AN EXPLORATION OF PATHWAYS TO EMOTIONAL OUTBURSTS AND VIOLENCE IN AUTISTIC ADULTS

by

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THESIS OVERVIEW

Autistic people experience considerable interpersonal and intrapersonal challenges across their lifespan. These difficulties include being misunderstood resulting in increased stigma and judgement from others. Autistic people are overly represented in the criminal justice system (CJS). Autistic people in the CJS are intrinsically misunderstood and can experience poor treatment from their first contact with the CJS through to the care they experience if they are detained within forensic or mental health services. This thesis aims to explore the risk factors that are associated with violent behaviour in autistic adults, and following this, the triggers that autistic adults have experienced in an inpatient setting, resulting in increased emotional outbursts whilst being detained in a mental health hospital.

The systematic literature review identified research between 2014 and 2022 that aimed to ascertain risk factors associated with autistic adults and violent behaviour. Data were extracted from these research papers and results indicated two broad categories: co-occurring psychiatric diagnoses and individual risk factors. The individual risk factors posited were further broken down into two categories: those associated with the autism diagnostic criteria, and factors that were not explicitly related with the diagnosis of autism.

Following this, an empirical research study is presented whereby autistic adults in a secure mental health hospital were interviewed to identify specific triggers in their current environment that resulted in increased emotional outbursts. Autistic adults were identified by their multidisciplinary teams (MDT) as having experienced emotional outbursts in the setting, and being appropriate for engaging in the research. Participants then volunteered to engage in a semi-structured interview that was specifically designed for the purpose of this study. Data were

analysed using reflexive thematic analysis and posited three overarching themes: having a lack of personal agency, not living in a therapeutic environment, and not feeling cared for.

Overall, the present thesis aimed to facilitate further understanding of the aetiology of both violent behaviours and emotional outbursts in the context of the CJS. Through further understanding of these behaviours, clinical recommendations have been made to provide additional support for autistic service users and their teams to ensure meaningful and appropriate interventions and care provision. In addition, the current thesis explores the barriers to change in secure services and comments on why services may not be currently facilitating recommendations posited by previous research.

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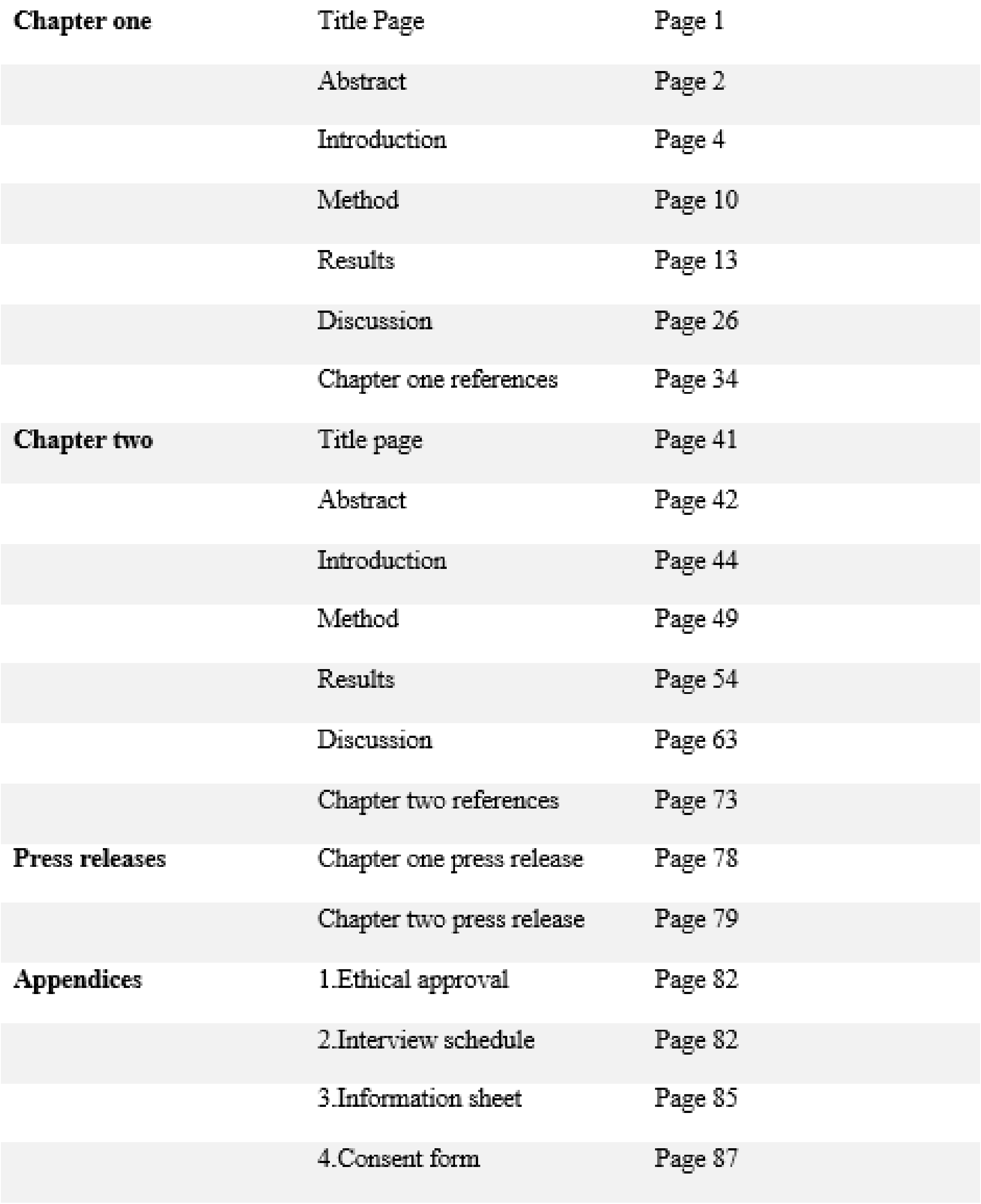


CHAPTER ONE: A SYSTEMATIC REVIEW OF CO-OCCURING MENTAL HEALTH DIAGNOSES AND INDIVIDUAL RISK FACTORS IN AUTISTIC ADULTS WHO BEHAVE VIOLENTLY

Abstract

Introduction

When autistic people come into contact with the criminal justice system (CJS), they are intrinsically misunderstood. In order to support autistic people in the CJS we need a clearer understanding of the behaviour that leads to this contact. Research suggests both comorbidities and individual risk factors are important to consider when understanding why autistic people behave violently.

Methods

The review included papers identifying risk factors of violent behaviour in autistic adults. A systematic literature search was conducted using electronic databases PsychINFO, Psycharticles, MEDLINE and PubMed, between 2014 and 2022. Inclusion criteria included research with clear definitions of autism diagnosis and violence. Data were extracted from the papers, and the papers were appraised using the mixed method appraisal tool.

Results

Of 1,552 screened papers, eleven papers met the inclusion criteria and the extracted data were grouped into two overarching headings: comorbidities and individual risk factors. The papers identified that a diagnosis of ADHD, conduct disorder or other psychiatric diagnoses were associated with an increased likelihood of an autistic person behaving violently. Individual risk factors associated with violence in autistic adults included characteristics associated with the autism diagnostic criteria, and individual factors including having a lower household income, and difficulties with sleep.

Discussion

The findings indicated the need for individual risk assessments in autistic adults who engage in violent behaviour. Some clinical recommendations have been made to target specific factors that may impact on the likelihood of an autistic person engaging in violence.

Introduction

Autism Spectrum Disorder (ASD) is diagnosed on the basis of a dyad of impairments: social communication and interaction, and restricted and repetitive interests (American Psychological Association; APA, 2013). Autistic people will have experienced impairments in these areas in their early development and across different contexts (APA, 2013). One in one hundred adults and children worldwide are thought to be autistic (World Health Organisation, 2022), however this number appears to be rising, with a recent study in America identifying 1 in 36 children as being autistic (Maenner et al., 2023). A diagnosis of autism is associated with lifelong difficulties in relationships, education and employment (Geller, 2015), as well as an overall lower quality of life (ven Heijst & Geurts, 2014). Factors associated with a lower quality of life include perceived stress and experience of bullying (Hong et al., 2018), as well as lack of employment, lack of support and not being in a relationship (Mason et al., 2018). In addition, co-occurring mental health conditions have been identified as more common in autistic populations compared to non-autistic populations (Lai et al., 2019). These difficulties appear to be consistent across the lifespan, with both autistic children and adults experiencing considerable interpersonal and intrapersonal challenges. A further concern is that autistic people have appeared to be over-represented within the criminal justice system (CJS; Alexander et al., 2011; Hare et al., 2000; Im, 2016; Scragg & Shah, 1994), where they are intrinsically misunderstood (Slavny-Cross et al., 2022).

Autism and the criminal justice system (CJS)

The CJS is a single system involving a number of agencies, including the police, the courts and the Ministry of Justice. Autistic people may have contact with any one of these agencies and this contact may result in detention within a forensic setting, such as a prison or psychiatric hospital, which are also part of the CJS. Many studies exploring this relationship have identified an over-representation of autistic people both having contact with the CJS (Collins et al., 2022) and being detained within forensic settings (Alexander et al., 2011; Hare et al., 2000; Im, 2016; Scragg & Shah, 1994).

Despite the acknowledgement that autistic people are over-represented in the CJS, studies exploring the reasons for this over-representation have been criticised due to risk of bias (Collins et al., 2022; King & Murphy, 2014). King and Murphy’s (2014) review identified that despite all papers in their review reporting an increased prevalence of autism (3- 27%), it was difficult to compare the results between papers due to lack of consistency. Consequently, King and Murphy (2014) described that although it seemed likely that autistic people may have been over-represented in the CJS, this was not conclusive. In a recent update of King and Murphy’s 2014 review, Collins et al (2022) similarly reported high levels of sampling bias in the papers reviewed, as well as low levels of gold standard diagnosis for autism (Collins et al., 2022). In both of these reviews, the CJS was used to describe any contact with police, courts, and detainment within forensic settings, which may have impacted on the range of prevalence rates, as well as the methodological and sampling biases reported.

In forensic settings specifically, such as prisons and secure mental health hospitals, the exact prevalence of autism is unknown (Esan et al., 2015), however, most sources agree that autistic people are overly represented in these settings (Alexander et al., 2011; Hare et al., 2000; Im, 2016; Scragg & Shah, 1994). In Im’s (2016) literature review, he reported the prevalence rate of autistic people in forensic settings as 1.5-18%, suggesting a consistent over-representation compared to 1% of the general population. This estimate, though, includes a large range of prevalence estimates. Research looking to identify why autistic people enter the CJS and remain in forensic settings has resulted in inconsistent findings (Collins et al., 2022;

King & Murphy, 2014), however a number of factors associated with autistic people coming in to contact with the CJS have been explored.

Characteristics associated with autism may be related to offending, such as communication difficulties, social misunderstanding and idiosyncratic interests and obsessions (King & Murphy, 2014; Helverschou et al., 2016). In addition, stress may be an intrinsic motivation for offending behaviour in autistic offenders (Helverschou et al., 2016). Research has identified that many autistic offenders' personal accounts differed from their forensic reports, and that autistic people may be quick to admit to offences and even admit to offences that they had not committed (Helverschou et al., 2016). These findings suggest a lack of appropriate adaptation of the CJS process for autistic offenders, who may behave in ways to placate the situation resulting in increased charges (Helverschou et al., 2016).

Autistic people coming into contact with the CJS are likely to be misunderstood and misrepresented (Slavny-Cross et al., 2021; Taylor et al., 2009). Research has highlighted the need for further understanding of autism in the CJS to ensure fair consideration and treatment of autistic people in these settings (Slavny-Cross et al., 2021; Taylor et al., 2009). Without a broader understanding of the context in which autistic people find themselves in the CJS, it remains difficult to recognise appropriate treatment and intervention for autistic offenders that commit particular offences, such as violent crime.

Autism and violence

A number of autistic people who enter the CJS and are subsequently detained within forensic settings, have committed violent offences. Some studies have identified that autistic people are more likely to commit violent offences than non-autistic people, however these findings are not consistent (Collins et al., 2022; Im, 2016; King & Murphy, 2014). Following the shooting at

Sandy Hook Elementary school in 2012, carried out by an autistic man, the question of whether there was a link between autism and violence was publicised by the media (Im, 2016). Autism is not directly linked to, nor does it cause, violent behaviour (Ghaziuddin et al., 1991; Im, 2016). Consequently, it is important to recognise the underlying mechanisms that cause an autistic person to behave violently. This would allow forensic settings to provide appropriate interventions and identify the level of support required to support effective understanding and rehabilitation.

Previous literature reviews have explored the association between autism and violent risk (Del Pozzo et al, 2018; Im, 2016). Del Pozzo et al (2018) suggested that third variables are intrinsic in this relationship, such as historical experiences, environmental factors and comorbid psychiatric disorders. The scope of the literature reviewed by Del Pozzo et al’s (2018) is unclear, with the dates of the literature and the search terms not being reported. In addition, Del Pozzo et al (2018) did not appraise the quality of the literature they reviewed, and therefore further systematic exploration is necessary to determine a meaningful conclusion.

