam was observed to struggle to interpret and respond accurately to the questions. Therefore, alternative, and more creative approaches to data collection may be more appropriate for participants with language difficulties and more severe symptoms of ASD. Nonetheless, data in this study was reported in the form of first-person quotes, reflecting participants' views.

Ethical Considerations

Ethical Approval

This study received ethical approval from the UCC Clinical Psychology Research Ethics Committee.

Informed Consent

Participants were provided with an electronic version of the information sheet prior to attending the interview, outlining the purpose of the research, as well as informing them of their rights regarding participation. During the interview, participants were given the opportunity to ask questions or express any concerns about the research. Participants signed an electronic consent form and returned the form via email.

Anonymity

All data gathered for the purpose of this research was anonymised. Participants were assigned a pseudonym, which was utilised throughout the research process. Any references to specific locations or persons that might compromise anonymity was removed from the interview transcripts.

Participant Well-being

No negative outcomes were anticipated as a result of participating in this research. Nonetheless, participants were informed of their right to withdraw from the study should they wish, and were advised to liaise with the organisation from which they were initially recruited in order to receive additional support should they experience distress following the interview. Participants were also provided with contact information for other community support services, including the Samaritans and the UCC Counselling Services.

Data Storage

The original video recordings have been deleted, and the transcripts are stored on the secure UCC OneDrive for a minimum of ten years.

Validity and Quality Assurance

Four principles of quality assurance underpinned the current study, consistent with Nizza et al.'s (2021) latest guidance for researchers' to produce excellence in IPA research. The four quality indicators include: (1) constructing a compelling, unfolding narrative, (2) developing a vigorous experiential and/or existential account, (3) close analytic reading of participants' words, and (4) attending to convergence and divergence (Nizza et al., 2021).

The first criteria, *constructing a compelling, unfolding narrative,* refers to the analysis telling a coherent and persuasive story. This operates both within and across themes (Nizza et al., 2021). In the current study, each GET conveyed carefully selected participant quotes, and interpretation of these accounts. A narrative was generated by illustrating a specific point with each quote, and using additional quotes to offer different perspectives. Across GETs, a sense of coherence was established by ensuring that all of the GETs contributed to the overall narrative around autistic peoples' experience of eye-contact in an interconnected way (Nizza et al., 2021).

Nizza and colleagues' (2021) second criteria, *developing a vigorous experiential and/or existential account,* refers to a focus on the important experiential meaning of participants' accounts, in order to give depth to the analysis. In the current study, I paid close attention to the experiential significance of participants' accounts, by paying particular attention to their meaning making. For example, in the GET 'motivations to make eye-contact', the experiential significance of being motivated to make eye-contact in the context of their autistic identity was evident in participants' accounts, and was revealed through data from the participants, and my interpretative analysis of the participants' experiences, (Nizza et al., 2021).

The third criteria, *close analytic reading of participants' words*, reflects IPA's commitment to interpretation and ideography (Nizza et al., 2021). Thus, in the current study, quotes were analysed and interpreted, to elaborate the way in which each participant made

sense of their experience of eye-contact. This process reflected the hermeneutic circle, as I simultaneously focused on each individual quote, while also considering the quote in relation to the wider transcript. I also examined linguistic features of quotes, including repetition, pronouns, metaphor, and particular words or phrases, which helped to reveal a deeper significance of the participants' experience of eye-contact (Nizza et al., 2021).

The final criteria, *attending to convergence and divergence,* identifies similarities and differences between participants (Nizza et al., 2021). In the current study, a balance between commonality and individuality was sought, by generating GETs across the participants, such as phenomenology of eye-contact, while also presenting converging and diverging quotes, in order to convey how different participants may interpret the same experience in different ways. This step also reflected the hermeneutic circle of moving between parts and the whole, as I considered individual personal quotes in the context of the wider personal narrative, and I also considered the experience of one or more participants in the context of the wider groups' experience (Nizza et al., 2021).

Validity of the current study was also enhanced through consultation with my academic supervisors. As mentioned in the empirical paper, one of my academic supervisors completed a coding audit to ensure validity in relation to the text being examined (Smith et al., 2009).

Subjectivity and Reflexivity

Reflexivity has been emphasised as an essential element of qualitative research, given the researcher's mediating role in analysing and interpreting the data (Willig & Stainton-Rogers, 2017). Reflexivity has been defined as 'a set of continuous, collaborative, and multifaceted practices through which researchers self-consciously critique, appraise, and evaluate how their subjectivity and context influence the research processes' (Olmos-Vega et al., 2022, p.2). Four interacting dimensions of reflexive processes have been identified, including personal, interpersonal, methodological, and contextual factors (Olmos-Vega et al.,

2022; Walsh, 2003). In the context of autism research, increased reflexivity on the part of the researcher has been emphasised, in order to acknowledge the potential impact of their own experiences and preconceptions on the research (Howard et al., 2019). Below, I provide an example of some of my reflexive practices throughout the research process.

Prior to the IPA data analysis, I completed a systematic review exploring autistic identity, which involved thorough reading of the literature relating to autistic peoples' perceptions and understandings of ASD. As suggested by Smith and colleagues (2009), the first crucial step in my personal reflexivity required me to 'bracket' my understandings and expectations based on my prior knowledge, in order to minimise the impact of subjectivity on the process of data analysis, and the identification of personal and group experiential themes. Throughout the research process, I maintained a reflexive journal to document my subjective views, emotional reactions and judgements as they arose throughout the interviews and the data analysis process. By documenting these biases and observations in my reflexive journal, I developed an increased conscious awareness of any active interpretations or fore-conceptions, and had the opportunity to discuss these biases with my academic supervisor.

From an interpersonal perspective, I reflected on the power dynamics at play (Olmos-Vega et al., 2022). I recognised my role as an 'outsider' in relation to autistic participants. I recognised that my identity and stance as a neurotypical was important, in addition to my implicit beliefs about eye-contact and social communication behaviours in general. This is illustrated in the following excerpt from my reflexive journal following an interview with Shane:

> *Noticed my own assumption that eye-contact is important as I asked the question 'what do you think is the most important thing about eye-contact?'. Shane's emotional reaction to this question caused me to reflect on my own worldview as a neurotypical, and to consider my implicit beliefs*

about eye-contact. Do I have an implicit belief that not making eye-contact must be a difficult and challenging experience, because I take eye-contact for granted in social interactions? What do I expect from another person during a social interaction in terms of eye-contact? Did the way I asked this question render me an outsider? Shane's emotional reaction may well have revealed his assumption that I do not fully understand the meaning of his experience.

I will aim to bracket my beliefs and expectations about eye-contact, and attempt to stay attuned to the participants' different standpoints. I need to be aware of my role as a non-autistic researcher, and imposing my value system about eye-contact on the participants, as well as noticing how my assumptions may influence my interaction with participants.

Throughout the process of data analysis, I reflected on whose views were being represented, given my position as the interpreter of the participants' views, and deciding what counts as 'valid' information. I also negotiated my position in relation to the hermeneutic interpretative stances of empathy and suspicion. This is reflected in the following excerpt during the process of developing experiential statements for Jason, as I reflected on the origins of my suspicions:

Aware that I had an emotional reaction to Jason's description of eye-contact in the transcript. His own understanding is that his eye-contact is now 'natural'. However, described 'prolonged' staring and noticing eye colours, which I wouldn't consider 'natural' eye-contact. Therefore, how I reacted to and interpreted Jason's account is based on my own knowledge about and experience of eye-contact, and 'appropriate' or 'typical' qualities to eye-contact. While developing experiential statements, I will

adopt a centre-ground position between empathy and suspicion. For example, I will understand the meaning of Jason's words as they appear, but adopt a questioning approach.

Below, I provide a reflexive statement, in order to make my position in relation to participants' transparent.

Reflexive Statement

I am a twenty-eight year old, white, female trainee clinical psychologist, currently completing my doctoral studies in Clinical Psychology. I have a Bachelor's degree and a Master's degree in Psychology. Given the focus of the current study, it is also important to disclose that I do not have ASD. Thus, it is through this, my neurotypical lens, that this study has been conducted.

As part of my clinical training, I have provided therapeutic interventions to autistic people and their families, and I am also aware of psychological models and frameworks related to ASD. I have conducted a systematic review on autistic peoples' understandings and perceptions of ASD, and thus have pre-existing knowledge about experiences of being autistic, and factors that influence autistic identity. I recognise that the knowledge I hold about ASD, has largely derived from observations of professionals who lack the lived experience of ASD, as well as theoretical literature that is often conducted by neurotypicals.

My identity as a neurotypical female has shaped my understanding and beliefs about social communication behaviours, including eye-contact. I use eye-contact to form social connections with others, and communicate non-verbal information. I also use eye-contact to gauge non-verbal social information from others. I therefore value eye-contact as a communicative device. I acknowledge my role as an 'outsider' in relation to ASD, and acknowledge the influence this may have had on the interview process. It is possible that some of my questions may have revealed my value system about eye-contact. It is also plausible that

some of the participants may have viewed me as an ‘outsider’ and so may have feared negative judgement. I therefore recognise the inherent power in my position as a researcher.

Given that the majority of the sample was male, my identity as a female researcher may also have influenced the participants’ level of comfort and willingness to share.

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Chapter 7: Discussion and Conclusion

Summary of findings

The overall aim of this thesis was to adopt a qualitative framework to explore autistic identity and autistic peoples' experience of eye contact.

In chapter two, the systematic review aimed to develop a better understanding of autistic identity by systematically searching for and reviewing qualitative research on autistic peoples' perceptions and understandings of ASD. Seventeen qualitative studies were synthesised using thematic synthesis. The thematic synthesis identified four over-arching themes: terminology; being different; self-understanding; and autistic people as experts by experience.

There was considerable variation in relation to preferences of terminology used, with some participants perceiving ASD to be a core part of their identity, while others preferred to understand ASD as a condition that is separate to who they are as individuals. Social comparison with others on the autism spectrum, and with other disability groups was another finding that emerged from the qualitative synthesis. This appeared to serve a self-enhancing function, as participants attempted to make sense of where they 'fit' on the autism spectrum of mild to severe forms of ASD, and some perceived ASD as a mental disability, that is positioned more favourably than physical disability.

Autistic participants also understood ASD in terms of positive and negative 'differences'. Across studies, differences largely reflected negative experiences of stigma and marginalization, and camouflaging was consequently employed in an attempt to conform to societal norms and expectations. The deleterious effects of camouflaging on participants' sense of self was identified. On the other hand, autistic traits that participants felt a sense of pride towards were also reported, and fostered a positive autistic identity. Evidence from the thematic synthesis suggested that an ASD diagnosis provided autistic people with a framework of self-

understanding. The diagnosis allowed some participants to transform their internalised sense of normative expectations, as they developed increased self-compassion and self-acceptance, and some emphasised that the onus was on society to change their views. Autistic participants researched ASD in order to make sense of their experience, and to develop a more holistic conception of ASD, while some participants avoided seeking information related to ASD as it was experienced as distressing. Based on their knowledge and experience, many participants did not feel adequately represented in the literature, and felt that those without ASD could never come from a 'bottom-up perspective', in contrast to autistic individuals.

In chapter five, the major research project aimed to explore autistic peoples' deliberate and self-conscious experience of eye-contact using an IPA qualitative methodology. In-depth interviews were conducted with nine autistic adults. Three interrelated GETs were identified, including 'Eye-contact: Awareness and motivation', 'Phenomenology of eye-contact', and 'Strategies to make eye-contact'. Participants experienced atypical eye-contact, characterised by unusual eye-contact patterns, and reduced attention to the eyes. Autistic participants demonstrated an awareness of the social function of eye-contact, such as conversational turn-taking, signalling an intention to communicate, and inferring how others are thinking and feeling. Both intrinsic and external motivations to make eye-contact were reported, that appeared to be largely influenced by the participants' perceptions of ASD, and a social expectation from the general population. For example, echoing findings from the systematic review, participants who perceived autism as a spectrum of varying ability did not want ASD to define them as individuals, and were motivated to be perceived as 'normal' by others. Conversely, others felt resigned to make eye-contact due to external demands of how a person should behave in society, despite their belief that eye-contact was for the benefit of neurotypicals. Similar to themes identified in the systematic review, many participants reported camouflaging their atypical eye-contact, by masking, or adopting compensatory strategies, in

order to appear neurotypical in certain contexts. However, despite the participants' best efforts to make eye-contact, eye-contact was experienced as 'hard work', and factors such as familiarity of the conversation partner, and cognitive and social processing difficulties appeared to inhibit effective eye-contact.

