An Exploration of Autism Spectrum Disorder, Psychosis and Self-esteem

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Abstract

This research aimed to explore self-esteem and psychosis in the context of Autism Spectrum Disorders (ASD). A systematic review was conducted to synthesise existing research into self-esteem in Autism. This review employed a mixed methods design, where qualitative accounts were used to clarify and expand on quantitative findings.

The review examined 18 studies; twelve used quantitative methods, 3 were mixed methods and 3 were qualitative. The results of the review were divided into 3 key areas: self-esteem in ASD compared to neurotypical controls, factors influencing self-esteem in ASD populations, and secondary mental health outcomes associated with self-esteem. The review highlighted that self-esteem is significantly lower in ASD populations compared to neurotypical controls and is associated with mental health difficulties including anxiety and depression, with factors such as social isolation and feelings of difference negatively impacting on self-esteem in Autistic populations. Social connectedness was shown to be protective against low self-esteem.

An empirical study was then conducted to explore the lived experience of those with co-morbid ASD and psychosis. Semi-structured interviews were conducted with six participants recruited from an Early Intervention Service and analysed using Interpretative Phenomenological Analysis. Five superordinate themes were identified: experience of psychosis; experience of ASD; overlap between ASD and psychosis; emotional difficulties; treatment with EIS. This study highlighted the pervasive, long-term impact of ASD on participants' social and emotional wellbeing, in addition to the additive and amplificatory effect of psychosis on difficulties experienced in the context of ASD. The findings from both studies were critically discussed and evaluated.

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Chapter One

Introduction

Word Count: 622 words

Introduction

Autism Spectrum Disorder (ASD) is characterised by difficulties with social communication and restricted, repetitive patterns of behaviour, interests or activities. As ASD is a developmental disorder, these behavioural markers emerge in early childhood, though are sometimes masked by the limited social demands of the early years, or, in adulthood, by learned coping strategies (APA, 2013). For this reason, though the average age of diagnosis of ASD is 55 months, recent research suggests that the rate of adult ASD diagnoses is increasing (Brett et al., 2016). Social communication difficulties in ASD predispose those with the condition to high levels of social adversity, including peer victimisation, marginalisation, and social isolation (Bejerot & Mörtberg, 2009; Chatzitheochari, 2014a; Humphrey & Symes, 2010a, 2011; Schroeder et al., 2014), with research estimating that those with ASD are four times more likely to have these difficulties compared to neurotypical peers (Wainscot et al., 2008).

The difficulties associated with ASD have been shown to be related to several adverse mental health outcomes, for example, low self-esteem (Cooper et al., 2017; Humphrey & Hebron, 2015b; Jamison & Schuttler, 2015). Self-esteem is generally understood to encapsulate one's global view of oneself and the estimation of personal success (Butler & Gasson, 2005). In addition to transdiagnostic difficulties such as self-esteem, it is widely accepted that there is a high level of comorbid mental health diagnoses amongst those with ASD (Crane et al., 2019; Kerns et al., 2015; van Steensel et al., 2011). There is a large body of evidence demonstrating the co-occurrence of ASD with affective disorders, such as social anxiety and obsessive-compulsive disorder (van Steensel et al., 2011), in addition to psychosis (Cochran et al., 2013; De Giorgi et al., 2019). Psychosis is broadly defined as losing touch with reality, often in the form of hallucinations and delusions. Psychosis can also cause cognitive and communication difficulties in addition to behavioural changes (NIMH, 2020).

ASD and psychosis have long been posited to be related conditions with co-morbidity estimates ranging from 3.6% (Davidson et al., 2014) to 28% (Mouridsen et al., 2008). This overlap has been explored in relation to genetics, neurobiology and cognitive neuroscience where candidate genes, brain regions and cognitive processes have been implicated. For example, it has been shown that there are relatively high levels of heritability, not only for each disorder independently, but between disorders, suggesting significant genetic overlap (Daniels et al., 2008; Larsson et al., 2005; P. F. Sullivan et al., 2012). Important identified shared cognitive deficits have also been found in higher-order social cognition such as social reciprocity and theory of mind (Baron-Cohen, 1989; Frith, 1996; Pina-Camacho et al., 2016) in addition to rigid, inflexible thinking styles (Leung & Zakzanis, 2014). Shared experiential risk factors such as disorganised parental attachment, bullying and social exclusion have also been identified (Sossin, 2015), suggesting environmental overlap. Despite this wide-ranging body of evidence, our understanding of the clinical manifestation of this co-morbidity, in addition to the lived experience of those with both ASD and psychosis, is limited.

This thesis aims to explore co-morbidities associated with ASD. Firstly, through a systematic review of the literature around self-esteem and ASD, followed by an empirical study of the experience of co-morbid ASD and psychosis, which aims to further the literature around the overlapping features of these conditions. Due to the marginalisation of Autistic individuals which has been shown to be reflected within the research literature (MacLeod, 2019), the researcher has chosen to prioritise giving this population a voice. To achieve this, the systematic review employed mixed methods, whereby qualitative accounts were used to inform and expand on quantitative findings. The empirical paper also utilised qualitative methods, with Interpretative Phenomenological Analysis being employed to provide in-depth experiential accounts of co-morbid ASD and psychosis.

Note on language use

The language used to describe neurodevelopmental conditions has been a great source of debate in recent years, with the trend moving away from diagnostic terminology towards a more strengths-based, spectrum understanding of conditions such as ASD (Dyke & Russell, 2019). In the systematic review chapter of this portfolio the term “high-functioning Autism” is used in order to denote the exclusion of those with co-morbid learning difficulties and disabilities. The term “neurotypical” is used, in line with the neurodivergence movement (Dyke & Russell, 2019), to denote those who do not have any neurodivergences including ASD, ADHD and learning disabilities. The empirical paper predominantly uses the term “ASD” to reflect both language use in the wider literature handling ASD with mental health co-morbidity, in addition to reflecting the preferred language of the service in which this research was based. In line with the recommendations of the National Autistic Society (Kenny et al., 2015), the term “autistic” is used to describe those with a diagnosis of ASD.

Chapter Two

Systematic Review

Autism and self-esteem: A mixed-methods systematic review

This paper has been developed for submission to Research in Autism Spectrum Disorders. Author guidelines are outlined (Appendix A). Word count limit 10,000 words.

Word Count: 8,110

High-functioning autism and self-esteem: A mixed-methods systematic review

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Abstract

Background

Self-esteem has been found to be low in high-functioning autistic populations. This review aims to determine whether this is significant compared to neurotypical controls, and to understand both the factors influencing self-esteem, and the potential mental health outcomes of having high-functioning autism and low self-esteem.

Methods

Thomas and Harden's (2005) framework for mixed methods systematic reviews was utilised. Narrative synthesis was used to analyse quantitative data, whilst thematic analysis was used for qualitative data. These data were then mapped onto a matrix and integrated according to similarities and differences.

Results

A total of 18 peer-reviewed studies were included in the review. Twelve used quantitative methods, 3 were mixed methods and 3 were qualitative. Self-esteem was found to be significantly lower in high-functioning autism compared to neurotypical controls. Several factors influencing self-esteem in Autistic populations were identified including cognitive profile, social exclusion and victimisation, feelings of difference and social connectedness. Self-esteem was found to be significantly related to both anxiety and depression, though this effect was also seen in neurotypical controls.

Conclusions

Self-esteem is significantly lower in high-functioning autism than neurotypical controls and is related to poorer mental health outcomes, though further research is required into effective psychological interventions for self-esteem and psychiatric co-morbidity in this group. Social belonging is important in promoting positive individual and collective self-esteem meaning that autistic people may benefit from interventions which promote social connectedness.

Key words: high functioning autism, self-esteem, anxiety, depression, social connectedness

Introduction

Autism Spectrum Disorder (ASD) is a neurodevelopmental condition characterised by deficits in social communication and restricted, repetitive patterns of behaviour, interests, or activities (DSM-5; APA, 2013). ASD can broadly be divided into "high-functioning" (HFA) and "low-functioning" (LFA) autism, with the former exhibiting normal or above average intellectual functioning and the latter exhibiting below average intellectual functioning or concurrent intellectual disability (Baron-Cohen, 2000). Those with HFA are likely to present with deficits in social- emotional reciprocity including difficulties with back-and-forth conversation, non-verbal communication including modulating appropriate eye contact and difficulties in understanding, developing, and maintaining relationships (Del Barrio, 2016). Highly restrictive interests with unusual intensity, cognitive and behavioural inflexibility and additional sensory needs are also commonplace (APA, 2013). Due, in part, to these difficulties, people with HFA often experience social isolation (Kasari & Sterling, 2013), social exclusion, including exclusion from employment, (Howlin, 2013) and are more likely to experience peer-victimisation and bullying than neurotypical peers (Bejerot et al., 2009.; Chatzitheochari et al., 2014; Humphrey & Symes, 2010, 2011). Research into the causes of these experiences has suggested that key risk factors include social communication difficulties, differences in social understanding (Garner & Hinton, 2010; Wainscot et al., 2008) and stereotyping and stigma leading to discrimination towards those on the Autistic spectrum (Humphrey & Symes, 2010b).

The psychological consequences of this social adversity are widespread. Psychiatric co-morbidities are high across the lifespan, with depression, anxiety disorders, eating disorders, obsessive-compulsive disorder and psychosis all commonly co-ocurring with HFA (Ghaziuddin & Zafar, 2008; Joshi et al., 2010, 2013; Kincaid et al., 2017) with a two to four times incidence rate compared to neurotypical peers (Moseley et al., 2011). Transdiagnostic difficulties such as sleep disorders, emotional dysregulation and low self-esteem have also been shown to be elevated in HFA (K. Cooper et al., 2017b; Morie et al., 2019; Polimeni et al., 2005; van der Cruijsen & Boyer, 2021) highlighting the prominent levels of psychosocial difficulty experienced by this population.

Self-esteem is a broad concept incapsulating several domains of identity including self-concept (the global, overarching view of self), and self-efficacy (the notion of estimation of success at personally valued tasks) which has been described and discussed in the literature for several decades (Butler & Gasson, 2005). Self-esteem is generally understood to develop once self-concept is formed (Calhoun et al., 1977.; Rosenberg, 1986), as views on the established self emerge (Rosenberg, 1979). Broken down further, the dual process model (Bosson et al., 2000) differentiates conscious self-judgements and beliefs, otherwise called explicit self-esteem, from unconscious self-judgements and beliefs, or implicit self-esteem. Research investigating the degree of inter-relatedness of these domains has indicated only low to moderate correlations between them, suggesting that they are related but independent concepts (Bosson et al., 2001; Hofmann et al., 2005; Krizan et al., 2008). This relationship was demonstrated by DeHart and Pelham (2007), who found that the magnitude of change to implicit self-esteem following negative life-events was moderated by levels of explicit self-esteem, with those with low levels of explicit self-esteem experiencing a decrease in implicit self-esteem, whilst those with high levels of explicit self-esteem did not.

Another way in which self-esteem has been conceptualised is in differentiating individual self-esteem and collective self-esteem. Individual self-esteem refers to levels of both implicit and explicit self-esteem, whereas collective self-esteem relates to the level of positive identification one has with their social group (Sánchez & Vilain, 2009). Much like implicit and explicit self-esteem, individual and collective self-esteem, though separate concepts, have been shown to be significatly positively correlated (Marmarosh et al., 2005; Sharma et al., 2014). In addition to improving individual self-esteem, high levels of collective self-esteem have also been shown to be protective against psychological distress, particularly in marginalised groups (Sánchez & Vilain, 2009).

Whilst high levels of both individual and collective self-esteem are widely considered psychologically protective (Dumont & Provost, 1999; Kidd & Shahar, 2008; Sánchez & Vilain, 2009; Sharaf et al., 2009) low self-esteem has consistently been linked to psychological distress and psychiatric illness (Bosacki et al., 2007; Cervera et al., 2003; Kaplan & Wadden, 1986; Mann et al., 2004; McClure et al., 2010; Neumark-Sztainer et al., 2007; Silverstone & Salsali, 2003). In a large study utilising longitudinal data, Orth et al (2009) found that low self-esteem operated as a consistent risk factor for depression in all phases of adult life, and was later replicated in an adolescent sample (Orth et al., 2014). Furthermore, in their study of self-esteem in psychiatric patients, Silverstone and Salsali (2003) found that all psychiatric patients demonstrated low self-esteem to varying degrees, with those with major depressive disorders, eating disorders and substance use having the lowest levels. Low self-esteem has also been shown to be associated with high levels of anxiety and suicidality (Nguyen et al., 2019). In addition to being a risk factor for psychological distress in and of itself, self-esteem has also been shown to moderate the relationship between negative life events and stressors and affective disturbance (Corning, 2002; Dumont & Provost, 1999).

Literature exploring risk factors for developing low self-esteem is somewhat limited; however, available research indicates that psycho-social adversity has a substantial impact on the development of low self-esteem (Hall-Lande et al., 2007; Harter, 1993; Nguyen et al., 2019). Trauma (including neglect and emotional, sexual, and physical abuse), high levels of educational stress and social isolation have all been shown to be related to low self-esteem

(Hall-Lande et al., 2007; Harter, 1993; Kucharska, 2017; Maguire et al., 2015; Nguyen et al., 2019; Reiland & Lauterbach, 2008).

When considering the risk factors for low self-esteem, there is an evident overlap with the experiences of many on the Autistic spectrum. For example, it is well established that those with HFA are disproportionately likely to experience inter-personal trauma and social isolation (Bejerot & Mörtberg, 2009; Chatzitheochari, 2014b; Humphrey & Symes, 2010b, 2011; Kasari & Sterling, 2013) both of which are important risk factors for low self-esteem (Hall-Lande et al., 2007; Ngyuen et al., 2019; Harter, 1993). Given this overlap, it is unsurprising that research suggests that those with HFA typically exhibit lower levels of self-esteem than their neurotypical peers (R. Cooper et al., 2021; Humphrey & Hebron, 2015a; Jamison & Schuttler, 2015). It is unclear, however, to what extent the social difficulties experienced by this population contributes to self-esteem. Furthermore, whilst levels of psychiatric co-morbidity are high in both populations (Joshi et al., 2013; Joshi et al., 2010; Orth et al., 2010; Orth et al., 2014), the relationship between HFA, self-esteem and mental health difficulties warrants further investigation.

Despite these areas of overlap and similarity, a review of the relationship between Autism and self-esteem has yet to be completed. We therefore intend to address this gap in the literature, with the following aims: (1) to synthesise available data on self-esteem in HFA, compared to neurotypical controls, (2) to synthesise available data on factors which influence self-esteem in HFA, (3) to synthesise data regarding the relationship between HFA, self-esteem, and mental health difficulties; and (4) to highlight implications for clinical practice and further research. An overarching aim of the review was to explore the *nature* of self-esteem in HFA, which necessarily involves the inclusion of both quantitative and qualitative accounts.

Methods

This systematic review utilised the PRISMA guidelines regarding conducting systematic reviews to explore the relationship between Autism and self-esteem and was registered on PROSPERO (CRD42021255517).

Inclusion criteria

As this review was focused on self-esteem in high-functioning Autism, papers reporting on those with low-functioning autism or co-morbid intellectual disabilities were excluded. The decision to focus on HFA was made due the potentially confounding nature of co-morbid intellectual disability on self-esteem in ASD. Papers reporting exclusively on Autistic people with co-morbid neurodevelopmental disorders such as ADHD were also excluded due to the potentially confounding effect of co-morbidity.

Due to the prioritisation of the exploration of the nature of self-esteem in HFA, in addition to the breadth of the aims, the inclusion criteria were similarly broad. Studies were included in the review if they explored self-esteem in Autistic individuals using either quantitative, qualitative or mixed-methods methodology. Studies published from 1980 (when autism was initially introduced as a pervasive developmental disorder in DSM III (APA, 1980)) were included. Quantitative and mixed-methods studies were required to use a clear, validated measure of self-esteem such as the Rosenberg Self-esteem Scale (RSES). For inclusion, studies needed to be peer-reviewed original primary research papers. Case studies, systematic reviews, book chapters, conference papers, opinion pieces and review articles were excluded. Research focussed on family members or carers of autistic people. Non-English articles were not eligible for inclusion.

Search Strategy

Databases searched included PsychINFO, PubMed, Medline, CINAHL, ScienceDirect and OVID. Manual searches were also conducted of relevant review papers and empirical articles to identify any studies that were not yet included in the literature databases. Search terms were (a) terms related to Autism (e.g., Asperger's, ASD) AND (b) terms related to self-esteem (e.g., 'self-concept') with (c) terms related to mental health difficulties (e.g. 'mental health problem*'). Searches were conducted in April 2021. Table 1 below shows the full search terms used.

Table 1 Search terms

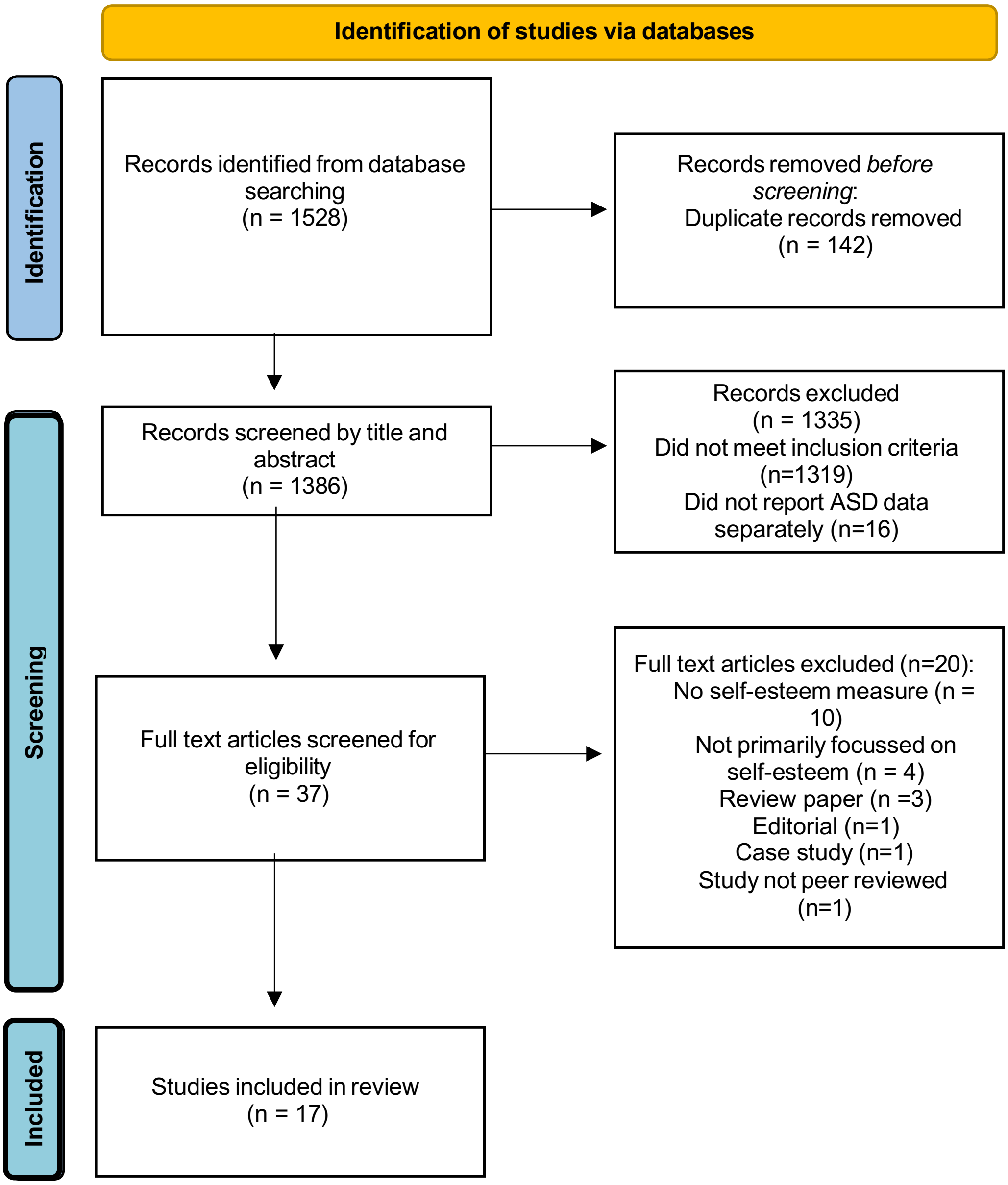
Autism	Self-esteem	Mental Health Difficulties
"autis*"	"self-esteem"	"mental health problem*"
"asperg*"	"self-worth"	"mental disorder*"
		"mental health difficult*
"pervasive developmental disorder"	"self-concept"	"mental health disorder*"
"PDD"	"self evaluation"	"psychiatric co-morbid*"
"autism spectrum disorder"	"self attitude"	"anxiet*"
"autism spectrum condition	"self liking"	"depressi*"
	"self competen*"	
	"self perception*"	

The initial search returned 1528 results which were considered for inclusion in the review. Duplicated were removed from the search results. All titles and abstracts were screened by researcher GS. Full-text screens against the inclusion and exclusion criteria were then conducted by GS with 20% being reviewed by researcher, JP. Any disagreements regarding inclusion were discussed with the research team and resolved by consensus. This resulted in a final sample of 17 independent studies (see Figure 1 for PRISMA flowchart).

Results

From the initial 1528 results, 18 studies met the inclusion criteria. The total number of studies screened, assessed for eligibility, and excluded or included at each stage are detailed in a PRISMA flowchart (Fig. 1).

Figure 1. PRISMA flowchart



Data extraction and synthesis

Data extraction was conducted by GS using a predetermined data extraction template of key study characteristics including author, year of publication, age and gender of participants, research setting, research methods, presence of control group, self-esteem and mental health measures, key self-esteem findings and secondary mental health findings (see Table 2).

Quantitative data from the included studies were then analysed using narrative synthesis due to the methodological and clinical heterogeneity between studies, whilst thematic analysis was used to analyse qualitative data reflexively, using both predetermined and emerging codes, in line with Braun and Clarke's approach (2006). Qualitative papers were initially coded by researcher GS, with second researcher JH coding 10% of papers. Any disagreements between researchers were resolved by discussion and consensus was reached. These codes were then grouped and organised into five key themes: impact of diagnosis, social connectedness, negative self-judgement, feelings of difference and stigma, and mental health difficulties. Quantitative and qualitative data were then combined in alignment with Thomas and Harden's framework for mixed methods systematic reviews (2005); results were pooled side by side in a matrix to determine how qualitative findings informed and clarified the quantitative results (Table 3). Table 4 shows the contribution of included papers to the three key areas of the review: self-esteem in HFA compared to neurotypical controls, factors influencing self- esteem in those with HFA and secondary mental health outcomes associated with self-esteem.