In 2016, Im reviewed the literature exploring violence in autism between 1943 and 2014. Im (2016) reviewed 65 papers, exploring the prevalence of, and risk factors resulting in, violence by autistic people. Regarding prevalence of violence by autistic offenders, results were varied. One report suggested no relationship between violence and autism, with prevalence rates being similar to a non-autistic population (Ghaziuddin et al., 1991). However, other studies found higher rates of violence in an autistic population of offenders in both the community and within forensic settings (Scragg & Shah, 1994; Woodbury & Smith, 2006). Further prevalence studies reported a higher representation of autistic people in forensic settings based on a sample of violent offenders (Hare et al., 2000; Siponmaa et al., 2001; Soderstrom et al., 2005).

Im’s (2016) review included consideration of both child and adult offenders. Studies exploring aggression in children found increased levels of aggression in autistic samples (Bronsard et al., 2010; Mayes et al., 2012). Im (2016) concluded that although some of the prevalence studies suggested an over-representation of autistic people in forensic settings, the relationship between autism and violence remains unclear. He reported the selection biases in forensic populations and lack of significant differences in community samples meant they were unable to suggest a conclusive relationship between autism and violence. Of note, the lack of specificity in the violence explored in the review; for example, by including literature on both aggression in autistic children as well as violent offending in autistic adults, is hypothesised to have resulted in a lack of clarity in the relationship presented in Im’s (2016) review.

Im (2016) identified comorbid psychopathology, a diagnosis of Asperger’s syndrome, and deficits in social cognition and emotion regulation as associated causes of violent risk. Further findings outlined in the literature identified demographic information as relevant to level of risk, such as being male (Langstrom et al., 2009), and age (Langstrom et al., 2009; Kanne & Muzurek, 2011); both younger age (6-11) and older age (26 years and above) were related to an increase in violent risk (Im, 2016). Im (2016) provided a meaningful overview of the relationship between autism and violence, based on evidence up to 2014, as well as providing recommendations for treatment approaches with the aim to reduce violence in autistic people. Im’s (2016) review provided a useful starting point in understanding the relationship between autism and violence prior to 2014. However there were a number of limitations in the review and they did not include the use of a quality appraisal tool to critically appraise the research papers from which they determined their conclusion. The review suggested future research should seek further clarity in both ASD diagnosis and definition of violence (Im, 2016).

Rationale and scope of current review

The current review aims to update and refine Im's (2016) review, considering evidence from the last 8 years, which have seen changes to ASD diagnostic criteria (APA, 2013). Although not all of the diagnoses in the reviewed papers will be using the current diagnostic criteria, which was updated in 2013, it is hypothesised that the papers will draw on this more up to date understanding of the diagnosis. The current review will provide an up to date summary of the literature from 2014 identifying the risk factors associated with violent offending in autistic adults. The search will be conducted from 2014 to ensure all literature published following Im's (2016) review is included, however any literature that was previously reviewed by Im (2016) will be excluded from the current review to reduce duplication.

To increase the specificity of the current review, it will include research on autistic adults only. Clear inclusion criteria have been determined to ensure clarity in the use of the term 'violence', where researchers have referred to 'aggression' synonymously, only papers that define 'physical aggression' towards others and specify this in their results will be included. In addition, papers that look at the prevalence of autistic adults within the CJS and forensic settings will not be included. The prevalence of autistic people in these services has been extensively researched and it has been concluded that this is difficult to determine with any confidence. The more important question of why autistic people come into contact with these services, and how they can be supported is the focus of the current review.

For the purposes of the current review, autism spectrum disorder (ASD) refers to the diagnostic criteria in the Diagnostic and Statistical Manual of Mental Disorders – 4th or 5th edition (DSM-IV and DSM V), or the International Classification of Diseases – 10th or 11th edition (ICD 10 and ICD 11). Violence is defined by intentional threats, attempts or infliction of bodily harm on another person. Studies where these definitions have not been clearly reported have not been included.

In line with the best practice guidelines (Siddaway et al., 2019), the current review includes a quality appraisal tool to explore the quality of the research relevant to this field and aid in the description of suggested findings.

Aims

- To provide an understanding of the evidence on risk factors associated with violent offending in autistic adults in papers published since 2014.
- To critically analyse the quality of the research outlining risk factors associated with violent offending in autistic adults using a quality appraisal framework.
- To review and consider the evidence in order to identify how this could be used to inform treatment and clinical recommendations.
- To provide recommendations for future research on violent offending in autistic people.

Method

Search strategy

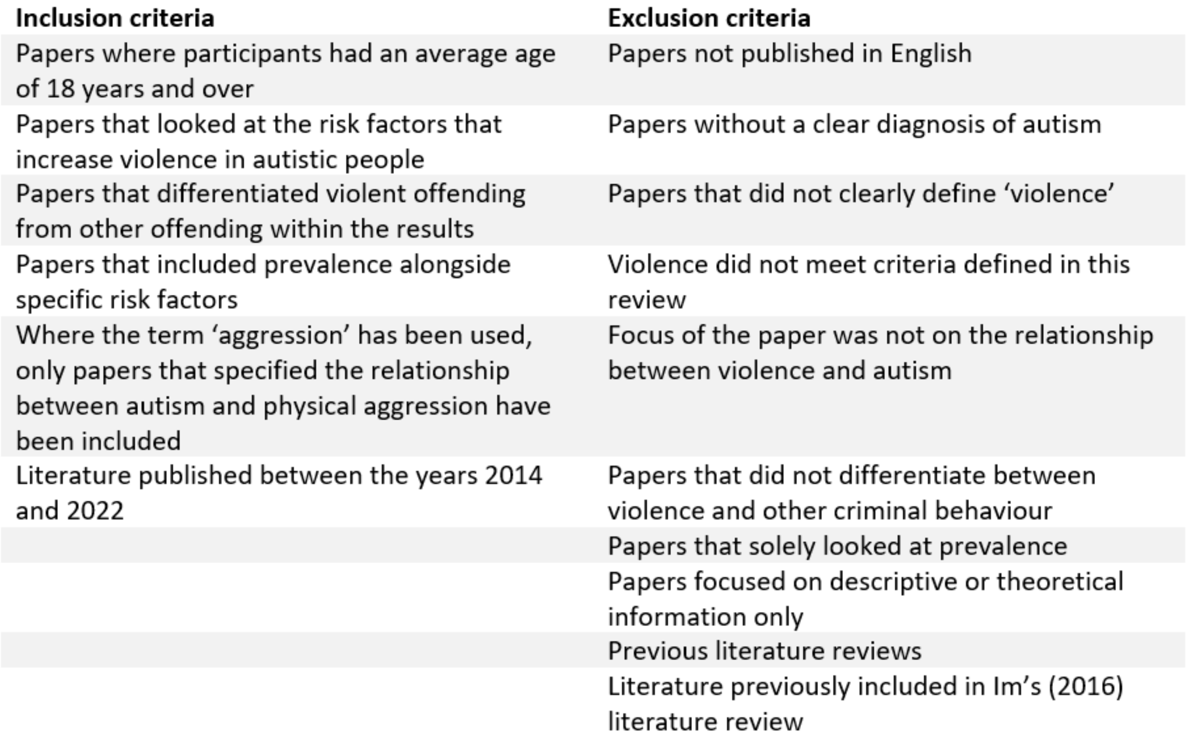
A systematic search of the literature was conducted in June 2022, using electronic databases PsychINFO, Psycharticles, MEDLINE and PubMed. All published research between 2014 and 2022 was searched using the following search terms taken from Im's (2016) original review: "autism", "autistic disorder", "high-functioning autism", "autistic spectrum disorder", "Asperger's", "Asperger's disorder", "Asperger's syndrome", "pervasive developmental disorder" AND "violence", "aggression", "murder", "rape", "assault", "criminal", "crime", and "offending". All searches were conducted through abstract and title searches.

Inclusion and exclusion criteria

The identified articles were reviewed to ensure that they met the criteria outlined in table 1.

Table 1.

Inclusion and exclusion criteria.



Inclusion criteria	Exclusion criteria
Papers where participants had an average age of 18 years and over	Papers not published in English
Papers that looked at the risk factors that increase violence in autistic people	Papers without a clear diagnosis of autism
Papers that differentiated violent offending from other offending within the results	Papers that did not clearly define 'violence'
Papers that included prevalence alongside specific risk factors	Violence did not meet criteria defined in this review
Where the term 'aggression' has been used, only papers that specified the relationship between autism and physical aggression have been included	Focus of the paper was not on the relationship between violence and autism
Literature published between the years 2014 and 2022	Papers that did not differentiate between violence and other criminal behaviour
	Papers that solely looked at prevalence
	Papers focused on descriptive or theoretical information only
	Previous literature reviews
	Literature previously included in Im's (2016) literature review

Papers included in this review looked at adult participants only, this was identified through average age of the participants being over 18 years. Papers were screened by identifying the focus of the research; only papers that clearly explored the reasons why autistic people behave violently were included in the review. Papers that looked at prevalence of autistic violent offenders were included only if the paper also included specific factors that increased this risk. Papers were included where violent offending was differentiated from other criminal behaviours in the results section. Papers that used 'aggression' to describe violent behaviour were included only where physical aggression was differentiated from other types of aggression, such as verbal aggression or aggression directed towards the self.

Papers were excluded where they did not offer a clear description of a diagnosis of autism, for example, papers that included ‘suspected autism’ and ‘autistic traits’. Papers that did not include a clear definition of ‘violence’ in their method were excluded, or where the definition did not meet the criteria outlined in this review, for example, violence directed towards the self, or property. Papers were excluded if the focus of the paper was not on the relationship between violence and autism, for example, where the focus was on intervention or risk assessment. Furthermore, papers that did not separate violent offending from other criminal behaviour were excluded, such as papers that explored the relationship between autism and the criminal justice system in a broader sense. Lastly, papers that described what we know about this relationship theoretically, were excluded, along with previous literature reviews.

Quality appraisal

The mixed method appraisal tool (MMAT, Hong et al., 2018) was used to assess the quality of the papers. The MMAT has been successfully used by other literature reviews in this field (Collins et al., 2021; Collins et al., 2022). The MMAT is a quality appraisal tool used to rate the quality of research including qualitative, quantitative, and mixed methods, it allows the user to explore the methodological quality of papers using five categories, which are determined by the method used within the research. Examples of the categories for qualitative papers include considering whether the results are adequately derived from the data; for quantitative, non-randomised, papers, the appraiser would explore whether there are complete outcome data and whether the sample is representative of the target population. The MMAT is a validated tool that has been developed and updated based on feedback from researchers; the tool uses core criteria to assess the quality of papers allowing for efficient appraisal (Hong et al., 2018).

Data extraction

Data from the included studies were extracted and summarised (see table 2). The data extracted included author name(s), publication date and country, participant details, nature of violence and diagnoses, and summary of findings.

Due to the mixed methods of the reviewed papers, neither a meta-synthesis nor a meta-analysis was appropriate to analyse the data. To extract the data from each of the papers, the primary author recorded the findings identified by the researchers in each study in detail. Following this, the findings that were relevant to the identified research question were summarised across papers; for example, studies that identified a significant association of the same risk factor for violence in autistic adults. When the findings were collated across studies the primary author categorised them into subheadings, such as, comorbidities.

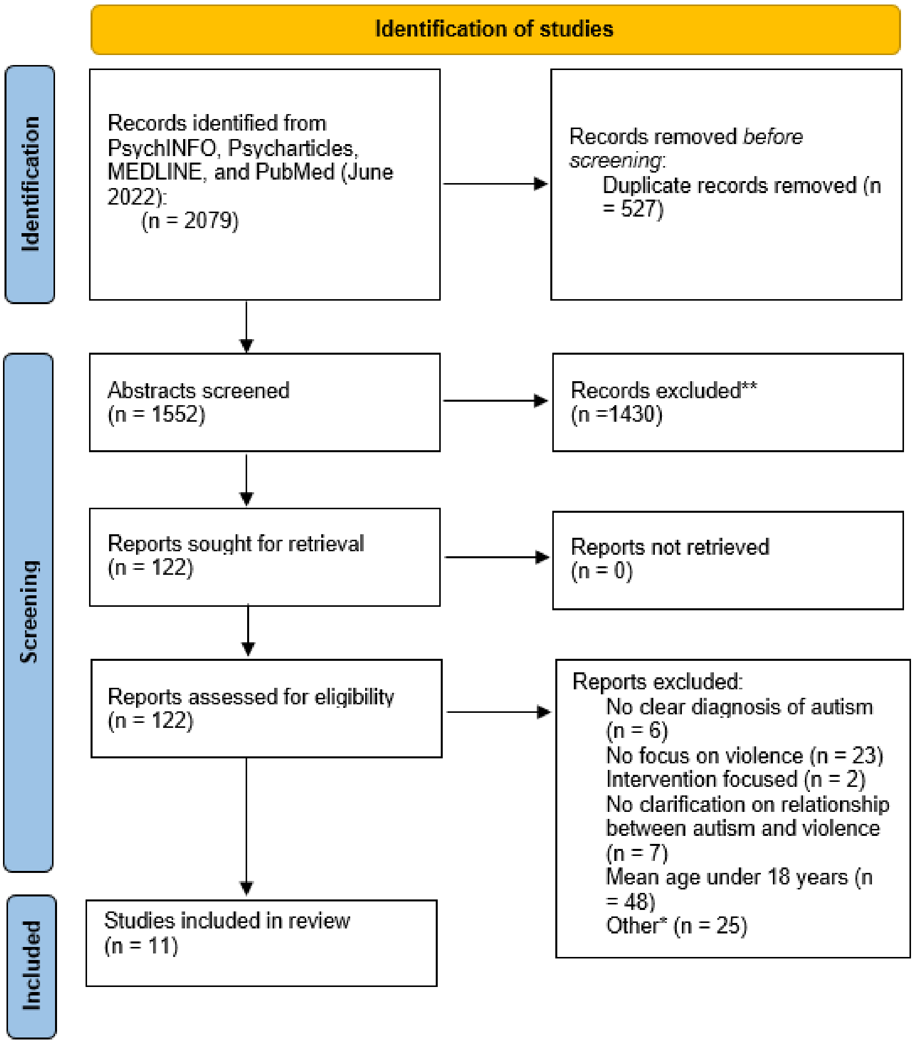
Results

Identification of studies

The initial search yielded 2079 papers (see figure 1). Following 527 duplicates being removed, 1552 titles and abstracts were screened using the above inclusion and exclusion criteria. Based on this screening, 122 papers were deemed suitable for full-text review. Full-text review resulted in 11 papers being included. See figure 1 for a breakdown of this process. References for all included papers were screened for further relevant research, however no further papers were identified.