Limitations

There are several limitations to consider when interpreting the findings of the thesis. In the systematic review, the included articles largely represented sampling from WEIRD (Western, educated, industrialised, rich, democratic) populations (Rad et al., 2018). Thus, the findings likely only represent a subset of autistic individuals given that autism is a 'spectrum' disorder. Furthermore, there was a higher percentage of overall female participants in the included articles, which is not representative of the gender ratio typically observed in the sample population.

Articles focusing on the female autistic phenotype, and changing classification systems were excluded during screening, as they were evaluated as focusing narrowly on one aspect of autistic identity, rather than capturing the understanding and perceptions of autism more generally. Therefore, future reviews may explore autistic identity from these perspectives. Overall, however, the findings from the thematic synthesis provide more credible and potentially transferable claims to knowledge than is possible in any one qualitative study.

The major research project aimed to recruit a fairly homogenous sample of autistic participants, and therefore autistic people with an ID were not included. It is important to incorporate the voices of autistic people of all abilities in research; therefore, future research may consider using more flexible methodologies in order to consider the experiences of less cognitively able autistic individuals (Leedham et al., 2020). Although meaningful and rich data was obtained from participants using IPA methodology, challenges with language difficulties were observed, and some participants demonstrated limited capacity to introspect on their

thoughts and feelings, and articulate their emotional or physiological experiences. Therefore, future research may consider interviewing both autistic participants and a close relative or partner, in order to integrate a first and third person perspective on eye-contact.

Finally, the idiographic nature of IPA means that findings are not representative of all autistic peoples' experience of eye-contact. Nonetheless, this research makes a significant contribution to the field of autism research, and has several important clinical implications, which are outlined in the next section.

Contribution and Clinical Implications of the Thesis

The findings from this thesis collectively make an important and novel contribution to understanding factors influencing autistic identity, and the experience of making eye-contact from the perspective of autistic individuals. It has been asserted that autistic peoples' insights are crucial for researchers to have access into autistic ways of thinking (Bertilsdotter Rosqvist et al., 2019; MacLeod et al., 2014). As such, the first-person perspective in the current thesis aimed to keep the voice of the autistic participants at the forefront of the research.

The systematic review makes a significant contribution to the extant literature, as it was the first review to qualitatively synthesis how autistic people understand and perceive ASD, in order to inform autistic identity. The review highlighted that autistic identity is not one defined entity, given the heterogenous nature of the autism spectrum. However, the findings may inform our understanding of factors influencing autistic identity, including terminology, awareness of differences, society's role of defining 'normal', and the importance of identifying with other autistic community members. Based on these findings, the review highlighted the importance of autistic people having the opportunity to express their preferred terminology to honour their sense of identity. The review also identified participants' felt sense of positive and negative differences associated with ASD. Importantly, their experience of negative differences often led to camouflaging, which hindered their ability to express their true selves.

Therefore, there is benefit in service providers adopting a balanced and comprehensive view of ASD, in which both challenges and strengths are acknowledged. Given the link between autistic identity and mental health outcomes (Cooper et al., 2017), professionals working with autistic individuals may consider the various factors influencing autistic identity in service planning and provision to promote mental health and well-being in the context of autistic identity. In addition, clinicians may also reflect on their own positioning in relation to ASD, to consider the clinical, ethical, and political implications of their ways of understanding this construct (Moore et al., 2022).

The major research project is the first qualitative study to interview autistic participants in order to gain insight into their experience and sense-making of eye-contact. While the findings reflected the heterogenous phenomenological experiences of eye-contact among a sample of autistic adults, a number of similarities were identified which may have clinical implications. For example, consistent with the theme related to feeling 'different' in the systematic review, many participants in the major research project employed camouflaging strategies to mask or compensate for their atypical eye-contact. Given the potential negative impact of continuous camouflaging on autistic peoples' mental health and well-being (Cassidy et al., 2020; Hull et al., 2017), service providers and clinicians may consider these implications when supporting autistic people to make eye-contact.

The empirical paper also identified the possible influence of processing difficulties on autistic peoples' experience of eye-contact. Despite some participants' best efforts to make and maintain eye-contact, difficulties managing competing demands during social interaction, and reading non-verbal social information from the eyes and face, appeared to hinder their ability to make effective eye-contact. This finding suggests that other cognitive processes may need to be targeted concurrently during psychological intervention aimed at supporting autistic people to make eye-contact.

The study also highlighted the importance of autistic individuals having the '*choice'* to make eye contact. Eye-contact was experienced as unnecessary, challenging, and exhausting by some of the participants. However, these participants made eye-contact in an attempt to appear neurotypical. This reflects the 'double empathy problem' (Milton, 2012), in which autistic peoples' behaviour is misinterpreted by neurotypicals, causing them to camouflage their ASD-specific style of social interaction (Mitchell et al., 2021). Therefore, affording autistic individuals the choice to make eye-contact is consistent with the neurodiversity movement, which advocates the development of a diversity-valuing society (Cage & Troxell-Whitman, 2020). In order to address wider societies' attitudes and internalised beliefs about autistic peoples' unique social communication style, intervention may also involve educating the general population about communicative differences between autistic and non-autistic people.

Based on the findings from this thesis, clinicians and professionals working with autistic individuals should be aware of autistic peoples' diverse understandings and perceptions of ASD, as well as this populations' different experiences of making eye-contact, and adapt their clinical practice and intervention as appropriate. Collectively, both studies contribute to the evidence base to inform the provision of services to autistic individuals, and promote practices that support autistic individuals' mental health and well-being.

Conclusion

The aim of this thesis was to adopt a qualitative framework to explore autistic identity, and autistic peoples' experience of eye contact. A systematic review exploring autistic identity and an empirical research project exploring autistic peoples' experience of eye contact generated insights into the experience of being autistic, and added to the extant field of autism research. The combined findings of these studies have important clinical implications for clinicians and services providing support to autistic individuals.

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Appendices

Appendix A: Autism Submission Guidelines

1. What do we publish?

1.1 Aims & Scope

Before submitting your manuscript to Autism, please ensure you have read the Aims & Scope.

1.2 Article Types

The Journal considers the following kinds of article for publication:

Research Reports. Full papers describing new empirical findings;
Review Articles
(a) general reviews that provide a synthesis of an area of autism research;

(b) critiques - focused and provocative reviews that may be followed by a number of invited commentaries, with a concluding reply from the main author.

Both full Research Reports and Review Articles are generally restricted to a maximum of 6,000 words, including all elements (title page, abstract [200 words maximum], notes, tables, text), but excluding references. Editors may ask authors to make certain cuts before sending the article out for review.

Short Reports. Brief papers restricted to a maximum of 2,000 words with no more than two tables and 15 references. Short reports could include other approaches like discussions, new or controversial ideas, comments, perspectives, critiques, or preliminary findings. The title should begin with 'Short Report'.
Letters to the Editors. Readers' letters should address issues raised by published articles. The decision to publish is made by the Editors, in order to ensure a timely appearance in print. Letters should be no more than 800 words, with no tables and a maximum of 5 references.

1.3 Writing your paper

The SAGE Author Gateway has some general advice and on how to get published, plus links to further resources.

1.3.1 Make your article discoverable

When writing up your paper, think about how you can make it discoverable. The title, keywords and abstract are key to ensuring readers find your article through search engines such as Google. For information and guidance on how best to title your article, write your abstract and select your keywords, have a look at this page on the Gateway: How to Help Readers Find Your Article Online.

2. Editorial policies

2.1 Peer review policy

Autism operates a strictly anonymous peer review process in which the reviewer's name is withheld from the author and, the author's name from the reviewer. The reviewer may at their own discretion opt to reveal their name to the author in their review but our standard policy practice is for both identities to remain concealed. Each new submission is carefully read by one of the Editors to decide whether it has a reasonable chance of getting published. If the Editor thinks it does not have this chance, at least one other Editor will be consulted before finally deciding whether or not to send the manuscript out for review. Autism strives to do this within two weeks after submission, so that authors do not have to wait long for a rejection. Feedback is also provided on how to improve the manuscript, or what other journal would be more suitable. Each manuscript is reviewed by at least two referees. All manuscripts are reviewed as rapidly as possible, and an editorial decision is generally reached within (e.g.) 6-8 weeks of submission.

2.2 Authorship

All parties who have made a substantive contribution to the article should be listed as authors. Principal authorship, authorship order, and other publication credits should be based on the relative scientific or professional contributions of the individuals involved, regardless of their status. A student is usually listed as principal author on any multiple-authored publication that substantially derives from the student's dissertation or thesis.

2.3 Acknowledgements

All contributors who do not meet the criteria for authorship should be listed in an Acknowledgements section. Examples of those who might be acknowledged include a person who provided purely technical help, or a department chair who provided only general support.

Please supply any personal acknowledgements separately to the main text to facilitate anonymous peer review.

2.3.1 Third party submissions

Where an individual who is not listed as an author submits a manuscript on behalf of the author(s), a statement must be included in the Acknowledgements section of the manuscript and in the accompanying cover letter. The statements must:

- Disclose this type of editorial assistance – including the individual's name, company and level of input
- Identify any entities that paid for this assistance
- Confirm that the listed authors have authorized the submission of their manuscript via third party and approved any statements or declarations, e.g. conflicting interests, funding, etc.

Where appropriate, SAGE reserves the right to deny consideration to manuscripts submitted by a third party rather than by the authors themselves.

2.4 Funding

Autism requires all authors to acknowledge their funding in a consistent fashion under a separate heading. Please visit the Funding Acknowledgements page on the SAGE Journal Author Gateway to confirm the format of the acknowledgment text in the event of funding, or state that: This research received no specific grant from any funding agency in the public, commercial, or not-for-profit sectors.

Important note: If you have any concerns that the provision of this information may compromise your anonymity, you should withhold this information until you submit your final accepted manuscript.

2.4.1 National Institutes of Health (NIH) funded articles

If you have received NIH funding for your research, please state this in your submission and if your paper is accepted by Autism an electronic version of the paper will automatically be sent to be indexed with the National Library of Medicine's PubMed Central as stipulated in the NIH policy.

2.5 Declaration of conflicting interests

Autism encourages authors to include a declaration of any conflicting interests and recommends you review the good practice guidelines on the SAGE Journal Author Gateway. In particular, for working reporting on the development or evaluation of interventions the ICJME Conflict of Interest form provides an excellent template for considering a range of potential sources of conflict, and this can be uploaded and submitted with your manuscript if relevant.

Where an Editor of Autism is a lead or contributing author to a paper submitted to publication, the paper is always handled through the peer review process by another member of the Editor team and three reviews are obtained in each case. A statement is also published on each article where this occurs.

2.6 Research ethics and patient consent

Medical research involving human subjects must be conducted according to the World Medical Association Declaration of Helsinki

Submitted manuscripts should conform to the ICMJE Recommendations for the Conduct, Reporting, Editing, and Publication of Scholarly Work in Medical Journals, and all papers reporting animal and/or human studies must state in the methods section that the relevant Ethics Committee or Institutional Review Board provided (or waived) approval. Please ensure that you have provided the full name and institution of the review committee, in addition to the approval number.

For research articles, authors are also required to state in the methods section whether participants provided informed consent and whether the consent was written or verbal.

Information on informed consent to report individual cases or case series should be included in the manuscript text. A statement is required regarding whether written informed consent

for patient information and images to be published was provided by the patient(s) or a legally authorized representative.

Please also refer to the ICMJE Recommendations for the Protection of Research Participants

2.7 Clinical trials

Autism conforms to the ICMJE requirement that clinical trials are registered in a WHO-approved public trials registry at or before the time of first patient enrolment as a condition of consideration for publication. The trial registry name and URL, and registration number must be included at the end of the abstract.