Table 4. Contribution of included papers by review area

		Self-esteem in HFA compared to neurotypical controls	**Factors influencing self-esteem in those with HFA**	**Secondary mental health outcomes associated with self-esteem**
Quantitative studies	*Arwert & Sizoo (2020)*		✣	✣
	Berkovitis, Moody & Blacher (2020)		✣	
	Cooper, Smith & Russell (2017)	✣	✣	✣
	Cresswell & Cage (2019)		✣	
	Goddard, O'Dowda & Pring (2017)	✣		✣
	Jamison & Schuttler (2015)	✣		✣
	Mazurek (2014)		✣	
	McCauley et al (2019)	✣	✣	✣
	McChesney & Toseeb (2018)	✣		
	Tan (2018)		✣	✣
	van der Cruijsen & Boyer (2021)	✣		✣
	Williamson & Slinger (2008)			✣
	Zimmerman et al (2017)		✣	✣
Mixed methods studies	*Berkovitis, Moody & Blacher (2020)*		✣	
	Cooper et al (2020)		✣	
	Hebron & Humphrey (2014)	✣		✣
Qualitative studies	*Leedham et al (2020)*		✣	✣
	Mogensen & Mason (2015)		✣	
	Tan (2018)		✣	✣

Quality and bias

Quality appraisal was conducted by GS using the Mixed Methods Appraisal Tool (MMAT; Hong et al., 2018; Appendix M). All studies were initially assessed against the following two screening questions prior to inclusion in the review: 1. Are there clear research questions? 2. Do the collected data allow to address the research question? No studies were excluded on the basis of not meeting these criteria. Qualitative studies were then further assessed on items 1-5, quantitative studies on items 6-10 and mixed method studies on items 11-15. A quality percentage was then calculated for each study by dividing the number of criteria met by the total number of applicable criteria and multiplying by 100. 'Can't tell' responses were considered the same as 'no' responses for the purpose of quality percentage calculations, though were coded as such in the table. Once all studies had been initially quality rated, a second coder, JP, then rated 20% of studies, selected at random. Any disagreements were discussed and resolved by consensus. Overall, all studies had a quality rating of at least 60%, with 11/17 studies having a quality rating of 80% or higher. See Table 5 for a summary of quality appraisals and supplementary materials for full quality ratings.

Table 5. Summary of quality appraisals using the MMAT

			Qualitative criterion					*Quantitative criterion*					*Mixed methods criterion*					
Study	**S1**	**S2**	**1**	**2**	**3**	**4**	**5**	**6**	**7**	**8**	**9**	**10**	**11**	**12**	**13**	**14**	**15**	Quality percentage (%)
Leedham et al (2020)	Y	Y	Y	Y	Y	Y	Y	-	-	-	-	-	-	-	-	-	-	100
Mongensen & Mason (2015)	Y	Y	Y	N	Y	Y	Y	-	-	-	-	-	-	-	-	-	-	80
Tan (2018)	Y	Y	Y	Y	Y	Y	Y	-	-	-	-	-	-	-	-	-	-	100
Arwet & Sizoo (2020)	Y	Y	-	-	-	-	-	Y	Y	Y	CT*	Y	-	-	-	-	-	80
Cooper, Smith & Russell (2017)	Y	Y	-	-	-	-	-	Y	Y	Y	CT	Y	-	-	-	-	-	80
Cresswell & Cage (2019)	Y	Y	-	-	-	-	-	Y	Y	Y	CT	Y	-	-	-	-	-	80
Goddard, O'Dowda & Pring (2017)	Y	Y	-	-	-	-	-	Y	CT	Y	CT	Y	-	-	-	-	-	60
Jamison & Schuttler (2015)	Y	Y	-	-	-	-	-	Y	CT	Y	CT	Y	-	-	-	-	-	60
Mazurek (2014)	Y	Y	-	-	-	-	-	Y	Y	Y	CT	Y	-	-	-	-	-	80
McCauley et al (2019)	Y	Y	-	-	-	-	-	Y	CT	Y	CT	Y	-	-	-	-	-	60
McChesney & Toseeb (2018)	Y	Y	-	-	-	-	-	Y	Y	Y	CT	Y	-	-	-	-	-	80
van der Cruijsen & Boyer (2021)	Y	Y	-	-	-	-	-	Y	CT	Y	CT	Y	-	-	-	-	-	60
Williamson & Slinger (2008)	Y	Y	-	-	-	-	-	Y	CT	Y	CT	Y	-	-	-	-	-	60
Zimmerman et al (2017)	Y	Y	-	-	-	-	-	Y	CT	Y	CT	Y	-	-	-	-	-	60
Berkovits, Moody & Blacher (2020)	Y	Y	Y	Y	Y	Y	Y	Y	CT	Y	CT	Y	Y	Y	Y	Y	Y	86.7
Cooper et al (2020)	Y	Y	Y	Y	CT	Y	Y	Y	Y	Y	CT	Y	Y	Y	CT	Y	Y	80
Hebron & Humphrey (2014)	Y	Y	Y	Y	Y	Y	Y	Y	CT	Y	CT	Y	Y	Y	Y	Y	Y	86.7

**CT denotes 'can't tell'*

Description of studies

Of the 17 peer-reviewed studies which met the inclusion criteria, 11 used quantitative methods, 3 were mixed methods and 3 were qualitative. Specific details of the included studies can be found in Table 2. The total number of participants across all studies was 14,145. Nine of the 17 studies were of adolescents, whilst the other 8 used adult populations. Two studies, one quantitative and one qualitative, focussed on Autistic women only. Seven studies utilised a control group of neurotypical controls (TDC) to determine whether rates of self-esteem were comparable between groups.

Self-esteem measures varied among quantitative studies with the most common measure being the Rosenburg Self-Esteem Scale (RSES), which was used in 6 studies. The private and collective self-esteem scale, Self-perception profile for adolescents/children (SPPA-A/SPPA-C), Beck Youth Inventory (BYI-II), Marsh Self-description Questionnaire-II (MSQ-II) and Implicit Association Test (IAT) were also used as measures of self-esteem. Several measures of anxiety and depression were also utilised across the included studies. These included: The State Trait Anxiety Inventory, Trait Depression Scale, Centre for Epidemiological Studies Depression Scale for Children (CES-DC), Multidimensional Anxiety Scale for Children (MASC-2), Strengths and Difficulties Questionnaire (SDQ) and Child Depression Inventory (CDI).

A full summary of study characteristics and findings can be found in Table 2.

Table 2. Key study characteristics

Author & Year	Age of All Participants	Recruitment setting	Methodology	% Male	Control group (Y/N)	Overall n	Self-esteem measure	Self-esteem findings	Secondary mental health measures	Secondary mental health findings
Arwert & Sizoo (2020)	19-64 years	Psychiatric outpatients	Quantitative	61	N	70	RSES	Rumination and self-esteem are significantly negatively correlated	Beck Scale for Suicidal Ideation; Rumination-Reflection Questionnaire, BDI-II	Low self-esteem and rumination are significantly associated with the severity of suicidality in those with ASD.
Berkovits, Moody & Blacher (2020)	Adolescents (mean age= 15.1y)	General population	Mixed Methods	86.8	N	38	Children's Hope Scale (self-efficacy)	For those with above average IQ, there was a negative correlation between ASD and self-esteem. Qualitative findings indicated both positive and negative consequences of ASD on identity.	Social Responsiveness Scale; Child Behaviour Checklist	The higher the number of negative statements about ASD, the more severe self-endorsed anxiety and depression.
Cooper, Smith & Russell (2017)	Mean age= 32.7 years	General population	Quantitative	53	Y	539	RSES; Private and Public Collective Self-esteem Scale	ASD group had significantly lower personal self-esteem than TD controls. Significant positive relationship between ASD identification and collective self-esteem	State Trait Anxiety Inventory; Trait Depression Scale	Significant negative relationship between both personal self-esteem and collective self-esteem and anxiety and depression.
Cooper et al (2020)	Quant Mean age: 36 years, Qual mean age: 18.76 years	General population	Mixed methods	36	N	Quant: 140, Qual: 15	Private and Public Collective self-esteem subscales	Significant positive correlation between valence of ASD attributes and collective self-esteem and between ASD social identification and collective self-esteem. Qualitative findings highlighted the multidimensional impact of ASD on identity and self-concept.		A greater number of negative ASD attributes with a greater magnitude were put forward than positive attributes which included mental health difficulties such as anxiety and depression. These were seen as intrinsic to ASD rather than as co-occuring.

Cresswell & Cage (2019)	12-18 years; mean age= 13.8)	School	Quantitative	87.5	N	24	Twenty Statements Task (TST); Autism Identity Questionnaire	Participants divided into four identity groups: marginalised, bicultural, assimilated and separated. There was a difference between groups on the proportion of positive, but not negative, statements produced about the self, with the marginalised group tending to generate fewer positive statements about themselves than the assimilated group.	SDQ	The four groups did not differ significantly on SDQ total difficulties scores, however those aligned with non-Autistic culture tended to generate more positive self-statements than those aligned to neither culture. Suggestion that Autistic adolescents should be encouraged to explore Autistic culture.
Goddard, O'Dowda & Pring (2017)	13-17 years	School	Quantitative	87.5	Y	32	Self-perception Profile for Adolescents (SPP); Self-defining and everyday memory task	ASD group had lower self-esteem than control group. Statistically significant negative correlation between number of negative self-defining memories and self-esteem in both groups.	Centre for Epidemiological Studies Depression Scale for Children (CES-DC)	Both groups showed a statistically significant negative correlation between depression and self-esteem, irrespective of ASD diagnosis.
Hebron & Humphrey (2014)	ASD= 14y 2m; Dyselxia= 14 y 1m; C= 14 y 7m	School	Mixed methods	ASD= 86.4%; Dyslexia= 81%; C= 82.6%	Y	62	Beck Youth Inventories-II (BYI-II)	ASD group had significantly lower self-concept than the control group.	BYI-II	The ASD group had significantly higher levels of anxiety and depression than the control group. Qualitative analysis revealed that problems in social relationships and understanding the nature of the AS were common contributory factors to the mental health difficulties of participants.
Jamison & Schuttler (2015)	14-19y	Community social group	Quantitative	0	Y	52	Harter's Self-Perception Profile for Adolescents (SPPA); Youth Quality of Life Instrument-Research Version (YQOL-R)	Females with ASD had lower global self-worth than TD controls and self-reported lower self-competence.	Harter's Self-Perception Profile for Adolescents (SPPA); Youth Quality of Life Instrument-Research Version (YQOL-R)	There was a significant relationship between internalising symptoms (both anxiety and depression) and self-worth in both the ASD and non-ASD groups. Those with ASD reported higher levels of internalising symptoms than their non-ASD counterparts.

Leedham et al (2020)	43-64 years	NHS Diagnostic ASD service	Qualitative	0, 100% female	-	11	-	Receiving a diagnosis was most often experienced as validating and facilitated a transition from being self-critical to self-compassionate.	-	Some participants experienced stigma from mental health services who did not offer support due to their ASD diagnosis.
Mazurek (2014)	18-62 (m=32.4y)	Community	Quantitative		N	108	RSES	Loneliness is positively correlated with self-esteem and predicted depression, anxiety, life satisfaction and self-esteem.	PHQ	N/A
McCauley et al (2019)	8-16y	Community	Quantitative		Y	75	Marsh Self-Description Questionnaire-II; LSE	Youth (8-16) with ASD reported significantly lower self-esteem than TDC.	Multidimentional Anxiety Scale for Children (MASC-2); Center for Epidemiological Studies-Depression Scale (CES-D)	Depression and self-esteem were negatively related irrespective of diagnostic group. Anxiety was more closely related to low self-esteem in the ASD group than in the TYP group. ToM ability was inversely related to self-esteem in youth with ASD but not with TYP self-esteem.
McChesney & Toseeb (2018)	Mean age= 10.68y	Community	Quantitative	50.5 (79 in ASD group)	Y	13,285	RSES	Children without ASD were happier, had higher self-esteem, and were more prosocial when compared with children with ASD.	SDQ	Latent class analysis showed that 31% of ASD children were in the 'optimum class' (high self-esteem, happiness and pro-sociality) compared with 62% of those without ASD. 32% of children with ASD were in the 'very low prosociality class' (high happiness and self-esteem but low prosociality) compared with 7% of children without ASD.
Mogensen & Mason (2015)	13-19 years	General population	Qualitative	Unknown	-	5	-	Whether the diagnosis was experienced as positive or negative depended on the extent to which it facilitated knowledge and control. For many, diagnosis was experienced as validating in relation to their sense of difference.	-	-
Tan (2018)	22-65 years	General population	Qualitative	37.8	-	37	-	In receiving a diagnosis of ASD, most participants reported finding an explanation for their atypicality and the development of a more valued self-concept.	-	-

van der Cruijsen & Boyer (2021)	8-16y	Community	Quantitative		Y	62	Explicit SE: RSES (1x children, 1x adolescents 1x parents). Implicit SE: IAT	ASD group showed lower levels of explicit self-esteem according to the RSES compared to TDC. Implicit self-esteem did not differ between youth with and without ASD.	Parent-reported child behaviour checklist (CBCL); Child depression inventory (CDI)	Explicit self-esteem was negatively related to depression symptoms, whereas implicit self-esteem was negatively related to externalizing symptoms
Williamson & Slinger (2008)	11-15y; Mean age= 13y	Secondary school	Quantitative	68.4	Y	38	The Self Perception Profile for Children	ASD group reported lower social competence, peer likability and peer approval. There was no significant main effect of group on importance ratings of approval or global self-worth.	The Children's Depression Inventory; The Spence Children's Anxiety Scale	No significant main effect of group (ASD or TDC) on anxiety or total depression scores.
Zimmerman et al (2017)	18-66y	ASD support services and online ASD forums	Quantitative	64.3	N	42	RSES; The Six-Factor Self-Concept Scale for Adults (SFSCS)	Participants with better non-verbal reasoning, cognitive flexibility and social cognition reported more negative self-concept and lower self-esteem. Participants with stronger executive functioning were more likely to experience negative self-concept, whereas those with impaired executive functioning were more prone to anxiety.	Depression, Anxiety and Stress Scales 21 (DASS 21)	Self-esteem and self-concept were not significantly associated with anxiety

Table 3. Analysis Matrix

	Narrative synthesis	**Thematic analysis** ***Qualitative themes and key quotes***
Self-esteem in ASD compared with typically developing controls (TDC)	Self-esteem was generally shown to be lower in those with ASD compared to TDC. This was demonstrated in children and young people (Hebron & Humphrey, 2014; Goddard, O'Dorda and Pring, 2017; McChesney, 2018; van der Cruijsen, 2021, McCauley et al., 2019; Jamison, 2015) and adult populations (Cooper, Smith & Russell, 2017). Whilst ASD group showed lower social competence, Williamson and Slinger (2008) found no main effect of group on global self-worth in their youth sample. Global self-worth and self-competence shown to be lower in females with ASD compared to TDC (Jamison & Schuttler, 2015) Difference shown by van der Cruijsen (2021) between implicit and explicit self-esteem in those with ASD compared to TDC. Whilst the ASD group showed lower levels of explicit self-esteem, there was no significant difference in implicit self-esteem between groups.	N/A
Factors influencing self-esteem in those with ASD	**Cognitive profile:** Berkovitis et al (2020) found a significant relationship between high IQ and low self-esteem, whilst Zimmerman (2017) demonstrated an inverse relationship between non-verbal reasoning ability, cognitive flexibility, social cognition and executive functioning and self-esteem. Theory of Mind ability was also shown to be inversely related to self-esteem in those with ASD (McCauley, 2019) **Loneliness:** Mazurek (2014) found that lonliness was positively correlated with self-esteem in those with ASD, even after controlling for ASD symptomatology. **Rumination**: Arwert & Sizoo (2020) found that rumination was significantly negatively correlated with self-esteem. **ASD identification**: It has been shown that ASD identification can be protective against low self-esteem both individually (Cresswell & Cage, 2019), and collectively (Cooper, Smith & Russell, 2017; Cooper et al., 2020).	**Impact of diagnosis:** Validation, positive self-judgement *'The challenges are far less than they used to be when I didn't know I was autistic. Because I no longer blame myself for the ways in which I seem not to keep up with others sometimes... I mean, I was just weird and different and broken, I felt in so many ways. And now...Now, I'm a normal autistic person, not an abnormal neurotypical' (Tan, 2018)."* **Negative self-judgement:** Being broken and/or fundementally flawed *'something dark and deeply wrong (Tan, 2018)* **Social connectedness**: social belonging, social isolation *'all throughout school I [was] bullied or excluded in various ways...It's still really bad, I still spend a lot of time alone, because of...other people not accepting me' (Cooper et al., 2020)"* **"Feelings of difference/ Stigma:** disability as inherently flawed, stereotypes, assumptions *'that damn word doesn't make me, me' (Leedham et al., 2020)"*

Secondary mental health outcomes associated with self-esteem	**Anxiety and depression:** Several studies showed a significant inverse relationship between self-esteem and measures of anxiety and depression (Hebron & Humphrey, 2014; Jamison, 2015; Zimmerman et al., 2017; McCauley et al., 2019; Goddard et al., 2017; Cooper, Smith & Russell, 2017). In several studies, this relationship was found irrespective of ASD diagnosis (Hebron & Humphrey, 2014; Jamison, 2015; Goddard et al., 2017; Williamson & Slinger, 2008). McCauley (2019) found, however, that whilst low self-esteem was related to anxiety in both those with and without ASD, the relationship was more significant in the ASD group. In their exploration of implicit and explicit self-esteem in those with and without ASD, van der Cruijsen et al (2021) found that explicit self-esteem was negatively related to depression symptoms whilst implicit self-esteem was negatively related to externalising symptomatology. **Suicidality:** Low self-esteem was shown to be related to the severity of suicidality in psychiatric outpatients with ASD (Arwert & Sizoo, 2020)	**Mental health difficulties:** Commonly long-standing difficulties with anxiety and/ or depression. Descriptions of suicidal ideation and attempted suicide also present.

Self-esteem in HFA compared with neurotypical controls (TDC)

Eight of the included studies sought to investigate levels of explicit self-esteem in those with HFA compared to a control group (R. Cooper et al., 2021; Goddard et al., 2017; Humphrey & Hebron, 2015a; Jamison & Schuttler, 2015; McCauley et al., 2019; McChesney & Toseeb, 2018; van der Cruijsen & Boyer, 2021; Williamson et al., 2008). All studies utilised neurotypical controls as their control group. Three studies utilised the RSES as their measure of explicit self-esteem (Cooper, Smith & Russell, 2017; McChesney & Toseeb, 2018; van der Cruijsen & Boyer, 2021), two used the SPP-A (Goddard, O'Dowda & Pring, 2017; Jamison & Schuttler, 2015), one used the BYI-II (Hebron & Humphrey, 2014) and one used the MSQ-II (McCauley et al., 2009) all of which are validated measures of explicit self-esteem (Hagborg, 1993; Marsh & O'Neill, 1984; Steer et al., 2001). Seven out of the 8 studies found that explicit self-esteem was significantly lower in those with HFA compared to TDC group (Hebron & Humphrey, 2014; Goddard, O'Dorda and Pring, 2017; McChesney, 2018; van der Cruijsen, 2021, McCauley et al., 2019; Jamison, 2015; Cooper, Smith & Russell, 2017. Four of these 7 studies reported effect sizes using Cohen's *d* ranging from 0.26 (McChesney et al., 2017) to 0.84 (van der Cruijsen & Boyer, 2021) with a mean effect size of 0.56, suggesting that this is an important clinical difference. In contrast, Williamson & Slinger (2008) found that, whilst the HFA group showed significantly lower levels of social competence than TDC, there was no significant group difference in global self-worth. This difference could be partially explained by the relatively small sample size used in this study (n=38), which is substantially smaller than all other included papers, with the exception of Goddard, O'Dowda and Pring (2017) whose sample size was comparable (n=32).

Significant group differences in explicit self-esteem were found in child (McCauley et al., 2019; McChesney & Toseeb, 2018; van der Cruijsen & Boyer, 2021), adolescent (Cooper, Smith & Russell, 2017; Goddard, O'Dowda & Pring, 2017; Hebron & Humphrey, 2014; Jamison & Schuttler, 2015; McCauley et al., 2019; van der Cruijsen & Boyer, 2021) and adult populations (Cooper, Smith & Russell, 2017), indicating that this difference is stable across the lifespan. Although most participants across these studies were male, differential levels of self-esteem were also seen when investigating females with HFA (Jamison & Schuttler, 2015), where global self-worth and self-competence were significantly lower than in TDC, suggesting that this effect is not gender specific.

When considering implicit and explicit self-esteem separately, van der Cruijsen and Boyer (2021) found that, whilst explicit self-esteem levels were significantly lower in those with HFA compared to TDC, there was no significant between-groups difference in implicit self-esteem. It is suggested that this could be due to implicit self-esteem being more state-like than explicit self-esteem, which is considered more stable (van der Cruijsen & Boyer, 2021) and therefore more likely to be representative of longitudinal self-esteem.

Factors influencing self-esteem in HFA populations

Cognitive profile

Three studies investigated the impact of various domains of cognitive functioning on explicit self-esteem in HFA populations. Berkovits, Moody and Blacher (2020) studied the impact of IQ on self-esteem and found that IQ only had a significant impact on explicit self-esteem when it was ‘above average’ (as determined by the Wechsler Intelligence Scale for Children); those with above average IQ were significantly more likely to have low explicit self-esteem compared to those with average or low IQ. Non-verbal reasoning ability, cognitive flexibility, social cognition ability, and executive functioning were all shown to be inversely related to explicit self-esteem in those with HFA (Zimmerman et al., 2017). It is unclear, however, whether these cognitive effects on self-esteem are also seen within neurotypical populations as these studies did not utilise a control group. In contrast, theory of mind ability was shown to be inversely related to explicit self-esteem in HFA, but not in neurotypical controls, suggesting a unique contribution to self-esteem in HFA, most likely due to theory of mind deficits within this population (McCauley et al., 2019).

Qualitative studies highlighted the complex interaction between cognitive skills and self-esteem in HFA as several participants described both cognitive advantages and disadvantages to the condition. One participant commented ‘autism is the latest buzz word for genius’ (Berkovits, Moody & Blacher, 2020), whilst others valued the creativity they felt autism had given them (Berkovits et al., 2020; Cooper et al., 2021). Several participants across studies talked of the restricted interests diagnostic domain (DSM-5; APA, 2013), coined ‘Autistic passion’ by one participant (Tan, 2018), as a cognitive strength of being on the Autistic spectrum (Berkovits et al., 2020; Mogensen & Mason, 2015; Tan, 2018). However, some participants described feeling less intelligent and gifted than their neurotypical peers (Tan, 2018).

Social isolation

One quantitative paper examined the relationship between self-reported loneliness and explicit self-esteem in adults with HFA (n=108) using the RSES and found that loneliness was positively correlated with self-esteem (Mazurek, 2014). Furthermore, it was found that loneliness was predictive of levels of self-esteem, depression, anxiety, and overall life-satisfaction, even after controlling for the effects of HFA symptomatology (Mazurek, 2014), suggesting that loneliness is likely to be an important contributory factor to self-esteem irrespective of HFA diagnosis.

Qualitative findings also highlighted the importance of social isolation and exclusion in influencing self-esteem in Autistic people. One participant stated, 'all throughout school I [was] bullied or excluded in various ways…It's still really bad, I still spend a lot of time alone, because of…other people not accepting me' (Cooper et al., 2020). Many participants spoke of feelings of difference and of struggling to fit in; for example, 'I felt different... like an outsider sort of…I don't know why, I couldn't fit in, I couldn't talk…I got lost' (Mongensen & Mason, 2015). Conversely, social connectedness was highlighted as being both positive and protective of self-concept and self-worth. Participants described connecting with other Autistic people as finding 'my tribe' and 'other people with spots' and was experienced as 'liberating' and 'feeling like I had a place in the world' (Tan, 2018). The contrast between social isolation and connectedness was highlighted by one participant: 'I'm blessed to [now] have such lovely people around who care enough not to be bothered by my weird quirks… it makes a change after years of bullying and being penalised for being odd' (Leedham et al., 2020).