Figure 1.

Identification of studies



*Other = includes papers included within Im's (2016) review, book chapters and literature reviews.

Table 2.

Data extraction

Author/s	Date	Country	Participants	Nature of violence	Sample type (eg., community)	Diagnosis	Comparison group Y/N?	Summary of findings	Quality appraisal score
Allely & Faccini.	2019	USA	Case study, 21-year-old male.	Mass shooting (9 victims)	Prison	ASD (ADOS-2)	N	Denial/difficulty adjusting to having an ASD, feeling less-than others, defective and not-normal, engaging in a downward spiral accompanied by depression, thoughts of suicide, and not cooperating with treatment.	1*
Allely et al.	2017	USA	Case study, 20-year-old male.	Mass shooting (26 victims)	Forensic (case study died by suicide following offence)	Asperger's and OCD.	N	Intense preoccupation with mass murders, refusal of treatment, failure to accept diagnosis.	1*
Blackmore et al.	2022	England	1570 (1142 male, 428 female), M age = 33 years (SD 12)	Participants had contact with the CJS – 10% of ASD group for violent offences.	Community and forensic settings	1130 (72%) diagnosed with ASD	Y	Males with ASD less likely than males w/o ASD to commit violent crimes. Males with ASD more likely to commit violent crimes than females with ASD. Individuals with ADHD more likely to come in to contact with CJS than ASD alone (2x more likely).	4*
Cohen & Tsiouris.	2020	USA	2243 (1310 males, 933 females). M age of ASD p's 42.7 (SD 11.8), non-ASD 50.5 (12.3)	Measured with IBR-MOAS (measures aggressive behaviour and setting events)	Community	149 males with ASD, 55 females with ASD. All participants had a diagnosis of ID (either mild, moderate or profound)	Y	Sleeping problems linked to increase in all types of aggression in both ASD and non-ASD. Frustration, discomfort and change were identified as triggers for aggression linked with ASD.	4*
Edwards & Higham.	2020	England	Case study, 38-year-old male.	Extensive history of violence and aggression including physical altercations with family, throwing a brick through his neighbour's window and physical assaults on staff.	Medium secure psychiatric hospital	OCD and ASD	N	Difficulties with self-esteem and identity, high levels of anxiety. Rigidity of thinking around interpretation of others' behaviour. Lack of insight in to diagnoses. Lack of empathy for victims/difficulties with theory of mind.	1*
Heeramun et al.	2017	Sweden	295,734. Non-ASD M age* 21.2 (SD 3.6), ASD M age 20.3 (SD 3.4).	Violent crimes included completed or attempted homicide or manslaughter, assaults (including gross	Community and forensic settings	5,739 had a diagnosis of ASD (ICD 9/10 and DSM IV)	Y	ASD cohort more likely to commit violent crime. ASD + ADHD or conduct disorder was associated with an increase of violent criminality. ASD alone did not result in an increased risk.	4*

			Non-ASD 50.9% male, ASD 67.1% male. *M age measured at time of study – retrospective data included participants from 15 years of age.	bodily harm and other assaults) and unlawful threat with or without a weapon, sexual crimes (including rape, sexual coercion, sexual exploitation, indecent exposure, or child molestation), robbery, and arson.		1608 of individuals with ASD also had an ID.		Individuals with ASD + ID were less likely to be convicted of a violent crime. Psychiatric disorder and drug and alcohol misuse were also associated with risk in ASD.	
Hofvander et al.	2019	Sweden	269 males, aged 18-25 years.	Violent offenders recruited through the Development of Aggressive Antisocial Behavior Study (DAABS) – hands on violent offences (including sexual).	Prison	10% (26) had an ASD diagnosis: Asperger's syndrome, autistic disorder, PDD not otherwise specified	Y	ASD group had an early onset of psychosocial problems, were more likely to have lived in a foster home. 73.1% met criteria for childhood ADHD, 38.5% had childhood conduct problems. Many of the ASD cohort did not receive a diagnosis until adulthood (79%: therefore, did not receive treatment).	4*
Levante et al.	2022	Finland	43, 33 male and 10 female. M age 24.8 (SD 6).	Questionnaire provided to parents of participants Re: aggressive behaviour before and during COVID-19 lockdown.	Community	High functioning or low functioning ASD. 74.4% had a comorbid ID. Other comorbidities also included.	N	Aggressive behaviour increased during COVID-10 lockdown. Poor adherence to sleep-wake routine resulted in increased aggression, as well as more anxiety and anger. Similarly, increased feelings of anxiety and anger caused increased aggression in adults with ASD.	2*
Murphy.	2014	England	20 males. M age for preoccupied group and non-preoccupied group: 35.3 (SD 16.7) and 33 (SD 9.7)	All participants in high secure psychiatric care. Offences include murder, manslaughter, wounding with intent, threats to kill. Experience of anger measured using the STAXI	High secure psychiatric hospitals	ASD diagnosed by researcher and forensic psychiatrist at admission (ICD 10 criteria). Comorbidities of psychosis and personality disorder noted.	N non-ASD group. Compared offenders with ASD who offended due to preoccupation (PO) and those who did not (NPO)	Those whose offences were more linked to preoccupation were less likely to have comorbidity and more likely to have a singular ASD diagnosis. Associations with offence and social naivety, poor interpersonal conflict skills, poor perspective taking. Suggest that the individuals who offended due to preoccupation were linked to their ASD, however individuals with NPO linked to offence likely offended due to complex comorbidities and other factors.	4*

Van Buitenen et al.	2021	The Netherlands	394 male participants, M age 31.7 (SD 0.49)	All participants had been detained in penitentiary psychiatric centres (PPC). Violent offences were determined by offences that caused damage to a human victim.	Penitentiary Psychiatric Centres (secure services)	ASD (DSM IV or V). Number of comorbidities also noted; 78.9% had at least one comorbid diagnosis	N	Increased comorbidities related to increased risk of violent offending, as well as negative social network and influenceability.	5*
van den Boogert et al.	2021	The Netherlands	101 participants, M age 32.9 (SD 12.4). 52% males.	The following measures were used: Reactive-proactive aggression questionnaire and The aggression questionnaire -short form.	Inpatient and outpatient ASD services	ASD (DSM 5),	N	An association between sensory processing difficulties and aggressive behaviour was found. Those with higher sensory sensitivities reported higher reactive aggression and anger, those with low registration of sensory input reported more proactive aggression. Increased sensory seeking was related to increased reactive and proactive aggression and anger.	5*

Summary of papers

Of the 11 studies, three were conducted in the UK (England), three in the USA, two in Sweden, one in Finland, and two in the Netherlands (see table 1). All three case studies were conducted on men. Of the eight quantitative studies, five recruited both male and female participants, and three used only male participants. Data were collected retrospectively through national data sets, such as the National Adult ADHD and ASD service in the UK (Blackmore et al., 2022), the Stockholm Youth Cohort (Heeramun et al., 2017), and the Development of Aggressive Antisocial Behaviour Study (Hofvander et al., 2019). Other papers collected data through relevant services, such as the penitentiary psychiatric centres in the Netherlands (van Buitenen et al., 2021), the New York State Office for People with Developmental Disabilities (Cohen & Tsiouris, 2020), high secure psychiatric care units in the UK (Murphy, 2014) and inpatient and outpatient units specialising in neurodevelopmental disorders in the Netherlands (van den Boogert et al., 2021). Further papers identified participants through online surveys (Levante et al., 2022) or via case studies (Allely et al., 2017; Allely & Faccini, 2019; Edwards & Higham, 2020).

Violent offending described in the studies included: mass shooting (Allely et al., 2017; Allely & Fancini, 2019), physical aggression towards others as measured by behavioural scales (Cohen et al., 2020; Levante et al., 2022; van den Boogert et al., 2021). Other studies defined violence as offences that caused damage to a human victim (van Buitenen et al., 2021). Murphy (2014) defined violence as murder, manslaughter, wounding with intent and threats to kill, and Hofvander et al (2019) included “hands-on violent offences”. Heeramun et al (2017) identified violent crime as attempted homicide or manslaughter, assaults, unlawful threats, sexual crimes, robbery and arson; as per the Swedish Penal Code. Blackmore et al (2022) included a number of offences in their study, however categorised these and for the purposes of this review, the category of “violent offending” was included. In Edwards & Higham’s (2020) case study, they describe assaultive behaviour towards others, resulting in the individual being managed in isolation and high secure environments.

Although exploring the prevalence of violent offending in autistic populations was not one of the aims of the current review, and is not commented on in the findings, four of the reviewed papers presented prevalence of violence in their samples, alongside risk factors associated with the behaviour. Of the four papers that commented on the prevalence of violent offending in autistic samples, one paper found autistic offenders were less likely to commit a violent crime than non-autistic offenders (Blackmore et al., 2012). Heeramun et al (2017) found a higher proportion of autistic offenders had committed a violent crime than non-violent offenders, however this was not the case when other variables were accounted for. Hofvander et al (2019) found autistic offenders were more likely to have committed a violent sexual offence against a child, however found no further differences between autistic and non-autistic offenders. Allely et al (2017) reported ‘strong evidence for ASD’ in 8% of the Mother Jones database of mass shooters, and an indication of ASD traits in a further 21% of the sample. In this paper, it is not clear how the authors have defined strong evidence for, or traits of, ASD, however this does not appear indicative of a formal assessment for, or diagnosis of, autism.

Quality Appraisal

Eight of the included studies used quantitative methods, two of which were rated 5* on the quality appraisal tool, five were rated 4*, and one was rated 2*. Of the three qualitative case studies included in the review, all were rated 1* (see table 1). It is important to note that due to the research question and the nature of the studies appraised, it is unlikely that case studies would score highly. Despite this, these case studies provided meaningful data to the review.

The case studies each described autistic men who had engaged in violent behaviour and explore the factors that likely impacted this. The quality of these papers was compromised by the high level of subjectivity in analysis and interpretation. In addition, the validity of these papers is called in to question due to the specificity of the associated factors to the individual described.

The quality of quantitative studies was relatively high, however they were compromised by lack of complete outcome data (Cohen et al., 2020; Heeramun et al., 2017; Hofvander et al., 2019) and lack of clarity regarding how the target population is represented in the samples chosen (Levante et al., 2022; Murphy, 2014). Levante et al (2022) used a snowball method of recruitment, using social media to access participants, which was hypothesised to cause bias in the represented sample. In addition, they developed questionnaires for the specific study and did not report on levels of validity and reliability, subsequently receiving the lowest quality appraisal score, of 2*. Many of the studies did not report on drop-out rates and depending on the recruitment method a judgement was made regarding whether this was likely to make the study vulnerable to bias or not. For example, studies using retrospective data or volunteer samples, where drop-out rates were not recorded, were assumed to have had a complete data set (Murphy, 2014; van den Boogert, 2021).

Findings

Across the papers, results could be grouped into two broad topic areas. Papers that looked at comorbidities provided insight into the co-occurring psychiatric diagnoses most associated with violent offences in autistic people, and papers looking at individual risk factors identified specific difficulties autistic people might face that are associated with violent offending. The individual risk factors identified were split into factors commonly associated with autism, as understood by diagnostic criteria, and those that were not.

Comorbidity.

Several papers in this review identified an association between autistic people with comorbidities of other mental health and developmental disorders, and violent offending. Though there were significantly different prevalence rates reported by studies, it was consistently reported that autistic people were more likely to have a diagnosis of either ADHD or conduct disorder. Heeramun et al (2017) found 25.8% of autistic offenders had ADHD, versus 2.5% of non-autistic offenders, and Hofvander et al (2019) found 73.1% of autistic offenders met the criteria for what they termed ‘childhood ADHD’, compared to 62.2% of non-autistic offenders. Similarly, Heeramun et al (2017) identified that 4.5% of autistic offenders had conduct disorder, compared to 0.4% of non-autistic offenders. Hofvander et al (2019) found 88% of their autistic sample had conduct disorder, versus 77.3% of non-autistic participants. The difference in prevalence rates identified is likely due to the methodology in the papers and the samples used.