2.8 Reporting guidelines

2.8.1 Transparent reporting of trials

The relevant EQUATOR Network reporting guidelines should be followed depending on the type of study. For example, all randomized controlled trials submitted for publication should include a completed CONSORT flow chart as a cited figure and the completed CONSORT checklist should be uploaded with your submission as a supplementary file. Systematic reviews and meta-analyses should include the completed PRISMA flow chart as a cited figure and the completed PRISMA checklist should be uploaded with your submission as a supplementary file. The EQUATOR wizard can help you identify the appropriate guideline.

The What Works Clearinghouse (WWC) guidelines should be followed when submitting in single-case design (SCD) and meet the standards outlined for internal validity of the SCD.

Other resources can be found at NLM's Research Reporting Guidelines and Initiatives

2.8.2 Sample selection and demographic characteristics

Autism now requires authors to report the following information for all Research Reports (including systematic reviews):

i. procedures for sample selection and recruitment; and
ii. major demographic characteristics, including age, gender, race/ethnicity and socioeconomic status.

Including this information will provide greater clarity regarding sample characteristics and generalisability of the findings, even when such characteristics are not used in the analysis (although we encourage investigation of subgroup differences, where possible). It should also encourage researchers to consider the way in which context and culture contribute to their findings.

If authors are unable to report some or all of this information, its absence must be acknowledged with a clear statement of explanation (e.g., 'specific data on socioeconomic status and educational attainment levels were not recorded'). Manuscripts that contain neither the required information nor an appropriate statement will be returned prior to consideration by the editors.

2.8.3 Community involvement

Autism encourages research that is actively carried out 'with' or 'by' members of the Autistic and autism communities (rather than 'to', 'about', or 'for' them), often referred to as 'co-production', 'participatory research', 'patient and public involvement' or 'integrated knowledge translation'.

We therefore now require authors to include a community involvement statement at the end of the Methods section for Research Reports, outlining whether autistic people or family members, community providers, policy makers, agency leaders or other community stakeholders were involved in developing the research question, study design, measures, implementation, or interpretation and dissemination of the findings. Community members should be duly acknowledged – as authors or in the acknowledgements section – depending on the extent and nature of their contribution. We recommend that authors follow the BMJ's editorial guidelines for documenting how community stakeholders were involved in their research.

If community members were not involved in the study, authors should state this.

For more details about the reasoning behind this journal requirement, and editorial expectations of authors, please download this FAQs document.

2.9 Data Policy Statement

Autism supports open research practices and FAIR principles. As such encourages authors to share their data wherever possible and submit their data (or a link to it) and where applicable, their syntax/command files for the analyses presented in the contribution. Authors can make data available through a third party data repository or on the journal website as a supplementary data file.

If cited data is restricted (e.g. classified, require confidentiality protections, were obtained under a non-disclosure agreement, or have inherent logistical constraints), authors should notify the editor at the time of submission. The editor shall have full discretion to follow their journal's policy on restricted data, including declining to review the manuscript or granting an exemption with or without conditions. The editor shall inform the author of this decision prior to review.

Where data is sensitive and cannot be shared in an open forum, authors are encouraged to share metadata and provide a contact for requesting access if the raw data itself cannot be made available.

Data can be submitted with your article and hosted on the SAGE Autism website where we work with Figshare to host data content. Authors can use a recognised third party data repository service to host their data such as Open Science framework. Authors may use their institution's data sharing repository.

Autism also encourages authors to delineate clearly the analytic procedures upon which their published claims rely, and where possible provide access to all relevant analytic materials. If such materials are not published with the article, we encourage authors to share to the greatest extent possible through a digital repository (above).

Autism encourages authors to use data citation practices that identify a dataset's author(s), title, date, version, and a persistent identifier. In sum, data should be referenced and cited, where possible, as an intellectual product of value.

3. Publishing Policies

3.1 Publication ethics

SAGE is committed to upholding the integrity of the academic record. We encourage authors to refer to the Committee on Publication Ethics' International Standards for Authors and view the Publication Ethics page on the SAGE Author Gateway.

3.1.1 Plagiarism

Autism and SAGE take issues of copyright infringement, plagiarism or other breaches of best practice in publication very seriously. We seek to protect the rights of our authors and we always investigate claims of plagiarism or misuse of published articles. Equally, we seek to protect the reputation of the journal against malpractice. Submitted articles may be checked with duplication-checking software. Where an article, for example, is found to have plagiarised other work or included third-party copyright material without permission or with insufficient acknowledgement, or where the authorship of the article is contested, we reserve the right to take action including, but not limited to: publishing an erratum or corrigendum (correction); retracting the article; taking up the matter with the head of department or dean of the author's institution and/or relevant academic bodies or societies; or taking appropriate legal action.

3.1.2 Prior publication

If material has been previously published it is not generally acceptable for publication in a SAGE journal. However, there are certain circumstances where previously published material can be considered for publication. Please refer to the guidance on the SAGE Author Gateway or if in doubt, contact the Editor at the address given below.

3.2 Contributor's publishing agreement

Before publication, SAGE requires the author as the rights holder to sign a Journal Contributor's Publishing Agreement. SAGE's Journal Contributor's Publishing Agreement is an exclusive licence agreement which means that the author retains copyright in the work but grants SAGE the sole and exclusive right and licence to publish for the full legal term of copyright. Exceptions may exist where an assignment of copyright is required or preferred by a proprietor other than SAGE. In this case copyright in the work will be assigned from the author to the society. For more information please visit the SAGE Author Gateway.

3.3 Open access and author archiving

Autism offers optional open access publishing via the SAGE Choice programme. For more information on Open Access publishing options at SAGE please visit SAGE Open Access. For information on funding body compliance, and depositing your article in repositories, please visit SAGE's Author Archiving and Re-Use Guidelines and Publishing Policies.

4. Preparing your manuscript for submission

4.1 Formatting

Autism asks that authors use the APA style for formatting. The APA Guide for New Authors can be found on the APA website, as can more general advice for authors.

4.2 Artwork, figures and other graphics

For guidance on the preparation of illustrations, pictures and graphs in electronic format, please visit SAGE's Manuscript Submission Guidelines.

Figures supplied in colour will appear in colour online regardless of whether or not these illustrations are reproduced in colour in the printed version. For specifically requested colour reproduction in print, you will receive information regarding the costs from SAGE after receipt of your accepted article.

4.3 Supplementary material

This journal is able to host additional materials online (e.g. datasets, podcasts, videos, images etc) alongside the full-text of the article. For more information please refer to our guidelines on submitting supplementary files.

4.4 Terminology

4.4.1 Terminology about autism and autistic people

Autism has researched and produced its own guidance on terminology and language used in autism research. Please consult the guide here: autism terminology guidelines.

4.4.2 Language used to discuss race and ethnicity

Likewise, Autism has also produced the following guidance to be considered when writing about race and ethnicity. Please consult the guide here: race and ethnicity language guidelines.

4.5 Reference style

Autism adheres to the APA reference style. View the APA guidelines to ensure your manuscript conforms to this reference style.

4.6 English language editing services

Authors seeking assistance with English language editing, translation, or figure and manuscript formatting to fit the journal's specifications should consider using SAGE Language Services. Visit SAGE Language Services on our Journal Author Gateway for further information.

5. Submitting your manuscript

Autism is hosted on SAGE Track, a web based online submission and peer review system powered by ScholarOne™ Manuscripts. Visit http://mc.manuscriptcentral.com/autism to login and submit your article online.

IMPORTANT: Please check whether you already have an account in the system before trying to create a new one. If you have reviewed or authored for the journal in the past year it is likely that you will have had an account created. For further guidance on submitting your manuscript online please visit ScholarOne Online Help.

5.1 ORCID

As part of our commitment to ensuring an ethical, transparent and fair peer review process SAGE is a supporting member of ORCID, the Open Researcher and Contributor ID. ORCID provides a unique and persistent digital identifier that distinguishes researchers from every other researcher, even those who share the same name, and, through integration in key research workflows such as manuscript and grant submission, supports automated linkages between researchers and their professional activities, ensuring that their work is recognized.

The collection of ORCID iDs from corresponding authors is now part of the submission process of this journal. If you already have an ORCID iD you will be asked to associate that to your submission during the online submission process. We also strongly encourage all co-authors to link their ORCID ID to their accounts in our online peer review platforms. It takes seconds to do: click the link when prompted, sign into your ORCID account and our systems are automatically updated. Your ORCID iD will become part of your accepted publication's metadata, making your work attributable to you and only you. Your ORCID iD is published with your article so that fellow researchers reading your work can link to your ORCID profile and from there link to your other publications.

If you do not already have an ORCID iD please follow this link to create one or visit our ORCID homepage to learn more.

5.2 Information required for completing your submission

You will be asked to provide contact details and academic affiliations for all co-authors via the submission system and identify who is to be the corresponding author. These details must match what appears on your manuscript. At this stage please ensure you have included all the required statements and declarations and uploaded any additional supplementary files (including reporting guidelines where relevant).

5.3 Lay Abstracts

As part of your submission you will be asked to provide a lay abstract of your article. Lay abstracts are a brief (max 250 words) description of the paper that is easily understandable. These abstracts will be made widely available (to the general public, and particularly to autistic people and their families). As such, lay abstracts should avoid both technical terminology and the reporting of statistics. Examples of lay abstracts are provided in recent issues of the journal.

Authors may consider the following questions when composing their lay abstract.

a. What is already known about the topic?
b. What this paper adds?
c. Implications for practice, research or policy

Authors may also find the following resources helpful on this topic:

How to write a summary paragraph
Self Advocacy Resource and Technical Assistance Center (SARTAC): Plain Language
Center for Plain Langauage: Five steps to Plain Language

5.4 Permissions

Please also ensure that you have obtained any necessary permission from copyright holders for reproducing any illustrations, tables, figures or lengthy quotations previously published elsewhere. For further information including guidance on fair dealing for criticism and review, please see the Copyright and Permissions page on the SAGE Author Gateway

6. On acceptance and publication

6.1 SAGE Production

Your SAGE Production Editor will keep you informed as to your article's progress throughout the production process. Proofs will be sent by PDF to the corresponding author and should be returned promptly. Authors are reminded to check their proofs carefully to confirm that all author information, including names, affiliations, sequence and contact details are correct, and that Funding and Conflict of Interest statements, if any, are accurate. Please note that if there are any changes to the author list at this stage all authors will be required to complete and sign a form authorising the change.

6.2 Online First publication

Online First allows final articles (completed and approved articles awaiting assignment to a future issue) to be published online prior to their inclusion in a journal issue, which significantly reduces the lead time between submission and publication. Visit the SAGE Journals help page for more details, including how to cite Online First articles.

6.3 Access to your published article

SAGE provides authors with online access to their final article.

6.4 Promoting your article

Publication is not the end of the process! You can help disseminate your paper and ensure it is as widely read and cited as possible. The SAGE Author Gateway has numerous resources to help you promote your work. Visit the Promote Your Article page on the Gateway for tips and advice.