Feelings of difference

Qualitative exploration of self-concept and identity in those with HFA highlighted the feelings of difference and atypicality experienced by many. This was expressed through self-descriptors such as 'freak', 'different,' 'weird', 'broken' and 'something [being] dark and deeply wrong' (Berkovits et al., 2020; Humphrey & Hebron, 2015a; Leedham et al., 2020; Mogensen &

Mason, 2015; Tan, 2018). In addition to explicit negative self-judgements, societal stigma around differences seen in those with HFA were also evident. Neurotypical ideals were referenced and experienced as being suggestive of inherent defectiveness in neurodiversity (Leedham et al., 2020). Stereotypes of autism were also cited as contributory to feelings of difference as they led to people being treated differently on the basis of their diagnosis (Berkovits et al., 2020; Cooper et al., 2021; Leedham et al., 2020); for example, being expected to have an excellent memory or being unable to manage relationships (Berkovits et al., 2020; Cooper et al., 2021; Mogensen & Mason, 2015). The effects of this stigma were not only internalised stigma, but feelings of frustration: 'that damn word doesn't make me, me' (Leedham et al., 2020).

HFA identification and the impact of diagnosis

Three studies quantitatively explored the impact of adopting an HFA diagnosis or identity on self-esteem using the Autism Identity Questionnaire (Cresswell & Cage, 2019) and the Collective Self-esteem Scale (Cooper, Smith & Russell, 2017; Cooper et al., 2021). One quantitative study focussed on the impact on individual explicit self-esteem (Cresswell & Cage, 2019) while two (one quantitative and one mixed methods) focussed on collective self-esteem (Cooper et al., 2017; Cooper et al., 2021). All three studies found that HFA identification was protective against low explicit self-esteem (Cooper et al., 2017; Cooper et al., 2021; Cresswell & Cage, 2019), suggesting that collective self-esteem promotes individual self-esteem. Social belonging was an important theme in the qualitative literature also, with several participants describing an enhanced sense of belonging post-diagnosis, which was particularly pertinent given the sense of social exclusion that had previously been the case for many (Leedham et al., 2020; Mogensen & Mason, 2015; Tan, 2018).

The most prominent theme in the qualitative literature, however, was the impact of HFA diagnosis on self-concept and explicit self-esteem. Many participants spoke of a shift in their sense of identity post-diagnosis which, on the whole, was experienced as positive. For example, one participant explained: ‘The challenges are far less than they used to be when I didn’t know I was Autistic. Because I no longer blame myself for the ways in which I seem not to keep up with others sometimes… I mean, I was just weird and different and broken, I felt in so many ways. And now…Now, I’m a normal Autistic person, not an abnormal neurotypical’ (Tan, 2018). In this extract it is evident that diagnosis was experienced as explanatory and as a way of re-framing difficulties associated with HFA into a more positive and accepting narrative. This was also seen in relation to the reframing of other mental health difficulties, where receipt of an HFA diagnosis was seen to be relieving of the pressure to be ‘cured’ and associated sense of failure when psychiatric treatment had previously been ineffective (Tan, 2018), in addition to providing a more fitting explanation of their difficulties than psychiatric diagnosis alone could offer (Leedham et al., 2020). The validating effect of diagnosis was also shown through the type of self-judgements made pre- and post- diagnosis. Qualitative accounts were littered with negative self-descriptors such as ‘weird’ and ‘freak’, however self-talk was seen to improve post-diagnostically (Leedham et al., 2020; Tan, 2018). This therefore highlights the constructive nature of an HFA diagnosis in improving self-concept in HFA (Cooper et al., 2021; Mogensen & Mason, 2015; Tan, 2018).

In addition to diagnosis being viewed as transformative to identity, diagnosis was also experienced by many as validating which, in turn, had a similarly positive impact on self-concept (Cooper et al., 2021; Leedham et al., 2020; Mogensen & Mason, 2015; Tan, 2018). For some, however, it was suggested that a diagnosis came too late in their life and would have had a bigger impact on their self-worth had it been given earlier: ‘getting diagnosed was helpful because it made me understand why I do certain things…it would have been nice to know that when I was a kid, it’s not me being wrong, it’s me being different’ (Tan, 2018).

Secondary mental health outcomes associated with self-esteem

Suicidality

Three studies considered the impact of low self-esteem on suicidality, one of which was quantitative (Arwert & Sizoo, 2020) and two were qualitative (Leedham et al., 2020; Tan, 2018). Arwert & Sizoo (2020) investigated the impact of rumination and explicit self-esteem on suicidality in those with HFA and found that rumination and self-esteem had a significant effect on suicidality, with those with high levels of rumination and low self-esteem experiencing increased suicidal thoughts and intent. Low explicit self-esteem, measured by the RSES, was shown to be associated with current suicidal ideation but not historical suicidality suggesting a temporally specific relationship between constructs. Rates of suicidality were shown to be elevated within HFA populations, especially in females (Arwert & Sizoo, 2020); an effect which was reflected within qualitative findings (Leedham et al., 2020; Tan, 2018). Feelings of hopelessness derived from life-long difficulties with atypicality, feelings of failure and adverse social experiences were described as contributory to suicidal ideation (Leedham et al., 2020; Tan, 2018). Receipt of an HFA diagnosis and finding HFA-positive communities were described as protective against suicidality (Leedham et al., 2020; Tan, 2018).

Anxiety and Depression

Six quantitative studies explored the relationship between HFA, explicit self-esteem and affective symptomatology (anxiety and depression). Results consistently showed a significant moderate inverse relationship between explicit self-esteem and measures of both anxiety and depression (Cooper et al., 2017; Goddard et al., 2017; Humphrey & Hebron, 2015; Jamison & Schuttler, 2015; McCauley et al., 2019; Zimmerman et al., 2017) with anxiety and depression levels increasing as explicit self-esteem levels decreased. This relationship was, however, found to be evident irrespective of HFA diagnosis in some studies which utilised a neurotypical control group (Goddard et al., 2017; Humphrey & Hebron, 2015a; Jamison & Schuttler, 2015; Williamson et al., 2008). McCauley (2019) found an inverse relationship between explicit self-esteem and anxiety in both the HFA and TDC groups, however also found that the strength of this relationship was significantly higher in the HFA group. This indicates that explicit self-esteem is an important contributory factor to experiences of both anxiety and depression irrespective of HFA, but that this may be more significant in those with HFA. Qualitative findings highlight the impact of ineffective treatments for co-morbid mental health difficulties in perpetuating both distress and feelings of inadequacy and failure (Tan, 2018).

Differences were reported in the relationship between dimensions of self-esteem and secondary mental health outcomes. Whilst implicit self-esteem was shown to be negatively correlated with externalising symptomatology in those with HFA, explicit self-esteem was significantly negatively related to depressive symptomatology (van der Cruijsen et al., 2021).

Discussion

Overview

This review is the first to explore the relationship between HFA and self-esteem and provides an overview of the current literature exploring levels of self-esteem within the HFA population, in addition to factors contributing to its development and associated mental health outcomes. Included studies focussed predominantly on the study of explicit self-esteem, though some papers were also interested in implicit and collective self-esteem. Perhaps the most striking finding was that 7/8 studies which explored explicit self-esteem in Autistic samples compared to neurotypical controls, found that explicit self-esteem was significantly lower in the HFA group. This was found in studies with participants from across the lifespan and across gender identities suggesting that levels of explicit self-esteem are consistently lower in Autistic populations irrespective of age or gender.

We were also able to identify several factors which were included in the literature to support in explaining the development of, often poor, explicit self-esteem in Autistic individuals. First, various cognitive skills were shown to influence self-esteem in HFA; for example, cognitive flexibility, strong non-verbal reasoning and having an above average IQ were shown to be detrimental to explicit self-esteem (Zimmerman et al., 2017). Though potentially counter-intuitive, these findings are consistent with the wider literature around neurodiversity, cognitive functioning, and self-esteem. Above average IQ in HFA populations has been shown to be related to poorer mental health outcomes (Sterling et al., 2008), in addition to intellectual giftedness being found to be related with poorer self-esteem in ADHD populations (Foley-Nicpon et al., 2012b). Various explanations of this relationship have been suggested. One suggestion is that feelings of difference, already associated with neurodiversity, are amplified by above average intelligence (Foley-Nicpon et al., 2012b; Janos et al., 1985); a suggestion which is consistent with the qualitative finding in this review that feelings of difference are common in this population (Berkovits et al., 2020; Humphrey & Hebron, 2015a; Leedham et al., 2020; Mogensen & Mason, 2015; Tan, 2018). Alternatively, it is suggested that, as higher IQ is related to increased cognitive awareness (Barnhill, 2001), those from neurodiverse populations who have an above average IQ may have increased awareness of their social and functional difficulties and may therefore be more sensitive to negative social feedback which, in turn, is likely to impact on individual, explicit self-esteem (Zimmerman et al., 2017). This suggestion of increased awareness as contributory to low self-esteem may also explain why relatively strong social cognition and executive functioning were also shown to be related to low explicit self-esteem in this population in this review (Zimmerman et al., 2017).

Feelings of difference and social isolation were key themes in the qualitative literature. Experiences of exclusion, loneliness and difference were regularly described by participants as being internalised as a sense of defectiveness or fault, thus impacting negatively on self-concept. Quantitative exploration of these factors was limited, however, with only one study finding a significant inverse correlation between loneliness and levels of explicit self-esteem in HFA. Nonetheless, there is a breadth of literature exploring the impact of HFA on experiences of social adversity including difficulties in forming and maintaining relationships (Bauminger & Kasari, 2000; Prior et al., 1998) and experiences of bullying (Van Roekel et al., 2010) which are significantly elevated in HFA relative to neurotypical peers. Additionally, there is a strong literature indicating the harmful effects of social adversity, including isolation and peer victimisation on self-esteem in neurotypical populations (Overbeek et al., 2010; Salmivalli et al., 1999; C. Stewart et al., 2017; van Geel et al., 2018).

Taking elevated levels of social difficulty in HFA with these findings and qualitative descriptions of the interrelatedness of social adversity and self-esteem, it is possible that further quantitative research of the impact of social adversity on self-esteem in Autistic populations would echo findings from non-HFA samples, though this requires further investigation.

Though several factors were identified which contributed to low self-esteem in HFA, positive Autistic identification (or collective self-esteem) was consistently found to be protective of explicit self-esteem (Cooper et al., 2017; Cooper et al., 2021; Cresswell & Cage, 2019). This was very much echoed qualitatively, with participants describing the relief of receiving a diagnosis and the experience of finding others with the same diagnosis who had experienced similar difficulties. Social connectedness has also been shown to enhance explicit and collective self-esteem in neurotypical samples (Begen & Turner-Cobb, 2015; Lee & Robbins, 1998) in addition to collective self-esteem being shown to mediate the relationship between levels of social connectedness and both positive and negative changes in mood (Begen & Turner-Cobb, 2015), highlighting the importance of social connectedness in influencing psychological wellbeing. This therefore suggests that promoting social connectedness in HFA could not only improve individual self-esteem, but also psychological wellbeing more broadly.

In contrast to social identification, the impact of receiving a diagnosis of HFA on self-esteem has only been explored qualitatively. Experiential accounts were generally positive and highlighted the post-diagnostic sense of relief and belonging which had not previously been experienced for many. Despite this, the issue of late diagnosis was a significant one, with several accounts raising the long-standing difficulties with identity and social exclusion prior to diagnosis, in addition to a strong sense of frustration at not being diagnosed sooner. The issue of late diagnosis is well-documented, especially in women and older adults (Corden et al., 2021; Leedham et al., 2020; Morris, 1985; Stagg & Belcher, 2019) with many receiving multiple mental health diagnoses before being diagnosed with HFA (Leedham et al., 2020; Stagg & Belcher, 2019; Tan, 2018). Like the receipt of any potentially life-changing information, receiving a diagnosis of Autism requires the re-evaluation of one's identity and the integration of this new information into one's self-concept and self-esteem (Morris, 1985). The later in life a diagnosis is received, the more difficult this process is likely to be (Stagg & Belcher, 2019). Taken together, these findings highlight the importance of timely diagnosis in promoting positive self-concept and opening up opportunities for positive group identification with neurodiverse peers.

Finally, this review found that low explicit self-esteem was shown to be significantly related to increased levels of anxiety, depression, and suicidality, with anxiety and depression being the most investigated outcomes. Interestingly, in studies where a control group was utilised, the identified relationship between low self-esteem and affective symptomatology was also seen in the control group, suggesting that this relationship is unlikely to be specific to Autistic populations. Indeed, a meta-analysis of longitudinal studies by Sowislo & Orth (2013) highlighted the significant impact of self-esteem on depression across the lifespan and irrespective of gender, whilst a significant inverse relationship between self-esteem and anxiety has also been evidenced within neurotypical populations (Rosenberg, 1962). Interestingly, Sowislo & Orth (2013) found that self-esteem had a more significant impact on depression than depression had on self-esteem, suggesting that addressing low self-esteem could be an effective way to improve mood. Given the high levels of co-morbidity between affective symptomatology and low individual self-esteem, it is unsurprising that psychological cognitive-behavioural models of self-esteem incorporate both anxiety and depressive symptoms (Fennell, 1997). Here, activation of negative beliefs about the self (coined 'the bottom line') leads to increased anxiety around the exposure of these beliefs and to an increase in self-critical thinking leading to depressed mood (Fennell, 1997). The implementation of this model has been shown to be effective at improving both anxiety, and depressive symptomatology in neurotypical (Kolubinski et al., 2018) and Autistic populations (Spain & Blainey, 2017) but have only been found to improve individual self-esteem in neurotypical populations (Kolubinski et al, 2018). Though it is clear that self-esteem is related to affective disorders in Autistic people, further research needs to be done to determine how clinical interventions can support improvements in individual self-esteem in this population.

Clinical Implications

There are several clinical implications of this review. Firstly, due to high levels of co-morbidity between low self-esteem and affective disorders, it may be useful for clinicians within mental health services to assess self-esteem and to consider using self-esteem specific models to improve psychological well-being, where appropriate. Secondly, we have shown that diagnosis of HFA is likely to play a key role in both the development and improvement of both individual and collective self-esteem and should therefore be promoted. This is especially important in groups where HFA is often missed, namely in females (where masking behaviours are especially high) and in mental health service users (where multiple diagnoses and ineffective treatments are likely to have been given). Finally, following the identification of HFA, promoting social connectedness, especially with Autistic communities is another important recommendation. By promoting positive social relationships with other Autistic people, both collective and individual self-esteem are likely to be improved, thus potentially improving overall psychological wellbeing.

Research Implications

This review has highlighted several gaps in the existing literature regarding self-esteem and Autism. First, although the qualitative evidence is clear regarding the impact of HFA diagnosis on self-esteem, this is yet to be explored quantitatively. Without this, we are unable to ascertain the reliability or magnitude of this effect. Quantitative exploration utilising longitudinal designs would also be helpful in determining whether this is a time-limited effect or whether diagnosis makes a long-lasting impact on self-esteem in this group. Second, much of the research into individual self-esteem focusses on explicit, as opposed to implicit, self-esteem. It could be useful to determine whether the factors shown to influence explicit self-esteem also impact on implicit self-esteem as this could have clinical implications due to the association between implicit self-esteem and externalising behaviours (van der Cruijsen et al., 2021). Third, further research into the treatment of low self-esteem in this population is clearly warranted given the high incidence in this population and evidence suggesting that current psychological interventions for low-self-esteem are limited in their efficacy (Spain & Blainey, 2017). This limited efficacy could be due to difficulties in this population generalising knowledge from one area to another, therefore limiting the application of strategies learnt in therapy to day-to-day life (Spain & Blainey, 2017. Alternatively, it could be attributed to pervasive social-communication difficulties often resulting high levels of peer rejection and social isolation which serves to continually reinforce poor self-esteem (Spain & Blainey, 2017); in this case, echoing the clinical implications of this review, promoting social connectedness alongside therapeutic input may enhance its efficacy, a hypothesis which warrants further investigation. Finally, though social adversity has been related to low explicit self-esteem in neurotypical samples, research is required to determine whether this is replicable within Autistic populations. This is especially important given the high levels of social adversity experienced in this community.

Limitations

A key limitation of this review is the heterogeneity of data included, as this limited the level of analysis which could be completed. Having not undertaken a meta-analysis of the data, is has not been possible to determine the magnitude of the reported effects. The exclusion of neuro-developmental co-morbidities is another limitation of this review. As ASD commonly co-occurs with learning disabilities (O'Brien & Pearson, 2004) and other neurodevelopmental disorders such as ADHD (Antshel et al., 2013), we may have excluded important, potentially relevant data. In doing so, our findings can also not be easily generalised to those with neurodevelopmental co-morbidity.

Conclusions

This review has shown that self-esteem is consistently lower in HFA compared to neurotypical controls; an effect which is stable over the lifetime and is unaffected by gender identity. Several factors have been shown to influence self-esteem in Autistic populations. Cognitive profiles such as having an above average IQ and social adversity were seen to contribute to poor self-esteem, whilst social belonging and positive collective self-esteem were shown to be protective factors. Offering interventions which focus on promoting social connectedness are likely to be useful in increasing self-esteem in this group. Self-esteem is closely related to mental health outcomes, especially affective symptomatology, though further research is recommended to develop effective interventions to improve self-esteem and psychological wellbeing in Autistic populations.

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Chapter 3

Bridging Chapter

Word Count: 518 words

Bridging Chapter

The systematic review aimed to explore co-morbidity in HFA by synthesising the literature on self-esteem in Autistic people. This focussed on three key areas: self-esteem in Autistic people compared with neurotypical controls, factors influencing self-esteem in Autistic people and secondary mental health outcomes associated with self-esteem. The findings of the review indicated that self-esteem is significantly lower in Autistic people than neurotypical controls and showed that particular domains of a person's cognitive profile (e.g. high IQ) and loneliness were related to poor self-esteem, whilst group identification through the receipt of a diagnosis of HFA was protective against low self-esteem. Experiences of stigma were also described as contributory towards low self-esteem. Of particular interest to mental health services, the review also highlighted the impact of low self-esteem, with affective symptomatology, such as anxiety and depression, being commonly experienced by this group, in addition to suicidality.

Low self-esteem has also been implicated in psychosis, which along with HFA, is the focus of the empirical paper. Like its relationship with affective disorders, self-esteem has also been shown to be a risk factor for psychosis, with those with low self-esteem being more likely to develop psychosis (Hinojosa-Marqués et al., 2021). Interestingly, self-esteem has also been shown to impact on psychotic symptomatology both in terms of intensity and associated distress (Smith et al., 2006). According to Smith and colleagues (2006), low self-esteem was associated with increased severity and intensity of persecutory delusions and auditory hallucinations, with the latter containing more negative content. Furthermore, higher self-esteem was associated with the severity of grandiose delusions (Smith et al., 2006). This relationship between self-esteem and paranoid symptomatology was also found by Monserat et al (2020), who additionally found that the relationship was amplified by anxiety and tempered by social closeness. These findings suggest an important contribution of self-esteem to the development of psychosis and highlights the influences of other domains of clinical presentation on this relationship.

The experience of psychosis has also been shown to impact on self-esteem, indicating a bi-directional relationship (Vass et al., 2015). Self-esteem has been found to be lower in those who have experienced psychosis, irrespective of age, gender, type, or course of psychosis (Vass et al., 2015). Internalised stigma is considered a possible explanatory mechanism for this relationship (Vass et al., 2015) and has been shown, along with low self-esteem, to impact on quality of life even post-resolution of psychotic symptoms (Vass et al., 2015).

The literature clearly indicates that those with both HFA and psychosis are likely to experience low self-esteem, which can lead to poorer clinical outcomes and quality of life. Whilst it would be reasonable to consider an amplificatory effect of having co-morbid HFA and psychosis, for example, with regard to self-esteem, research in this area is extremely limited.

The aims of the empirical paper are therefore to continue to explore co-morbidity in Autistic populations and to begin to address the gaps in the literature, by exploring the experience of co-morbid HFA and psychosis, not only in terms of self-esteem, but with consideration to the general experience of living with, and receiving support for, both conditions.

Chapter 4

Empirical Paper

The Experience of Co-morbid Autism Spectrum Disorder and Psychosis within an Early Intervention for Psychosis Service

This paper has been developed for submission to The Journal of Psychology. Author guidelines are outlines in Appendix B. No word count limit.

Word Count: 8,000

The Experience of Co-morbid Autism Spectrum Disorder and Psychosis within an Early Intervention for Psychosis Service

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Abstract

Autism and psychosis have long been posited to be related conditions with rates of co-morbidity being estimated at between 3.6% and 28%. Little is known, however, about the subjective experience of this co-morbidity. This study aimed to explore this phenomenon through the investigation of lived experience of adults with both conditions. This study used Interpretative Phenomenological Analysis to explore the lived experience of co-morbid Autism and psychosis in six adult participants (5 male, 1 female) aged 23-35 years. Participants spoke of their experiences of psychosis and Autism both independently and in relation to one another. Most participants considered these conditions related with psychosis most commonly described as having an additive or amplificatory effect on experiences associated with Autism, such as difficulties with sensory perception, and cognitive intensity and fixation. Participant experiences of treatment received by early intervention services were also explored, with social support with housing, benefits and employment being frequently cited as most valuable. Experiences of psychological therapy were also discussed. Most striking from these experiential accounts was the frequently widespread, chronic nature of the difficulties experienced in the context of Autism, both in their own right and in conjunction with psychosis. Therefore, though different for everyone, the impact of this condition should not be underestimated in this population: *'It's literally a part of your entire life'*. Due to this, adaptations are required for this group to ensure that the treatment received within early intervention services is appropriate and effective.

Key words: Autism, psychosis, early intervention service, mental health, co-morbidity

Introduction

ASD and psychosis have long been posited to be related conditions. From the early 20th Century, Autism was considered a symptom of schizophrenia (Bleuler, 1908) and "childhood psychosis" (Kanner, 1965; 1943). Contemporary conceptualisations, however, have moved from the identification of a single disorder to two distinct disorders, namely ASD and psychosis (APA, 2013). In separating these conditions, the focus is now on co-morbidity, which is estimated at between 3.6% (Davidson et al., 2014) and 28% (Mouridsen et al., 2008); this wide range of estimates is likely to be attributed to methodological heterogeneity plus the complexity, dimensionality and multi-factorial nature of the conditions (Treise et al., 2021).

Several theoretical approaches have been explored in order to develop our understanding of the shared features of these conditions including genetics, neurobiology and cognitive neuroscience, where candidate genes, brain regions and cognitive processes have been implicated (Daniels et al., 2008; Larsson et al., 2005; P. F. Sullivan et al., 2012) . Important identified shared cognitive deficits have consistently been found in higher-order social cognition such as social reciprocity and theory of mind (Baron-Cohen, 1989; Frith, 1996; Pina-Camacho et al., 2016) in addition to rigid, inflexible thinking styles (Leung & Zakzanis, 2014). Shared experiential risk factors such as disorganised parental attachment, bullying and social exclusion have also been identified (Sossin, 2015), suggesting environmental overlap; however, research exploring potential mediating effects of these factors is limited. Although this research provides a sound theoretical underpinning to the bio-psycho-social relatedness of ASD and psychosis, it has chiefly focussed on shared genotypic and phenotypic features within non-clinical populations, thus limiting its clinical application. This research identifies that the conditions are related, but not how this co-morbidity is clinically manifested, or what the needs are of those experiencing both ASD and psychosis (ASD-P). Further linking the identified overlapping features with targeted interventions also remains understudied.