Both Blackmore et al (2012) and Heeramun et al (2017) identified an increase in criminal behaviour in autistic offenders with ADHD. Blackmore et al (2012) identified that autistic offenders with a diagnosis of ADHD were twice as likely to come in to contact with the CJS, importantly, however, they did not report on a specific association between violent offending and comorbid autism and ADHD. Heeramun et al (2017) found autistic offenders with a diagnosis of either ADHD or conduct disorder were more likely to commit a violent offence.

Van Buitenen et al (2021) provided further support to the hypothesis that comorbidities increase violent risk in autistic offenders. They included data on all autistic male offenders in the four penitentiary psychiatric centres in the Netherlands. In their sample of 425 participants, they found that 78.1% of autistic offenders had at least one comorbidity, with the highest comorbidities being substance use disorders at 39.8%, schizophrenia and psychosis at 31.7% and other neurodevelopmental disorders at 24.1% (Van Buitenen et al., 2021). They found that as the number of comorbidities increased, so did the risk of violence. This is supported by Heeramun et al (2017), who similarly identified comorbid psychiatric disorders were associated with an increase in violent criminality in autistic offenders.

The three case studies in this review all reported case studies of autistic males with comorbid psychiatric diagnoses. Allely et al (2017) described the case of Adam Lanza who perpetrated a mass shooting killing 26 people at Sandy Hook Elementary school in 2012. They described a comorbidity with obsessive compulsive disorder (OCD) and high levels of anxiety. They suggested these comorbidities resulted in a lack of ability to cope with daily life. Allely & Faccini (2019) who outlined the case of Dylann Roof, the perpetrator of a mass shooting, killing nine people at a Methodist Church in South Carolina in 2015, identified a comorbidity of anxiety disorder and obsessive compulsive traits. Edwards & Higham’s (2020) case study referred to an autistic man in secure psychiatric care, who has engaged in violent behaviour both in the community and in inpatient settings. They suggested the impact of high levels of anxiety and low levels of self-esteem as a risk factor for violent behaviour. Conversely, Heeramun et al (2017) reported that some comorbidities can act as a protective factor against violence in autistic offenders. They identified that participants in their study who had a diagnosis of both autism and intellectual disability (ID) were less likely to commit violent crime than autistic people without ID (Heeramun et al., 2017).

In summary, the findings reviewed here suggested some co-occurring psychiatric diagnoses in autistic people may be relevant and important risk factors for violent offending. The studies have collectively posited three comorbidities in particular: ADHD, conduct disorder and substance misuse. However, pathways to violent offending are heterogeneous and narrowing the specific traits and individual risk factors associated with these diagnoses are critical in understanding the aetiology of violent offending in autistic people.

Individual risk factors.

A number of the studies suggested specific risk factors that may influence an autistic person's likelihood of committing a violent offence. These risk factors were identified through collection of general data, such as demographic information and background histories, as well as more specific data collection on particular variables, such as sleep, sensory processing and shifting impairment. In addition, information relating to the person's autism diagnosis was suggested as a risk factor, including both age that they were diagnosed, and their access to support. These individual risk factors can be separated in to two categories: those associated with the autism diagnostic criteria and those not specifically associated with the diagnosis of autism. For the purpose of this section, sleep was identified as an individual risk factor rather than a comorbidity.

Risk factors associated with the autism diagnostic criteria.

Autism diagnosis.

Heeramum et al (2017) found that people with a later diagnosis of autism (at a higher age) were increasingly at risk of violent offending. Similarly, Allely et al (2017) and Allely and Faccini (2019) found a lack of acceptance of the diagnosis of autism and subsequent denial of further support was a risk factor in the case studies described. Allely et al (2017) outlined that Adam Lanza refused to accept his diagnosis of Asperger's syndrome and refused all intervention after four weeks of engagement. Dylann Roof was described as having difficulties adjusting to his diagnosis of autism, resulting in feelings of being "less than" his peers (Allely & Faccini, 2019).

Characteristics of autism.

Some of the studies outlined specific risk variables likely to be associated with a diagnosis of autism. Restricted interests were identified by two of the case studies, in particular a preoccupation with violent offences and weapons, namely firearms (Allely et al., 2017), racism and terrorism/hate groups (Allely & Faccini, 2019). Social difficulties were identified by two of the case studies. Higham & Edwards (2020) described rigid beliefs around others' behaviour, leading to possible misinterpretation and social difficulties. Furthermore, Higham & Edwards (2020) described a lack of theory of mind and an inability to empathise with victims as a risk factor. Allely & Faccini (2019) identified social communication difficulties and difficulties socialising with peers, as well as significant difficulties with relationships.

Murphy (2014) specifically looked at the role of preoccupation in violent offences committed by autistic offenders. He found that a number of autistic offenders in high secure psychiatric care had preoccupations regarding wrongdoing, rejection, pornography and deviant sexual interests. He further identified additional risk factors related to autism, such as interpersonal conflicts, routines being disrupted, poor interpersonal skills, relational difficulties and specific interests.

Van den Boogert et al (2021) found those with higher sensory sensitivities reported higher levels of anger and reactive aggression, those with lower sensory sensitivity were associated with higher levels of proactive aggression. Increased sensory seeking behaviours were associated with both reactive and proactive aggression, as measured by the reactive-proactive aggression questionnaire where reactive aggression is described as an angry and defensive response to a provocation, and proactive aggression is instrumental and organised aggression (Van den Boogert et al., 2021).

Risk factors not associated with the autism diagnostic criteria.

Demographic information.

Blackmore et al (2022) found an association between being male and violent offending, with autistic males being more likely to perpetrate all offences than autistic females, including violent offending.

Background histories.

Van Buitenen et al (2021), Heeramun et al (2017) and Hofvander at al (2019), all identified specific factors relating to an autistic person's history that were associated with their violent risk. Heeramun et al (2017) identified a number of parental and familial characteristics associated with an increased risk of violence in autism, including living in households with a lower income, maternal psychiatric disorders, parental criminality and migrant households. Van Buitenen et al (2021) identified that autistic individuals with a negative social network were more likely to engage in violence. Within their study, a negative social network was identified using a risk assessment tool where exposure to antisocial peers and family, engaging in social groups with a negative connotation, social isolation and rejection from prosocial network influences were considered (Van Buitenen et al., 2021). Environmental influences were also found in Hofvander et al's 2019 study, who identified that autistic individuals with a history of violent criminality were more likely to have spent increased time in foster care.

Sleep.

Although sleep difficulties are one of the most common complaints for autistic adults (Halstead et al., 2021), sleep has been identified as a risk factor not associated with autism as it is not associated with the diagnostic criteria for autism. Both Cohen and Tsiouris (2020) and Levante et al (2022) identified sleep as a risk factor to violent offences. Cohen and Tsiouris's (2020) study looked at individuals in the community with an intellectual disability, accessing services in New York (USA), their sample included 4675 individuals (204 with a diagnosis of autism). They explored triggers of aggression in this sample, including whether autism was associated with particular triggers, and types of aggression. They found sleeping difficulties in all comparison groups were associated with an increase in physical aggression towards others. Levante et al (2022) identified participants online, and 43 parents of autistic adults completed an online survey regarding aggression, behavioural difficulties, sleep-wake routine and negative emotional states. This study supported the association with sleep difficulties made by Cohen and Tsiouris (2020) and found that autistic adults engaged in increased physical aggression towards others during the COVID-19 lockdown when they did not adhere to their sleep-wake routine.

Other.

Cohen and Tsiouris (2020) found that “frustration”, “discomfort” and “change” were likely to act as triggers of physical aggression in autistic adults. These triggers were determined from the settings events of aggressive incidences as rated by staff working with the individuals. Van Buitenen et al (2021) found autistic individuals with increased susceptibility to be influenced by negative social networks were more likely to engage in violent acts.

The results of the reviewed papers indicated a number of risk factors, the identification of which is hypothesised to support the development of interventions and support for autistic individuals who commit violent offences as well as identifying high risk autistic individuals, and providing additional support, prior to contact with the CJS.

Discussion

The purpose of this review was to provide an understanding of the evidence on risk factors associated with violent behaviour in autistic adults since 2014. Further understanding of these risk factors will allow forensic staff and clinicians to provide more meaningful interventions and support to autistic people who have contact with, and are detained within, the CJS. Following a systematic search of the literature between 2014 and 2022, data extraction and a quality appraisal of the identified papers, the findings posited were described in two broad categories: comorbidities and individual risk factors.

Comorbidities and individual risk factors for violent offending in autistic adults

Co-occurring psychiatric diagnoses appear to be important in identifying which autistic people may be at increased risk of engaging in violent behaviours. Consistent with previous findings in the CJS (Collins et al., 2022; King & Murphy, 2014; Im, 2016) the current review identified that comorbidities with ADHD and conduct disorder were associated with increased violent behaviour in autistic offenders (Blackmore et al., 2022; Heeramun et al., 2017; Hofvander et al., 2019). In addition, in the current review, van Buitenen et al (2021) identified further comorbidities of interest, including substance use disorder, schizophrenia and psychosis; previously identified by Del Pozzo et al (2019).

Individual risk factors were identified for autistic offenders which have similarly been found in non-autistic offenders, such as demographic variables (Blackmore et al., 2022; Hofvander et al., 2019; van Buitenen et al., 2021) parental histories (Heeramun et al., 2017) and sleep difficulties (Cohen and Tsiouris, 2020; Levante et al., 2022). Further risk factors specifically associated with a diagnosis of autism were identified by a number of papers; preoccupation (Allely et al., 2017; Allely & Faccini, 2019; Murphy 2014), sensory sensitivities (van Buitenen et al., 2021), impaired theory of mind (Higham & Edwards, 2020) and social difficulties (Allely

& Faccini, 2019; Higham and Edwards, 2020). Factors associated with receiving a diagnosis of autism, such as age the diagnosis was received (Heeramun et al., 2017) and acceptance of the diagnosis (Allely et al., 2017; Allely & Faccini, 2019) also conveyed increased risk.

Im (2016) similarly concluded that risk factors associated with violent behaviour in autism included impaired theory of mind, intense and restricted interests, sleep difficulties and co-occurring psychiatric diagnoses. Risk factors not identified in the current review, but posited in Im's (2016) review included less severe overall and social affect symptoms, and both younger and older age. Furthermore, Im (2016) identified that higher parental income was associated with increased violent behaviours where the current review identified lower socioeconomic status as an individual risk factor. These additional risk factors were likely identified due to the broader scope reviewed in Im's (2016) paper. Some of the factors not identified by the current review were associated with increased risk in children and adolescents, such as a younger age (between 6-11 years), less severe overall symptoms and higher parental income. In the current review, a novel risk factor was identified regarding the age in which people received their autism diagnosis and their acceptance of the diagnosis.

Literature quality

The appraisal of the papers reviewed in the current paper indicated differing levels of quality. Seven of the eight quantitative studies scored 4/5* or 5/5* on the quality appraisal tool, however all three of the qualitative studies scored just 1*, indicating a high level of bias.

Previous reviews have suggested a significant lack of good quality research as a considerable difficulty in reaching viable conclusions in this field of interest (King & Murphy, 2014; Im, 2016). King and Murphy (2014), who provided a systematic review of autistic people and the CJS, and Im (2016), who reviewed more specifically literature on autism and violence, did not use quality appraisal tools in their reviews but concluded that there were a number of methodological issues in the papers reviewed, such as biased samples, and lack of consistency in language and methods used. A more recent update of the King and Murphy (2014) review did include a quality appraisal tool (Collins et al., 2022) and found similar issues in their papers.

It is hypothesised that the higher level of quality in the current review is indicative of the narrower scope of literature reviewed. Previous reviews have looked more broadly at the relationship between autistic people and the CJS, with less specificity in the participants, nature of violence, and diagnosis of ASD. Previous reviews have specifically identified that many of the samples were derived from forensic and mental health services, allowing for bias in the samples. Of the eleven papers included, three of the papers reviewed in this paper recruited samples from both the community and inpatient services or forensic settings, and two studies recruited their samples in the community. Samples recruited through forensic and hospital settings may differ from community samples, due to the higher levels of co-occurring mental health difficulties. This is important to consider when determining whether the likelihood of violent behaviour is associated with autism, or whether it is a cause of mental health diagnoses and/or other, individual, factors. Although the quality of the papers was, overall, relatively good; due to the different populations and recruitment methods used, direct comparison between the studies is difficult.

Limitations

The current review is limited by the available research in the specified field. Just eleven papers met the inclusion criteria, resulting in a limited scope of data. Although the purpose was to increase the specificity of the research question, much of the literature of interest did not meet the criteria due to lack of clarity in both the definition of violence and the diagnosis of autism.

There remain considerable gaps in the current research field, for example it has been recommended that research explore the association between trauma in autistic adults and violent behaviours (Im, 2016). Over the past six years this continues to be an area with a stark lack of research, despite research having suggested trauma as a risk factor for violence in non-autistic people (Bosqui et al., 2014; Neller et al., 2005), as well as research suggesting increased experiences of trauma in people with developmental disorders (Peterson et al., 2019; Reiter et al., 2007).