Appendix B: Database Searches (Keywords and Subject Headings) 29/10/21

PsychInfo

TI (MM 'Autism Spectrum Disorders' OR Autis* OR ASD OR Asperger* OR 'Pervasive Developmental Disorder') OR AB (MM 'Autism Spectrum Disorders' OR Autis* OR ASD OR Asperger* OR 'Pervasive Developmental Disorder')

AND

((DE 'Self-Perception') OR (DE 'Self-Concept')) OR (DE 'Labeling') OR Identit* OR 'Self*Concept' OR 'Self*Perception' OR Label* OR Insider*

AND

AB (((((DE 'Experiences (Events)') OR (DE 'Attitudes')) OR (DE 'Perception')) OR (DE 'Narratives')) OR (DE 'Meaning')) OR (DE 'Insight') OR Perception* OR perspective* OR understand* OR view* OR feel* OR opinion* OR insight* OR belief* OR comprehen* OR experience* OR attitude* OR mean* OR narrative* OR interpretation*

AND

(DE 'Qualitative Methods') OR (DE 'Mixed Methods Research') OR Qualitative OR Mixed Method* OR Interview* OR 'semi structured interview*' OR survey OR 'open*ended' OR 'open ended' OR 'semi-structured interview*' OR 'unstructured interview*' OR 'focus group*' OR 'thematic analysis' OR IPA OR 'interpretative phenomenological analysis' OR 'Grounded Theory' OR ethnograph*

MEDLINE

TI ((MM 'Autism Spectrum Disorder') OR (MM 'Autistic Disorder') OR (MM 'Asperger Syndrome') OR Autis* OR ASD OR Asperger* OR 'Pervasive Developmental Disorder') OR AB ((MM 'Autism Spectrum Disorder') OR (MM 'Autistic Disorder') OR (MM 'Asperger Syndrome') OR Autis* OR ASD OR Asperger* OR 'Pervasive Developmental Disorder')

AND

(MH 'Self Concept') OR Identit* OR 'Self*Concept' OR 'Self*Perception' OR Label* OR Insider*

AND

AB (MH 'Attitude') OR (MH 'Perception') OR Perception* OR perspective* OR understand* OR view* OR feel* OR opinion* OR insight* OR belief* OR comprehen* OR experience* OR attitude* OR mean* OR narrative* OR interpretation*

AND

(MH 'Qualitative Research') OR Qualitative OR Mixed Method* OR Interview* OR 'semi structured interview*' OR survey OR 'open*ended' OR 'open ended' OR 'semi-structured interview*' OR 'unstructured interview*' OR 'focus group*' OR 'thematic analysis' OR IPA OR 'interpretative phenomenological analysis' OR 'Grounded Theory' OR ethnograph*

CINAHL

TI ((MM ‘Autistic Disorder’) OR (MM ‘Asperger Syndrome’) OR Autis* OR ASD OR Asperger* OR ‘Pervasive Developmental Disorder’) OR AB ((MM ‘Autistic Disorder’) OR (MM ‘Asperger Syndrome’) OR Autis* OR ASD OR Asperger* OR ‘Pervasive Developmental Disorder’)

AND

(MH ‘Self Concept’) OR Identit* OR ‘Self*Concept’ OR ‘Self*Perception’ OR Label* OR Insider*

AND

AB (MH ‘Attitude’) OR (MH ‘Narratives’) OR (MH ‘Perception’) OR Perception* OR perspective* OR understand* OR view* OR feel* OR opinion* OR insight* OR belief* OR comprehen* OR experience* OR attitude* OR mean* OR narrative* OR interpretation*

AND

(MH ‘Qualitative Studies’) OR Qualitative OR Mixed Method* OR Interview* OR ‘semi structured interview*’ OR survey OR ‘open*ended’ OR ‘open ended’ OR ‘semi-structured interview*’ OR ‘unstructured interview*’ OR ‘focus group*’ OR ‘thematic analysis’ OR IPA OR ‘interpretative phenomenological analysis’ OR ‘Grounded Theory’ OR ethnograph*

Web of Science

TI=(Autis* OR ASD OR Asperger* OR ‘Pervasive Developmental Disorder’) OR AB=(Autis* OR ASD OR Asperger* OR ‘Pervasive Developmental Disorder’

AND

ALL=(Identit* OR ‘Self*Concept’ OR ‘Self*Perception’ OR Label* OR Insider*))

AND

AB=(Perception* OR perspective* OR understand* OR view* OR feel* OR opinion* OR insight* OR belief* OR comprehen* OR experience* OR attitude* OR mean* OR narrative* OR interpretation*))

AND ALL=(Qualitative OR Mixed Method* OR Interview* OR ‘semi structured interview*’ OR survey OR ‘open*ended’ OR ‘open ended’ OR ‘semi-structured interview*’ OR ‘unstructured interview*’ OR ‘focus group*’ OR ‘thematic analysis’ OR IPA OR ‘interpretative phenomenological analysis’ OR ‘Grounded Theory’ OR ethnograph*)

ERIC

(MJMAINSUBJECT.EXACT(‘Autism’) OR MJMAINSUBJECT.EXACT(‘Pervasive Developmental Disorders’) OR MJMAINSUBJECT.EXACT(‘Asperger Syndrome’)) OR ti(Autis* OR ASD OR Asperger* OR ‘Pervasive Developmental Disorder’)

OR

(MJMAINSUBJECT.EXACT('Autism') OR MJMAINSUBJECT.EXACT('Pervasive Developmental Disorders') OR MJMAINSUBJECT.EXACT('Asperger Syndrome')) OR ab(Autis* OR ASD OR Asperger* OR 'Pervasive Developmental Disorder')

AND

MAINSUBJECT.EXACT('Labeling (of Persons)') OR MAINSUBJECT.EXACT('Self Concept') OR Identit* OR 'Self*Concept' OR 'Self*Perception' OR Label* OR Insider*

AND

(MAINSUBJECT.EXACT('Attitudes') OR MAINSUBJECT.EXACT('Beliefs') OR MAINSUBJECT.EXACT('Perception')) OR ab(Perception* OR perspective* OR understand* OR view* OR feel* OR opinion* OR insight* OR belief* OR comprehen* OR experience* OR attitude* OR mean* OR narrative* OR interpretation*)

AND

(MAINSUBJECT.EXACT('Mixed Methods Research') OR MAINSUBJECT.EXACT('Qualitative Research')) OR (Qualitative OR Mixed Method* OR Interview* OR 'semi structured interview*' OR survey OR 'open*ended' OR 'open ended' OR 'semi-structured interview*' OR 'unstructured interview*' OR 'focus group*' OR 'thematic analysis' OR IPA OR 'interpretative phenomenological analysis' OR 'Grounded Theory' OR ethnograph*)

Appendix C: Quality Assessment Results

Critical Appraisal Skills Programme

		Bertilsdotter Rosqvist (2012)	Lewis (2016)	Hickey et al., (2018)	Hurlbutt & Chalmers (2002)	Huws & Jones (2015)	Huws et al., (2008)	Jones et al., (2013)	Jones et al., (2015)	Lilley et al., (2021)	MacLeod et al., (2013)	Punshon et al., (2009)	Stagg & Belcher (2019)	Tan (2017)	Winstone et al., (2014)
1	Was there a clear statement of the aims of the research?	1	1	1	1	1	1	1	1	1	1	1	1	1	1
2	Is qualitative methodology appropriate?	1	1	1	1	1	1	1	1	1	1	1	1	1	1
3	Was the research design appropriate to address the aims of the research?	1	1	1	1	1	1	1	1	1	1	1	1	1	0.5
4	Was the recruitment strategy appropriate to the aims of the research?	0.5	1	1	0.5	1	1	1	1	1	0.5	1	1	1	0.5
5	Was the data collected in a way that addressed the research issue?	1	0.5	1	1	1	1	1	1	1	0.5	1	1	1	0.5
6	Has the relationship between the researcher and participants	1	1	0	0.5	1	1	1	0	1	0.5	0.5	1	0.5	0.5

	been adequately considered?													
7	Have ethical issues been taken into consideration?	0	1	1	0	1	1	1	1	1	0	1	1	1	1
8	Was the data analysis sufficiently rigorous?	1	1	1	1	1	1	1	1	1	0.5	1	1	1	1
9	Is there a clear statement of findings?	1	1	1	1	1	1	1	1	1	1	1	1	1	1
10	How valuable is this research?	1	1	1	1	1	1	1	1	1	1	1	1	1	1
	Total Score	8.5	9.5	9	8	10	10	10	9	10	7	9.5	10	9.5	8
	Rating	A	A	A	B	A	A	A	A	A	B	A	A	A	B

Scoring Tool

1= 'Yes' 0.5= 'Can't tell' 0= 'No'	A= 8.5-10 points (High quality paper) B= 5-8 points (Moderate quality paper) C= <5 (Lower quality paper)

Mixed Methods Appraisal Tool (MMAT)

	Methodological quality criteria	**Bury et al., (2020)**	**Cooper et al., (2021)**	**Corden, Brewer and Cage, (2021)**
S1	Are there clear research aims?	Yes	Yes	Yes
S2	Do the collected data allow to address the research questions?	Yes	Yes	Yes
Qualitative				
1.1	Is the qualitative approach appropriate to answer the research question?	Yes	Yes	Yes
1.2	Are the qualitative data collection methods adequate to address the research question?	Yes	Can't tell	Yes

1.3	Are the findings adequately derived from the data?	Yes	Yes	Yes
1.4	Is the interpretation of results sufficiently substantiated by data?	Yes	Yes	Yes
1.5	Is there coherence between qualitative data sources, collection, analysis, and interpretation?	Yes	Yes	Yes
Quantitative descriptive				
2.1	Is the sampling strategy relevant to address the research question?	Yes	Yes	Yes
2.2	Is the sample representative of the target population?	Can't tell	Can't tell	Can't tell
2.3	Are the measurements appropriate?	Yes	Yes	Yes
2.4	Is the risk of nonresponse bias low?	Yes	Yes	Yes
2.5	Is the statistical analysis appropriate to answer the research question?	Yes	Yes	Yes
Mixed Methods				
3.1	Is there an adequate rationale for using a mixed methods design to address the research question?	Yes	Yes	Yes
3.2	Are the different components of the study effectively integrated to answer the research question?	Yes	Yes	Yes
3.3	Are the outputs of the integration of the qualitative and quantitative components adequately interpreted?	Yes	Yes	Yes
3.4	Are divergences and inconsistencies between quantitative and qualitative results adequately addressed?	Yes	Yes	Yes
3.5	Do the different components of the study adhere to the quality criteria of each tradition of the methods involved?	Yes	Yes	Yes
	Score (%)	4****	4****	4****

MMAT Scoring Tool

5*** or 100% quality criteria met
4**** or 80% quality criteria met
3*** of 60% quality criteria met
2** or 40% quality criteria met
1* or 20% quality criteria met

For mixed methods studies, the overall quality of a combination cannot exceed the quality of the weakest component. Therefore, the overall quality score is the lowest score of the study components (Hong et al., 2018).

Appendix D: Thematic Synthesis: Summary of Themes

Theme	Subtheme	Content of theme	Appears in studies	Sample quotes
Terminology	Autism as part of me	Describes participants' sense of autism as integral to who they are. Autism is described as part of a person's identity and cannot be separated.	Bertilsdotter Rosqvist, 2012 Bury et al., 2020 Corden et al., 2021 Huws & Jones, 2015 Macleod et al., 2013 Tan, 2018	*'But I actually am my disability. If disability is what they say now. But I actually am my Asperger's, because it's here. For me, it's, I am my brain. I have a little difficulty knowing what the soul is and things like that, but I think the Asperger's is, it's in the brain, it is me, in other words, for me I am my Asperger's.' (*Bertilsdotter Rosqvist, 2012, p.125) *''defines a little bit of your personality'' or ''really a lot of [your] identity''* (Bertilsdotter Rosqvist, 2012, p.125) *'I cannot speak for everyone, but I don't view my autism as a 'disorder'. This upsets me. It is just another way of seeing the world'* (Bury et al., 2020, p.8) *'[I] am autistic, it is an integral part of me and not a [separate] part that can be taken away. [Without] it [I] would be someone else'* (Bury et al., 2020, p.7) *'[I'm] learning to be proud of my autism;' 'Autism is an attribute.'* (Corden et al., 2021, p.9) *'... these are things that are about me, they're me'* (Huws and Jones, 2015, p.4) *'autism is much more a part of someone's identity in the same way that someone's gender is or someone's sexuality or whatever . . .'* (Macleod et al., 2013, p.43)
	Autism as something I have	Describes autism as a condition, separate to who they are as individuals.	Bury et al., 2020 Corden et al., 2021 Lewis, 2016 Hickey et al., 2018 Macleod et al., 2013	*'opening with 'person' emphasises shared humanity with neurotypicals.'* (Bury et al., 2020, p.8) *'It's like a mind within a mind. Or a mind outside a mind that's kind of influencing your behaviour in a way that you don't want it to.'* (Hickey et al., 2018, p.361) *'It is a condition that is meant to make social relationships more difficult. And that could also bring you in awkward situations and things like that. And you happen not to worry about that too much and just see it as an autism thing.'* (Hickey et al., 2018, p.361) *'Slowly I have become more accepting of my condition, but it still causes me a lot of grief'.* (Lewis, 2016, p.350) *'I must have had this in my mind cos I do suffer from Asperger syndrome, well I've technically been diagnosed with it, I don't know*