Although the treatment pathway for those experiencing psychosis is well-established (NICE, 2014), there are currently no clinical guidelines, tools or interventions specifically developed for use in comorbid cases (Bell et al., 2018) . Research pertaining to the clinical investigation and treatment of ASD-P is in its infancy, with research by Larson and colleagues (2017) being the first of its kind to investigate the clinical characteristics of ASD-P compared to ASD and psychosis alone. This study demonstrated that those with ASD-P are phenotypically different compared to their singularly affected counterparts. For example, those with ASD-P were found to show significantly fewer lifetime stereotyped, repetitive or restricted interests and behaviours whilst being more likely to have had a history of affective disturbance compared to those with ASD alone (Larson et al., 2017). Although Larson et al (2017) did not have a control group with psychosis alone, a later study by Treise et al (2021), who included a matched psychosis-only control group, found those with ASD-P to differ from those with psychosis alone, in relation to elevated affective symptomatology. Those with ASD-P were also more likely to experience acute and transient psychosis than the general population (Larson et al., 2017; Treise et al., 2021). This therefore indicates that those with ASD-P have unique needs, distinct from those with either ASD or psychosis alone.

Due to this, questions are raised as to the appropriateness of current mental health services for those with ASD-P. As with first-episode psychosis, the first presentation of ASD-P is likely to be treated within an Early Intervention for Psychosis Service (EIS). EIS services are internationally well-established (Marshall & Rathbone, 2011) and offer a holistic range of interventions including anti-psychotic medication, CBT for psychosis, family interventions and social support over a 3-year period to promote sustained recovery from psychosis (NICE, 2014). Although EISs have been found to be effective in reducing distress, relapse rates and hospital admissions (Bird et al., 2010; Garety et al., 2008; Kam et al., 2015; Singh, 2010), this is not necessarily the case for the ASD-P subset of this group. Research has instead indicated poorer treatment outcomes including more unsuccessful medication trials and polypharmacy (Larson et al., 2017; Sunwoo et al., 2020; Treise et al., 2021), in addition to sustained significant interpersonal difficulties (Sunwoo et al., 2020) . As individuals with ASD are likely to experience long-standing poor social functioning in relation to self-care, building and maintaining relationships and securing and remaining in employment (Bishop-Fitzpatrick et al., 2015; Park et al., 2019), questions are raised around the suitability of time-limited interventions, such as those offered within EIS. Further investigation is required to ascertain not only what support might look like for this group, but also whether EIS service goals applying to first-episode psychosis are applicable for those with co-morbid Autism.

Whilst initial investigations into overlapping phenotypic features of ASD-P have been fruitful, research is yet to focus on the *nature*, or phenomenon, of this co-morbidity. Understanding of the experiential, phenomenological domains of ASD-P is arguably central to informing appropriate and effective assessment, formulation, and intervention in this group. This is particularly pertinent given evidence that those with ASD and other co-morbid mental health conditions frequently require adaptations to service provision, namely, psychological therapy, in order to improve efficacy (Spain & Happé, 2020).

In order to address this gap in the literature, it is important for an appropriate methodology to be selected. In employing a qualitative approach, we can offer an opportunity to dually affected service users to have their voices heard in a meaningful way. This is particularly important given the social communication difficulties and associated stigma faced by this group, whose voices are disproportionately likely to be unheard (MacLeod, 2019). Qualitative methodology also allows for the exploration of experience and the way in which this is both unique to the individual and shared with other affected individuals. As the in-depth exploration of the phenomenon of ASD-P is required, Interpretative Phenomenological Analysis (IPA) is an appropriate methodology; it allows participants to tell their story and places an emphasis on sense-making and the derivation of meaning from experience (Smith et al., 2009). Unlike other qualitative approaches, IPA is participant-led which is especially important in novel areas of investigation such as this, as it limits the impact of the researcher's ideas about participant priorities (Acker et al., 2018; Smith et al., 2009), promoting the exploration of the unique service-user experience of co-morbid ASD and psychosis.

Research Questions

In line with IPA the research questions of this study can be divided into first and second tier questions. As outlined by Smith and colleagues (2009), who explain that first tier questions should be broad and unassuming, our first tier question here is simply "What is the lived experience of those with ASD-P?". Our more specific, second tier question, based on the gaps in the literature and the clinical relevance of this research is: "How is treatment for ASD-P experienced within an Early Intervention Service?".

Methods

Design

This study was a qualitative exploration using semi-structured interviews of the experience of concurrent ASD and psychosis. Due to the phenomenological orientation of the research questions, Interpretative Phenomenological Analysis (IPA) was utilised as the qualitative framework.

Recruitment

Participants were purposively recruited from an NHS EIS, where individuals with concurrent ASD and psychosis are likely to present. The service offers a 3-year service to individuals aged 14-35 and is the first EIS service to implement a screening protocol to ensure that all service users on the caseload are screened for ASD (Treise et al., 2021). This protocol consists of screening questionnaires, case note reviews and diagnostic assessment, all of which are completed by the EIS. Service users who were identified as having ASD were considered for the study by their key worker (either their care co-ordinator or therapist), who provided eligible service users with an information sheet. To be eligible, individuals were required to have a formal diagnosis of ASD and psychosis and capacity to consent to participate. Individuals who presented with significant risk to self or others, or who's mental state was not considered sufficiently stable for engagement in the interview process were excluded, at the discretion of the key workers. Interested service users provided verbal consent to be contacted by the lead researcher prior to the interview.

Procedure

Ethics

The study was reviewed and approved by the Health Research Authority and NHS ethics (ref: 21/LO/0242) and NHS Trust R&D (HRA approval letter, Appendix C; REC approval letter, Appendix D).

Interviews

A semi-structured interview schedule was developed by the lead researcher in collaboration with clinical psychologists within the EIS. Service users with a diagnosis of ASD were consulted and asked to consider adaptations for the interview process based on the social communication difficulties frequently experienced by ASD populations. Based on this collaboration and the literature concerning the use of IPA with Autistic participants (Griffith et al., 2012; Macleod et al., 2018; Petalas et al., 2013) the following adaptations were made:

1. Participants were given the option of receiving the interview schedule in advance of the interview to allow for preparation time and familiarisation (Griffith et al., 2012; Macleod et al., 2018; Petalas et al., 2013)
2. Movement from one topic area to the next was explicitly stated to indicate change and aid attention switching
3. Telephone interviews were offered to reduce interpersonal stress, in addition to video and face-to-face options (Macleod et al., 2018).

The lead researcher conducted all interviews, which were audio recorded with consent and covered three broad topics: the experience of ASD and psychosis, the experience of receiving support from the EIS and hopes for the future. The schedule was used flexibly with additional prompts given when required and participants were encouraged to raise experiences which felt personally salient even if they had not been directly asked about them.

Interviews ranged from 34-63 minutes in length and were transcribed verbatim by the lead researcher. Identifying information was removed from transcripts to protect participant anonymity.

Data Analysis

> IPA is a qualitative approach underpinned by three key philosophical approaches: phenomenology, hermeneutics, and ideography (Pietkiewicz & Smith, 2014; Smith & Shinebourne, 2012) and aims to understand how participants make sense of and give meaning to their experience of a given phenomenon. This is achieved by a 'double hermaneutic' (Smith et al., 2009) in which the researcher aims to make sense of the participant making sense of their experience via the process of interpretation. In contrast to nomothetic research, which is underpinned by epistemological positivism and therefore aims to identify a generalisable, population-level "truth", IPA adopts an ideographic approach, which is concerned with the particulars of individual experience (Smith et al., 2009). This approach focusses on the analysis of experience on a single-case level (Pietkiewicz & Smith, 2014) and the identification of convergences and divergences between individual narratives (Smith et al., 2009).

Analysis was conducted by the lead researcher, who followed the IPA procedure recommended by Smith et al. (2009). Following transcription, the interviews were read several times to allow for familiarisation. The data were then 'free coded' by the researcher and exploratory comments noted. Researcher biases were noted and bracketed off to improve reflexivity (Willig, 2013), which is is considered essential for good quality qualitative research (Braun & Clarke, 2013). Reflexivity involves the researcher developing and maintaining an awareness of their own beliefs, assumptions, and experiences and the impact these have on their perception and interpretation of data.. This process was recorded in a reflective log, which was utilised throughout analysis and informed the interpretation of data. Each transcript was engaged with separately and emergent themes were identified based on both participant comments and researcher interpretation. Emergent themes were then organised into higher order superordinate themes. This process was repeated for all transcripts, with newly emergent themes being compared against established superordinate themes allowing for the investigation of convergence and divergence of experiential accounts across participants. Themes from all interviews were combined to construct a final table of superordinate and subordinate themes along with key illustrative quotes from across interviews to ensure themes were grounded in the data.

Quality assurance

As IPA is reliant upon the researcher's interpretation of the data, it is important to ensure these interpretations are valid and reflective of the data. In order to ensure this, the Yardley (Yardley, 2007, 2015) core principles for enhancing and assessing validity in qualitative research were referenced throughout the analysis process. The principles of sensitivity to context, commitment and rigour, coherence and transparency and impact and importance were met through the use of a reflective log kept by the lead researcher in addition to reflective discussions with the wider research team. Half of the transcripts were analysed by a second member of the research team and disagreements in interpretation discussed and resolved via consensus.

Results

Participants

A total of 6 participants were recruited, 5 male and 1 female. Participants were aged between 23-35 years old (mean= 28.3, SD= 5.92). Two participants had been diagnosed with Autism in childhood, whilst four were diagnosed as adults. All participants with an adult diagnosis of ASD were assessed and diagnosed within the EIS. All participants experienced psychosis within the last 3 years. See table 1 for demographic data.

Table 1. Participant demographic data

Participant number	Pseudonym	Age	Self-reported gender	Childhood or adulthood diagnosis of ASD
1	Sheila	35	Female	Adulthood
2	Joe	23	Male	Adulthood
3	Brian	32	Male	Childhood
4	John	23	Male	Adulthood
5	Jack	23	Male	Childhood
6	Adrian	34	Male	Adulthood

Results

Five superordinate themes were developed from the interviews (1) experience of psychosis; (2) experience of ASD; (3) overlap between psychosis and ASD; (4) emotional difficulties; (5) treatment with the EIS. Participants were given pseudonyms and identifiable information in quotations edited to protect anonymity. Table 2 shows the representation of participants within the themes. Superordinate and related subordinate themes are discussed in detail below.

Table 2. Representation of participants across themes

Superordinate and subordinate themes	Total	Sheila	Joe	Brian	John	Jack	Adrian
Experience of Psychosis	**6**	✤	✤	✤	✤	✤	✤
“Out to get me”: Suspiciousness and paranoia	6	✤	✤	✤	✤	✤	✤
“Escaping reality”	1					✤	
“A really awful time”: Trauma of psychosis	3	✤	✤		✤		
Experience of ASD	**6**	✤	✤	✤	✤	✤	✤
Diagnosis of ASD: “Understanding why I was struggling”	5	✤	✤	✤		✤	✤
“All the interactions would be better”: Social difficulties associated with ASD	6	✤	✤	✤	✤	✤	✤
Stigma of ASD: “No accurate portrayal of the average Autistic”	3	✤		✤	✤	✤	
“It’s all too much”: Environmental sensitivity	2	✤		✤			
Way of thinking: “It’s just different”	5	✤	✤	✤	✤	✤	
Overlap between ASD and Psychosis	**6**	✤	✤	✤	✤	✤	✤
The amplificatory effect of psychosis	5	✤		✤	✤	✤	✤
Pathways from ASD to psychosis	2	✤		✤			
Emotional Difficulties	**6**	✤	✤	✤	✤	✤	✤
“It traumatised me”: Impact of interpersonal difficulties	4	✤		✤		✤	✤
Alcohol and substance use: “Numbing myself”	2			✤			✤
“All sorts of difficult emotions”: Affective disturbance	3	✤		✤			✤
Self-esteem: “I’m just weird”	6	✤	✤	✤	✤	✤	✤
Treatment with EIS	**6**	✤	✤	✤	✤	✤	✤
Social support: “Being recognised by my community”	5	✤	✤	✤	✤	✤	
Psychological therapy: “Tools to cope”	5	✤	✤	✤	✤		✤
ASD informed support: “A mixed bag”	6	✤	✤	✤	✤	✤	✤

Experience of Psychosis

This superordinate theme captures participant descriptions of their psychotic experiences. In all cases, these were described as episodic, as opposed to chronic. Three subordinate themes encapsulated these experiences: *suspiciousness and paranoia, escaping reality* and *trauma of psychosis*.

“Out to get me”: Suspiciousness and paranoia

All participants gave a description of their psychotic experiences. In all cases, these included delusional beliefs, often with an interpersonal, paranoid element. Adrian described the development of persecutory ideas from uncertainty of a potential social transgression to persecutory ideas: *‘over the course of a few days, I got the impression that I’d upset someone in the neighbourhood, and then one night I kind of heard shouting and kind of ranting outside for about 3 hours at which point I got quite distressed…I ended up calling the police’.* The element of uncertainty and distress associated with the intentions of others was mirrored by Sheila who was held in a police cell when acutely unwell and recalled: *‘Two or three Pakistani men came in, which I thought was a bit inappropriate because, um, my friend, who was really unwell and in [a psychiatric hospital], she was really preoccupied on throwing acid in her face and the famous lady that presents the songs of praise at the moment…had acid thrown in her face so I felt as though Pakistani people weren't very friendly people to have walking in because they quite often throw in the faces of women.’*. Not only does Sheila’s experience highlight suspicious cognitions, it also draws attention to a tendency to connect ideas or experiences which are likely unconnected and jumping to conclusions. Interestingly, both Sheila and Adrian described difficulties with understanding the intentions of others outside of psychosis and attributed this to ASD, suggesting an amplification effect of psychosis.

“Escaping reality”

In contrast to Adrian and Sheila who experienced psychosis as distressing and interpersonally challenging, Jack exhibited elements of grandiosity and increased self-confidence, which was a stark contrast to his usual experience, and was able to enjoy these elements of his psychosis. He described *‘actually enjoying having psychosis because it sent me to a different world… which combined with my mania… It made me really, really, uh, elated and happy’.* When in the *’other world’* he described feeling that he had *‘more attention than I ever could have had’* and that he was ready to *‘change the world’* by being ‘*a mental health crusader*’. Most strikingly for Jack, this sense of empowerment was accompanied by a belief *‘that people were cheering for me and there for me’* which directly contrasted with his experiences of feeling ‘*isolated’*, which likely contributed to his enjoyment of part of his psychotic experiences.

“A really awful time”: Trauma of psychosis

All participants associated their psychotic episodes with distress. This was based on both psychotic symptoms and treatment received as psychiatric inpatients. Several participants referenced feeling confused and overwhelmed by their experiences, particularly by the *‘intensity of thought processes’* (Sheila). Joe recalled of his time in hospital: *‘it was scary being around there because every little thing that was happening, I thought was playing into some bigger narrative...it was a really confusing time…I wasn’t compliant to everything because I had no idea what was going on… [and] I could tell that... they’d had enough of me’.* Similarly, John spoke of the confusion and fear he faced during the process of admission. He recalled being *‘dragged’* into an ambulance and seeing a *‘really large spider in the corner by the door as I was being led through it’*. The content and strength of the descriptive language used by Joe and John was interpreted as indicative of a felt sense of powerlessness and vulnerability.

Sheila, on the other hand, described the inpatient setting as environmentally challenging: *'it was bright and noisy and just… completely overwhelming'*. This highlights the sensory difficulties experienced by Sheila, which were interpreted as amplifying her distress.

Experience of ASD

Participants gave in-depth descriptions of the various ways in which a diagnosis of ASD has impacted their lives.

Diagnosis of ASD: "Understanding why I was struggling"

All participants referenced the utility of receiving an ASD diagnosis, though the reasons for this varied. For several participants, the diagnosis helped make sense of their difficulties both for them and for others around them. For Sheila, the diagnosis was pivotal in helping her employer to *'understand why I was struggling'* and that '*it wasn't just psychosis'* but rather she was *'overwhelmed'* by her environment. Similarly, Joe had experienced *'difficulties communicating with my manager, and that definitely had some autism aspects'* and reflected that *'it would have been useful to have had an autism diagnosis then'*. These accounts were interpreted as indicating that a formal diagnosis provided valuable validation of difficulties that could not be fully otherwise explained.

As referenced by Joe, other participants agreed that late diagnosis was problematic. In addition to minimising the amount of support available within employment, it also impacted on education. For Sheila, this impact was social (*'they would just ignore me…it was really confusing')*, emotional (*'I wasn't given the opportunity to understand the emotional turmoil I was in')* and academic (*'it all just slumped my grades')*, whilst for Joe and John the lack of structure limited their ability to engage in mainstream education. Participants commonly reflected on the utility of earlier support *'if there was just more support…in the educational setting, I would have communicated much better and found it much easier'* (Sheila).

"All the interactions would be better": Social difficulties associated with ASD

All participants talked about difficulties with social communication. For most participants this was discussed as a global and chronic issue, affecting most social interactions. When John was asked if things would be different without ASD he noted *'all of the interactions would be better…it would be a different life'*. This was echoed by Adrian who described significant difficulties *'with striking a conversation generally'*. The impact of these difficulties was widespread and significant; '*I couldn't fit into this world properly and it felt overwhelming…I'm not particularly good at presenting myself.'* (Jack), *'I ostracised myself by talking like a dumb arse every time I open[ed] my mouth…I felt bad not being able to talk to people'* (John). These accounts highlight the perceived social consequences of these difficulties in addition to the elements of internalisation of blame for these. The use of derogatory self-descriptive language highlights the negative impact of these challenges on self-concept.

Difficulties with social communication were also noted during the interview process with participants frequently benefitting from scaffolding in the form of summarising, clarifying and re-focussing.

> *Researcher: So what I've understood from what you're saying, and tell me if I'm wrong…is that you felt that you weren't getting what you wanted to get across, that you weren't communicating as well as other people, and you weren't able to kind of do that as easily as other people might have been able to?*
>
> *John: I don't think I thought about that, but I think that's how it was.*

“No accurate portrayal of the average Autistic”: Stigma of ASD

Stigma was experienced on both an individual and group level. Brian reflected on the differential treatment he received at school due to his diagnosis *‘people would often respond to me with support assistance and that sort of thing which…felt kind of patronising’*. This was interpreted as frustration with people for not looking beyond the label and considering him as an individual. Jack commented on the unhelpfulness of stereotypical representations in the media which show *‘the very smart autistic or the very stupid autistic person [which is] not an accurate portrayal of the average autistic person…which is kinda annoying’* suggesting a consequence of feeling unseen and unrepresented.

Environmental sensitivity: “It’s all too much”

Sensitivity to environment was discussed in relation to the sensory aspects of an environment and to difficulty tolerating environmental change. Sheila provided several rich descriptions of sensory aspects of her environment and frequently cited these as *‘stressful’* and *‘overwhelming’*. The impact of this on her emotional wellbeing and functional ability was significant *‘I was working in a completely wrong environment…I was too sensitive to the lights and the sound and was very sensitive to the people who weren’t particularly nice’* which resulted in her being unable to sustain this employment. Sheila also described living in *‘a tiny house, it was so claustrophobic I can’t tell you’* indicating a generalised sensitivity to her environment. Brian, similarly, reported feeling *‘overwhelmed’* whilst living in shared accommodation: *‘it's a shock to be in an environment where there's a lot of other people around... when you're preparing your meal there are other people around often drinking, making a lot of noise’*. Both participants referenced these difficulties as contributory to the development of psychosis, suggesting that their heightened sensory and environmental experiences and associated distress were perceived as important triggers.

Way of thinking: "It's just different"

Several thinking styles were associated with ASD. Participants most commonly referenced an intensity and repetitiveness to their thought processes which was frequently related to restricted interests. *'I have intense hyper-fixations which meant…I got so attached to my video games that my grades were poorly affected'* (Jack), *'when some people have autism they have obsessions…I liked learning a lot…that was my schtick as it were'* (Joe). A tendency to rely on stereotypes was also identified *(He's not an aggressive man, but, yeah, he can lose it, but men do, don't they?,* Sheila) which was considered as compensation for difficulty in understanding social nuance by using clearer explanations of behaviour i.e. stereotypes. Difficulty mentalising was also seen in across several interviews, most explicitly exemplified by John: *'I don't know, because I don't live in that world, I don't I don't know how other people feel'.* This was interpreted as likely contributory to difficulties in understanding social communication and nuance, whilst also highlighting the sense of difference and otherness felt by John.

Overlap between ASD and Psychosis

This superordinate theme considers the ways in which ASD and psychosis were considered in conjunction to one another.

The amplificatory effect of psychosis

Fixation was cited as a shared cognitive phenomenon by three participants (Sheila, John and Adrian). John described this as *'the brain rushing off on itself whilst focussing on one specific* *thing'* which was echoed by Adrian who explained *'the biggest thing I struggled with with the psychosis is a kind of tendency to latch onto an idea and feel like it needs to be addressed…I get the feeling that comes along with the autism'.* Sheila commented that her already intense thoughts got *'out of control'* with psychosis. Based on these accounts, fixation in the context of psychosis was considered an amplification of fixation in an Autistic context, with an additional element of loss of control over thoughts.

For Jack, psychosis also played an amplifying role for his social communication difficulties. He explained: *'My words probably won't make sense because they're put into an autistic filter. Psychosis added into that probably makes it even more obscure. Just sort of imagine your speech going through filters and then it comes out a different way at the very end of the output if that makes sense. You can't take out the autistic one, but you can take out the psychosis one'.* This analogy was considered an insightful reflection on the relative permanence of difficulties associated with ASD irrespective of the amplifying effect of psychosis. Furthermore, Jack's perspective highlights the additive effect of both conditions, with communication being challenge enough due to ASD, but being amplified by periods of psychosis. His externalisation of his social-communication difficulties also signifies the lack of control Jack perceives himself to have over these difficulties.

Pathways from ASD to psychosis

Building on reported similarities, Sheila described how, at times of stress, her tendency to *'have intense thoughts'* and *'make connections'* would *'escalate to the point where they're just not quite making sense anymore'*, which was interpreted as referring to thought disorder. This therefore signifies a direct pathway from cognitive style attributed to ASD to psychotic symptomatology, with stress playing a catalytic role in this transition.

Similarly, Brian and Adrian talked about the development of paranoia from experiences of social anxiety, which they '*associated with Autism'* (Brian). Brain described long-standing difficulties with social anxiety, which had turned into concerns that he was *'being followed'* whilst Adrian described an evolution from being concerned he had *'upset someone in the neighbourhood'* to hearing *'shouting and kind of ranting outside for about 3 hours'* and believing himself in danger. In both instances, the transition from long-standing social anxiety to paranoia was preceded by increased stress or anxiety: *"over the course of a few days I was increasingly worried and anxious that I had done something wrong"* (Adrian). This is interpreted as highlighting the role, as seen with Sheila, of psychological stress in driving the movement between conditions. These experiences demonstrate that the catalytic effect of stress can be both discreet, affecting one domain of functioning at one time (i.e., thought disorder), and generalised, affecting multiple domains for extended periods (i.e., paranoid beliefs and auditory hallucinations).

In all examples, the transition from established, long-standing difficulties to acute psychosis was considered significant in understanding the experience of concurrence.