Methodological issues impacted on the quality of the literature reviewed. For example, some of the papers relied on retrospective data and did not report incomplete data sets or drop-out rates (Murphy, 2014; van den Boogert, 2021). In addition, one paper used a snowball method to recruit participants, likely resulting in a high level of bias (Levante et al., 2022). All the qualitative data in the review were taken from individual case studies. The data presented in qualitative studies were specific to the individual described, and therefore the findings may not be reflective of the broader autistic population. For example, although all case studies described comorbid psychiatric diagnoses in their cases, it is important to recognise that these comorbidities may not result in increased violent offending in the wider autistic population and may have been relevant just to the individuals described. A further limitation of the current review is that the qualitative research in the review does not explore the perspectives of relevant risk factors from the cases themselves. The absence of larger scale qualitative data in this field reduces the opportunities for exploring risk factors from autistic people’s perspectives, and removes their voice from the field of literature.

The review is further limited due to the different methodologies used in the papers, this makes it difficult to differentiate between the risk factors in terms of the severity and nature of the impact that they have on violence and physical aggression; limiting the clinical application in treatment prioritisation. A limitation relating to the specific nature of the systematic literature review is that a second rater for the quality appraisal of the papers was not used, having a second rater would have increased the reliability of the appraisal.

Clinical Implications and recommendations for future research

Given that a reliable set of risk factors are more commonly associated with violence in autistic people, there remains a question regarding how this can be usefully employed to reduce risk and support autistic people, as well as increasing their quality of life. Although there is not currently enough evidence to clearly identify interventions and pathways for reducing violence in autistic people, we can unpick some of the identified risk factors to identify interventions that might be helpful. For some factors this seems more straightforward, for example, for sleep difficulties and substance use disorder, where effective interventions exist for autistic people (Halstead et al., 2021; Helverschou et al., 2019). For autistic adults who have engaged in violent behaviours and have difficulties with sleep, research has suggested that education, advice and talking therapy are the preferred sleep interventions amongst autistic adults (Halstead et al., 2021). Only 7% of autistic adults reported wanting medication only as a sleep-related intervention (Halstead et al., 2021). By identifying sleep as a risk factor for violent behaviour in autistic adults, a treatment recommendation would be to prioritise non-pharmacological sleep intervention strategies. Autistic adults with diagnosed substance use disorder have been found to benefit from cognitive behavioural therapy (CBT) for substance use disorders that has been adapted to meet their ASD needs, including elongating the treatment and providing additional psychoeducation (Helverschou et al., 2019). By identifying substance use disorder as a risk factor for violent behaviour, this intervention could similarly be identified as a priority for autistic adults to support in managing their risk.

Other factors associated with violent offending in autistic people are unlikely to be amenable to change, such as age of diagnosis – though they may highlight advantages of optimising services more broadly. In regards to the more static risk factors, such as sociodemographic factors, and age of autism diagnosis, the key here is likely to lie in risk profiling for autistic people who have not yet offended. It is suggested that mental health services providing autism diagnoses for children and adolescents could be identifying these risk factors and facilitating discussions with local services around crime prevention.

Given that the current review has identified a number of different risk factors that might impact differently on autistic people, individual formulation is heavily indicated as an approach to explore and manage the risk of violence. The paper supports the recommendation of person-centred care and individualised risk assessments in autism (NICE, 2020). Autism is a heterogenic diagnosis and each person will have different experiences and risk factors that need to be identified and explored by clinicians and supporting professionals. By providing individualised and person-centred care plans, both in the community and in forensic and mental health services, we can better understand and manage risk.

Further effort should be put into developing clarity in the language used in this field of research. With more consistency in definitions for violence, autism and criminal behaviour, a more accurate understanding of this relationship can be reviewed. Further research is needed to clarify the gender differences of violent behaviour in autistic adults, as well as particular age groups. Both older age, and younger age have been associated with increased risk (Im, 2016), however future research should aim to clarify the distinction between ‘violent’ behaviour in autistic adults, and ‘aggressive’ behaviour in autistic children. To provide more specific treatment recommendations, future research should aim to explore all suggested risk factors in one data set, using the same methodology. This would allow for risk factors to be compared and differentiated in regards to how they impact on an autistic adult's risk. In addition, qualitative studies are recommended to determine the personal experiences of autistic adults who engage in violent offending. Qualitative research would be pertinent to determine autistic peoples' perceptions of the risk factors that led them to behave in this way and to facilitate their voices being heard in the research field.

Conclusion

This review aimed to update and review the current understanding of why autistic individuals commit violent offences. Although there are notable gaps in the research field, and some methodological difficulties, the findings of the current review supported findings posited by previous reviews identifying that risk factors for violent offending in an autistic population include comorbidities, such as ADHD, conduct disorder and substance misuse; difficulties associated with the dyad of impairments in autism, including sensory sensitivities, restricted interests and preoccupation; and individual risk factors, such as socio-demographic backgrounds, sleep difficulties and increased susceptibility to negative peers. Whilst we have identified factors that can increase risk of violence in autistic adults, there is a subtlety and a specificity that we need to explore further. To make more specific treatment recommendations, further research is recommended to explore the specificity in language, as well as identifying the nature of the impact of these risk factors on a person's risk of violence, including frequency and severity.

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CHAPTER TWO: TRIGGERS TO INTENSE EMOTIONAL RESPONSES IN AUTISTIC ADULTS THAT HAVE BEEN IDENTIFIED AS SHOWING EMOTIONAL OUTBURSTS IN A SECURE SETTING

Abstract

Introduction

Autistic people have difficulty recognising and regulating their emotions, which can result in increased emotional outbursts. In secure mental health settings, autistic people face both social and physical constraints. The specific triggers in these settings for autistic people are underexplored and specialist autism services are under-researched, making it difficult to develop appropriate settings for this population.

Method

Participants were recruited through a secure inpatient autism specialist service in the UK. All participants were reported by their clinical teams as having experienced emotional outbursts in the setting. Participants engaged in a semi-structured interview exploring triggers for emotional outbursts in the hospital. Data were analysed using reflexive thematic analysis.

Results

Three over-arching themes were generated: 1. ‘having a lack of personal agency’, 2. ‘not being in a therapeutic environment’ and 3. ‘not feeling cared for’ and each theme had two subthemes. The two subthemes for theme 1 were I’m “voiceless and powerless”, and “I’m stuck here”. Theme 2 was divided into “this is the opposite of an ASD friendly ward” and “it’s an invasion of privacy”, and for theme 3 the subthemes were “no-one cares about us” and “there’s really no harm in people respecting each other”.

Discussion

Recommendations were discussed with reference to previous research and evidence, as well as specific recommendations made by the participants in the study. The impact of recommendations not being followed is discussed in reference to each theme, as well as the current barriers to change in mental health services.

Introduction

Autism and emotional dysregulation

Autism is associated with intensified emotional responses and poor emotional control (Geller, 2005; Mazefsky et al., 2013), and this can result in increased aggression and emotional expression (Beck et al., 2020). Autistic people can often experience variable and intense states of arousal, resulting in aggression as a way to experience relief from negative feelings (Geller, 2005). Expression of these emotional states can vary across individuals and across time (Chung et al., 2022).

Aggressive behaviours displayed by autistic people have been referred to as ‘challenging behaviours’ (Chiang, 2008), ‘externalising behaviours’ (Neuhaus et al., 2019) and – when in the context of an observable emotional response – ‘emotional outbursts’ (Chung et al., 2022).

Further terms used interchangeably with emotional outbursts include ‘temper outbursts’, ‘tantrums’, ‘rages’ and ‘meltdowns’ (Chung et al., 2022). For the current research, given a focus on the emotional underpinnings of observable behaviour, the term emotional outburst is preferred. However, when describing previous literature, the term identified within that literature has been used.

Autistic people can find it difficult to regulate their emotions due to their intense emotional response to triggers (Mazefsky et al., 2013). Many autistic characteristics have been associated with difficulties in emotion regulation, such as difficulties in identifying and recognising one’s own emotions, and labelling and sharing emotions with others (Mazefsky & White, 2015), as well as deficits in theory of mind, including difficulties in recognising others’ perspectives (Samson et al., 2012). Autistic people may have impairments such as cognitive inflexibility and difficulties perspective taking, resulting in difficulties developing adaptive strategies, for example cognitive reappraisal (Mazefsky et al., 2013). Autistic people who struggle to adopt emotion regulation strategies are likely to experience increased negative emotions, and express maladaptive behaviours, such as ‘temper tantrums’, swearing and impulsivity (Samson et al., 2015). A lack of emotion regulation strategies can similarly result in increased externalising behaviours (Neuhaus et al., 2019), and aggression (Mazefsky & White, 2015).

Emotion dysregulation can cause considerable difficulties in education, employment and relationships for autistic people across the lifespan (Geller, 2005). Furthermore, the behavioural manifestations of poor emotional regulation can have a significant negative impact on the mental health and wellbeing of autistic people. For example, externalising behaviours are one of the most common presenting difficulties for families with autistic children who present to mental health services (Neuhaus et al., 2019). When difficulties with externalising behaviours continue to adulthood, this can impact on an autistic person’s wellbeing and quality of life, interfering with the ability to succeed vocationally and live independently (Ballaban-Gil et al., 1996).

In the context of poor emotion regulation, autistic people may develop individualised ways of managing and expressing their emotions such as stimming, such as stereotyped or repetitive movements (Kapp et al., 2014), internalising (Neuhaus et al., 2014), self-injurious behaviours (Hirstein et al., 2001), and emotional outbursts (Chung et al., 2022). Due to a lack of understanding, non-autistic people often misinterpret the behaviour of autistic people (Kapp et al., 2014) resulting in interpersonal conflicts and judgement. When you consider an environment which has increased monitoring and expectations of behaviour, such as forensic, or secure hospital settings, these misunderstandings can result in significant, life-altering, difficulties for autistic people.

Despite the considerable, life-long, impact emotion dysregulation has on the lives of autistic people, research into the experience of emotions in autistic people has been limited (Mazefsky et al., 2013). To better understand the experience of emotions, recognise the triggers for these emotions and identify how to better support autistic people to develop additional strategies, further research is needed. The autism community, including autistic adults, families of autistic people and stakeholders have suggested further research should focus on issues that impact on autistic people’s day-to-day lives (Pellicano et al., 2014). In addition, the majority of research focuses on autistic children, often ignoring autistic adults altogether (Pellicano et al., 2014). In order to support autistic adults effectively in their ability to regulate emotions and reduce subsequent emotional outbursts, we need to develop a better understanding of the aetiology of these emotions (Ashworth & Tully, 2016), and to understand them in the context that the autistic person is currently in.

Autism and secure settings

As described in chapter one, it is reported that autistic people are overly represented in secure settings, including prisons and secure psychiatric hospitals (Alexander et al., 2011; Hare et al., 2000; Im, 2016; Scragg & Shah, 1994). The exact prevalence of autistic people who have offended is unknown; however, it is clear that there is a significant number of autistic people in forensic settings (Esan et al., 2015).

The importance of addressing the context and environment for which autistic people find themselves in was identified by Wing (1997), who reported that autistic individuals in inappropriate settings were more likely to engage in challenging behaviour. Autistic people in prison will likely experience difficulties arising from the social and physical constraints of the environment; the same can be said for secure hospitals and some autistic people may find these settings challenging and distressing due to the lack of specialist knowledge and implementation of restrictions (Allely, 2018). Conversely, other researchers have suggested that autistic people may benefit from such environments, due to the predictable routine and clear expectations depicted in the settings (Allen et al., 2008).

A literature review by Robertson and McGillivray (2015) identified that autistic people may experience increased difficulties in secure environments, including interpersonal conflicts, isolation and longer terms of imprisonment. They posited that autistic people may experience increased victimisation and social misunderstandings, resulting in frustration and rumination. Where these feelings are expressed as emotional outbursts, it could be misunderstood as challenging or resistant behaviour by staff, resulting in increased restrictions being placed on the individual (Robertson & McGillivray, 2015). In addition, the lack of available intervention programmes for autistic people in both prisons and secure hospitals, results in limited opportunities to engage and address their risk of recidivism, and consequently longer periods of stay in these settings (Robertson & McGillivray, 2015). Given the impact that emotion dysregulation difficulties have on autistic people throughout their lives (Ballaban-Gil et al., 1996; Geller, 2005), it is important to develop services that support and enhance these skills for autistic people, rather than increasing the difficulties they face.

A lack of empirical evidence to provide appropriate guidance has resulted in difficulties developing specialist autism services (Woodbury-Smith & Dein, 2014). Many autistic people in the criminal justice system and in secure hospital settings are not receiving care that is ‘tuned’ in to their specific needs (Woodbury-Smith & Dein, 2014). An important factor in developing appropriate pathways for autistic people who offend is further qualitative research identifying the needs and experiences of autistic people in these pathways, as well as sufficient training for staff involved in their care (Woodbury & Dein, 2014).

It is pertinent to develop a better understanding of the needs of autistic people in secure environments, and recognise the impact of their environment on their well-being and presentation. By exploring the needs of the individuals’ in these services, we can create more suitable settings allowing for effective rehabilitation and therapeutic environments where autistic people can feel able to engage in programmes and activities to better manage and reduce challenging behaviour.