				to what extent I've got it but I don't feel that I suffer from it.' (Macleod et al., 2013, p.46)
	Autism as a spectrum disorder	Describes participants' awareness of diversity on the autism spectrum.	Bertilsdotter Rosqvist, 2012 Bury et al., 2020 Cooper et al., 2021 Hickey et al., 2018 Huws & Jones, 2015 Jones et al., 2013 Lilley et al., 2021 Macleod et al., 2013	*'Autism is a SPECTRUM, not a cookie cutter diagnosis. I may not 'look' autistic, but I am on a very large spectrum filled with a diverse group of people.'* (Bury et al., 2020, p.8) *'…the spectrum is quite varied, and quite—you know, you might be able to tick the box in some areas, but not in others'* (Cooper et al., 2021, p.709) *'There were obviously people who were severely incapacitated by it. Who hardly spoke a word and were kind of – they had to have other people there with them as well. And on the other end – at the other end of the spectrum, I suppose – there were, there was a guy there [who] was doing a course at the university. And he seemed extremely lucid. So it's very difficult to see where I fit into.'* (Hickey et al., 2018, p.363) *'There's all different kinds. There's [friend's] boyfriend has it and he's worse than what we've got. There's three different colleges. There's [place A] who's got people who's got it but not as bad [as us]. Then there's [place B] who's got it, but a little bit worse than what we've got, but not as bad, then there's don't know what it's called now, [place C], they've got it really bad'* (Huws & Jones, 2015, p.4) *James described how 'different people are affected in different ways', and John said that it was 'much more broad than you could imagine very possibly.'* (Huws & Jones, 2015, p.4) *'Just because he's got Asperger's syndrome, he's not going to be the same as that person … everyone's going to be different … everybody to be quite honest with you, everybody is individual … Most things can't help me because I'm just so different, I'm unlike, like everybody is'* (Jones et al., 2013, p.138) *'such a diverse and disparate diagnosis*.' (Lilley et al., 2021, p.7) *'the other problem is that with traits, the way they manifest themselves, it can be that one particular person on the spectrum has one trait but then the other person will be completely the opposite.'* (Macleod et al., 2013, p.43)
	Autism as a disability	Describes participants' understanding of ASD as	Bertilsdotter Rosqvist, 2012	*'something happens in your brain but it's not really like being disabled like in a wheelchair.'* (Huws & Jones, 2015, p.5)

		disability and the way in which most participants struggle to relate to current concepts of disability.	Huws & Jones, 2015 Lewis, 2016 Jones at al., 2015 Lilley et al., 2021 Macleod et al., 2013	*'I'm not really disabled-disabled, I've just got like communication and just socialising problems and that. I'm just a bit disabled, not all, not loads disabled.'* (Huws & Jones, 2015, p.5) *'Someone who is, okay, someone who isn't able to do things that you and I can do. Someone can't run as fast, someone can't talk as fast, someone can't use their hands or speak.'* (Jones at al., 2015, p.1499) *'I don't see myself as disabled….Did I have anxiety attacks, depression, feel awkward socializing, have some difficulty with things like routine changes, and seem obsessive? Sure. But I graduated from high school with good grades, I went to college, and got married just like everyone else.'* (Lewis, 2016, p.351) *'I wasn't quite comfortable with disability' because 'a lot of signs were there that I was succeeding at things that 'people like that' don't succeed at, so could that be me?'* (Lilley et al., 2021, p.6) *'It's no different to someone with a disability using the disability card to get something which technically you don't . . . need for that reason.'* (Macleod et al., 2013, p.46)
Being different	Negative difference	Describes participants' experience of challenges and stigma associated with ASD, and attempts to be 'normal'.	Cooper et al., 2021 Corden et al., 2021 Hickey et al., 2018 Hurlbutt & Chalmers, 2002 Huws & Jones (2008) Huws & Jones (2015) Jones et al., 2013 Jones et al., 2015 Lewis, 2016 Lilley et al., 2021 Punshon et al., 2009 Tan, 2018	*'It felt very negative at first, like something was broken that could not be fixed;' 'I also had quite negative views about autism and felt like people were insulting me when they said that I was very likely to be autistic'* (Corden et al., 2021, p.9) *'…all throughout my school I've been bullied or excluded in various ways … It's still really bad, I still spend a lot of time alone, because of my social issues and other people not accepting me.'* (Cooper et al., 2021, p.709) *'And I tried to smile like they smiled. And I think it helped me up to a point, to mix up with other people. But all the time I was hiding my true self. That was the problem. Inside I was feeling sort of bad. I wasn't really supposed to be like that. But it got me sort of with other people and that.'* (Hickey et al., 2018, p.361) *'So I got to a stage where I was so used to being mistaken by others, misinterpreted, misunderstood; I thought, well, sod it. If you're going to misunderstand me, I'm not going to even, going to … I just closed off later on in life. I just thought, sod it'* (Hickey et al., 2018, p.363) *'And, there's the mad scientist stereotype as well … where some people think that sort of like, people with Asperger's are very scientific and … like Star Trek and don't um … and they sort of just*

				enclosed in their own little worlds, which is true of people with autism, but well not true for people with Asperger's.' (Jones et al., 2013, p.139) *'Umm, I kind of just feel, I feel like I am just marked. Like people just have, some people just kind of treat me different, and I don't want to be treated different, I just wanted to be treated how I was [before receiving a diagnosis]. And I just, ehh, I don't really like talking about it.'* (Jones et al., 2015, p.1498) *''I've always been an outsider.'* (Lilley et al., 2021, p.6) *'Which self? Which pretend mask?'; 'I'd just kind of been all these characters and I didn't know who I was'* (Lilley et al., 2021, p.6) *'He measured himself against a series of normative life goals – 'You better start ticking some boxes, meet a girl, settle down, whatever' – and said he felt 'frustrated', 'alone', 'isolated' and 'disillusioned' because he could not meet these expectations.'* (Lilley et al., 2021, p.6) *'There was this dip . . . I think because I felt like well, you know, I was feeling a bit hopeless, you know that maybe this wasn't something I could overcome . . . I am never going to be like one of these 'normal' people and you know . . . and I thought 'I am stuck being like this now.'* (Punshon et al., 2009, p.278) *'I started using alcohol to mask the illness'* (Punshon et al., 2009, p.275) *'I was trying to cover it up and pretend I was 'normal' and pretend that everything was okay when inside I was dying of pain because it was all going wrong and it was all difficult and nothing made sense.'* (Punshon et al., 2009, p.276) *'Most people, I say 'Have you ever heard of Aspergers?' And they go 'That's that thing where people do strange things' and I say 'well no not everybody'* (Macleod et al., 2013, p.45)
	Positive difference	Describes participants' acknowledgment of strengths and unique attributes associated with ASD, and pride of their autistic identity.	Bury et al., 2020 Cooper et al., 2021 Corden et al., 2021 Hurlbutt & Chalmers, 2002 Huws & Jones, 2015 Jones et al., 2015 Lewis, 2016 Lilley et al., 2021	*'... it is a help and it is a hindrance, and you can have someone who thinks 'oh Jesus, why do I have this, it really affects me' and someone who's just like 'gee, I've got a better IQ than most people, why not flaunt it. You can understand some things better than other people'* (Huws & Jones, 2015, p.5) *'I also understand that some of the personality traits which others led me to believe were faults or failings are not so, and may be applied in ways which render them as assets' (*Lewis, 2016, p.350)

			Punshon et al., 2009 Tan, 2018	*'The overall thing that I must emphasize is that I have never had the feeling that there was anything wrong with me. Different – yes, special – yes, unique – yes, able – very much so, superior – yes, special – yes, but defective – never!'* (Lewis, 2016, p.351) '*A number described themselves as 'nerds', with John saying that he could 'outthink' most of his peers at high school and that his pattern-matching abilities sometimes make him 'actually feel a bit like the character that Dustin Hoffman was' in the 1988 film Rain Man.'* (Lilley et al., 2021, p.6) *'[Name] is knocked back by my memory and people have asked me, 'How can you remember all this?''* (Punshon et al., 2009, p.278) *'We are one rung up on the evolutionary ladder. That's what I think . . . we have got no social intelligence but academically . . . social intelligence isn't necessarily always a good thing. I know it sounds a bit arrogant but a superiority complex [laughs] a little bit.'* (Punshon et al., 2009, p.278) *'But, as I look back, I mean I think it sort have been dominant influence in my life. It's basically, I think my Asperger's traits have sort of is the reason I have been able to be successful in my job, that I did well at school, that I lived my life the way I did'* (Tan, 2018, p.165)
Self-understanding	Seeing world through autism lens	Describes way in which diagnosis increases self-understanding, and provides meaning to present and past experiences. Understanding mental health difficulties in context of ASD.	Bertilsdotter Rosqvist, 2012 Cooper et al., 2020 Corden et al., 2021 Hickey et al., 2018 Huws & Jones, 2008 Lewis, 2016 Lilley et al., 2021 Punshon et al., 2009 Stagg & Belcher, 2019 Tan, 2018	*'[The diagnosis] led me to re-evaluate my life;' 'It changed everything. Things finally made sense.'* (Corden et al., 2021, p.9) *'When I got diagnosed everything started to fall into place, and I started to look at myself, and how I can improve on the bad attributes, the loneliness and everything else.'* (Cooper et al., 2020, p.709) *'Well, for example, you have an explanation why is it [that] you find it difficult to meet people and relate to them. Once you have a few explanations, you find themselves out a bit. '* (Hickey et al., 2018, p.361) *'Just that label, getting it last year, saying I've got a degree of autism. I knew it wouldn't be a cure or anything but it just explains those one or two things about your character. Like I've got this, like, secret world of animals and I have stories about them. And I used to be sort of – inside I used to feel ashamed about it.*' (Hickey et al., 2018, p.361)

				'Knowing what I have has helped me find out why I was always struggling at school and that, because I struggled, I was struggling at school and I was always getting into trouble (...). It helped like, the staff understand that, why I was always struggling and that.' (Huws & Jones, 2008, p.103) *'And what was my life before diagnosis? It was bits and pieces of disconnected things . . . I was a failure, right? And there was no centre. [But] there was a centre, me, the centre is I'm Autistic. And that explained all of that.'* (Lilley et al., 2021, p.8) *'It was almost like I was revisiting my whole life and realised, actually I'm not a bad person, I'm not faulty.'*(Lilley et al., 2021, p.8) *'An entire lifetime of struggles to understand social difficulties fell away in a moment'.* (Lewis, 2016, p.349) *'I wouldn't have blamed myself because I used to self-harm when I was younger and I don't think I would . . . if I had known I had Asperger's earlier. I would have been more aware of my problems . . . and better able to cope with them.'* (Punshon et al, 2009, p.276) *'A relief, because for years and years everything has been put down to anxiety and depression. Everything from the last 30 years made sense, it just all fitted in and it made sense.'* (Stagg & Belcher, 2019, p.353) *'Now because I know officially about the condition, I can say oh right I'm getting wheezy probably because I'm also getting anxious and now you know I could never go anywhere without my puffer in this pocket and my other puffer in the other pocket and whatever and now I think do I need to take it?'* (Stagg & Belcher, 2019, p.354) *'I mean looking back like I guess that certain like childhood experiences I had like it make a lot more sense in the context of, well, I'm autistic. (...) I remember one memory that sticks out to me. My dad took me to a baseball game. And it was way too loud and I just could not deal with it.'* (Tan, 2018, p.165)
	A new normal	Describes an increased self-acceptance and an alternative standard of normality following ASD diagnosis, as well as emphasising the role of wider society in defining 'normal'.	Bertilsdotter Rosqvist, 2012 Corden et al., 2021 Hickey et al., 2018 Hurlbutt & Chalmers, 2002 Huws & Jones, 2015	*'And so there was also this along with getting the diagnosis, that I actually got a language, too. For the first time in my life, I could express myself and my own inner being—who I am, so to speak. Before that, I couldn't.'* (Bertilsdotter Rosqvist, 2012, p.122) *'And it was actually a feeling of, that I actually felt enormously satisfied with the diagnosis. It felt as though I'd become normal. Because, well, because there were other people who had it and*