Emotional Difficulties

Emotional difficulties were commonly referenced by several participants. These were organised into four subordinate themes: *impact of interpersonal difficulties, rumination, affective disturbance, substance and alcohol use and self-esteem.*

"It traumatised me": Impact of interpersonal difficulties

Sheila, Jack and Adrian described periods of bullying during their childhoods; strikingly, both Sheila and Adrian were bullied by people they considered friends. *'It was a close friend who ended up…stealing my stuff and kind of demanding money and all sorts of things like that'* Adrian explained. He felt that the '*psychological effects'* of this were exacerbated by the perpetrator being his *'one close friend at school at that time…had I been able to branch out and make more friends it would have been a lot easier to cope'*. Similarly, Sheila recalled feeling isolated: *'I complained about her bullying…but because she was a popular girl who had sway with the girls they just literally didn't talk to me even though I was in their year, it was horrible'*. Though not caused by bullying, Brian also shared feelings of isolation following the loss of his one significant friendship: '*Losing that friendship I think was important. Yeah, the friendship kind of felt important because I would joke about like social things and incidents that went wrong and that kind of thing. That kind of felt like it took away part of the problem. But when I lost that I turned to using the opiates more often.'*. These accounts are considered connected based on their desire for social connectedness being juxtaposed with peer rejection and victimisation, resulting in feelings of distress and isolation. These adverse social experiences are reminiscent of later feelings of prosecution in the context of psychosis, for example, Adrian's account of hearing *'shouting and ranting'*, suggesting that these adverse experiences may increase vulnerability for later psychosis.

Social connectedness, on the other hand, was described as beneficial to wellbeing. These social connections were often formed in the context of niche interests *'I joined the anime society and we went out a couple of times which was good'* (Joe), *'things are much easier now…there's a whole bunch of people I've got to know through work… I guess working in software means* *there's lots of people who have similar interests to me… we started to do all sorts of things outside work as well'* (Adrian).

Affective disturbance: "All sorts of difficult emotions"

When discussing mental health difficulties, affective difficulties were regularly referenced. Jack, though being supported by a psychosis team, felt that *'the real problem is depression, really…it's the one thing I haven't really been able to crack'.* He went on to explain that this depression had been recurrent over his life, with some episodes resulting in suicidality *'I wanted to end my life…I was looking at any possible opportunity, and then when I was in hospital I had a couple of suicide attempts'.* This account represents the hopelessness caused by depression and its relationship with suicidality. The long-standing nature of Jack's affective difficulties were mirrored by Joe's experience. *'I was depressed for a long time…it comes and goes…one episode was in my final year [of school]….it all kind of returned and I lost my ability to act normal because it takes up energy I guess'.* This account was interpreted as Joe referencing the physical and emotional toll of masking behaviours he was implementing to *'act normal'.*

"Numbing myself": Alcohol and substance use

Both Joe and Adrian reported using alcohol to manage anxiety. Joe explained *'Well when I was sixteen things were up and down I was kind of using alcohol, having it in the day at sixth form. Um, so to cope with the social, kinda social anxiety and didn't really become a problem, I kind of stopped using it, but then then later on, like, um, when I was about eighteen I began using opiates, making morphine from opium poppy seeds to ease the anxiety, taking diazapam as well as a legal option that was available...I was taking quite large amounts of that to kind of block it out and that was when I was kind of heading to university for the first time'.* From Joe's account it is evident that he was using both alcohol and substances to manage his anxiety and his increased reliance on substances for self-medication was interpreted as this becoming a more established coping strategy to cope with increased social demands with age, such as increased independence at university. This was highlighted by Joe's reflection that *'the drugs have made me less resilient in a way…I didn't adapt to find coping strategies that didn't involve drugs'*.

Self-esteem: "I'm just weird"

When talking about themselves, participants frequently used self-critical, derogatory language, which was interpreted as indicating poor self-esteem. John, for example described himself as *'lazy and weird,'* with *'weird interests'*, whilst Jack stated that he is*' like a child… I can't fit the pieces in my life…like a responsible 20-year-old'.* This language also points to feelings of difference and difficulty finding a place in the world, potentially deepening poor self-concept. This poor self-esteem was additionally considered as an internalisation of the social adversity and interpersonal trauma several participants had experienced. For example, John not only described himself as *'weird'* but also explained *'people just saw me as the weird kid…'they'd tell me [that]'.*

Further to the use of pejorative language, participants tended to blame themselves for their difficulties through phrases such as *'burdening myself'* (Sheila) and *'ostracising myself'* (John), which could be reflective of an internalisation of difficulties, exacerbating existing ideas of difference or inadequacy.

Treatment with EIS

“Tools to cope”: Psychological therapy

All participants reported having received psychological therapy. For many, it was the receipt of *‘practical tools’* (Sheila) *‘that…can put into practice’* (Adrian) which was most valued. Sheila gave the example of *‘photographs of a textbook which lists different responses to situations…a sort of cheat sheet for grounding yourself’* (Sheila). The benefit of a *‘cheat sheet’* here was seen to emphasise the difficulty in managing emotions expressed by Sheila, in addition to highlighting the need of a clear structure to do this. The application of structure to manage difficult thoughts and feelings was also described by Adrian *‘I would think of different explanations of things and… assign probability’* (Adrian). The researcher reflected that this approach allowed Adrian ‘*to apply quite a logical framework to understanding the illogical’* which Adrian agreed *‘played to [his] strengths’*. The use of *‘analogies’* (in this case the ‘passengers on the bus’ metaphor used within Acceptance and Commitment Therapy) was referenced by Joe as *“unhelpful”* and *‘confusing’*, whilst others suggested that *‘identifying your thoughts and feelings’* (Adrian) and *‘needing to talk about heavier stuff’* (John) were challenging. These challenges were interpreted as indicative of difficulties with aspects of therapy which rely on abstract concepts and require introspective thinking.

Social support: “Being recognised by my community”

Social support, including help with benefits, housing, employment, and social connectedness, were cited by most participants as the most beneficial aspect of the support they received from the EIS. The social groups run by the EIS were attended by Joe and Jack who both described finding them *‘useful’* and *‘like having a community’*, which contrasted with earlier descriptions of social isolation. This was emphasised by Joe who stated *'you're able to have a chat with someone that you wouldn't… you wouldn't get a nice long chat with someone on a walk, you would just be stuck at home doing nothing'*. The clear contrast between what he perceives the group allows him to do and what he would otherwise be doing suggests that Joe values support with initiating and maintaining social contact, which he may not be able to independently manage. Sheila also described significantly benefitting from the social support offered, she explained *'I wouldn't have housing without [the EIS] I wouldn't have job that I've got. I wouldn't have anything. I wasn't sort of being recognised by the community in a way that I...I wasn't getting the support that I needed, so wouldn't have any of that. I would probably be homeless somewhere on the street, if alive at all...'*. The language used by Sheila emphasises the sense of ostracization experienced and therefore the transformative effect of her social needs being met at last. The expression "*if alive at all*" emphasises the gravity and hopelessness of the social adversity experienced by Sheila and therefore the significance of the support received.

ASD informed support: "A mixed bag"

Whilst most participants felt that the EIS had a *'good understanding of Autism'* (John), it was suggested that this knowledge needed to be more individualised. Joe described the input from professionals as *'general'* but would have preferred *'more explanation of what Autism meant for [him]';* a sentiment which John echoed. In Jack's experience, service understanding of the impact of ASD was *'a mixed bag'*. He explained: *'they were using different approaches on how to deal with Autism. And one of them wasn't particularly ideal, and one of them was more understanding. The less helpful approach was essentially telling me my Autism doesn't have to define me [but] it can be quite hard to… just ignore it or make it less of a presence when it's literally a part of your entire life, and it can be hard to accommodate for someone with Autism* *if you don't understand what they're really like*'. Jack's perspective was understood to highlight the importance of adopting a person-centred approach in providing validation of experiences in addition to the need to take the time to understand the needs of the individual for appropriate adaptations to be made. Jack's account highlights assumptions made by professionals and the stigmatising impact of these; though told Autism didn't need to define him, he felt that it necessarily does. The perceived lack of exploration of the salience of Autism to the individual could be indicative of a more specific lack of exploration around the relationship between Autistic and psychotic experiences. Indeed, whilst participants spoke of the interrelatedness of their experiences with these conditions, their reports of service support seem to be more binary, managing psychosis and ASD separately.

Discussion

Overview

This study aimed to explore the experience of concurrent ASD and psychosis in dually affected individuals, in addition to exploring how support and treatment from an EIS was experienced. Experiences of psychosis and ASD were considered both independently and in conjunction to one another. In-depth, semi-structured interviews were conducted with 6 eligible participants and five superordinate themes identified (1) experience of psychosis (2) experience of ASD (3) overlap between ASD and psychosis (4) emotional difficulties (5) treatment with EIS.

Participant descriptions of psychosis were varied, however did share some core characteristics. First, all presentations were described as episodic and acute. This reflects the wider literature around psychotic presentations in Autistic individuals, which has found that psychosis is more frequently acute and transient in in this population compared to non-Autistic controls (Treise et al., 2021; Larson et al., 2017). Second, it was commonplace for participants to describe delusional ideas which were often interpersonally oriented such as persecutory beliefs. In some accounts, the development of these beliefs were preceded with interpersonal uncertainty, such as the fear of having upset someone (Adrian) or feeling unsafe in the presence of others (Sheila), suggesting that feelings of personal vulnerability, in addition to difficulties understanding social nuance may have been related to the development of paranoia. The relationship between feelings of personal vulnerability and paranoia is well-documented within the neurotypical population (Meisel et al., 2018), and has been implicated, along with a history of adverse interpersonal experiences and social communication difficulties as a significant contributory factor to the development of paranoia in ASD populations (Spain et al., 2016). In their theoretical framework of paranoia in Autistic populations, Spain and colleagues (2016) suggest that social communication difficulties increase the likelihood of social interactions being experienced as adverse which, in turn, may lead to the development of beliefs about others being unsafe or threatening, ultimately resulting in paranoia. This trajectory is reminiscent of the experiences of some participants within this study and is therefore likely to be a useful framework for understanding the development of psychotic experiences in this population.

In considering experiences of ASD, participants most commonly discussed social communication difficulties, which included difficulties with effective verbal communication and in forming and maintaining friendships, both of which are in line with the wider literature around ASD (Kuzminskaite et al., 2020). As suggested by Kelly et al (2018) these challenges highlighted a sense of isolation for many, in addition to frequently being internalised as ‘their fault’. Further to self-blaming narratives, derogatory and self-critical language such as ‘weird’ and ‘not normal’ was utilised by participants, which was interpreted as emphasising poor self-concept, formed as a result of social communication challenges. Peer victimisation was also commonly described, often at the hands of a trusted individual, which is hypothesised to not only have influenced self-esteem in respondents, but also to have contributed to episodes of emotional difficulty experienced. These experiences are echoed within other qualitative accounts of self-esteem in Autistic populations (Leedham et al., 2020; Tan, 2018), in addition to reflecting quantitative research which consistently indicates that self-esteem is significantly lower in Autistic individuals compared to neurotypical controls (Cooper et al., 2021; Goddard et al., 2017; Humphrey & Hebron, 2015b; Jamison & Schuttler, 2015; McCauley et al., 2019; McChesney & Toseeb, 2018; van der Cruijsen & Boyer, 2021; Williamson et al., 2008). When considered in conjunction with findings indicating self-esteem being negatively impacted by psychosis (Gureje et al., 2016; Smith et al., 2006) this could suggest a compounding effect of psychosis on self-esteem in Autistic populations, though further investigation is required to ascertain if this is the case.

In exploring difficulties associated with their conditions, descriptions of psychosis were often acute, contrasting with more chronic descriptions of difficulties associated with ASD. This is most likely explained by the transient nature of the psychosis experienced by these participants, as opposed to ASD which was considered enduring and was indeed reflected upon within a wider context and over a longer period than psychosis. This distinction was eloquently summarised by Jack, who compared both conditions to filters which influence aspects of your life; whilst the psychotic filter *‘can be removed’* the autistic one cannot. This finding is particularly striking considering 4/6 participants received a diagnosis of ASD as adults and therefore will inevitably have experienced their reported difficulties without understanding the cause, likely increasing distress (Leedham et al., 2020; Wylie, 2014). Furthermore, participants who received an adult diagnosis from the EIS indicated a lack of post-diagnostic work which limited their understanding of the way in which ASD is salient to them and of how it is related to their concurrent mental health difficulties. As suggested by Scattoni et al (2021), a lack of post-diagnostic work limits the utility of receiving a diagnosis and often means that advances in wellbeing cannot be made. This is therefore a suggested area for improvement.

The contrast in longevity between conditions could also contribute to our understanding of the descriptions of the ways in which the two conditions are related. The four key comparative domains were in sensory experiences, fixations, intense thought processes and social communication difficulties. For all experiences, participants described these experiences in the context of ASD and allocated an, in the case of sensory experiences and fixations, amplificatory, and in the case of intense thought processes and social communication difficulties, transitional role to psychosis. Fixations, or obsessive thoughts on a narrow topic, were considered as the most commonly overlapping phenomenon and, whilst fixation is a widely accepted cognitive process in ASD (Carpenter, 2007; Cooper et al., 2021), the research into its role in psychosis is limited, potentially indicating a unique phenotypic feature of this co-occurrence. As research in this area is in its infancy, further research is required to determine the generalisability of these experiences.

Affective difficulties were another significant area of exploration for participants and were often intrinsically linked with accounts of both psychosis and ASD. In line with Treise et al (2021), these affective experiences often predated psychotic symptoms, which is likely indicative of the influence of the impact of social communication difficulties and the associated experiences of social adversity, which have consistently been highlighted as risk factors for the elevated affective symptomatology experienced in Autistic populations (Rai et al., 2018; Stewart et al., 2006).

Reflections on treatment included both community support from the EIS and inpatient treatment. Admissions to inpatient units were generally experienced as frightening and confusing, with several difficult interpersonal and sensory experiences noted, such as being *'dragged'* to an ambulance (John). This narrative is reflective of the findings of Maloret and Scott (2018) who demonstrated elevated levels of distress in Autistic inpatients due to high levels of unpredictability and uncertainty, in addition to high levels of sensory input. These findings suggest that the additional needs of Autistic individuals should be both considered and accommodated for, to reduce the amount of distress felt in this environment.

Social support, including help with housing, benefits, employment and social connectedness was consistently cited as the most useful part of support from the EIS, reflecting the social difficulties commonly experienced in populations with Autism (McVey et al., 2018) and psychosis (Cornblatt et al., 2012). This preference for practical support was echoed in participant experiences of psychological therapy, where practical, logical and easily applicable skills were cited as the most beneficial aspects. Interventions which involved the use of analogy were not seen as beneficial, whilst aspects of therapy which required introspection and mentalisation were often difficult to engage with. This may be explained by concrete, literal, thinking in ASD, in addition to difficulties with emotional recognition and theory of mind in this population (Baron-Cohen, 2000; Tracy et al., 2011; Uljarevic & Hamilton, 2013). It is therefore suggested that further research is conducted into the ways in which psychological therapy can be appropriately adapted for dually affected individuals.

Clinical applications

There are several important clinical implications of these findings:

1. As this study builds on the evidence of increased social adversity in ASD populations in addition to highlighting the utility of social interventions, the social needs of dually affected individuals should be comprehensively assessed, and appropriate intervention offered.
2. Psychological therapists should consider providing scaffolding to support Autistic individuals who struggle with introspection and mentalisation to build these skills. Practical, problem-solving approaches should be considered where appropriate.
3. Post-diagnostic work should be offered to aid the individual in understanding what a diagnosis of Autism means for them and how it might interact with their psychotic symptomatology.
4. Given accounts of the amplificatory and additive effect of psychosis on ASD and in line with Spain et al's (2016) model of paranoia in ASD, mental health professionals should move towards a more holistic approach of assessment, formulation, and intervention where these conditions are concurrently considered.

Strengths and limitations

The key strength of this study was its provision of a voice to a marginalised population which allowed us to begin to understand the experience of co-morbid ASD and psychosis. The use of experts by experience in the development of the topic guide and general interview design led to adaptations which considered the social communication needs of this population, therefore promoting effective engagement with the research process.

Whilst this study allowed a detailed exploration of the experience of this co-morbidity, the qualitative methodology in addition to the small sample size means that, to ascertain whether these findings are representative of the experiences of others in this population, further research employing quantitative methodology is required. In addition to the small sample size, 5/6 participants were male which, whilst representative of the higher proportion of men in both ASD and psychosis populations (Baron-Cohen et al., 2011; Ochoa et al., 2012), limits the voice of female experience, which research has consistently indicated is likely to be different due, for example, to different social experiences (Kirkovski et al., 2013; Lai et al., 2015). Further exploration of the female narrative may therefore be beneficial to explore the role of gender on the experience of comorbid ASD and psychosis.

Conclusion

This study aimed to investigate the experience of comorbid ASD and psychosis, in addition to understanding the experience of receiving treatment for this within an EIS. On the basis of this, we aimed to use our findings to consider ways in which services can be adapted to best meet the needs these individuals. Areas of convergence between experiential accounts were explored in relation to psychosis, ASD and treatment, and divergences noted. Most striking from these accounts was the frequently widespread, chronic nature of the difficulties experienced in the context of Autism, both in their own right and in conjunction with psychosis. Therefore, though different for everyone, the impact of this condition should not be underestimated in this population: *'It's literally a part of your entire life'* (Jack).

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Chapter Five

Additional Methodology and Design Chapter

Word Count: 3,510

Additional Methodology and Design Chapter

This chapter offers additional information on the design and methodology sections of the empirical paper, providing further details on the qualitative research design and the Interpretative Phenomenological Analysis (IPA) method.

Ontology and Epistemology

Ontology is concerned with whether there is an objective truth or reality, whereas epistemology is concerned with if it is possible to know this objective truth about reality (Braun & Clarke, 2006, 2013). Ontology can be considered along a continuum ranging from realism, where an objective truth exists and can be both measured and generalised, to relativism, where truth is considered subjective and knowledge contextual (Braun & Clarke, 2013; Killam, 2013). From a relativist ontology reality does not exist outside of the individual's construction of it (Sullivan, 2016); value exists only in the meaning of experience (Killam, 2013). Whilst quantitative research is underpinned by a realist ontology (Avis, 2005), qualitative investigation is often concerned with the subjectivity of experience, and the relationship between knowledge and experience.

Epistemology can similarly be considered on a continuum ranging from positivism to constructionism (Braun & Clarke, 2013). Whilst positivism posits that truth can be both accessed and measured, constructionism considers knowledge as context-specific and evolving based on culture and experience (Killam, 2013; Madill et al., 2000).

Critical realism can be considered as both ontological and epistemological in position (Fletcher, 2017). It is underpinned by a realist ontology in which ‘reality’ is assumed to exist regardless of researcher perception (Fletcher, 2017; Lawani, 2020), whilst adopting a constructivist epistemology. In short, critical realism allows for the presence of a “true” reality, whilst acknowledging that this is experienced through subjective perception, a position which is commonly adopted by Interpretative Phenomenological Analysis (Braun & Clarke, 2013).

Research into mental health conditions and developmental disorders poses an ontological and epistemological dilemma. The notion of diagnosis is itself a realist one, where a pattern of symptoms is considered a true indication of a disorder or condition (Lovett & Hood, 2011); however, the experience of having a condition lends itself to constructionist interpretation. Taking a critical realist perspective can provide a balanced perspective, capturing where diagnosis and experience intersect. This study therefore adopted a critical realist ontological and epistemological position to explore the lived experiences of those with a diagnosis of both ASD and psychosis.

Ethical Considerations

Potential for distress

Given the emotive topic, the potential distress to participants was considered throughout the duration of the interview. The use of a topic guide (Appendix E) rather than an interview schedule meant that participants could talk about and expand upon aspects of their experience as and when they felt comfortable to do so. The researcher gave participants a copy of the topic guide so that they were aware of what the interview would entail and could highlight if there were any questions they did not want to answer. In order to help maintain confidentiality, interviews took place in a room on the ward out of view from communal areas. At the end of the interview, participants were given a paper debrief form (Appendix F) so that they could keep a visual reminder of the support available should they require it.

Coercion

It was made clear to participants that it was entirely their choice whether they participated in this research. It was emphasised verbally, in addition to on the information sheet (Appendix G) and consent form (Appendix H), that the treatment that they will receive from the EIS would not be impacted by their decision to participate, or not.

Consent

Consent was gained prior to contacting potential participants to discuss the study by key workers within the EIS. These key workers were required to determine whether the participants had capacity to consent in the first instance, in line with the Mental Capacity Act 2005. Written consent was also gained from all participants prior to the interview by the researcher. All participants were considered to have capacity to consent both prior to being contacted by the researcher, and prior to participation in interviews.

Confidentiality

Confidentiality was respected at all times. Participants were informed that all information given as part of the interview would remain confidential, unless significant risk to self or other was indicated. This was also outlined in the consent form (Appendix H). If significant risk to self or other was disclosed during a face-to-face interview, the researcher would have remained with the participant until their care team had been informed and a plan formulated. Should this have occurred during a telephone or online interview, the participant would have been asked to stay on the line until appropriate arrangements had been made. If the participant left the call and did not answer when called back, emergency services may have been called (if indicated). There were no breaches of confidentiality in this study. All data was anonymised to ensure this was the case.

Data protection

Participants remained anonymous throughout the research process. They were allocated a participant number and were asked to select a pseudonym, which was used in quotations. Transcription was completed by the researcher and once transcribed, all identifiable data was redacted. Identifying documents (e.g., consent forms), were stored separately on a password protected Microsoft Word file, on a password protected laptop, which only the researcher had access to. These documents will be deleted upon completion of the study. Interview recordings and transcripts will be stored anonymously by participant number in accordance with the Data Protection Act and GDPR guidelines for 10 years following the completion of the study, after which they will be destroyed.

Interviews and Topic Guide

The topic guide was initially developed by researcher GS with consideration to the existing literature on co-morbid ASD and psychosis and with reference to the research questions. The topic guide was then reviewed by researchers NM and CT and any queries were resolved via discussion and consensus. To ensure that the topics were salient to the participant group and that questions were clear and easily understood, CPFT R&D funded patient participation with the study, at a rate of £10 per hour. A flyer was designed and distributed through researcher

NM, a clinical psychologist on the At-Risk Mental State (ARMS) pathway of the EIS in Cambridge (Appendix I). ARMS service users with a diagnosis of ASD were selected as expert collaborators due to there being a small number of those with co-morbid ASD and psychosis on the EIS caseload; thus, consulting with any of these individuals could have limited the study recruitment pool. As the priority for patient involvement was to explore the adaptations needed for interviews, based predominantly on issues with social communication associated with ASD, recruiting individuals with diagnosed ASD was key, irrespective of whether they had experienced only 'psychotic-like' symptoms.

Two expert collaborators volunteered to support with the design of the topic guide. Collaborators were sent the initial topic guide via email and asked to consider the following:

(1) Do the questions make sense?
(2) Do you think the topics and questions are appropriate for the area of study? Do they feel relevant to your experiences?
(3) Is there anything you would like to add?
(4) Is there anything you would like to change?

A meeting was then arranged in August 2020 to discuss these questions and the topic guide in detail. As a result of the collaboration with the identified experts-by-experience, in addition to familiarisation with the literature around using IPA with those with ASD (Howard et al., 2019), the following adaptations were made to the design of the interview:

1. Participants received a copy of the topic guide in advance of the interview to allow for preparation time and familiarisation (Griffith et al., 2012; Macleod et al., 2018; Petalas et al., 2013).
2. Each new question and topic were explicitly introduced, to aid with attention switching and to indicate change. This was an adaptation of the 'stop and start' cards used by

Humphrey and Lewis (2008).

3. Telephone interviews were offered to reduce interpersonal stress for the participant. All participants were able to choose between face-to-face, video and telephone interviews (Macleod et al., 2018).

Some linguistic changes were agreed to increase clarity, in addition to the order or prompting questions being revised.

Analysis

As the research question called for the exploration of experience, it was considered fitting with phenomenological enquiry and IPA was therefore selected as an appropriate analytic method.