The current study

The current study looks specifically at autistic adults currently detained in a secure hospital and explores their experience of triggers for intense emotional states in this environment. Previous literature has predominantly focused on children and young people and has relied on the perceptions of their parents and caregivers to determine triggers of negative emotional experiences as manifested in the form of emotional outbursts (Beauchamp-Châtel et al., 2019; Goldin et al., 2013; Tureck et al., 2013).

The current study recruited autistic adults, who were identified by their clinical teams as experiencing emotional outbursts in the context of a secure setting. The study qualitatively explored the specific triggers in secure services experienced by these individuals, from their perspective, with the aim of making clinical recommendations to improve the environment to better meet autistic adults' needs, and reduce their experience of emotional outbursts.

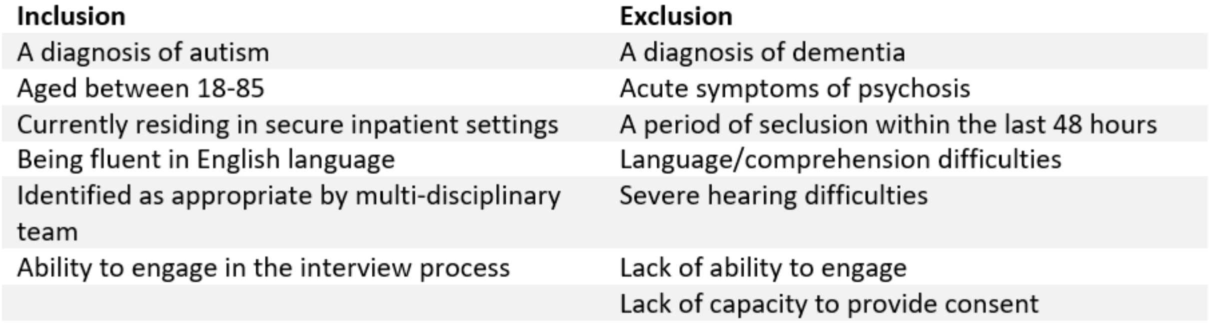
Method

Participants

Participants were recruited from a secure psychiatric hospital in the United Kingdom. All participants were residing in medium or low secure wards specialising in the care of autistic adults. Inclusion and exclusion criteria were sent to the responsible clinicians on four specialist autism units in the hospital, which consisted of approximately 35 autistic adults at the time of recruitment, who identified all participants that met these criteria (see table 1). Of these service users, five were not considered to meet the criteria; one due to being non-verbal, and four due to their mental state at the time of recruitment. In addition, a summary of the study was sent to multidisciplinary teams to identify whether individuals would be able to engage meaningfully in the study. For example, it was considered whether the service users had experienced triggers for intense emotional responses, and expressed subsequent emotional outbursts in the setting, and whether they would be able to manage the questions in the interview without experiencing distress.

Table 1.

Inclusion and exclusion criteria.



Inclusion	Exclusion
A diagnosis of autism	A diagnosis of dementia
Aged between 18-85	Acute symptoms of psychosis
Currently residing in secure inpatient settings	A period of seclusion within the last 48 hours
Being fluent in English language	Language/comprehension difficulties
Identified as appropriate by multi-disciplinary team	Severe hearing difficulties
Ability to engage in the interview process	Lack of ability to engage
	Lack of capacity to provide consent

Of the twelve participants who expressed further interest, three were later excluded: two due to being discharged from inpatient settings, and one due to being in a period of seclusion. Of the nine participants, the mean age was 33.5 years (*SD* = 10.4; range = 24–55). All participants were recruited from male wards in the hospital, six participants identified as male (66.6%), and three participants identified as female (33.3%). Seven participants had a diagnosis of 'childhood autism' (77.7%), and two had a diagnosis of 'Asperger's syndrome' (22.2%). Eight of the participants had engaged in either physical or verbal aggression in the last year, as reported on the risk management information system, Datix. All participants were noted, by their care team, to have experienced emotional triggers whilst in the secure hospital setting.

For the purpose of the study and to maintain anonymity, all participants were given a participant number which was subsequently assigned a pseudonym based on a random geographical location.

Measures

A semi-structured interview was created for the purposes of the current study (see appendix 2). The semi-structured interview consisted of five main sections: introduction, impact of having emotional outbursts, contextual pathways for emotional outbursts (i.e., emotional triggers), impact of COVID-19 on emotional triggers and closing questions. The interview consisted of 16 open-ended questions, to facilitate shared personal experience, with 33 follow-up questions and/or prompts to support the focus of the interview. The interview schedule was presented to a consultancy group of autistic adults at the University of Birmingham, in order to ensure that the interview schedule was appropriate for the target population. Modifications were made, for example, including the option for participants to write answers down, take questions away to think through, and the use of emotions cards if necessary.

In line with research, and where appropriate, the interview was adapted depending on the topics raised and explored in the interview, and certain topics were built upon or removed for certain participants. This method allowed for further exploration of particular topics of interest and provided the participants a degree of freedom in what they wanted to express in the interview (Horton et al., 2004).

For the purpose of the current paper, emotional outbursts were defined as a behavioural response with an emotional or explosive component. This behaviour might include verbal or physical aggression, towards others, the self, or objects. At the beginning of each interview, a collaborative definition of the term ‘emotional outburst’ was determined with the participant. Alternate terms identified by participants included “rage flare” (Jackson), and “aggression” (Lincoln). In order to ensure a shared meaning, each participant provided a definition of an emotional outburst that was meaningful to them, such as “shouting would be a less serious one [break]…attacking people would be a more serious one” (Brooklyn); “9 out of 10 times it’ll be verbal and then, if you tick my buttons, you’ve pressed the buttons too many times, and no one’s come to your aid, then yeah it might be violent” (Lincoln); “it cou-could just also be a build-up of emotion” (Jordan). Examples of the behavioural responses identified by participants included “punch[ing] the wall” (Phoenix), “intimidating people” (Hamilton), and “punching stuff” (Jordan).

Procedure

The study received ethical approval through the Science, Technology, Engineering and Mathematics Ethical Review Committee at the University of Birmingham on the 2nd of August 2021 (see appendix 1.) and was conducted in line with the depicted guidance and regulations. Data collection spanned across April and May 2022. All individuals meeting the specified criteria, as determined through their responsible clinicians and supporting multi-disciplinary teams (MDT), were provided with additional information regarding the current study through an identified member of their MDT. Those who expressed further interest were provided with an information sheet (see appendix 3). Following this, participants were provided with an opportunity to discuss the information sheet with the principle researcher prior to providing written consent (see appendix 4). Written consent was collected in person by the principle researcher prior to arranging the interview.

Semi-structured interviews were facilitated face to face by the principle researcher in the hospital. Each participant was given the choice of where they preferred the interview to be held. Eight of the interviews were held in the ward environment, in private rooms, and one interview was facilitated outside of the ward. One of the interviews was facilitated with a supporting staff member present, at the request of the participant, all other interviews were facilitated one-to-one. Eight of the interviews were conducted in one sitting, and one interview took place over two separate meetings. All interviews were recorded via an encrypted voice recorder, and were transcribed and anonymised, prior to the recording being deleted.

Analysis

All transcripts were analysed using reflexive thematic analysis (RTA) by the principle researcher. The purpose of using RTA was to develop an understanding of patterns and themes across the whole dataset to determine shared experiences between the participants.

The analysis process was guided by the six phases depicted by Braun and Clarke (2022). Familiarisation with the dataset facilitated meaningful insight and initial interpretation of the data. Following this, the full transcripts were individually coded, using both latent and semantic coding. Codes were then clustered across transcripts to form higher level codes and initial tentative themes. Throughout this process, codes were reformed across and within transcripts. For the next phase, re-engagement with the entire data set facilitated the review of the initial themes and further theme development. Themes were then refined and named, before beginning the final phase, of the analysis write up.

As an example of the process, the quote “questioning nurses is apparently a really evil thing for patients to do” (Austin), was given the code label of ‘not having a voice’, this code label was subsequently identified in a subtheme of ‘experience of having no power’ and positioned in the theme of ‘having a lack of personal agency’. Following further refinement, the quote was placed under the subtheme of ‘not having power in decision making’ within the overarching theme of ‘having a lack of personal agency’. The perception of being unable to question or voice concerns regarding the participant’s own care was identified as not having personal agency due to the perceived lack of ability to influence their own circumstances. This was particularly relevant in the process of decision making and the perception of not having the power to influence this process. To represent the participants’ voice throughout the paper, the subthemes were re-named using quotes from the transcripts; ‘not having power in decision making’ was subsequently named ‘I’m “voiceless and powerless”’.

The data were analysed from the position of recognising that individuals will interpret and experience the same reality in different ways. The purpose of identifying and developing patterns and themes across the dataset was to generate a collaborative meaning of these perceptions which appropriately reflected the experiences of the individuals. This critical realist approach aims to aid our understanding of the experience described by creating a bridge between the ontological reality and our epistemological knowledge (Vincent & O'Mahoney, 2018).

Reflexivity.

The use of reflexivity and the subjectivity of the researcher enhances the credibility and trustworthiness of the data presented in the findings (Smith, 2006).

Throughout the process of data collection, a reflective diary was written by the principle researcher and used to support the interpretation of the data. Prior to conducting this research the principle researcher had three years of experience working in specialist autism and neurodiversity inpatient services. In addition, they had experience managing and exploring the aetiology of emotional outbursts in these environments through Healthcare Assistant and Assistant Psychology roles. The present data were analysed in an inductive manner, with constant reflection on these experiences, including through use of the reflective diary, the principle researcher attempted to maximise the inductive nature of the analysis and bracket her own experience. Despite this, the previous experience and understanding of the principle researcher could not be ignored or dismissed completely, and played a role in the interpretation of the data.

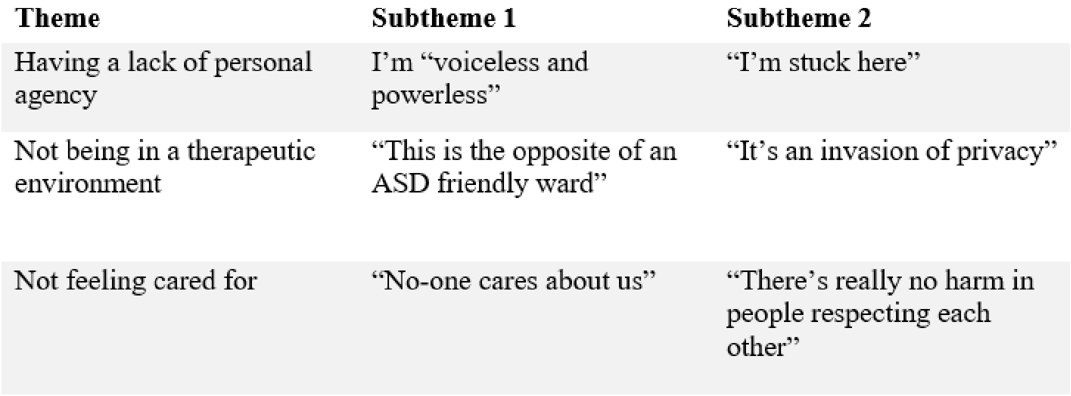
All data analysis was led by the principle researcher, however it was discussed and explored with the research supervisor, an academic researcher at the University of Birmingham. The research supervisor had been researching emotional outbursts in neurodiverse populations since 2005, working with families and stakeholders of children who engaged in emotional outbursts. Throughout the analysis process, mutual understanding of the data was discussed, with the principle researcher making the final interpretative decisions.

Results

The data were interpreted and analysed, and the principle researcher created three broad themes: *having a lack of personal agency*, *not living in a therapeutic environment* and *not feeling cared for*. Each theme had two subthemes which were named using quotes from the participants' transcripts (see table 3). All three themes encapsulated and represented experiences reported by the participants in the context of experiencing intense emotional responses in the secure hospital.

Table 3.

Themes and subthemes.



Theme	Subtheme 1	Subtheme 2
Having a lack of personal agency	I'm "voiceless and powerless"	"I'm stuck here"
Not being in a therapeutic environment	"This is the opposite of an ASD friendly ward"	"It's an invasion of privacy"
Not feeling cared for	"No-one cares about us"	"There's really no harm in people respecting each other"

Having a lack of personal agency

All participants described the experience of lacking personal agency in their own circumstances and decision making; being unable to question decisions regarding their care as "questioning nurses is apparently a really evil thing for patients to do" (Austin), and having restrictions imposed on them that left them feeling “confused” as the rules “[don’t] make sense” (Devon). The subthemes of being “voiceless and powerless” (Austin), and “I’m stuck here” (Jackson) described the experience shared by the participants of having nowhere to turn in a system that they felt did not empower them to develop and create collaborative, and appropriate, plans for their care and progress.