			Jones et al., 2015 Lewis, 2016 Lilley et al., 2021 Macleod et al., 2013 Punshon et al., 2009 Stagg & Belcher, 2019 Tan, 2018	*because there wasn't anything especially weird about me in that case.'* (Bertilsdotter Rosqvist, 2012, p.122) *'I give myself space to be me;' '[I'm] letting myself be the real me.'* (Corden et al., 2021, p.9) *'I'm not pressurising myself to be like everyone else. You know, it doesn't matter if I like being on my own, living on my own. That's fine. It's 'cause I – you know, people with Asperger's are like that. So I can feel like I'm not somebody who's failed to have a relationship, failed to have children, failed to hold down a job or get to a higher position in a job'* (Hickey et al., 2018, p.362) *'But inside we're just all the same. It's just something some people have, and some people don't have. Because people with autism, you can't really tell unless kinda of like you know them really well. I'm no different at the end of the day. I'm Jemma, that's it. At the end of the day, people with autism are just the same as people who haven't [got it], but they've just got something wrong with them, that's it. They're still the same no matter what'* (Huws & Jones, 2015, p.5) *'Now I don't want to be like anybody else, period. I don't necessarily see the idea of NT as perfection. Hey, regular people do stupid, mean, and often evil things that people with autism would never do. I am supposed to look up to that? I don't think so! I am tired of having to do 100% of the changing, and there is no change with most people without autism.'* (Hurlbutt & Chalmers, 2002, p.106) *'I feel more confident and comfortable in my own identity, which allows me to accept the things I have difficulty with and appreciate the things I am good at'* (Lewis, 2016, p.350) *'I spent so much of my life living with this paradigm that I'd made out of books that this is somehow what life is meant to be about. But that paradigm was based on neurotypical people. Fake it until you make it . . . Now, whether I can re-invent myself, I don't know.'* (Lilley et al., 2021, p.7) *'I would say people with autism are not different due to their brains, they are different because YOU think that they can't do anything right, but they can. I mean look at YouTube, man. There are a lot of people on there who are pretty famous. I can name two examples of them, Temple Grandin and Jessie Saperstein.'* (Jones et al., 2015, p.1498)

				'It's not really you, it's society I find that you know, they have the problem because we have to fit into the mainstream and it's difficult. It's lack of under- standing really. My mum and dad . . . that's what they do because I am not in a wheelchair they think . . . put too many demands on me.' (Punshon et al., 2009, p.280) *'it's helped me start to tick off emotions. I've realised what these feelings are that I have… . I've identified a couple of months ago, guilt. For the first time I've realised what guilt feels, and I can look back on my life and see all the times I've felt guilty but didn't know…Yes. It was a revelation. Fantastic'* (Stagg & Belcher, 2019, p.354) *'Okay, I really—there really is such a thing as not being able to do eye-contact well. And that's okay, just deal with it'.'* (Tan, 2018, p.165)
	Autistic community	Describes the way in which meeting other autistic people leads to a sense of self-acceptance, and fosters a sense of collective identity.	Bertilsdotter Rosqvist, 2012 Corden et al., 2021 Hickey et al., 2018 Jones et al., 2013 Jones et al.,, 2015 Lewis, 2016 Macleod et al., 2013 Punshon et al., 2009 Tan, 2018	*'Other people go through the same;'' '[I'm] less alone.'* (Corden et al., 2021, p.9) '*When you've got friends who've got autism, there's no point going home crying because everybody's there for you, you're there for everybody else. It's really easier.'; 'Knowing that there's, I'm not the only person out there'* (Jones et al., 2013, p.138) '*I think of a lone jelly bean all by myself. No friends, until he realizes, I'm not alone; I'm not the only jelly bean. There are jelly beans just like me, I'm not alone.'* (Jones et al., 2015, p.1499) '*I finally knew that I was not alone who felt different',' It was like I found my people!' 'This was a revelation, that I was indeed part of a much larger group of people how have similar experiences.'* (Lewis, 2016, p.349) *'Seeing somebody else I may be able to see similarities with myself..'* (Macleod et al., 2013, p.43) *'I know my tribe.'* (Tan, 2018, p.166) *'Well, to me it feels liberating, sort of—comes to mind, but it's, I feel it's been wonderful that I'm like, I don't know, sort of, I was excited when I first got my diagnosis. I felt I just want to meet other people like me. It's like I've been an animal with spots. All my life I've been around other animals without spots and I feel I can start meeting other people like me with spots, you know?'* (Tan, 2018, p.166)

Autistic people as experts by experience	Researching autism to inform self-perception, and need to increase awareness about ASD		Macleod et al., 2013 Jones et al., 2013 Bertilsdotter Rosqvist, 2012 Lewis, 2016 Hurlbutt & Chalmers, 2002 Huws & Jones, 2008 Jones et al., 2015 Corden et al., 2021 Punshon et al., 2009 Jones et al., 2013 Cooper et al., 2021	*'But, I mean, who is actually the expert? Is it Gillberg who has kind of sat and looked it up in the books and who has kind of met a lot of people with Asperger's, or is it I who am in fact living with Asperger's and have been doing so all my life?'* (Bertilsdotter Rosqvist, 2012, p.124) *'researchers and people without Asperger's but with professional knowledge could never ''come from a bottom-up perspective'' in contrast to ''we who have been living with Asperger's.'* (Bertilsdotter Rosqvist, 2012, p.124) *'It took time, but I read around a lot, learned online…'; 'Mostly I've learned from other people online about how to help myself.'* (Corden et al., 2021, p.9) *'I am committed to the cause of autism. I want to see people who are proud to have autism and accept themselves for who they are and all that they are. Too often in the past, people didn't listen to people with autism. Most people do not know about autism, much less what a person deals with. So, educating people about autism is key*.' (Hurlbutt & Chalmers, 2002, p.106) *'I hope that our thoughts will provide educators and students of the future with insight into our deepest thoughts and the workings of our imagination. Through people such as you and your students and colleagues, we will become more widely known to special educators of the future and historians.'* (Hurlbutt & Chalmers, 2002, p.106) *'I haven't read the book on autism which is in the library. I don't really want to read about my autism … because it'll probably get us upset or something because I'm reading about something I've got'* (Huws & Jones, 2008, p.104) *'People don't know what it is unless you've actually got it, cos when you've got it, you kind of like know that you've actually got it.It would be hard to describe something that other people don't understand You don't know what it's like' til you've actually got it, like how it affects you totally and like, it does really, sort of like, get to you, it gets under your skin.'* (Jones et al., 2013, p.138) *'When I found out I had it [Asperger's] I had to look it up, and I observed myself and compared myself to everyone else. If I was doing something different I assume it's an Asperger's thing.'* (Jones et al., 2015, p.1497)

				Participants started blogs, became speakers, started online or in-person support groups, and participated in research studies in an effort to help the adult ASD community.(Lewis, 2016, p.352) *'I knew there was something wrong with me from an early age . . . loads of different psychiatrists and psychologists . . . I had read loads of books and stuff . . . to try and find out why I was the way I was but . . . I never really found a satisfactory answer.'*(Punshon et al., 2009, p.274) *'To be honest I had certain issues with some of the information that was around, particularly the leaflets and the more succinct stuff because personally I don't feel that autism and Asperger's is something that you can put in a nutshell . . . it used to worry me because I didn't feel like I was really included in it'.* (Macleod et al., 2013, p. 44) *'I've read just about every type of information: Books by professionals and autistic people, first-hand accounts on websites and in internet discussions . . . I tend to disagree with the simplifications in leaflets'* (Macleod et al., 2013, p. 44)

University College Cork, Ireland
Coláiste na hOllscoile Corcaigh

Systematic Review Research Protocol

Title: A systematic review of autistic identity from the perspective of young people with Autism Spectrum Disorder

Main reviewer: Alison Garvey

Second reviewer: Michaela Hammond

Research Supervisor: Dr Christian Ryan

Date of submission:

I declare that the content of this assignment is all my own work. It has not been submitted in respect of any other course/module. Where I have used the work of others it is acknowledged and referenced accordingly.

The following case study is submitted in partial fulfilment of the requirements of University of Cork Doctor of Clinical Psychology. As such it is an academic exercise rather than a clinical report. Pseudonyms have been used throughout to protect the identity of patients, carers, staff etc.

Signed: Alison Garvey Date: 09th April 2021

Background

Adolescence is a unique developmental period where establishing an individual identity is recognised as a critical task contributing to long term development (Erikson, 1963; Jones et al., 2015). Identity development is primarily understood as a social process, as adolescents reportedly construct their identities through social comparisons with others, and through interpretations of their own experiences (Harter, 1999; Jones et al., 2015). However, for young people with autism, this developmental period may present unique challenges as they navigate social expectations and interpersonal relationships (Jones et al., 2015). While social cognitive differences associated with the condition can lead to an assumption that identity is not an area of concern, or is poorly developed among this population; a growing body of qualitative literature indicates that identity construction is of major concern for young people with autism, and that negotiating the idea of 'being autistic' is a crucial part of this developmental process (Mesa & Hamilton, 2021; Mogensen & Mason, 2015). Erikson (1968) postulated that there is a relationship between identity development and mental health (Cresswell & Cage, 2019). Indeed, autism research has found that individuals with autism who had a lower social identity with other people with autism presented with lower self-esteem and higher levels of depression and anxiety when compared to controls. Conversely, it was reported that having a positive social identity with other autistic group members was a protective factor against poor mental health (Cooper et al., 2017). In light of these mental health implications, the importance of understanding how young people with autism make sense of autism as part of their identity is important.

Autism has been defined as an 'invisible disability', which means that traits associated with autism may not be discernible to others (Large & Serrano, 2018). In this way, individuals with autism may choose to deny their diagnosis, accept it, or feel compelled to assert it in the face of denial by others (MacLeod et al., 2013). Prior research has explored factors influencing the acceptance or rejection of an autism diagnosis, and what it means to be 'normal' as a person with autism. For example, individuals on the autism spectrum often report the use of social camouflaging to make autistic traits less visible, and appear more like non-autistic peers. However, the use of social camouflaging has been linked to identity confusion and detrimental effects on mental health (Cage et al., 2018; Cage & Troxell-Whitman, 2019; Hull et al., 2017). Conversely, young people with autism who viewed autism as a positive aspect of their identity expressed pride about being autistic (Jones et al., 2015; Mogensen & Mason, 2015; Riccio et al., 2021). Thus, it is evident that being autistic may hold different meanings among this population.

Discourses of autism present in the sociocultural contexts in which young people grow up are likely to influence their autistic identity (Brownlow, 2010). For example, frameworks of understanding autism

have shifted across time. Within the medical model, autism is primarily understand in terms of deficit, and the focus is on amelioration towards what is considered 'normative standards' (Mesa & Hamilton, 2021). On the other hand, the more recent autism acceptance movement maintains that autism is a normal human variation that should be accommodated by an informed society (Gobbo & Shmulsky, 2016). Thus, within this framework, individuals with autism are seeking to understand who they are, rather than who they are expected or told to be (Large & Serrano, 2018). The problem and solution are therefore within the person-environment fit, rather than the individual (Gobbo & Shmulsky, 2016). There is evidence to suggest that young people with autism position themselves in relation to both discourses (Humphrey & Lewis, 2008). In addition to divergent frameworks for understanding autism, descriptions and terms for autism have changed significantly throughout the years, somewhat reflecting changes in the most commonly used diagnostic criteria (Bury et al., 2020). For example, Autistic disorder, Asperger's syndrome, and Pervasive developmental disorder not otherwise specified were all combined into the single category of Autism Spectrum Disorder (ASD). Furthermore, there is increased discussion surrounding the language or terminology that should be used when referring to someone who is diagnosed with an ASD, mostly in relation to person-first or identity first language. Person-first language is recommended by the American Psychological Association (APA; 2012), and is widely used in clinical and research settings, for example 'person with autism' (Bury et al., 2020). However, the autism acceptance movement advocates identity first language, thereby deliberately claiming the 'disability' as integral to their identity, for example 'autistic person' (Bury et al., 2020). Therefore, for young people with autism, making sense of their autistic identity involves navigating these various, and often competing discourses of autism (Mesa & Hamilton, 2021).

Coinciding with the autism self-advocacy movement, there has been growing interest in the perceptions and experiences of individuals with autism (Carrington & Graham, 2001; Griffith et al., 2011) and acknowledgement of the value of understanding their first-person perspectives (Müller et al., 2008). Indeed, exploring the way in which young people with autism make sense of their diagnosis, and negotiate autism as part of their identity can inform mental health and well-being in this population (Mesa & Hamilton, 2021). However. there are currently no reviews that systematically explore this area. A synthesis of the existing qualitative literature may increase impact, as qualitative synthesis aims to produce a 'systematic logic' in which diverse findings from a specific topic are drawn together and integrated systemically to produce more transferable and reliable knowledge claims (Williams et al., 2019).