Theoretical orientation of IPA

IPA is underpinned by three key philosophical approaches: phenomenology, hermeneutics, and ideography (Pietkiewicz & Smith, 2014; Smith & Shinebourne, 2012). Phenomenological enquiry seeks to capture and understand the lifeworld of the individual and invokes a lived process, unfurling meanings which are unique to the person's relationship with the world (Smith et al., 2009). Language has been posited as central to this process, as it can be utilised and analysed in order to access the meaning of one's experience (Heidegger,1962; Freeman & Cameron, 2008)) and, as such, is necessarily interpretative (Smith et al., 2009). As IPA is concerned with the examination of a given phenomenon, the researcher is required to facilitate the interpretative analytic process, and thus enters into the double hermeneutic; the researcher attempts to make sense of, and derive meaning from, the participants' attempts to make sense of their lifeworld or experience (Smith & Osborn, 2008; Smith et al., 2009). As the researcher will inevitably bring their own experiences and beliefs to this process of interpretation, it is recommended that the researcher strives to bracket their own personal experiences when considering participant accounts (Moustakas, 2011; Smith et al., 2009).

In contrast to nomothetic research, which is underpinned by epistemological positivism and therefore aims to identify a generalisable, population-level "truth", IPA adopts an ideographic approach, which is concerned with the particulars of individual experience (Smith et al., 2009). This approach focusses on the analysis of experience on a single-case level (Pietkiewicz & Smith, 2014) and the identification of convergences and divergences between individual narratives (Smith et al., 2009).

Analysis process

IPA does not dictate a single method of analysis, instead highlighting the need for both an inductive and iterative approach (Smith et al., 2009; Smith, 2007). Though not prescriptive, Smith (2007) suggests a six-step analysis process, moving from initial familiarisation with data to the in-depth analysis of individual accounts and resulting in the identification of patterns across accounts. The application of this process to this research is outlined below.

1. *Reading and re-reading the original data*

   The first step in the IPA method is immersion into data. It is recommended that this is achieved by reading and re-reading transcripts to familiarise oneself with its content. In this study the researcher followed this approach, whilst also listening to the audio recordings of interviews to take note of non-verbal communicative cues such as pauses and changes in tone, which deepened the researcher's access to the participant's world. As recommended by Smith et al (2009), the researcher made notes of their recollection of the interview and their most striking observations during this period of familiarisation. This assist in bracketing off their own experiences to re-focus on the data at hand. The following excerpt is taken from the researcher's reflective diary following familiarisation with Brain's interview:

> *My overall feelings on Brian's interview:*
>
> *- Very emotive interview. Really get the sense of the emotional difficulties caused/ perpetuated by ASD which were personally affecting.*
>
> *- Feeling abnormal with the associated desire to be normal combined with the knowledge that his deficits are what they are evokes a feeling of hopelessness/ helplessness.*
>
> *- Very insightful guy who has clearly spent a long time considering his difficulties. The sense of rumination is saddening, it would be nice for him to be more future-oriented.*
>
> *- I experienced him as very personable/ likeable. I wonder whether he agreed with this? Over-estimation of deficits due to low SE or previous experiences of social rejection?*
>
> *- Drug use extremely prominent- get the sense that this is both a remedy and a poison and the associated emotional turmoil that comes with this duality.*

2. *Initial noting*

   This stage of analysis involves creating a comprehensive commentary on the data by free noting. This commentary is constructed by the consideration of three levels of analysis: descriptive (what is said), linguistic (how it is said), and conceptual (what it may signify) (Smith et al., 2009). An example of this is provided in Appendix J.

3. *Developing emergent themes*

   In developing emergent themes, the researcher is required to reduce the volume of detail within the data set whilst maintaining its complexity, nuance, and narrative (Smith et al., 2009; Smith 2007). This process involves the hermeneutic circle in which the researcher moves from analysis of discrete parts of the dataset, to the whole, where the interpretation of the part is in done in relation to the whole and the interpretation of the whole in relation to the part (Smith et al., 2009). Through this process, the data is re-organised to reflect connections and patterns resulting in emergent themes.

4. *Searching for connections across emergent themes*

   As recommended by Smith et al (2009), emergent themes were initially recorded chronologically, before being re-organised to reflect clusters of associated themes. This process involves the consideration of emergent themes in relation to the scope of the research question to consider their relevance to them. Upon completion of these steps, the researcher is left with a structure which allows one to communicate the most significant and interesting features of the account.

5. *Moving to the next case*

   Once analysis of the individual transcript is completed, the researcher will then turn their attention to the next participant transcript, repeating steps 1-4. Key to this process is the bracketing off of any previous analysis to maintain the idiographic focus on individual experience (Smith et al., 2009).

6. *Looking for patterns across cases*

   The final stage of analysis using IPA involves searching for patterns across participant accounts, which may involve taking a more theoretical perspective as shared concepts are represented through themes across cases. Themes may be renamed in light of the reconfiguration of the meaning of ideas across participant accounts. These themes can then be organised into superordinate and subordinate themes. An example of this process is outlined in Appendix K.

Quality assurance and reflexivity

Reflexivity is considered essential for good quality qualitative research (Braun & Clarke, 2013) and involves the researcher developing and maintaining an awareness of their own beliefs, assumptions, and experiences and the impact these have on their perception and interpretation of data. IPA calls for the process of bracketing to promote reflexivity throughout the research process. In this study, the lead researcher (GS) kept a reflective diary throughout. This allowed the researcher to develop a greater awareness and understanding of their attitudes and beliefs towards Autism, psychosis, and treatment within EIS. This was especially important given the lead researcher's previous employment within EIS where they worked closely with service users with co-morbid Autism and psychosis. Two excerpts from the reflective diary are provided below. The first outlining the researcher's early reflections on their experiences working with this demographic, the second, the researcher's post-interview reflections.

1. **Example reflective journal entry regarding own experiences of working with individuals with co-morbid ASD and psychosis within an EIS:**

   Working in [the EIS], I remember the frustration I felt when working with individuals with ASD who either did not yet have a diagnosis or had only recently been diagnosed. It was frustrating to see people who had experienced significant difficulties throughout their lives, who had always felt different and struggled to understand the world around them, having never been recognised as Autistic, or given a framework for understanding their difficulties. When psychosis was then added to the picture, this often enhanced feelings of otherness or weirdness felt. Clinically speaking, it was often quite difficult to know how to best to work with this group which left me with feelings of frustration and guilt. Whilst CBT for psychosis was the service offering, it didn't always feel like the most useful approach. Service users sometimes struggled with basic emotional literacy which then had a knock-on effect on the efficacy of CBT techniques reliant on the identification of thoughts and feelings. When I think about working with this group of people, one particular individual comes to mind. This person was bright, kind and absolutely hilarious, but lived in a constant state of confusion and anxiety. This person received a diagnosis of ASD as an adult, and I can say with absolute certainty that this was not early enough. Sadly, this person took his own life, and his passing highlighted the importance of identifying and addressing the specific mental health needs of Autistic individuals to reduce the likelihood of further tragedies.

2. **Example reflective journal entry post interview for Sheila:**

   Sheila's account of her experiences has really left me with a sense of her vulnerability which has made me feel almost protective over her. At times, Sheila made me feel quite uncomfortable with her use of racial stereotypes which felt racist to me (e.g. Pakistani men throw acid in the faces of women). On reflection, I considered that her social communication difficulties may have meant that she is over-reliant on stereotypes to understand social behaviour, as they are often very black and white ways of looking at and understanding the world. When I thought of it like that, it again highlighted her vulnerability and made me consider how others may receive these kinds of comments. I wondered whether this had a bearing on her social relationships. Another thing which made me consider the impact of her difficulties on social relationships was the overall intensity of her communication. The level of detail that she provided, the rapid rate of her speech and the tangential nature of it all felt very overwhelming for me, and I found I really had to concentrate to follow her trail of thought. I felt very aware of the fact that 1. It was in my interest to pay close attention to what she was saying, how she was saying it and to try to make sense of it and 2. That, as a mental health professional, I am likely to have much more patience for and empathy towards her communication style than, probably most, lay people. These reflections made me feel quite sad for Sheila as I experienced her as quite likeable but was aware that I might not have given her the same time and attention outside of the research and clinical contexts.

Yardley (2000; 2015) suggested four key principles for the assessment of quality and validity of qualitative research (1) sensitivity to context, (2) commitment and rigor, (3) transparency and coherence and (4) impact and importance. Table 1 summarises the way in which this study met these principles.

Table 1- Quality assurance

Guideline	**Steps taken**
Sensitivity to context	• Participants were offered a range of options regarding medium (in-person, video call or telephone call) and duration (offered the opportunity to break the interview into multiple session) of interview. This was to help participants feel as comfortable as possible, particularly regarding social communication difficulties they may experience. • Participants were offered a copy of the topic guide prior to the interview to familiarise themselves with the questions and allow any areas which did not want to be discussed to be raised. • 1:1 interviews allowed for privacy when discussing emotive topics (though the option to invite a friend/ family member/ carer was offered if this would enhance comfort). • Empathy and respect for the participant was demonstrated throughout the interview process by the researcher to help participants feel at ease, in addition to helping participants to feel empowered to decide what they felt comfortable sharing. • Time was spent building rapport with participants prior to commencing the interview to reduce the power imbalance between participant and researcher, in addition to reducing any anxiety felt by participants regarding the interview. • Interviews were adapted wherever possible to the social communication difficulties experienced by this demographic to enhance the depth of exploration of experiences (e.g., topic

Commitment and rigor	guide seen prior to interview, clear sign posting when moving from one topic to another, frequent summarising and clarifying by the researcher). • Sampling was purposive. • Analysis was systematic in nature and involved several members of the research team to promote accurate interpretation and appropriate bracketing of pre-existing biases and researcher experiences. • Reflection and reflexivity were promoted throughout the research process. The researcher made use of a reflective journal throughout, in addition to individual and group supervision. Reflections were considered in relation to the data and were often checked to ensure that they were grounded in the data.
Transparency and coherence	• Each stage of the research process was clearly documented both in supervision notes and in the researcher's reflective diary. • Participants will be offered an executive summary of the research upon completion.
Impact and importance	• The findings of this research provide new knowledge within the fields of psychosis, Autism, and early intervention in psychosis services. These findings have clinical importance and relevance and lay the path for further research in these areas. • This research has given a voice to individuals who are often marginalised and unheard.

Chapter 6

Discussion and Critical Evaluation

Word Count: 3,185

Discussion and Critical Evaluation Chapter

This chapter considers the findings of both the systematic review and the empirical paper and their unique and combined contributions to the field of clinical psychology. Wider clinical and research applications are also explored, in addition to the strengths and weaknesses of the papers. Researcher reflections on the research process are also included.

Researcher Reflections

Given my background working within EIS, I was becoming increasingly aware of the co-morbidity of psychosis and ASD, in addition to the myriad of other social and emotional difficulties faced by this group. Working with this population was often challenging and was worsened by the lack of evidence-based approaches to working with this population. The desire to begin to fill this gap in the literature resulted in this project. Whilst it has been a challenging one, made all the more challenging by the COVID-19 pandemic, my passion for this population provided me with the necessary motivation to overcome the obstacles that came my way.

As a relative novice to both mixed methods approaches and IPA, this portfolio certainly pushed me outside of my comfort zone. However, it also allowed me to develop my understanding, knowledge and skills in these areas and has demonstrated to me the phenomenological power of qualitative approaches, both independently and in conjunction with quantitative methodologies. Undertaking this portfolio has cemented my interest in both Autism and psychosis and has, in particular, deepened my appreciation for the multi-faceted and highly complex interactions between Autism and mental health.

Summary of findings

The systematic review aimed to collate, summarise, and critically consider the existing literature around Autism and self-esteem. The findings of the review were divided into (a) self-esteem in ASD compared to neurotypical controls, (b) factors influencing self-esteem in ASD populations, and (c) secondary mental health outcomes associated with self-esteem. A strong body of evidence indicated that self-esteem is significantly lower in those with ASD compared to neurotypical controls. Several contributory factors were identified and were broadly grouped into cognitive profile, social isolation, feelings of difference, and ASD identification and the impact of diagnosis. The first three categories encapsulated factors which had a negative impact on self-esteem in Autistic populations, whilst the final category was highlighted both quantitatively and qualitatively to be protective against poor self-esteem. Finally, the review highlighted the impact of poor self-esteem on anxiety, depression, and suicidality, which were all elevated in Autistic participants.

The empirical paper aimed to gain an in-depth understanding of the experience of co-morbid ASD and psychosis. Findings were divided into five key superordinate themes: experience of psychosis; experience of ASD; overlap between ASD and psychosis; emotional difficulties; treatment with EIS. Most pertinent to the findings of the systematic review were participant descriptions of long-standing emotional difficulties associated with their experiences of ASD, including internalised stigma and poor self-esteem. The positive impact of both the receipt of a diagnosis of ASD and increased social connectedness were also reminiscent of the protective nature of these experiences highlighted in the systematic review. Finally, the empirical paper emphasised and built upon the interrelatedness of ASD and mental health outcomes including psychosis, anxiety, and depression.

Combined Discussion

The significant impact of factors associated with ASD on emotional well-being was well-documented across both the systematic review and empirical paper. In line with the wider literature, both papers highlighted the frequency of experiences of affective disturbance, namely anxiety, depression, and suicidality in Autistic participants (Hedley & Uljarević, 2018; Hollocks et al., 2019). The systematic review highlighted the influencing role of self-esteem in this affective disturbance. In both papers, low self-esteem was experienced in the context of ASD; however, as participants in the empirical study had also experienced psychosis, which has also been shown to have a detrimental impact on self-esteem (Vass et al., 2015), it is difficult to ascertain the degree to which negative self-concept is attributable to each condition, or indeed whether co-morbid ASD and psychosis had an additive negative effect on self-esteem. Nonetheless, both investigations support the existing body of literature indicating that self-esteem is low in both populations (Cooper et al., 2021; Goddard et al., 2017; Humphrey & Hebron, 2015; Jamison & Schuttler, 2015; McCauley et al., 2019; McChesney & Toseeb, 2018; van der Cruijsen & Boyer, 2021; Williamson et al., 2008; Hinojosa-Marques et al., 2021; Vass et al., 2015). Descriptions of the self were echoed across both papers, with participants utilising pejorative language such as 'weird' to describe themselves and internalised stigma being described across accounts. Clinically, these results indicate that self-esteem is likely to be an important consideration for assessment, formulation, and intervention across mental health services, given its transdiagnostic nature.

Though these findings have clear clinical implications, Spain and Blainey (2017) demonstrated that CBT for low self-esteem in Autistic populations had limited efficacy. Several hypotheses for this were presented, including pervasive social-communication difficulties often resulting high levels of peer rejection and social isolation which serves to continually reinforce poor self-esteem (Spain & Blainey, 2017). Evidence of this maintenance cycle was seen across both papers, with participants discussing the difficulties fitting in, in addition to high levels of interpersonal adversity and trauma being reported. Although further investigation is required to understand ways in which self-esteem may be improved therapeutically, the promotion of social connectedness was a fruitful pathway to improving emotional well-being and self-esteem across both papers. The systematic review highlighted the importance of collective self-esteem in promoting positive self-concept (Cooper et al., 2017; Cooper et al., 2021; Cresswell & Cage, 2019), whilst the empirical paper emphasised the benefits of social support, including through social groups, in promoting a sense of community and belonging. These findings are echoed in the general literature which demonstrates the positive effect of social belonging on psychological wellbeing, across the lifespan and irrespective of neurodevelopmental status (Cramm & Nieboer, 2015; Hagerty et al., 1996; Lamblin et al., 2017; Leedham et al., 2020; Tan, 2018). Therefore, promoting social connectedness within mental health settings could be an effective way of preventing further reinforcement of poor self-esteem, therefore leading to overall improvements to self-esteem and wellbeing.

Receipt of a diagnosis of ASD was frequently experienced as therapeutic in and of itself across participant accounts. For many, receipt of a diagnosis was normalising and served to validate the difficulties they had been experiencing. This is reflective of the wider literature, which highlights the validating nature of diagnosis, in addition to the potential for the opening up of avenues for increased support, particularly in childhood in the context of education (Dockrell et al., 2019; Shulman et al., 2019). Indeed, several participants in the empirical study reflected on the social and emotional difficulties experienced within mainstream education, and the lack of support they received due to not being identified as Autistic. The issue of late diagnosis was also highlighted across qualitative accounts included in the systematic review, emphasising its detrimental effect. Interestingly, four out of six participants included in the empirical study received a diagnosis of ASD within the EIS, post first-episode psychosis. As Autism has been shown to increase the likelihood of known risk-factors for psychosis, including interpersonal trauma and social isolation (Sossin, 2015), this raises the question of whether these risk factors would have been as pronounced with the early identification of and support for ASD and, indeed, whether their mental health trajectories would have been the same.

Systematic Review Critical Review

The systematic review employed mixed methods methodology, including both quantitative and qualitative literature. Whilst the quantitative literature was utilised to highlight differences in self-esteem between ASD and neurotypical populations, both quantitative and qualitative findings were considered in relation to factors affecting self-esteem and associated mental health outcomes. In line with the recommendations of Thomas & Harden (2005), as quantitative and qualitative studied different dimensions of the phenomenon of self-esteem in ASD, the review appropriately utilised a convergent, segregated approach to data analysis, before integrating evidence forms (Stern et al., 2020). Utilising a mixed-methods approach allowed for the combination of both objective, positivist and subjective, constructionist paradigms, thus providing a more complete, overarching picture which encompasses the inherent complexity of self-esteem within ASD populations (Stern et al., 2020). For example, while quantitative studies included in this review highlighted that self-esteem was significantly lower in those with ASD compared to neurotypical controls, the reductionist nature of quantitative methodology did not allow for an understanding of the multi-factorial nature of self-esteem within this group. Qualitative findings, on the other hand, demonstrated that, experientially, self-esteem appeared to improve following a diagnosis of ASD, as receipt of the diagnosis provided validation and a framework for understanding social communication difficulties experienced by participants. Therefore, though self-esteem may remain objectively lower than neurotypical controls, this is an incomplete narrative which was made to be more robust with the consideration of qualitative accounts. Therefore, in utilising a mixed-methods approach, the review provides a robust, multi-dimensional consideration of the phenomenon of self-esteem in ASD, which maximises its potential for clinical application (Stern et al., 2020).

Thematic analysis was considered an appropriate method for qualitative analysis due to its ability to draw out convergences and divergences across large data sets (Braun & Clarke, 2006). This approach, is, however, inherently influenced by the researcher's experiences and beliefs and is therefore prone to researcher bias (Braun & Clarke, 2006). To minimise the risk of bias, a second researcher analysed 10% of qualitative papers and any disagreements in coding or thematic development were discussed and resolved by consensus and in reference to the literature. This risk could have been further reduced, however, by the involvement of a second researcher in the pooling and integration of quantitative and qualitative findings (Thomas & Harden, 2005). The use of a reflective log during the analytic process could also have been beneficial in promoting researcher reflexivity and thus objectivity.

In setting out inclusion and exclusion criteria for the review through a process of familiarisation and scoping of the existing literature, the researcher made the decision to exclude co-morbid neurodevelopmental conditions such as learning disabilities and ADHD. This was to reduce the volume of literature and to narrow the focus of the review, particularly given the aims of the empirical paper. Despite this, as levels of co-morbidity between neurodevelopmental conditions are high (Francés et al., 2022), including papers which considered the relationship between co-morbid developmental conditions and self-esteem could have provided a more robust representation into self-esteem in Autism. Of particular interest would be the influence of co-morbid conditions on self-esteem in this population, as this review highlighted the impact of IQ, experiences of stigma, feelings of difference and the impact of diagnosis on self-esteem, all of which are also relevant to other neurodevelopmental conditions (Foley-Nicpon et al., 2012a; Mueller et al., 2012; Shifrer, 2013). Therefore, although beyond the scope of this review, this is an identified area for future investigation.

Empirical Paper Critical Review

The aim of the empirical paper was to provide an in-depth experiential and phenomenological account of co-morbid Autism and psychosis. In line with recommendations for participant numbers for IPA studies undertaken as part of the Doctorate in clinical psychology (Turpin et al., 1997), the researcher set out to recruit 6-8 participants. Though six participants were successfully recruited, this is at the lower recommended limit. Recruitment beyond these six participants was limited by the COVID-19 pandemic, as it resulted in changes to service provision in the host service: namely the stopping of Autism diagnostic assessments. This therefore limited the recruitment pool, despite several individuals being on the waiting list for diagnostic assessment and therefore likely appropriate participants once this service resumed. Though not problematic due to the idiographic nature of IPA research (Smith et al., 2009), additional participants could have allowed further depth of understanding of the phenomenology of co-morbid ASD and psychosis, through the exploration of further convergences and divergences in experiential accounts.

This study additionally set out to provide a voice to marginalised individuals, whose voices are so often unheard (MacLeod, 2019). First, the use of IPA meant that ideography was an essential component of the analysis process (Smith et al., 2009), meaning that analysis was necessarily in-depth and focussed on individual experiences and meaning making. Second, the researcher employed several adaptations to promote participant engagement with the research process. As suggested by Boivin et al (2018), the use of PPI in the design of the topic guide, promotes clarity and engagement with the subject matter, in this case by ensuring that the language used was clear and concise and that questions were appropriate and salient to the experiences of participants (Boivin et al., 2018). Specific adaptations accounting for the social communication needs of participants were also implemented, including clearly signifying movement between topics (Humphrey & Lewis, 2008), providing participants with a copy of the topic guide prior to the interview for familiarisation and preparation purposes (Griffith et al., 2012; Macleod et al., 2018; Petalas et al., 2013), and the choice between online, in-person or telephone interviews (Macleod et al., 2018).

The position and experience of the researcher was another important area for consideration throughout the research process (Smith et al., 2012; Smith et al., 2009). The lead researcher had a background in working in EIS and consequently in working clinically with those with co-morbid Autism and psychosis. This meant that the researcher was experienced in forming alliances with this group and was adept at providing scaffolding for effective communication, accommodating for the social communication difficulties often experienced by this group. These skills meant that the researcher was able to create a safe space for the discussion of personal, and sometimes distressing, information, and was able to promote effective communication and engagement throughout the interview. On the other hand, however, due to the double hermeneutic inherent in IPA, the background, experiences and beliefs of the researcher are necessarily implicated in the analysis process (Smith et al., 2009), potentially biasing interpretations of participant accounts. This is especially pertinent when considering accounts of treatment received from EIS, with the researcher previously being a provider and the participant being a recipient. In order to address and account for the potential impact of these differing perspectives on the subject matter, the researcher was mindful of continually engaging in a bracketing process both independently and alongside collaborating researchers to protect against biased interpretation (Smith et al., 2009).

Awareness of researcher biases was enhanced by all interviews being transcribed directly by the researcher. This allowed the researcher to immerse themselves in the data and consider the meaning of nuanced and non-verbal communication such as tone, rate and volume of speech, and the frequency and duration of pauses and hesitations. The resultant analysis was therefore in greater depth and was conducted with greater awareness of the double hermeneutic.

Clinical implications

This portfolio highlights the importance of timely diagnosis of Autism and the consequences when this is not the case, both in terms of self-esteem and mental health co-morbidity more generally. Importantly, the majority of participants for the empirical paper were diagnosed within the EIS, where they had been referred due to psychotic symptomatology. This EIS is somewhat unique, in that it offers routine ASD screening to all service users to ensure that this co-morbidity is appropriately identified (Treise et al., 2021). Although the empirical paper highlighted the lack of integrated support for this group, with support for psychosis and ASD being perceived as generally separate, the positive impact of diagnosis was also emphasised. When consideration is given to these experiences, in addition to the high levels of mental health co-morbidity in Autistic populations (Crane et al., 2019; Kerns et al., 2015; van Steensel et al., 2011), the implementation of routine screening across mental health services would likely be a useful and effective way of improving service provision to this population.