Being “voiceless and powerless” encapsulated the feeling amongst the participants that their “control [was] taken away from [them]” (Lincoln). Many of the participants described being unable to voice their opinions and share their experiences as they would not be believed, with “staff think[ing] they know better” (Devon). Lincoln reported that “it’s always the patient that’s wrong and not the staff”, despite their belief that “[staff] don’t always know better” (Lincoln). In this subtheme, the “complete imbalance of power” (Austin) is explored; participants described feeling at the mercy of the staff who, at times, would decline requests and impose restrictions because “hey, it’s just ‘cause they don’t want to” (Paris). Hamilton suggested “just because you have the power to reject someone doesn’t mean that, like, that…that it doesn’t come from responsibility, you have the responsibility to be appropriate with the power” highlighting their similar experience that staff had rejected suggestions and requests without consideration and clear communication.

In this subtheme, having rules and restrictions placed upon the participants was included, the experience of many of the participants was that of rules being unjustified and not being communicated appropriately, leaving them feeling “powerless and voiceless”. Participants described the impact of having rules and restrictions imposed on them in the setting, and Devon reported “if there is less restrictions, I do a lot better”, and noted that confusion regarding some of the restrictions can lead to “aggression” (Devon). Similarly, Lincoln reported that “restrictions can rub you the wrong way” and that “living in a restrictive environment” is a trigger (Lincoln). Understandably, the COVID-19 pandemic resulted in increased restrictions in the environment, and consequently, family visits and activities being cancelled; these increased restrictions were described by the participants as “bloody stupid” (Devon), and “frustrating” (Brooklyn & Jordan), resulting in participants being unable to see family and friends, which “made it really hard for [them]” (Pheonix).

The second subtheme of “I’m stuck here” (Jackson), described the sense of the participants losing their freedom and feeling that there “isn’t a drive to get people out” of hospital (Austin). Participants described the emotional trigger of not wanting to “be cooped up here” (Jackson), and having to “stay in a small box” (Hamilton), with Jordan reporting that “we’ve got no outlet, so we literally can’t go out of the building and have a walk”. Participants reported that because of the lack of outlet, this led to feelings such as “anger” (Brooklyn), and “frustration” (Devon & Brooklyn), and resulted in increased aggression, with Lincoln describing that “when I feel cornered I shout my mouth”, and “when I was in the community I could get away from that aggression” (Lincoln).

The feeling of losing their freedom and being “stuck” in the hospital system was exacerbated by a lack of hope that their progress back into the community was being prioritised. Lincoln reported that “the hospital can keep you for the rest of your life”, which was supported by Austin who noted that “there’s not really much impetus to try and get people moving out of this place”. The lack of push for progress was an ongoing theme throughout the data, with Devon suggesting that “sometimes doctors being overly cautious” was a trigger.

Not being in a therapeutic environment

The environment of the hospital wards was identified as a trigger for emotional outbursts by a number of participants, and led to the development of two subthemes regarding the environment; “this is the opposite of an ASD friendly ward” (Hamilton), and “it’s an invasion of privacy” (Austin). The subtheme “this is the opposite of an ASD friendly ward” summarised the triggers regarding autistic needs not being met on the wards such as sensory sensitivities, emotion regulation, and routine, as well as lack of therapeutic activities and lack of understanding from staff. “It’s an invasion of privacy” highlighted the lack of ability for the participants to escape the company of others, including staff and other peers. In particular, this subtheme covers the trigger concerning continual staff observations and being provoked by others.

In the “this is the opposite of an ASD friendly ward” subtheme, the lack of sensory modifications in the autism wards were highlighted by the participants, many of whom identified sensory sensitivities as triggers for emotional outbursts. One particular concern was the lighting, with Hamilton identifying that the lights in the hospital were “the brightest lights I’ve ever had in my life”, this was highlighted as a trigger for emotional outbursts, with Brooklyn reporting “I don’t like too much bright lights”, and Lincoln reporting “I’m light sensitive”, noting that the lights in the hospital cause “headaches and everything else”. In addition, the environment was described as a “loud, echoey environment” (Austin), with participants identifying specific noises that are distressing, such as “the office doors are normally get loud, when people get out and people shut them really, like slam the door” (Phoenix), and “high pitched and loud [noises are a trigger]” (Jackson). This trigger was associated with increased feelings of anger; “noise can be annoying and that, sometimes you feel angry” (Brooklyn), similarly expressed by Paris who reported staff “open and close the door and you’re like…that’s loud, I’m tryna sleep! Fuck off!” In addition, disruption to routine was identified as a trigger, with Jackson reporting “I have Asperger’s syndrome and err, you know, that, it involves routine and everything and seeing someone there [sitting in my seat] fucks up my routine basically”.

The lack of therapeutic activities was described as a trigger to emotional outbursts as participants felt they were not receiving appropriate treatment or being given the opportunity to engage in events to limit risky behaviours and work towards progress. Lincoln described being kept “bored all day, doing nothing all day”, and noted that “I’ve got nothing to do so I’ve gotta find things to do and unfortunately that triggers my risky behaviours” (Lincoln). Some participants appeared disheartened by the lack of therapy offered, with Hamilton reporting “they don’t, want to offer [therapy] to me, it would appear”, and Austin describing how “you’ve got patients left to rot here”. The lack of activities was further exacerbated during the COVID-19 pandemic, with participants reporting increased frustration during this time; “I’ve heard the excuse like we can’t do this because of the pandemic a million times” (Paris), “[COVID-19] was really bad, you know…everything was not-no, everything was cancelled” (Jordan).

In this subtheme, triggers related to the participants’ basic needs not being met were included. This involved not feeling they were in a safe and pleasant environment, as well as triggers around disruption to sleep, and receiving the right food. The hospital ward environment was described as “horrible, I think the current environment is really, again, not therapeutic” (Austin), with Paris describing their ward as “disgusting, that’s why I’m mainly in my room the whole time”. With a number of the participants reporting that their emotional outbursts had “got worse” (Lincoln), since being in hospital, as “the environment makes me more aggressive” (Lincoln). Devon reported that being in hospital can “deteriorate your mental health” and noted that “a lot of these triggers wouldn’t happen in the community” (Devon). Triggers specific in the environment included “not getting to sleep” (Paris), with Austin describing how “you’ve got a nightclub happening at 3 o’clock in the morning and then nobody can sleep”.

Not having an escape from others was represented under the subtheme of “it’s an invasion of privacy” (Austin). In particular, participant’s described the impact of regular observations, with Jackson reporting this has resulted in them “actually [throwing] something at the window” as they felt they were being “spied on” (Jackson). Participants were either on general observations, which meant having staff check on them every hour, or enhanced observations, which for the participants in this study, meant being checked on every 15 minutes. Participants reported this to be “a massive intrusion” (Austin), as they “don’t like being disturbed” (Lincoln), and this appeared to cause increased frustration with Devon describing “when someone keeps knocking on my door every 5 minutes [break] I said to myself ‘fucks sake am I ever gonna get a minute?’” In addition, participants described how their personal preferences on observations were not always adhered to, with Paris reporting they “don’t like being checked through [their] door”, however they found many staff would still do “checks through the door and everything” (Paris).

In addition to not being able to avoid staffing checks, participants described the impact of living with peers and reported this to be a trigger to emotional outbursts in some cases. In particular some found it difficult “dealing with p-my fellow um…peers, if you want” (Jordan), and that a trigger to an emotional outburst could be that “someone might take the mick out of you” (Jordan). Some participants reported that there were “too much people” (Pheonix) on the wards, and that it felt as though the hospital was “cramming, 10 autistic people in to a-a confined environment” (Austin), resulting in people “arguing all the time” (Austin).

Not feeling cared for

Not feeling cared for captured the two subthemes of “no-one cares about us” (Hamilton) and “there’s really no harm in people respecting each other” (Hamilton). There was a consistent pattern across the transcripts that suggested participants did not feel that staff on their teams, and the wider system they were detained within, were concerned about their well-being and quality of life. This appeared to have a considerable impact on levels of frustration and feelings of hopelessness amongst the participants.

The subtheme of “no-one cares about us” (Hamilton) encapsulated the feeling of being lonely and isolated in the system, and not having professionals fighting for the rights of the participants or working with them to facilitate therapeutic change. The quote used as the label for the subtheme captured that feeling, using inclusive language to describe how autistic people in the system have “no one” to look out for them. This is supported by other participants; Lincoln stated they “don’t care about that staffs feelings because they don’t give a toss about me, in my opinion the hospital doesn’t give toss about our feelings”. This feeling consequently resulted in a lack of concern regarding the impact of emotional outbursts on staff, and reduced inhibition when it came to engaging in aggressive behaviours. Hamilton reported “I know that it’s me against the world”, and stated that this subsequently meant their “defences are higher, stronger” (Hamilton). Other participants shared the experience of “no one cares about us”, with Paris reporting “[staff] don’t actually care”, and Devon stating “So, yeah I think that some staff, well basically, don’t give a crap”. At times, participants reported that this created a sense of lack of safety on the ward, with Austin describing a severe altercation involving physical aggression between two service users on the ward and “the nurses have all locked themselves in the office and aren’t coming to help”, causing Austin to feel threatened and reported that “this is not a safe environment”. The lack of safety was similarly identified by Devon who reported that when staff don’t engage in appropriate care “all you’re thinking about is your safety”. The feeling that staff did not prioritise the participants' safety and wellbeing was apparent across the transcripts. This was exacerbated by the lack of staffing available to create a safe, therapeutic space. Jordan identified not having enough staff as a trigger and reported "2,3 days we're short of staff…a little bit too much for me" and noted "you're like…why can't you just get staff?" (Jordan), Lincoln similarly identified that "they can't staff [the ward] properly" and Hamilton reported "there's always staff issues, with being shortages".

In this subtheme, the lack of use of care plans and understanding of the participants was captured; with many participants reporting that staff did not know what was best for them and did not regularly refer to their care plans to offer them the most appropriate support. Lincoln reported that "I've got a plan but it doesn't seem to be used" and that "since I've been on this ward it's never been actioned" (Lincoln). All service users in the secure hospital had care plans that should be collaboratively developed and consistently actioned by staff, however many participants reported that they were unaware of having a plan, or reported that they "dunno what's on there" (Phoenix) and other participants reported they were not appropriately or consistently used. Devon reported having a particular trigger regarding male staff and noted that their plan does "clearly say that if I can get irate, or anxious, it should be females available", however this was often not their experience on the ward.

The second subtheme in not feeling cared for, was named "there's really no harm in people respecting each other" (Hamilton) and summarised the perspective of the participants that they were not treated with respect, and often treated as less than staff due to their position as service users. This was highlighted by the experience of not being listened to, with participants reporting the struggle "just to try and get staff to fucking listen to me" (Paris) but experiencing that "[staff] don't wanna listen" (Lincoln), resulting in not getting requests met, with Jordan reporting that "you ask simple questions [break] but they haven't done either" resulting in "a head banging moment, not literally you understand [break] and it’s like….whhhyyy did you do that?” (Jordan).

Furthermore, participants reported that staff attitudes towards them can often be a trigger, with Lincoln reporting that “staff know how to push that button and they’ll press ‘em ‘til you snap”, Hamilton noted that “some people just deny the things you request because they know it will upset you” and some participants reported that language used by staff can result in feeling disrespected with Austin reporting there are “words they use commonly to undermine patients”, such as calling patients a “trouble maker” and describing patients as “entitled” (Austin). Jordan reported that “the way staff treat you as well” can be trigger, and that staff often have a lack of empathy towards the service users in the hospital; “I’d say it’s about staff understanding that…we’re here 24 hours a day, 7 days a week, 365 days a year” (Jordan).

The three themes generated from the data and described above identify a number of patterned experiences across the participants in the study that trigger emotional responses and behavioural outbursts in a secure hospital setting. Many of the triggers identified describe the impact of the staff and wider system on the wellbeing of the autistic adults in the study; including the lack of empowerment they feel and the significant emotional impact of being detained in secure services, the environment in which they are forced to live and the lack of priority placed upon their therapeutic needs. As well as the struggle of having a lack of privacy and being forced to have constant contact with both staff and peers, and not feeling cared for, looked after and prioritised by the system around them. All of these experiences were described in the context of having emotional outbursts in this setting and resulted in increased intense emotional states in the secure hospital setting.

Discussion

The aim of the current study was to qualitatively explore the triggers experienced by autistic adults in secure services, in particular, triggers resulting in intense emotional responses and emotional outbursts. All participants were recorded as having experienced emotional outbursts in the setting by their clinical teams and collaborative definitions of triggers and emotional outbursts were identified with each individual, as part of the semi-structured interview. Three overarching themes were generated from the data: having a lack of personal agency, not living in a therapeutic environment and not feeling cared for.

Having a lack of personal agency

The feeling of disempowerment experienced by service users detained in forensic and mental health settings is not a new phenomenon. The inherent power imbalance between a service user who is detained, often against their will, and the team who represent the system detaining them, is inevitable (Perlin, 1991). However, the impact that this can have on the relationship, and in particular on the service user, is often unspoken and unconsidered (Butchins, 2023; Perlin, 1991).

Previous qualitative studies exploring the experiences of people having involuntary mental health admissions have identified that service users have been left feeling ‘punished, violated, abused and helpless’ due to power imbalances in the service (Wyder et al., 2013). Research has suggested that services should aim to balance this power by allowing service users choice, by providing all necessary and available information to the service user regarding their care and treatment, and facilitating collaborative care by ensuring service users are involved in all treatment decisions (Wyder et al., 2013). These recommendations are underpinned by the recovery model of mental health, which identifies empowerment as one of the most important elements of maintaining a person’s well-being (Jacob, 2015).