Research Question

The aim of this review is to collate, evaluate and synthesis the qualitative research exploring how young people with autism make sense of autism as an aspect of their identity. Thus, the review will aim to address the following research questions:

1. What does being autistic mean to young people with autism?
2. How do young people with autism make sense of autism as an aspect of their identity?

Method

Search Strategy

An initial scoping search identified an inconsistency in title and keyword use in autism research exploring identity. For example, identity is described in many different ways throughout the literature, and concepts related to identity and autism, such as camouflaging in which people attempt to hide their identity, are not identified using a computerised search. Therefore, in order to fully integrate important concepts related to autistic identity, the search strategy will comprise two main methods. This proposed systematic review will be conducted in accordance with the PRISMA guidelines:

1. *Computerised search:* Literature will be sourced through electronic databases including PsychInfo, ERIC, Medline, CINAHL and Web of Science due to their relevance to the review question. Each database will be searched by the research student, in consultation with her research supervisor, an expert librarian, and a member of the autistic community as an expert by experience. The following strategy will be followed: Keywords and their synonyms will be entered into the database and truncated where appropriate. All individual searches for that column will be combined using the 'OR' Boolean operator into a single group. Each overall group will then be combined using the 'AND' function to produce a final list of document searches. These documents will be saved to Zotero, and screened for duplicates. Records of all searches in each database will be maintained. The search strategy will be based on three concepts, autism spectrum disorders, meaning making and identity. The SPIDER (Sample, Phenomenon of Interest, Design, Evaluation, Research type) tool was used to structure the search terms and eligibility criteria, and as a means of informing and standardising the search strategy. A sample search strategy using SPIDER can be found in Appendix 1.
2. *Citation chaining:* A backward searching method will also be carried out in which the bibliographies of key papers that match the eligibility criteria will also be manually searched to identify any further, relevant references. Forward searching will be carried out using Google

Scholar in order to identify any papers that have subsequently cited any key references. Any papers identified will be subject to the same screening and selection process.

Inclusion and exclusion criteria

Inclusion and exclusion criteria as defined by the SPIDER tool can be found in Tables 1and 2.

Table 1: Inclusion Criteria

Sample	As the developmental task of identity development becomes particularly salient during adolescence, the review will include studies that includes young people (12-21 years) who have a confirmed ASD diagnosis according to DSM or ICD criteria, and no intellectual disability.
Phenomenon	Studies exploring the experiences, perspectives, or views of adolescents with ASD on the meaning of autism, with specific reference to the way in which they experience ASD as part of their identity.
Design	Qualitative methods of data collection and analysis, including interviews, focus groups, online forums, open ended questions, thematic analysis, IPA etc.
Outcome measures	• Any qualitative work that includes narratives of adolescents with ASD which illuminates their experiences, perspectives, or views of what it means to be autistic • Any qualitative work that includes narratives of adolescents with ASD which explores the way in which they make sense of autism as part of their identity
Research Type	• Presents original qualitative data and analysis (including qualitative elements of mixed-methods studies) • Any study which utilizes survey data or statistical reporting of results will be excluded, as will commentaries or discussions on the subject. Qualitative data from a mixed methods study will be included • Any study which utilizes survey data or statistical reporting of results will be excluded, as will commentaries or discussions on the subject. Qualitative data from a mixed methods study will be included • Published in peer reviewed journal • Published in the English language • No restrictions regarding research location or published date

Table 2: Exclusion criteria

Sample	• Adults and adolescents with an intellectual disability • Children under the age of twelve
Outcome measures	• Studies exploring other people's (parents, teachers etc) perspectives of autism/ autistic identity • Studies that target narrow aspects of identity such as gender identity, or studies that aim to explore young people with autism's experiences within certain contexts e.g. their experiences of being autistic in school • Studies in which the results do not address what it means to be autistic, and/or the way in which young people with ASD experience autism as part of their identity
Research Type	• Any study which utilizes survey data or statistical reporting of results will be excluded, as will commentaries or discussions on the subject • Due to limited resources, studies published in languages other than the English language are unable to be translated and included in the review No full text available

Screening and Selection

Reviewers: The review process will include two reviewers; the main reviewer and another clinical trainee, who will act as the second reviewer. Any discrepancies that cannot be resolved through discussion will be brought to the research supervisor for a decision.

All potential articles will undergo a two-stage screening process based on the inclusion criteria:

Stage 1: All searches from the various databases will be transported to Zotero and places in separate folders (e.g. PsychInfo search folder). Searches will be combined in one folder and all duplicates will be removed. Initially, the main reviewer will screen all citations based on title and abstract. Articles that do not meet the inclusion criteria based on their abstracts will be excluded from the analysis. Subfolders will be created within Zotero to gather articles for potential inclusion/ exclusion. To ensure a clear audit trail, excluded studies will be moved to a specific 'Excluded Studies' Zotero folder. Each article will have a note attached to explain the decision making process. The second reviewer will cross check all of the screening articles to establish whether they agree with the decision.

Stage 2: Full text of all included citations will be obtained. Authors will be contacted for missing information from full text. If there is no response within two weeks, the article may be excluded on the basis of missing information. The full articles will be read in detail by both reviewers and they will meet to decide which papers meet the inclusion criteria, and again any articles that do not meet the inclusion criteria will be excluded from the review.

Data Extraction

A data extraction form was compiled based on research question, relevant literature, and also through consultation of qualitative systematic review papers (Appendix 2).

Quality Assessment

There are a number of different tools available to aid in the critical appraisal of qualitative research. The Critical Appraisal Skills Programme (CASP; CASP International Network, 2018) qualitative checklist will be used for critical appraisal as it is widely used and suitable for the purpose of the research (Appendix 2). This tool evaluates research along 10 dimensions of research quality (clear statement of aims; qualitative method appropriate; design appropriate; recruitment strategy appropriate; data collection appropriate; researcher- participant relationship; ethical issues considered; data analysis rigorous; clear statement of findings; value of research). A score of 0 will be given if the criteria is not met, 1 if it is unclear and 2 where it is definitely met. All studies will be rated with this tool and scores will be summated. Studies will then be assigned with a quality classification from A-C, where A denotes high quality research and total scores

of 8.5-10; B represents moderate quality research with total scores of 5-8; and C represents lower quality research, with higher likelihood of methodological flaws, with a total score of 5 or below (Hull et al., 2017, 2020). Reviewers will complete quality assessment separately and compare findings. The quality appraisal tool will be used to further explore findings rather than exclude them.

Data Synthesis

It is proposed that data will be synthesised using thematic synthesis, a qualitative approach that uses thematic analysis principles to reports of qualitative findings (O'Connor et al., 2018). In line with Thomas and Harden (2008) the synthesis will focus on content presented in the 'results' and 'findings' section of the article. The results section of each paper will be reviewed and text related to the research question will be highlighted. Following this, a coding framework will be developed to capture the range of findings reported. This framework will be developed through an iterative process and a discussion with the research team. Once the framework is developed, relevant text will be revisited and appropriate codes applied. Basic level codes will firstly be organised into descriptive themes based on similarities in content, which will be further interpreted to yield analytical themes. Analytic themes will be generated through additional coding, reflection and discussion with all reviewers (O'Connor et al., 2018; Thomas & Harden, 2008).

Dissemination Plan

Once approved, the systematic review will be registered with PROSPERO. Findings from this systematic review may be used to inform and develop services and interventions for people with ASD, particularly in relation to mental health and well-being. The systematic review write up will follow the guidelines of the 'Autism' journal with a view to publication.

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Appendices

Appendix 1: Search Terms Used for SPIDER search

Sample	**(**Autis* OR ASD OR Asperger* OR 'Autism Spectrum Disorder*' OR 'Autis* Diagnos*')
Phenomenon of Interest	**(**Identit* OR 'label' OR 'Self-concept' OR Camouflag* OR 'Self-perception' OR 'Self-View' OR 'Collective Identity' OR 'Social Identity' OR 'Group Identity')
Design/ Research Type	Qualitative OR Mixed Methods OR Interview* OR 'semi structured interview*' OR 'semi-structured interview*' OR 'unstructured interview*' OR 'focus group*' OR 'thematic analysis' OR 'IPA' OR 'Grounded Theory' OR ethnograph*
Evaluation	'perspective*' OR 'perception*' OR 'viewpoint*' OR 'view*' OR 'feel' OR 'opinion*' OR 'understanding' OR 'awareness' OR 'belief*' OR 'insight*' OR 'comprehension' OR 'experience*' OR 'concern*' OR 'attitude*' OR 'meaning'

Appendix 2: Data Extraction Tool

Table 3: Proposed Data Extraction Table

Author(s)	Title	Date of Publication	Location/ Country	Aims	Participant Characteristics		Data Collection Method	Data Analysis Approach	Key themes/ findings identified	Data extracts to support themes	Quality Rating

Appendix G: Information Sheet

Information Sheet

Thank you for considering participating in this research project. The purpose of this document is to explain to you what the work is about and what your participation would involve, to enable you to make an informed choice.

Purpose

Previous research has suggested that some individuals with autism spectrum disorder can experience difficulties with eye-contact when communicating with others. The purpose of this study is to explore the experience of using eye-contact for people with autism spectrum disorder. Should you choose to participate, you will be asked to take part in a one-to-one interview with the researcher using an online platform (Microsoft Teams). You will need a reliable internet connection, a smartphone/laptop and a private space in order to participate. You will receive an email with a link to the interview prior and you will also receive instructions on how to access this link. This interview will be video-recorded and is expected to take 60-90 minutes to complete.

Participation

During the interview, I am going to be asking you about your experience of eye-contact. To help you reflect on your experiences of eye-contact in everyday life, you are invited to keep a diary/written record of your experience of eye-contact for a week before the interview. The diary/ written record may be helpful to keep account of your thoughts, senses, emotions, and particular situations related to making eye-contact. For example, you may consider what the experience of eye-contact is like now and how this has changed over time, what factors make eye-contact easier or more difficult to maintain, and what kind of strategies you use to make eye-contact. The diary/written record will not be collected by the researcher; rather it is suggested as a reflective exercise to help you share a rich account of your experience of eye-contact during the interview.

Participation in this study is completely voluntary. There is no obligation to participate, and should you choose to do so you can refuse to answer specific questions or decide to withdraw from the interview. Once the interview has been concluded, you can choose to withdraw your details at any time up to two weeks after taking part in the study.

Instruction on Microsoft Teams

Microsoft Teams is the University College Cork's preferred online secure platform. Before your scheduled interview, you will receive a link via email. You simply have to click on the link 'Join

Microsoft Teams Meeting' in order to enter the meeting. You will not require a Microsoft Teams account to attend the meeting. Microsoft Teams includes a video recording feature which will be used in order to record the interview. These video recording will be stored temporarily on to the secure UCC OneDrive until time of transcription.

Anonymity and what will happen with your data after participating

All the information you provide will be kept confidential and anonymous. The only exception is where information is disclosed which indicates that there is a serious risk to you or to others. Once the interview is completed, the recording will immediately be saved to a folder on a secure UCC OneDrive. The interview will then be transcribed by the researcher, and all identifying information will be removed. Once this is done, the recording will also be deleted and only the anonymized transcript will remain. This will be stored on the University College Cork OneDrive system and subsequently on the UCC server. The data will be stored for a minimum of ten years. The information you provide may contribute to research publications and/or conference presentations. Furthermore, your data will also contribute to the write up of a Doctoral thesis.

Other Information

We do not anticipate any negative outcomes from participating in this study. However, should you experience distress arising from the interview, we would ask that in the first instance you contact the organization from which you originally heard about this research to receive further support. We have included the contact details for these organizations and for and other community services below:

- **RehabCare**
  Telephone: 021 490 7610
  Website: https://www.rehab.ie/rehabcare/
- **UCC Disability Services**
  Telephone: +353 (0) 21 490 4848
  Website: https://www.ucc.ie/en/dss/
- **Samaritans Ireland**
  Telephone: 116123
  Website: https://www.samaritans.org/?nation=ireland
- **UCC Student Counselling (For students within UCC)**
  Email: **counselling@ucc.ie**
  Website: https://www.ucc.ie/en/studentcounselling/contact/

This study has obtained ethical approval from the UCC Clinical Psychology Research Ethics Committee.