Another important area for clinical consideration is the knowledge and training of mental health professionals in relation to ASD and co-morbid mental health difficulties. Both the systematic review and empirical paper highlighted the often long-standing and significant mental health co-morbidity experienced by this population, ranging across both affective and psychotic disorders. In accordance with the wider literature, the empirical paper highlighted the clinical separation of ASD from mental health co-morbidity, often resulting in compartmentalised care. The experiential accounts from both the systematic review and empirical paper, however, highlight the complex interactions between ASD and mental health difficulties, with ASD often acting as a risk factor for adverse experiences, which in turn contribute to the development of mental health difficulties, whilst experiencing ASD and mental health difficulties concurrently are suggested to be phenomenologically different to either experience alone. This therefore indicates that effective interventions should consider the unique contribution of ASD to mental health presentations, in addition to the often additive and amplificatory effects of mental health difficulties on Autistic symptomatology. For movement to be made in this direction, training is likely to be required to develop the knowledge and skills of mental health professionals in effectively assessing and supporting individuals with ASD and mental health difficulties.

Directions for future research

Although the empirical paper aimed to understand both the experience of co-morbid ASD and psychosis and the experience of receiving treatment for this within EIS, the latter aim was relatively less explored than the former. Initial insights into the perceived separation of conditions and the difficult experiences faced within inpatient settings warrant further exploration to gain a deeper understanding of these experiences for appropriate adaptations to begin to be formulated. Further investigation outside of EIS would also be warranted, as the emphasis which EIS place on social support including housing, benefits, and social inclusion (NICE, 2014), which were cited as beneficial in the context of ASD by participants in the empirical paper, are relatively less focussed on in wider mental health services.

The identified amplificatory effect of psychosis on ASD is another avenue for further exploration. First, with regard to the application of this knowledge to psychological models and interventions aimed at this group and second, to exploration of the effect of other mental health difficulties, to understand whether this is a unique contribution of psychosis, or whether this is also relevant to other co-morbidities.

Conclusion

This thesis portfolio aimed to explore co-morbidity in the context of ASD, firstly in relation to low self-esteem and secondly in relation to psychosis. A systematic review was completed to explore differences in self-esteem for Autistic people compared to neurotypical controls, in addition to considering factors relating to the *nature* of self-esteem in ASD. This included factors which influence self-esteem in ASD and the mental health consequences associated with low self-esteem in this population. A qualitative empirical study was then completed to explore the experience of co-morbid ASD and psychosis. Taken together, the findings of the review and empirical study highlight the prominence of co-morbidities for those on the Autism Spectrum and the complex experiences associated with this, in terms of low self- esteem, affective disturbance, such as anxiety and depression, and psychosis. The portfolio emphasises the importance of the consideration of these complex interactions both clinically and in further research, in order to improve our understanding of these co-morbidities, service provision, and ultimately the lives of Autistic people with co-morbid mental health difficulties.

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Appendices

Appendix A
Research in Autism Spectrum Disorders Author Guidelines

Editorial Process

All submissions will first be checked against the Aims and Scope and Guide for Authors by the Editor-in-Chief. Papers found to conform, in principle, to the journal's remit and standards will be assigned to a handling Editor (an Associate Editor or the Editor-in-Chief) for further evaluation. If a paper meets the journal's criteria a minimum of two independent reviewers will be invited to comment on the paper's methodological rigour and significance. Based on these comments and additional opinions if necessary, the handling Editors will make a decision. All accepted papers will therefore have received comments from a minimum of two independent reviewers and be reviewed by one or more editors. **Please note that RASD currently operates single-blinded peer review.**

Human and Animal Rights

If the work involves the use of animal or human subjects, the author should ensure that the work described has been carried out in accordance with The Code of Ethics of the World Medical Association (Declaration of Helsinki) for experiments involving humans http://www.wma.net/en/30publications/10policies/b3/index.html; EU Directive 2010/63/EU for animal experiments http://ec.europa.eu/environment/chemicals/lab_animals/legislation_en.htm; Uniform Requirements for manuscripts submitted to Biomedical journalshttp://www.icmje.org. Authors should include a statement in the manuscript that informed consent was obtained for experimentation with human subjects. The privacy rights of human subjects must always be observed.All animal studies need to ensure they comply with the ARRIVE guidelines. More information can be found at http://www.nc3rs.org.uk/page.asp?id=1357

Declaration of interest

All authors must disclose any financial and personal relationships with other people or organizations that could inappropriately influence (bias) their work. Examples of potential competing interests include employment, consultancies, stock ownership, honoraria, paid expert testimony, patent applications/registrations, and grants or other funding. Authors must disclose any interests in two places: 1. A summary declaration of interest statement in the title page file (if double anonymized) or the manuscript file (if single anonymized). If there are no interests to declare then please state this: 'Declarations of interest: none'. 2. Detailed disclosures as part of a separate Declaration of Interest form, which forms part of the journal's official records. It is important for potential interests to be declared in both places and that the information matches. More information.

Use of inclusive language

Inclusive language acknowledges diversity, conveys respect to all people, is sensitive to differences, and promotes equal opportunities. Content should make no assumptions about the beliefs or commitments of any reader; contain nothing which might imply that one individual is superior to another on the grounds of age, gender, race, ethnicity, culture, sexual orientation, disability or health condition; and use inclusive language throughout. Authors should ensure that writing is free from bias, stereotypes, slang, reference to dominant culture and/or cultural assumptions. We advise to seek gender neutrality by using plural nouns ("clinicians, patients/clients") as default/wherever possible to avoid using "he, she," or "he/she." We recommend avoiding the use of descriptors that refer to personal attributes such as age, gender, race, ethnicity, culture, sexual orientation, disability or health condition unless they are relevant and valid. When coding terminology is used, we recommend to avoid offensive or exclusionary terms such as "master", "slave", "blacklist" and "whitelist". We suggest using alternatives that are more appropriate and (self-) explanatory such as "primary", "secondary", "blocklist" and "allowlist". These guidelines are meant as a point of reference to help identify appropriate language but are by no means exhaustive or definitive.

Author contributions

For transparency, we encourage authors to submit an author statement file outlining their individual contributions to the paper using the relevant CRediT roles: Conceptualization; Data curation; Formal analysis; Funding acquisition; Investigation; Methodology; Project administration; Resources; Software; Supervision; Validation; Visualization; Roles/Writing - original draft; Writing - review & editing. Authorship statements should be formatted with the names of authors first and CRediT role(s) following. More details and an example.

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MANUSCRIPT PREPARATION & SUBMISSION

Use of word processing software

Files must be saved in the native format of the word processor and the text should be in 10-point Arial font, single-column format, double spaced, with standard 1 inch page margins (2.54 cm). Please keep the layout of the text as simple as possible, as most formatting codes will be replaced on processing the article. In particular, do not use the options to justify text or hyphenate words. However, do use bold face, italics, subscripts, superscripts etc. Note that source files of figures and text graphics will be required whether or not you embed them in the text. See also the section on Electronic artwork below for details on preparing figures and graphics.

Language (usage and editing services)

Please write your text in good English (American or British usage is accepted, but not a mixture of these). Authors who feel they require support in editing to eliminate possible grammatical or spelling errors and to conform to correct scientific English may wish to use the English Language Editing service available from Elsevier's WebShop (https://webshop.elsevier.com/language-editing-services/language-editing/).

In relation to terminology, we ask that authors carefully consider their choice of wording when describing the patterns of strengths and difficulties that are associated with autism. Specifically, based on a paper by Kenny et al., (2015; http://aut.sagepub.com/content/early/2015/06/10/1362361315588200.abstract) we ask authors not to describe participants as 'low-functioning' or 'high-functioning' but to provide precise information about participants' abilities and areas of difficulty instead, ideally as assessed using relevant standardised tools. Autism should also not be described as a 'disease' or 'illness'. Finally, authors are encouraged to avoid language that inappropriately pathologizes certain characteristics or behaviours of autistic individuals (e.g., 'abnormality', 'impairment', 'deficit' etc) choosing less laden descriptions instead (e.g., 'difference'; 'tendency', 'preference', etc) - we note, however, that there are contexts where it may be appropriate to describe certain characteristics as, for example, an impairment (e.g., language impairment).

Types of Articles

Research in Autism Spectrum Disorders publishes the following types of manuscripts:
Brief reports: Papers of no more than 2,500 words that report an original piece of research of limited scope and/or that serves as proof-of principle for larger-scale studies.
Regular Articles: Papers of up to 6,000 words that report a substantive piece of research that makes a significant contribution and has clear implications for practice. Manuscripts reporting the results of randomized trials or interventions must demonstrate adherence to the CONSORT guidelines (http://www.consort-statement.org/) and include the relevant flow

diagram and completed checklist.
Reviews: Papers of up to 10,000 words that provide a comprehensive overview of a significant area of research. Quantitative (e.g., meta-analyses) and qualitative reviews are welcome as long as they go beyond a mere description of the available literature and synthesise new knowledge with clear implications for future directions and practice. For systematic reviews and meta-analyses, authors must demonstrate adherence to the PRISMA guidelines (www.prisma-statement.org) and include the relevant flow diagram and checklist.
Commentaries: We welcome brief commentaries of no more than 1,000 words that offer new insights on papers published in RASD or elsewhere. Commentaries on government policy and/or items in the media are also welcome. .
Registered Reports: Registered reports are a form of empirical article in which the rationale, methods, and proposed analyses are pre-registered and reviewed prior to research being conducted. This format seeks to neutralise a variety of unhelpful research practices and biases that contribute to the many inconsistencies in findings that currently exist in the autism and wider literature. This format is suitable for novel as well as replication studies and we particularly welcome submissions describing proposed studies involving under-represented groups in research such as the elderly, minority groups and individuals with complex support needs. For further details please click RASD Registered Reports Author Guidelines)

NOTE: Word limits do not include the title page, abstract, figure legends, tables and reference list.

Submission

Our online submission system guides authors stepwise through the submission process. The system converts article files to a single PDF file used in the peer–review process. Editable files (e.g., Word, LaTeX) are required to typeset your article for final publication. All correspondence, including notification of the Editor's decision and requests for revision, is sent by e–mail.

Elsevier accepts electronic supplementary material such as supporting applications, high resolution images, background datasets, sound clips and more. These will be published online alongside the electronic version of your article in Elsevier Web products, including ScienceDirect: http://www.sciencedirect.com. For further information, please visit our artwork instruction pages at https://www.elsevier.com/artworkinstructions

To increase the transparency of editorial information within the framework of single/ double blind peer review , RASD displays the number of unique reviewer reports received in the first round of review with each published article. This policy will be in place for original research articles submitted from 1 January 2016 that are accepted for publication.

Queries

For questions about the editorial process (including the status of manuscripts under review) or for technical support on submissions, please visit our Support Center.

Manuscript Format

All manuscripts must include a Title, Abstract and Highlights on separate pages, followed by the main manuscript text. The main manuscript text of brief reports, regular articles and quantitative reviews should include subsections carrying the headings Introduction, Methods, Results, Discussion & Implications. Reviews may deviate from this structure but must include a methods section that provides details on how the relevant literature was searched. The structure of commentaries is at the discretion of authors.

Essential Title Page Information

Title:Titles must be concise and informative and should have no more than 20 words. Titles are often used in information–retrieval systems. Avoid abbreviations and formulae where possible.
Author names and affiliations: Please clearly indicate the given name(s) and family name(s) of each author and check that all names are accurately spelled. Present the author's affiliation addresses (where the actual work was done) below the names. Indicate all affiliations with a lowercase superscript letter immediately after the author's name and in front of the appropriate address. Provide the full postal address of each affiliation, including the country name and, if available, the e–mail address of each author.
Corresponding author: Clearly indicate who will handle correspondence at all stages of refereeing and publication, also post-publication. **Ensure that the e–mail address is given and that contact details are kept up to date by the corresponding author**.
Present/permanent address: If an author has moved since the work described in the article was done, or was visiting at the time, a 'Present address' (or 'Permanent address') may be indicated as a footnote to that author's name. The address at which the author actually did the work must be retained as the main affiliation address. Superscript Arabic numerals are used for such footnotes.

Abstract & Keywords

The abstract page must include a structured abstract of no more than 250 words that includes the following subsections:
Background: A brief summary of the research question and rationale for the study.
Method: A concise description of the methods employed to test the stated hypotheses, including details of the participants where relevant.
Results: A brief description of the main findings.
Conclusions: This section must include a clear statement about the implications of the findings for practice.

Immediately after the abstract, a maximum of 6 keywords should be provided, avoiding general and plural terms and multiple concepts (for example, avoid 'and', 'of'). Be sparing with abbreviations: only abbreviations firmly established in the field may be eligible (e.g., ADOS, ASD, etc). These keywords will be used for indexing purposes.

Graphical Abstract

Graphical abstracts are optional but encouraged to draw more attention to the online article. The graphical abstract should summarize the contents of the article in a concise, pictorial form designed to capture the attention of a wide readership. Graphical abstracts should be submitted as a separate file in the online submission system. Please provide an image with a minimum of 531 X 1328 pixels (h X w) or proportionally more. The image should be readable at a size of 5 X13 cm using a regular screen resolution of 96 dpi. Preferred file types include TIFF, EPS, PDF or MS Office files.
See https://www.elsevier.com/graphicalabstracts for examples. Authors can make use of Elsevier's Illustration and Enhancement service to ensure the best presentation of their images.
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Introduction

The introduction should develop a clear rationale for the presented work on the basis of a concise overview of the relevant literature. Detailed literature reviews should be avoided.

Methods

This section will typically include sub–headings for a description of the Participants, Materials & Design, Procedures and Analysis. However, alternative sub–headings may be used to suit particular research approaches (e.g., case–studies, meta–analyses, imaging studies etc.)

The participants section should provide demographic information (age, sex, ethnicity, socio–economic status, etc.), and include details on where and how participants were recruited and how relevant clinical diagnoses were verified. Additional clinical information (e.g., intellectual functioning, co–morbidities, use of medication etc.) is desired and may be necessary for some research designs. Sample sizes should be justified by suitable power calculations although it is appreciated that it is not always feasible to obtain desired numbers of participants.

The materials, design and procedures must be described in sufficient detail for the work to be replicable. Authors must also include a statement confirming that the work was carried out in accordance with the ethical standards of the responsible committee on human experimentation (institutional and national) and with the Declaration of Helsinki as revised in 2000. In this context confirmation should also be given that participant or guardian informed consent was obtained where appropriate.

The analysis section should provide details of the statistical methods used including information on the significance thresholds and the methods used to correct for multiple comparisons where necessary. Information on inter–rater reliability and any data filtering / transformation that was applied should also be included here.

Results

The results should be set out transparently and in full and should conform to the formatting style of the American Psychological Association (http://www.apastyle.org/). Effect sizes must be reported for all significant and non–significant effects, and sufficient descriptive statistics must be provided for the effect size calculations to be replicated.

Tables

Please submit tables as editable text and not as images. Tables can be placed either next to the relevant text in the article, or on separate page(s) at the end. The formatting of tables should conform to APA guidelines (http://www.apastyle.org/).

Figures & Artwork
General points

- Make sure you use uniform lettering and sizing of your original artwork.
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- Number the illustrations according to their sequence in the text.
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- Provide captions to illustrations separately.
- Size the illustrations close to the desired dimensions of the published version.
- Submit each illustration as a separate file.

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Appendix C
HRA Approval Letter

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Health and Care
Research Wales

NHS
Health Research
Authority

Dr Joanne Hodgekins
Norwich Medical School
University of East Anglia
Norwich
NR4 7TJN/A

Email: approvals@hra.nhs.uk
HCRW.approvals@wales.nhs.uk

23 April 2021

Dear Dr Hodgekins

HRA and Health and Care Research Wales (HCRW) Approval Letter

Study title: **The Experience of Concurrent Autism Spectrum Disorder and Psychosis**
IRAS project ID: **291807**
Protocol number: **N/A**
REC reference: **21/LO/0242**
Sponsor **University of East Anglia**

I am pleased to confirm that HRA and Health and Care Research Wales (HCRW) Approvalhas been given for the above referenced study, on the basis described in the application form,protocol, supporting documentation and any clarifications received. You should not expect to receive anything further relating to this application.

Please now work with participating NHS organisations to confirm capacity and capability, in line with the instructions provided in the "Information to support study set up" section towardsthe end of this letter.

How should I work with participating NHS/HSC organisations in Northern Ireland andScotland?

HRA and HCRW Approval does not apply to NHS/HSC organisations within Northern Irelandand Scotland.

If you indicated in your IRAS form that you do have participating organisations in either of these devolved administrations, the final document set and the study wide governance report(including this letter) have been sent to the coordinating centre of each participating nation.
The relevant national coordinating function/s will contact you as appropriate.

Please see IRAS Help for information on working with NHS/HSC organisations in NorthernIreland and Scotland.

How should I work with participating non-NHS organisations?

HRA and HCRW Approval does not apply to non-NHS organisations. You should work with your non-NHS organisations to obtain local agreement in accordance with their procedures.

What are my notification responsibilities during the study?

The standard conditions document "*After Ethical Review – guidance for sponsors and investigators*", issued with your REC favourable opinion, gives detailed guidance on reportingexpectations for studies, including:

- Registration of research
- Notifying amendments
- Notifying the end of the study

The HRA website also provides guidance on these topics, and is updated in the light ofchanges in reporting expectations or procedures.

Who should I contact for further information?

Please do not hesitate to contact me for assistance with this application. My contact detailsare below.

Your IRAS project ID is **291807**. Please quote this on all correspondence.Yours
sincerely,
Katherine Ashley Approvals
Specialist

Email: approvals@hra.nhs.uk

Copy to: Ms Polly Harrison (sponsor contact)

List of Documents

The final document set assessed and approved by HRA and HCRW Approval is listed below.

Document	*Version*	*Date*
Evidence of Sponsor insurance or indemnity (non NHS Sponsorsonly) [Evidence of Insurance 1]	1	02 March 2021
Interview schedules or topic guides for participants [Topic Guide]	1	21 July 2020
IRAS Application Form [IRAS_Form_20042021]		20 April 2021
Letter from sponsor [Letter from Sponsor]	1	02 March 2021
Other [Debriefing Sheet]	2	13 April 2021
Other [Evidence of Insurance 2]	1	02 March 2021
Other [Supervisor CV- SC]	1	01 March 2021
Participant consent form [Consent Form]	2	13 April 2021
Participant information sheet (PIS) [PIS]	3	22 April 2021
Research protocol or project proposal [Project Proposal]	1	25 August 2020
Schedule of Events or SoECAT [Schedule of Events]	1	01 March 2021
Response to Additional Conditions Met		22 April 2021
Summary CV for Chief Investigator (CI) [CI CV]	1	13 April 2021
Summary CV for student [Gina Sergi CV]	1	15 February 2021

IRAS project ID	**291807**

Information to support study set up

The below provides all parties with information to support the arranging and confirming of capacity and capability with participating NHS organisations in England and Wales. This is intended to be an accurate reflection of the study at the time of issue of this letter.

Types of participating NHS organisation	Expectations related to confirmation of capacity and capability	Agreement to be used	Funding arrangements	Oversight expectations	HR Good Practice Resource Pack expectations
There is only one participating NHS organisation therefore there is only one site type.	Research activities should not commence at participating NHS organisations in England or Wales prior to their formal confirmation of capacity and capability to deliver the study.	An Organisation Information Document has been submitted and the sponsor is not requesting and does not expect anyother site agreement to be used.	No study funding will be provided to sites as per the Organisation Information Document	A Principal Investigator should be appointed at study sites	No Honorary Research Contracts, Letters of Access or pre-engagement checks are expected for local staff employed by the participating NHS organisations. Where arrangements are not already in place, research staffnot employed by the NHS host organisation undertaking any of the research activities listed in the research application would be expected to obtain a Letter of Access based on standard DBS checks and occupational health clearance.

Other information to aid study set-up and delivery

This details any other information that may be helpful to sponsors and participating NHS organisations in England and Wales in study set-up.

The applicant does not intend to apply for inclusion on the NIHR CRN Portfolio.

Appendix D
REC Approval Letter

London - Queen Square Research Ethics Committee

HRA NRES Centre Bristol
3rd floor, block B
Whitefriars
Lewins Mead
Bristol
BS1 2NT

Please note: This is an acknowledgement letter fromthe REC only and does not allow you to start your study at NHS sites in England until you receive HRA Approval

22 April 2021

Dr Joanne Hodgekins
Address Norwich Medical
SchoolUniversity of East Anglia
Norwich
Post Code
NR4 7TJ

Dear Dr Hodgekins,

Study title:	**The Experience of Concurrent Autism Spectrum Disorder and Psychosis**
REC reference:	**21/LO/0242**
Protocol number:	**N/A**
IRAS project ID:	**291807**

Thank you for your letter of response on the 22nd of April 2021. I can confirm the REC has received the documents listed below and that these comply with the approval conditions detailed in our letter dated 25 March 2021

Documents received

The documents received were as follows:

Document	*Version*	*Date*
Participant information sheet (PIS) [PIS]	3	22 April 2021

Other [Debriefing Sheet]	2	13 April 2021
Participant consent form [Consent Form]	2	13 April 2021
IRAS Application Form [IRAS_Form_20042021]		20 April 2021
Summary CV for Chief Investigator (CI) [CI CV]	1	13 April 2021

Approved documents

The final list of approved documentation for the study is therefore as follows:

Document	*Version*	*Date*
Evidence of Sponsor insurance or indemnity (non NHS Sponsorsonly) [Evidence of Insurance 1]	1	02 March 2021
Interview schedules or topic guides for participants [Topic Guide]	1	21 July 2020
IRAS Application Form [IRAS_Form_20042021]		20 April 2021
Letter from sponsor [Letter from Sponsor]	1	02 March 2021
Other [Evidence of Insurance 2]	1	02 March 2021
Other [Supervisor CV- SC]	1	01 March 2021
Other [Debriefing Sheet]	2	13 April 2021
Participant consent form [Consent Form]	2	13 April 2021
Participant information sheet (PIS) [PIS]	3	22 April 2021
Research protocol or project proposal [Project Prosopal]	1	25 August 2020
Summary CV for Chief Investigator (CI) [Chief Investigator CV]	1	15 February 2021
Summary CV for Chief Investigator (CI) [CI CV]	1	13 April 2021
Summary CV for student [Gina Sergi CV]	1	15 February 2021

You should ensure that the sponsor has a copy of the final documentation for the study. It is the sponsor's responsibility to ensure that the documentation is made available to R&D officesat all participating sites.

IRAS Project ID: 291807 **Please quote this number on all correspondence**

Yours sincerely

Christopher Cole
HRA Approvals Officer

E-mail: queensquare.rec@hra.nhs.uk

Appendix E
Topic Guide

University of East Anglia

cameo
Early Intervention Services

NHS
Cambridgeshire and Peterborough
NHS Foundation Trust

The Experience of Co-morbid Autism Spectrum Disorder and Psychosis within an Early Intervention for Psychosis Service

Topic Guide

1. **What is your experience of having both ASD and Psychosis?**
   - Do you think things would be different if you didn't have Autism? Why?
   - What impact do you think your conditions have on each other?
   - Do you see ASD and psychosis as separate? Why/why not?
   - Which diagnosis came first? In what ways was this helpful/ unhelpful?

We are now going to move on to another topic

2. **What is your experience of receiving treatment with Cameo?**
   - What treatment/ support have you received from Cameo?
   - What did you like/dislike about it?
   - Is there anything you found particularly difficult/ helpful?
   - To what extent did you feel that the service understood the impact of your Autism?

We are now going to move on to another topic

3. **What do you expect your future to be like?**
   - Cameo is a 3 year service, do you think you would need longer term support? Why/ why not?

- How will you know if the support that Cameo has offered you has worked/ been beneficial?
- What are your hopes for your mental health in the future?
- What does recovery mean to you? What would that be like?

Appendix F
Debrief Form

The Experience of Co-morbid Autism Spectrum Disorder and Psychosis in an Early Intervention for Psychosis Service

DEBRIEFING SHEET

Thank you for taking the time to participate in this study.

Sometimes people find that talking about their experiences can be difficult and sometimes distressing. If this is the case for you, you can contact:

- The person you usually see at CAMEO (e.g. care coordinator, psychologist or support worker)
- You can also contact the CAMEO duty worker on 01223 341510 during office hours (Monday-Friday, 9am-5pm)
- A family member, relative, friend or carer
- Mind telephone line: 0300 123 3393
- The Samaritans telephone line: 116 123 (open 24 hours a day)

If, out of office hours, you feel that you are in a mental health crisis or at risk of harming yourself you can contact the First Response Service on 111 option 2 (open 24 hours a day).

Kind regards,
Georgina Sergi

Appendix G
Participant Information Sheet

University of East Anglia

Early Intervention Services

NHS
Cambridgeshire and Peterborough
NHS Foundation Trust

The Experience of Co-morbid Autism Spectrum Disorder and Psychosis within an Early Intervention for Psychosis Service

Participant Information Sheet

The purpose of this leaflet is to explain the research and what will happen if you decide to take part.

What is the research about?
The aim of this research is to improve our understanding of what it is like to have experienced both psychosis and Autism and to give service users a voice within the research. By deepening our understanding, we are hoping that we can use this to improve the way services work with people with psychosis and Autism.

Who is undertaking the study and how is it funded?
The study is being undertaken by Georgina Sergi as part of her Doctorate in Clinical Psychology at the University of East Anglia. This research has the support of CPFT.

Why do you want me to take part?
You have been approached to take part in this study as you have been supported by the CAMEO team and have experienced both psychosis and Autism. By taking part, you will help to inform service providers about your experiences and, by doing this, we hope that this would improve services for those that have both conditions.

Do I have to take part?

No, you do not have to take part. This is voluntary and if you decide not to become involved you do not need to provide a reason. If you decide to participate and later change your mind, you can withdraw at any time up to 31/12/2021, at which point all anonymised data will be analysed. Whether or not you take part will not affect the service you receive now or in the future.

What would I have to do?

If you agree to participate, I will arrange to meet you online or in-person (in-line with government guidance around COVID-19) at a time and place convenient to you. There will also be the option to complete the interview over the telephone if this is more convenient. The interview would last approximately 60 minutes, and this can be split into several shorter sessions if you would like. In the interview I will ask you a variety of questions about your experience of having psychosis and ASD. If you would prefer, you can request to see the questions before the interview. I would like to audio record the interviews, but I will seek your permission in advance. If you prefer not to be recorded, I will make notes. Any recordings will be fully anonymised when transcribed and then the original recordings will be destroyed.

What happens if I become distressed?

If you become distressed at any point you can request a break or for the interview to be stopped. We can alert the Cameo team or a friend or family member if needed. We will also provide you with a debriefing sheet which will give you some contact numbers and things to do if you are distressed. If we become worried about your health or safety, we may need to break confidentiality and alert the relevant authorities; however, we would discuss this with you first.

Will I be paid?

As a thank you for taking part, you will be given a £10 Amazon voucher at the end of the interview.

Confidentiality

We will need to use information from your medical records for this research project.

This information will include your name, contact details and consent to be contacted about taking part in research. People will use this information to do the research or to check your records to make sure that the research is being done properly.

People who do not need to know who you are will not be able to see your name or contact details. Your data will have a code number instead. We will keep all information about you safe and secure.

Once we have finished the study, we will keep some of the data so we can check the results. We will write our reports in a way that no-one can work out that you took part in the study.

What are your choices about how your information is used?

- You can stop being part of the study at any time, without giving a reason, but we will keep information about you that we already have.
- In the event that you lose capacity to consent to taking part in the study, all identifiable data will be withdrawn from the study. Non-identifiable data may be retained.
- We need to manage your records in specific ways for the research to be reliable. This means that we won't be able to let you see or change the data we hold about you.

Where can you find out more about how your information is used?

You can find out more about how we use your information

- at www.hra.nhs.uk/information-about-patients/
- by asking one of the research team
- by sending an email to dataprotection@uea.ac.uk , or
- by ringing us on 01603 592431.

All information that is collected during the course of the research will be kept strictly confidential in line with the Data Protection Act. Data will be encrypted and saved on a password-protected laptop. Personal data will be destroyed upon publication of the research. No participant will be identifiable in the paper or in any other publication. However, if you say something that makes me think that you or somebody else is at risk of harm, I will have ,to pass this on to the appropriate body in accordance with Trust policy; however you will be told if this is going to happen.

Who has reviewed the study?

The ethical conduct of this study has been approved by an NHS Research Ethics Committee and UEA Ethics Board.

What do I do next?

If you are willing to consider taking part in an interview, please email, telephone or send a text message to Georgina Sergi (email: g.sergi@uea.ac.uk; mob: 07749725710)

). I will then contact you by email or telephone and would be happy to answer any questions you may have about the project. If you would like to take part in the study, we will also arrange a convenient time for us to meet, or to complete a telephone interview.

If you have any questions

If you would like any further information on the research, please contact Georgina Sergi at g.sergi@uea.ac.uk. If you have any concerns about the research you may contact Georgina's Academic Supervisor, Dr. Joanne Hodgekins on j.hodgekins@uea.ac.uk.

If you would like to make a complaint

If you have any concerns about this research, or about the care that you have received whilst with CPFT, please contact the Patient Advice and Liaison Service (PALS) on freephone 0800 3760775 (office hours Monday to Friday) or alternatively email pals@cpft.nhs.uk.

Appendix H
Consent Form

Participant Identification Number:

CONSENT FORM

Title of Project: **The Experience of Co-morbid Autism Spectrum Disorder and Psychosis within an Early Intervention for Psychosis Service**

Name of Researcher: Georgina Sergi

Please initial all boxes

1. I confirm that I have read and understand the information sheet dated x (version y) for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily. ☐
2. I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason, without this having any impact on the services I receive. ☐
3. I agree to you recording me (you can still take part without being recorded). Y / N (please circle)
4. I understand that I will not be named in any research reports, and my personal information will remain confidential. ☐
5. I understand that if the researcher thinks that I, or someone else, might be at risk of harm, they will have to contact the relevant authorities; however, they will try and talk to me first about the best course of action. ☐
6. I give consent for you to use anonymised quotes from me in any research output. ☐
7. I agree to take part in this research, and therefore to be interviewed. ☐

Name of Participant	Date	Signature
Name of Researcher	Date	Signature

Appendix I
PPI Flyer

Psychosis and Autism Spectrum Disorder (ASD) Research

An invitation for people with co-morbid psychosis, or psychotic-like symptoms, and ASD being supported by the Cameo Team.

Who are we?
My name is Gina Sergi and I am currently training to be a Clinical Psychologist. I used to work in the Cameo Team as a social worker and I am really interested in how we can improve the lives of people living with psychosis.

What is the research about?
We are becoming increasingly aware, both in teams such as Cameo, and in the wider research, that lots of people experience both psychosis and ASD. Studies have shown that there is a significant overlap between these conditions in terms of genes, brain structure and symptoms (for example, you might struggle to communicate effectively with other people), but this doesn't tell us much about what it is really like to have both conditions. This research aims to improve our understanding of lived experience by interviewing people with both psychosis and ASD. We would then hope to use this information in future projects to start to build more targeted interventions.

What will your role be?
As this research is interview-based, it is very important to get an idea of what questions will be useful to ask, and how I can ask them in a way that is clear and makes sense. Getting a sense from you, of what has stood out in your experiences so far with psychosis and ASD, might therefore help us to build these questions. Any feedback about the format of questioning will also be welcomed. There will also be opportunities to get involved with the

project in the longer-term if you would like to. This is something I am happy to discuss with you on an individual basis.

Payment of **£10 per hour** is available for both meeting time and any document reviews between meetings. Please check that receiving this payment will not affect any benefit conditions you may have. If you are unsure of this, please obtain specialist information and welfare rights advice before taking on this role.

Want to know more?

If you are interested in getting involved with this research, you can either:

1. Email me at g.sergi@uea.ac.uk
2. Ask your key worker (therapist, care co-ordinator, support worker etc) to pass this on- I will then contact you via your preferred method.

Appendix J
Initial Noting Example

Participant	**Emergent themes**	**Original transcript**	**Exploratory comments**	**Reflective commentary**
Sheila	Making connections between seemingly unrelated things Overwhelmed by intensity of thought process and perceived connectedness of events Feeling observed by others	**Sheila:** I think it was after this, I don't really remember, but I think it was after that I decided to be a good idea to get a hamster...and I I'd been given a goldfish by a boy that didn't like me very much. And he gave his hamster to my friend Stephanie and, um, the cat, they believe ate the hamster, which I didn't really believe. I didn't think that the mom wanted the hamster, but there were many different sort of, um, my dad killed our goldfish. Well, we all did by feeding it when my mom was away in Amsterdam on a hen do. And it was unusual for my mom to go away and leave us and that just there are these connotations...Amsterdam, hamster, it sounds.... I feel as though I was just swamped. But anyway, um, her cat supposedly ate this hamster. We killed the goldfish. He'd moved to Scotland and we'd killed both of his pets, um, and I anyway, we moved house, I was burning in this bedroom opposite Paul and Barbara and, uh, and, uh, decided it would be a good idea to have a hamster. I always wanted more substantial pets, but I knew that I wasn't going to happen. So I thought, well a hamster's quite small and we don't have a cat,	Contrast between being given something (as a gift?) and perception of not being liked by this person. Interpersonal commentary in recollection- potentially indicative of significance of others as a source of stress? 'Burning'- very powerful word and gives sense of sensory experience. Is this a literal burning? Perceptual distortion or representative of	*This explanation is extremely reflective of Sheila's self-reported cognitive intensity. She has connected things which seem* ***objectively*** *unlikely to be connected and are indeed details which neurotypical peers are unlikely to have recognised. This gives a real sense of why this thought process is overwhelming and leads to 'meltdowns'. Receiving the information was experienced as*

	Sensory experience Uncertainty around social norms exacerbating intense emotional reaction to 'faux pas' Suicide as logical solution to managing intense distress	um, so we'll get a hamster. Um, and my mom was fine about it. And, um, I decided that I would call the hamster Twiggy after the model from the 60s, so there's a connotation with the sex and that she thought she was going to give birth to a hamster…. And so we get the hamster. Um, and then I was off school one day and I always like this hamster all over me, all over my bedroom. And it would go down my top and all my clothes and everything and it was a bit ticklish and um, and there was just one day where I was in bed, I was ill and I had the hamster and in bed with me and it crawled down, and I let it crawl down and instead of sort of giving birth to the hamster, it went the wrong way, and it was just really awkward and a really difficult situation. I thought, oh my gosh, I shouldn't have had the hamster in bed with me and this is just terrible and it's just wrong. And there were these different circumstances within the village where a young girl, Janine, had been interfered with by a young boy. And I thought, oh, this is just awful. I've done this with the hamster and I just felt like the worst person ever and just thought I'd done something terribly, terribly wrong. And I think I'd even thought I knew about suicide at the time, I think I would have been one of those suicidal teenagers. But that just didn't cross my mind. I just I was just, um, psychotic. And my friend, whose Mum had talked about this. She was told by her friend's mom that she could be a hand	feeling overwhelmed/ uncomfortable. Is the sexualised connotation important within the context of her sexual development? Especially as this recollection is from adolescence. 'I let it' indicates self-blame. Perhaps this is part of the intense shame and embarrassment felt. Equating her behaviour with the behaviour of the boy due to sexual nature? Feels like a	*overwhelming, which, in addition to allowing me to empathise with Sheila's experiences, also adds clarity to her reported difficulties with peer relationships.*

	Rumination Difficulty understanding intentions of others	model. And I would say my psychotic response after this all happened was that, I, um, I was quite good at Art I was never really marked very well at Art which I didn't really understand. And a lot of my artwork that I'd done in a previous house had been taken away and gone when we moved to the new house, which I didn't really think about the time, but I really thought about afterwards after I responded in the way I did, and I thought it was a bit of an insult that her mom thought that should be a hand model because she was quite clever and she's really pretty as well, so why would you say to someone 'you can be a hand model'? I just thought that wasn't very nice.	very scary and vulnerable place to be. Difficulty understanding subjectivity. Potential example of difficulty understanding nuance of social behaviours and communication, i.e. if someone is clever and pretty why insult them?	

Appendix K
Developing Themes Example

Example of development of themes:

Emergent themes	**Quotes**	**Grouping of emergent themes**	**Subordinate theme**	**Superordinate theme**
Self-reported difficulty communicating with others Not being understood ASD leading to "different interactions" with people Conversations experienced as "awkward"	*"I think that everyone's on the spectrum to a degree, but I feel as though I struggle with communication more so than others, because I feel as though there have been barriers there which have been more in my mind than necessarily actually being there." (P1)* *"All of the interactions would be better. It would be a different life" (P4)*	*Self-reported communication difficulties*	***Social difficulties***	**Experience of ASD**
Communication difficult to follow in interview Researcher not understanding communication Researcher asking clarifying questions Researcher summarising to support communication	*P5: "Autism is not something that you should truly stick to as part of it necessarily part of your identity. At the same time 'cause I feel that it's important to develop some traits of your own that are that are desirable, and all that you think should be a part of you"* *Researcher: "Yeah, so you're not only autistic, you are autistic as a part of you, but you've got other stuff as well."* *P5: "Yeah, that's what I meant."* *P3: "I think I would know I'm not sure how to put it, how I'd know exactly... "*	*Communication difficulties in interview*		

Researcher offering scaffolding to aid communication	*Researcher: "That's ok...so I guess you've kind of said there about kind of firstly, the psychosis isn't really obvious and really sort of severe. So that's one thing I suppose you would recognise…And then you've also said there about kind of this instant sort of feeling of regret and the low mood and anxiety. So I wonder whether that might be a bit reduced if things were looking up for you, if things were moving in the direction you want them to."* *P3: "Yeah, yeah, well I think they would..."*	*Communication support offered by researcher*		
Feeling "lonely" Feeling "isolated" "Not fitting in" Unsure how to "fit in" Desire to "be normal" "Overwhelmed" in social contexts	*"Sometimes it felt like I couldn't fit into this world properly or I just didn't feel like I was…I was missing the signs or something. It it's not like, 100% percent I felt like I fit into every environment, and it felt overwhelming sometimes too. I'm not particularly good at presenting myself. I do my best, but I do my best to try and represent a friendly person." (P5)* *"I knew I was a bit odd and didn't really fit in because we'd moved and even before we moved I could be too intense with certain friends" (P1)* *"I wouldn't ostracise myself by talking like a dumb arse every time I open my mouth. But I think I ostracised myself because I felt bad not being able to talk to people, you know?" (P4)*	*Feeling different to others*		

ASD held responsible for difficulties making/maintaining relationships Wanting romantic relationships, but "unsure how to go about it"	*"I do struggle with striking a conversation just generally. Yeah. I mean, I haven't really tried dating but I get the feeling that it could could turn out to be quite awkward for me." (P6)*	*ASD influencing relationships*		

Appendix L
PRISMA Checklist

Section and Topic	Item #	Checklist item	Location where item is reported
TITLE			
Title	1	Identify the report as a systematic review.	Page 1
ABSTRACT			
Abstract	2	See the PRISMA 2020 for Abstracts checklist.	Page 2
INTRODUCTION			
Rationale	3	Describe the rationale for the review in the context of existing knowledge.	Page 3,4
Objectives	4	Provide an explicit statement of the objective(s) or question(s) the review addresses.	Page 5
METHODS			
Eligibility criteria	5	Specify the inclusion and exclusion criteria for the review and how studies were grouped for the syntheses.	Page 5
Information sources	6	Specify all databases, registers, websites, organisations, reference lists and other sources searched or consulted to identify studies. Specify the date when each source was last searched or consulted.	Page 5
Search strategy	7	Present the full search strategies for all databases, registers and websites, including any filters and limits used.	Page 6
Selection process	8	Specify the methods used to decide whether a study met the inclusion criteria of the review, including how many reviewers screened each record and each report retrieved, whether they worked independently, and if applicable, details of automation tools used in the process.	Page 6
Data collection process	9	Specify the methods used to collect data from reports, including how many reviewers collected data from each report, whether they worked independently, any processes for obtaining or confirming data from study investigators, and if applicable, details of automation tools used in the process.	Page 6,7
Data items	10a	List and define all outcomes for which data were sought. Specify whether all results that were compatible with each outcome domain in each study were sought (e.g. for all measures, time points, analyses), and if not, the methods used to decide which results to collect.	Page 10
	10b	List and define all other variables for which data were sought (e.g. participant and intervention characteristics, funding sources). Describe any assumptions made about any missing or unclear information.	-
Study risk of bias assessment	11	Specify the methods used to assess risk of bias in the included studies, including details of the tool(s) used, how many reviewers assessed each study and whether they worked independently, and if applicable, details of automation tools used in the process.	Page 7,8
Effect measures	12	Specify for each outcome the effect measure(s) (e.g. risk ratio, mean difference) used in the synthesis or presentation of results.	N/A

Section and Topic	Item #	Checklist item	Location where item is reported
			narrative synthesis and thematic analysis
Synthesis methods	13a	Describe the processes used to decide which studies were eligible for each synthesis (e.g. tabulating the study intervention characteristics and comparing against the planned groups for each synthesis (item #5)).	Page 10
	13b	Describe any methods required to prepare the data for presentation or synthesis, such as handling of missing summary statistics, or data conversions.	-
	13c	Describe any methods used to tabulate or visually display results of individual studies and syntheses.	Pages 12-16
	13d	Describe any methods used to synthesize results and provide a rationale for the choice(s). If meta-analysis was performed, describe the model(s), method(s) to identify the presence and extent of statistical heterogeneity, and software package(s) used.	Page 6, 17
	13e	Describe any methods used to explore possible causes of heterogeneity among study results (e.g. subgroup analysis, meta-regression).	N/A narrative synthesis and thematic analysis
	13f	Describe any sensitivity analyses conducted to assess robustness of the synthesized results.	N/A narrative synthesis and thematic analysis
Reporting bias assessment	14	Describe any methods used to assess risk of bias due to missing results in a synthesis (arising from reporting biases).	-
Certainty assessment	15	Describe any methods used to assess certainty (or confidence) in the body of evidence for an outcome.	Page 7,8
RESULTS			
Study selection	16a	Describe the results of the search and selection process, from the number of records identified in the search to the number of studies included in the review, ideally using a flow diagram.	Page 10
	16b	Cite studies that might appear to meet the inclusion criteria, but which were excluded, and explain why they were excluded.	Page 10
Study characteristics	17	Cite each included study and present its characteristics.	Pages 12-16

Section and Topic	Item #	Checklist item	Location where item is reported
Risk of bias in studies	18	Present assessments of risk of bias for each included study.	Page 7,8
Results of individual studies	19	For all outcomes, present, for each study: (a) summary statistics for each group (where appropriate) and (b) an effect estimate and its precision (e.g. confidence/credible interval), ideally using structured tables or plots.	N/A
Results of syntheses	20a	For each synthesis, briefly summarise the characteristics and risk of bias among contributing studies.	Page 7,8
	20b	Present results of all statistical syntheses conducted. If meta-analysis was done, present for each the summary estimate and its precision (e.g. confidence/credible interval) and measures of statistical heterogeneity. If comparing groups, describe the direction of the effect.	N/A
	20c	Present results of all investigations of possible causes of heterogeneity among study results.	N/A
	20d	Present results of all sensitivity analyses conducted to assess the robustness of the synthesized results.	N/A
Reporting biases	21	Present assessments of risk of bias due to missing results (arising from reporting biases) for each synthesis assessed.	-
Certainty of evidence	22	Present assessments of certainty (or confidence) in the body of evidence for each outcome assessed.	Page 7,8
DISCUSSION			
Discussion	23a	Provide a general interpretation of the results in the context of other evidence.	Page 23-25
	23b	Discuss any limitations of the evidence included in the review.	Page 27
	23c	Discuss any limitations of the review processes used.	Page 27
	23d	Discuss implications of the results for practice, policy, and future research.	Page 26
OTHER INFORMATION			
Registration and protocol	24a	Provide registration information for the review, including register name and registration number, or state that the review was not registered.	Page 5
	24b	Indicate where the review protocol can be accessed, or state that a protocol was not prepared.	Page 5
	24c	Describe and explain any amendments to information provided at registration or in the protocol.	N/A
Support	25	Describe sources of financial or non-financial support for the review, and the role of the funders or sponsors in the review.	Page 1
Competing interests	26	Declare any competing interests of review authors.	Page 1, page 27
Availability of data, code and other materials	27	Report which of the following are publicly available and where they can be found: template data collection forms; data extracted from included studies; data used for all analyses; analytic code; any other materials used in the review.	*

Appendix M
MMAT

Part I: Mixed Methods Appraisal Tool (MMAT), version 2018

Category of study designs	**Methodological quality criteria**	**Responses**			
		Yes	No	Can't tell	Comments
Screening questions (for all types)	S1. Are there clear research questions?				
	S2. Do the collected data allow to address the research questions?				
	Further appraisal may not be feasible or appropriate when the answer is 'No' or 'Can't tell' to one or both screening questions.				
1. Qualitative	1.1. Is the qualitative approach appropriate to answer the research question?				
	1.2. Are the qualitative data collection methods adequate to address the research question?				
	1.3. Are the findings adequately derived from the data?				
	1.4. Is the interpretation of results sufficiently substantiated by data?				
	1.5. Is there coherence between qualitative data sources, collection, analysis and interpretation?				
2. Quantitative randomized controlled trials	2.1. Is randomization appropriately performed?				
	2.2. Are the groups comparable at baseline?				
	2.3. Are there complete outcome data?				
	2.4. Are outcome assessors blinded to the intervention provided?				
	2.5 Did the participants adhere to the assigned intervention?				
3. Quantitative non-randomized	3.1. Are the participants representative of the target population?				
	3.2. Are measurements appropriate regarding both the outcome and intervention (or exposure)?				
	3.3. Are there complete outcome data?				
	3.4. Are the confounders accounted for in the design and analysis?				
	3.5. During the study period, is the intervention administered (or exposure occurred) as intended?				
4. Quantitative descriptive	4.1. Is the sampling strategy relevant to address the research question?				
	4.2. Is the sample representative of the target population?				
	4.3. Are the measurements appropriate?				
	4.4. Is the risk of nonresponse bias low?				
	4.5. Is the statistical analysis appropriate to answer the research question?				
5. Mixed methods	5.1. Is there an adequate rationale for using a mixed methods design to address the research question?				
	5.2. Are the different components of the study effectively integrated to answer the research question?				
	5.3. Are the outputs of the integration of qualitative and quantitative components adequately interpreted?				
	5.4. Are divergences and inconsistencies between quantitative and qualitative results adequately addressed?				
	5.5. Do the different components of the study adhere to the quality criteria of each tradition of the methods involved?				

Quality criteria used for systematic review are highlighted. Qualitative criteria are numbered 1-5, quantitative criteria are numbered 6-10 and mixed methods criteria are numbered 11-15 in Table 5.