If you have any queries about this research, you can contact Alison Garvey at 116223883@umail.ucc.ie. You can also contact her research supervisor, Dr Christian Ryan at Christian.ryan@ucc.ie

If you agree to take part in this study, please sign the consent form attached to this email and return via email

Appendix H: Consent form

Consent Form

Please attach your e-signature to this form and return via email to

116223883@umail.ucc.ie

I……(type name or attach e-signature) agree to participate in Alison Garvey's research study.

The purpose and nature of the study has been explained to me in writing.

I am participating voluntarily.

I give permission for my interview with Alison Garvey to be video recorded.

I understand that I can withdraw from the study, without repercussions, at any time, whether before it starts or while I am participating.

I understand that I can withdraw permission to use the data within two weeks of the interview, in which case the material will be deleted.

I understand that anonymity will be ensured in the write-up by disguising my identity and that extracts from my interview may be quoted in the thesis and any subsequent publications if I give permission below:

I confirm that I am 18 years old or above and have a previous diagnosis of an autism spectrum disorder (for example Asperger's Syndrome).

Signed (type name or attach e-signature): …….

Date: …….

Appendix I: Interview Schedule

IPA Interview Schedule

1. Preamble about research: Introduction, explain purpose of the research; confirm consent, explain interview will focus on experience of eye-contact from person's own perspective; confirm recording of interview via MS Teams.

2. Interview Questions

1. What was it that interested you in taking part in this research?

2. What do you think of when someone mentions 'eye-contact'?
   Probes: What comes to mind?

3. Growing up, what was your experience of using eye-contact?
   Probes: What did that mean to you? How did you make sense of that? How did you feel about yourself?

4. What do your family say about eye-contact?
   Probes: Was it ever discussed? Was it effected by your mood? Did they comment on change over time?

5. Did you undergo any social skills training growing up?
   Probes: What kind of social skills group or training did you have growing up? Was eye-contact a target for intervention? In your opinion, can difficulty with eye-contact be overcome? Can you imagine what it would feel like?

6. What kind of strategies do you use to make eye-contact?
   Probes: How did you learn this? What is this experience like for you?

7. What factors make it easier or harder to maintain eye-contact?
   Probes: If you know the person well, if you like/ dislike them, if they are an authority figure, same/ diff sex, stranger, talking about yourself/ talking about hobbies or interests? When listening to others? Do you experience a change in your ability to make eye-contact for longer conversations?

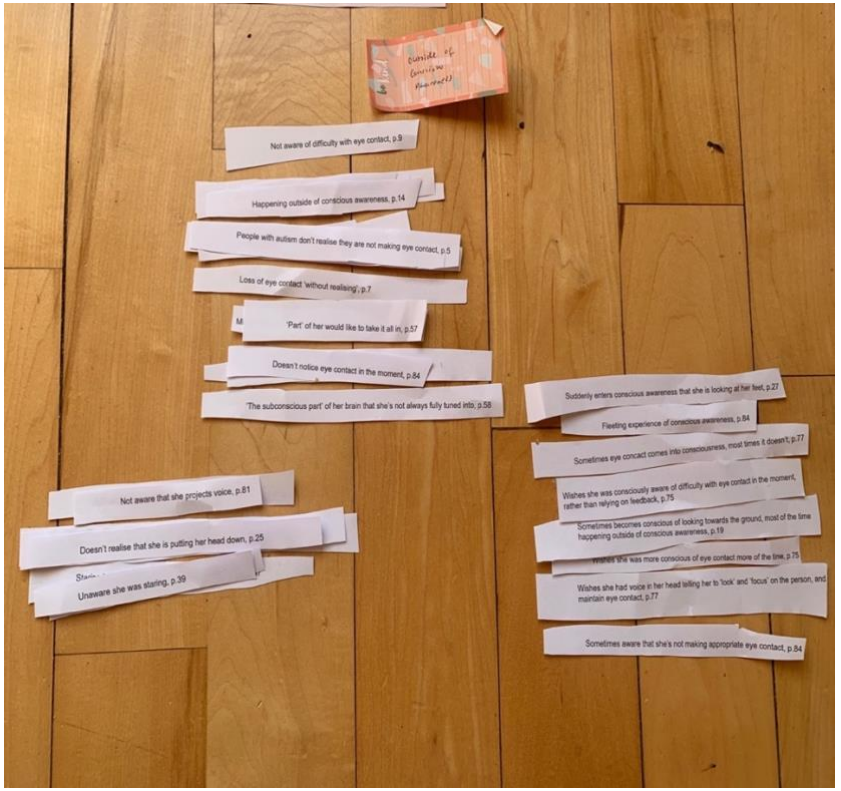
8. Can you tell me in your own words how you experience eye-contact now?
   Probes: What is it like for you? What does that mean to you? How has it been today during the interview? What happens? How do you feel? How do you cope?

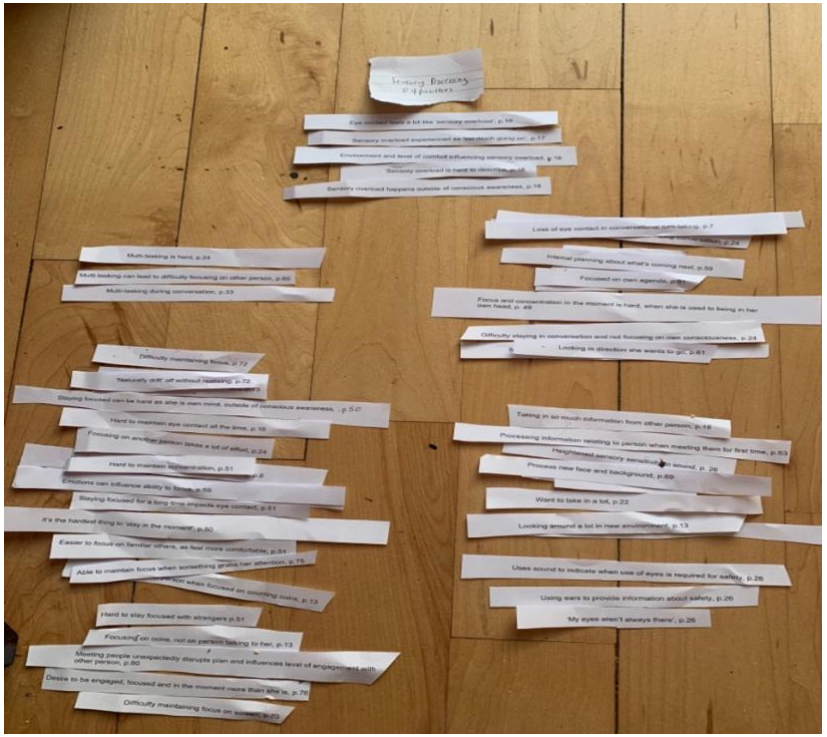
3. General Prompts:
Can you tell me more about that?
Why?
How?
How did you arrive at your decision?
Can you describe a typical example?
Tell me what you were thinking
How did you feel?

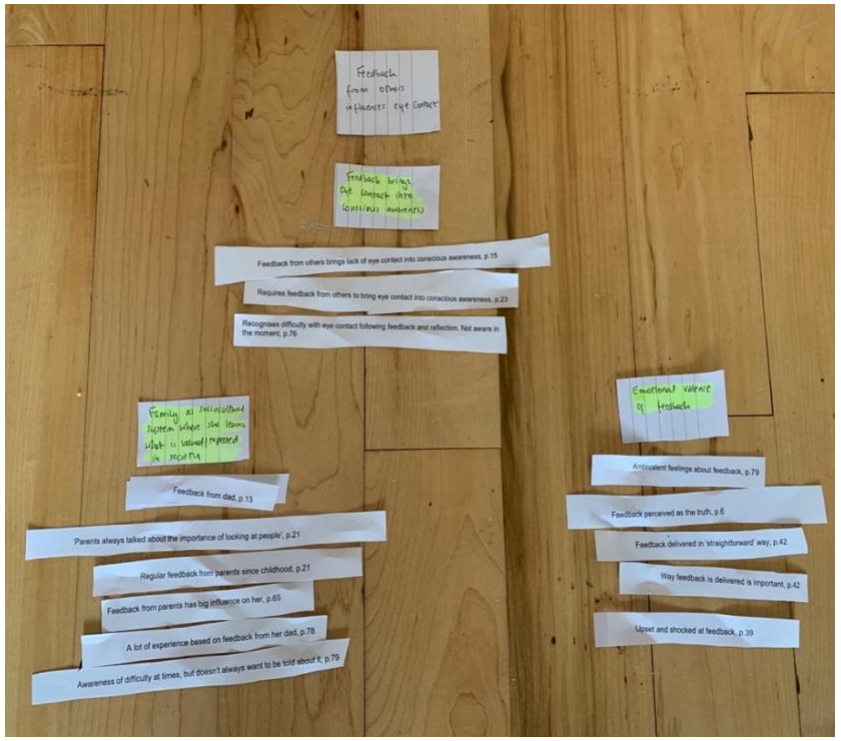
Does anything make it better/ worse?

4. Check in. Check whether participant has any questions

Appendix M: Organising and Clustering Experiential Statements




Sensory Processing Difficulties
Eye contact feels a bit like 'sensory overload', p. 16
Sensory overload experienced as 'too much going on', p. 17
Environment and level of comfort influencing sensory overload, p. 16
Sensory overload is hard to describe, p. 17
Sensory overload happens outside of conscious awareness, p. 16
Loss of eye contact in conversation/turn-taking, p. 7
Internal planning about what's coming next, p. 59
Focused on own agenda, p. 61
Focus and concentration in the moment is hard, when she is used to being in her own head, p. 49
Difficulty staying in conversation and not focusing on own consciousness, p. 24
Looking in direction she wants to go, p. 61
Multi-tasking is hard, p. 24
Multi-tasking can lead to difficulty focusing on other person, p. 60
Multi-tasking during conversation, p. 33
Difficulty maintaining focus, p. 72
Naturally drift off without realising, p. 72
Staying focused can be hard as she is own mind, outside of conscious awareness, p. 50
Hard to maintain eye contact all the time, p. 16
Focusing on another person takes a lot of effort, p. 24
Hard to maintain concentration, p. 51
Emotions can influence ability to focus, p. 59
Staying focused for a long time impacts eye contact, p. 51
It's the hardest thing to 'stay in the moment', p. 50
Easier to focus on familiar others, as feel more comfortable, p. 54
Able to maintain focus when something grabs her attention, p. 75
Hard to stay focused with strangers p. 51
Focusing on noise, not on person talking to her, p. 13
Meeting people unexpectedly disrupts plan and influences level of engagement with other person, p. 60
Desire to be engaged, focused and in the moment more than she is, p. 76
Difficulty maintaining focus on screens, p. 73
Taking in so much information from other person, p. 18
Processing information relating to person when meeting them for first time, p. 53
Heightened sensory sensitivities to sound, p. 26
Process new face and background, p. 69
Want to take in a lot, p. 22
Looking around a lot in new environment, p. 13
Uses sound to indicate when use of eyes is required for safety, p. 26
Using ears to provide information about safety, p. 26
'My eyes aren't always there', p. 26


Feedback from others influences eye contact
Feedback brings eye contact into conscious awareness
Feedback from others brings lack of eye contact into conscious awareness, p. 15
Requires feedback from others to bring eye contact into conscious awareness, p. 23
Recognises difficulty with eye contact following feedback and reflection. Not aware in the moment, p. 76
Family as safe place where she learns what is valued/expected in society
Feedback from dad, p. 13
'Parents always talked about the importance of looking at people', p. 21
Regular feedback from parents since childhood, p. 21
Feedback from parents has big influence on her, p. 65
A lot of experience based on feedback from her dad, p. 78
Awareness of difficulty at times, but doesn't always want to be told about it, p. 79
Emotional valence of feedback
Ambivalent feelings about feedback, p. 79
Feedback perceived as the truth, p. 6
Feedback delivered in 'straightforward' way, p. 42
Way feedback is delivered is important, p. 42
Upset and shocked at feedback, p. 39