Despite research and models making recommendations to balance the power in inpatient services, none of the participants in the current study felt empowered to make decisions regarding their care, nor did they feel listened to and respected by the service in regards to their treatment and plans for progress. Many of the participants appeared to take a passive approach to their care, for example, by not knowing what was on their care plans, or not knowing that they had one. When inherent power imbalances are present, patients can take a subordinate role, so as not to appear a “troublemaker” (Bell et al., 2018). Participants in the current study shared the experience of feeling that their words could be “used against [them] as abuse” (Lincoln), and felt they had “no recourse” (Austin). Mental health professionals may hold implicit negative attitudes towards their service users, and this can influence decisions and prejudiced behaviour towards service users (Kopera et al., 2015) resulting in misinterpretation of behaviour and increased restrictions. Implicit bias training can provide support in recognising and managing unconscious negative attitudes amongst staff and reduce the negative impact on service users (Merino et al., 2018), this is further explored in the recommendations.

The disempowerment experienced by autistic service users in inpatient care is underexplored, and much of the literature is based on non-autistic service users. The specific experience of autistic service users has recently been highlighted by Channel 4’s dispatches episode: Locked away: Our autism scandal (Butchins, 2023). The voices of autistic adults detained in mental health services were represented in the TV show, and supported the themes identified in the current study of feeling a lack of personal agency over their own treatment and care decisions (Butchins, 2023). Of note, Butchin’s (2023) televised portrayal of the experience of autistic people in mental health services should be interpreted with caution due to the lack of scientific data collection and analysis.

Although the presence of power imbalances are well known, the power imbalance in inpatient services remains a considerable concern at both a systemic and interpersonal level. There are a number of barriers to change in healthcare, including lack of knowledge, staff attitudes, and external barriers, such as time (Cabana et al., 1999). Further, staff's experience of 'confidence', 'de-motivation' and 'powerlessness' impact on the ability to implement meaningful change in mental health services (Laker et al., 2014). The barriers to change indicated by the research are consistent with the primary researcher's experience of the service in which the data were collected. Staff often appeared to be resistant to change and hold negative attitudes regarding the value of it; this is further supported by the current data, with participants identifying challenges in getting staff to listen to them, and staff being overly cautious.

Not living in a therapeutic environment

Many of the participants identified that their autistic needs were not met in the inpatient hospital setting. Although research has identified that the lack of empirical evidence makes it difficult to develop specialist autism services (Woodbury-Smith & Dein, 2014), the sensory sensitivities associated with an autism diagnosis are well documented. Autistic people are more likely to be sensitive to bright lights (Chamak et al., 2008), and noise (Landon et al., 2016). Both of which were identified as triggers by the participants in the current study, and it was reported by a number of participants that the noise and lights in the hospital setting were particularly difficult for them to process, resulting in increased emotional outbursts and having an impact on their overall well-being. This sensory sensitivity pathway to emotional outbursts has been highlighted by previous research (Chung et al. 2022) where sensory stimuli were identified as an antecedent to emotional outbursts in autistic young people (up to 25 years).

One of the main priorities of inpatient care is the safety of the service users. Regular staff observations are facilitated in order to ensure that the service users are safe and accounted for.

However, having regular observations as a blanket rule in services can be intrusive and impersonal (Cox et al., 2010). The monitoring of a service user's safety should be individualised and determined in collaboration with the service user (Cox et al., 2010; Kanerva et al., 2013). Participants in the current study reported that their preferences were not listened to and that they felt they were being "spied on" (Jackson) by staff. Participants felt that the observations were not conducted in an individualised manner; for example, although research has shown that autistic adults are at a higher risk of suicide (Newell, 2021), participants individually reported not being a suicide risk, and not having a history of suicidal ideation or behaviour; consequently meaning they did not feel the observations were warranted. The feeling that their care was not personalised or justified, resulted in increased frustration and feelings of anger towards the system.

Not feeling cared for

A further element of the recovery model of mental illness is being treated with respect and understanding (Jacob, 2015). Many of the participants reported feeling uncared for and disrespected by their staff teams and the wider system. Research has highlighted the importance of being 'acknowledged as a person', receiving personalised care and having 'staff that believe in you' when living in an effective therapeutic setting (Long et al., 2012). Participants in the current study identified that they felt staff did not listen to them or treat them in a respectful and personalised manner. The lack of respect that participants felt they received from others appeared to impact on their inhibition when expressing emotional outbursts, for example, Lincoln identified that due to feeling others did not care for them, they similarly "don't care about that staff's feeling" when engaging in emotional outbursts, or "aggression" as Lincoln termed this response.

Research has identified the importance of therapeutic relationships in secure services, and highlighted that when service users feel disrespected by their clinical teams this can have an overall effect on their dissatisfaction with the service and treatment they are receiving (Bressington et al., 2011). The participants' perception that the nursing team were not prioritising them or their well-being appeared to have an overall impact on the way in which they viewed the wider system and their ability to progress in it, with a number of participants identifying lack of progress and change as a trigger for emotional outbursts.

Limitations of the current study

One limitation of the current study lies in the definition and subjective nature of 'emotional outbursts' in secure services. All of the participants were identified as having experienced emotional outbursts by their clinical teams and via the risk reporting system, Datix. However, participants reported often feeling that staff would identify them as having an 'emotional outburst' despite them feeling they were appropriately expressing their emotions in a safe and contained manner. Participants identified this as "institutionalised behaviour" (Devon), whereby their emotional expressions could be used against them and reported as 'risk behaviours' or 'emotional outbursts' on their progress reports. In addition, many of the participants reported not perceiving themselves as engaging in emotional outbursts for significant periods of time, despite having risk related incidences recorded on their systems, and there appeared to be considerable differences in the reporting of incidences between staff and participants. It was hypothesised by the primary researcher that some participants may have felt unsafe discussing behaviours that may be considered 'risk behaviours' openly as they may have felt this would impact on the clinical perspective of them and their subsequent progress.

In addition, the role of the primary researcher may have impacted on the experiences shared in the interviews. When discussing the hospital and staffing teams, some participants used language that was interpreted as assuming the primary researcher was a part of that system, for example, when discussing staff in the hospital, Lincoln reported “your staff know how to push that button”. Although the primary researcher did not have any prior contact with any of the participants in the study, their role may have impacted on the data collected and analysed.

Lastly, the self-report interview may have resulted in some triggers being overlooked or under-explored in the analysis due to being overshadowed by triggers that were more consistent across the participants. Despite this being a limitation, the purpose of the research was to explore the collaborative experiences of the participants by getting their personal perspectives on the triggers for emotional outbursts in the environment.

Clinical implications and recommendations

The themes identified and explored in this paper highlight the need for further consideration to be placed upon the development and facilitation of autism specialist secure services, to support the wellbeing and safety of the service users. Prior research has identified a number of recommendations for balancing the power in these services, such as ensuring service users have access to all relevant information regarding their care, are included in their treatment decisions and are given choice where appropriate (Wyder et al., 2013). These recommendations are heavily indicated in the current paper and were suggested by the participants themselves. In particular, participants felt having choice in their multidisciplinary teams, including their psychologists and responsible clinicians, would enable them to feel more empowered in their care.

Further clinical recommendations implicated by the current study include the need for additional consideration regarding the ward environments. Identification of the sensory needs of autistic adults is necessary to ensure that the environment provides the appropriate level of sensory input to create a calm and therapeutic setting. Acknowledgement of the safety of the service users is equally necessary, for example, ensuring lighting allows for appropriate observation of the service users. However, collaboration is recommended with the service users on the unit to create a balance of the needs of the individual and the service; as well as to ensure that the service users feel involved in choices and decisions regarding the setting.

Many of the participants in the current study highlighted the lack of hope regarding their progress which impacted on their perception of being cared for and respected by the staff and the wider system. Research has identified the need for clear pathways for autistic adults in forensic and secure mental health inpatient settings (Woodbury & Dein, 2014), recommending that there needs to be adequately resourced inpatient and community pathways for autistic service users. By identifying appropriate community placements and having clear pathways that are communicated to the service user, it is hypothesised this would create an increased sense of hope and allow for the service users to feel supported and cared for. Where adequately resourced services are recommended, this would include facilitating specialised training for all staff in these services, as well as providing specialised therapeutic programmes and timetables (Woodbury & Dein, 2014). Research has identified the presence of implicit bias in mental health services (Kopera et al., 2015; Merino et al., 2018), the need for further training on implicit biases held by mental health professionals is recommended to ensure that behaviour is not misinterpreted as dangerous, resulting in disproportionate sentences and detainment in inpatient services (Merino et al., 2018).

Research has identified that boredom in inpatient mental health settings can have a significant impact on behaviour and well-being, resulting in increased smoking, aggression, absconsion and deterioration of mental health (Marshall et al., 2019). The lack of therapeutic activities on offer was identified in the current study as a trigger for emotional outbursts and was exacerbated by the recent COVID-19 pandemic. It is recommended that specialist autism units aim to create a collaborative understanding with the service users of what activities would be considered meaningful and therapeutic. Research has suggested that occupational therapists attend to boredom experienced by service users in inpatient mental health settings (Marshall et al., 2019), however it is recommended that this be considered an interdisciplinary problem and that all staff should be involved in ensuring that there are meaningful activities facilitated on the wards throughout the day. This recommendation is supported by research suggesting that mental health service users expect to receive therapeutic activities from nursing staff as well as further opportunities to build therapeutic relationships with all staff on their clinical teams (Hopkins et al., 2009).

As per the transforming care model, the current study heavily indicates person centred, individualised care, focused on creating a collaborative formulation of the needs of the individual, with the service user themselves, to identify a clear pathway through the system (NHS England, 2017). It is hypothesised that the participants in the study would have experienced reduced emotional outbursts if they felt they were empowered by, and involved in, their care and treatment. Being given the opportunity to work with the system to create a clear pathway for their own progress as well as inputting in to the therapeutic milieu of the wards would likely impact on all themes identified in the current paper.

All of the recommendations in the current paper are supported by previous research, the reason these are not being implemented needs further exploration. Of note, many of the participants in the current study felt that their recommendations and requests for change in the setting were not listened to. The difficultly of implementing change in services has been highlighted by previous research (Cabana et al., 1999; Laker et al., 2014). Research has suggested that interventions to increase openness to change may vastly differ from one service to another and therefore it is difficult to offer clear recommendations on how to manage this (Cabana et al., 1999). In order to determine why change is not being facilitated, it is important to recognise the barriers to change in the particular service (Cabana et al., 1999). Research has suggested measures to assess perceptions of barriers to change amongst staff, such as VOCALISE (Laker et al., 2014). It is recommended that services aim to determine the specific barriers to change amongst their staffing teams, and by identifying and addressing these barriers, services can facilitate appropriate training and support to overcome these.

Future research should aim to represent the voice of autistic adults in mental health systems by facilitating larger scale qualitative studies into the lived experiences of this population. By exploring the lived experiences of autistic adults in inpatient mental health settings we can develop a collaborative understanding and provide more in-depth meaningful clinical recommendations. Research should aim to explore what is going well in these services in order to educate future services in useful and positive practices that are currently being facilitated. Lastly, further research should aim to explore more clearly the barriers to change in secure mental health services, present research in this domain appears to focus on singular barriers, resulting in difficulties making generalised recommendations; research should aim to look at overarching barriers in services and explore how to overcome these.

Conclusion

This study explored the triggers to intense emotional experiences in autistic adults. The overarching themes identified in this paper included *having a lack of personal agency, not living in a therapeutic environment* and *not feeling cared for.* It is heavily indicated in the data that services should aim to work collaboratively with autistic service users in order to provide individualised, person centred care, as well as to acknowledge the inherent power imbalance that occur in secure settings. The difficulties in facilitating meaningful change in secure services is highlighted in the current paper. Services should aim to identify the specific barriers limiting the response to current recommendations. Future research should aim to continue to represent the voice of autistic adults in these services and explore their experiences through larger scale qualitative work.

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Chapter One: Press release

Research has identified that autistic people are over-represented in prisons and secure mental health hospitals, settings where they are misunderstood and underexplored. A new paper has reviewed the recent literature on why autistic people engage in violent behaviour, to help us to understand why autistic people are ending up in prisons and mental health hospitals and to see what we can do to better support them within these environments.

The new literature review explored research between 2014 and 2022 that aimed to identify why autistic people may behave violently. The research studies looked at specific factors that were present in autistic people who committed violent offences, described risk factors for specific autistic individuals who have committed violent offences or compared autistic and non-autistic people who have engaged violently to see what specific factors were relevant in autistic people. Eleven research papers were included in the review and the results suggested by the reviewed papers were split into two broad categories: co-occurring mental health diagnoses and individual risk factors.

According to the new literature review, research has found that co-occurring mental health diagnoses may be linked to violent behaviour in autistic adults. The most common co-occurring diagnoses in the research included ADHD, conduct disorder and substance use disorder, as well as other psychiatric diagnoses, such as schizophrenia and psychosis. One study included in the review found that as comorbid diagnoses increased, so did the likelihood of violent behaviour in autistic adults.

Further findings outlined that autistic people may be more likely to engage in violent behaviour if they experience increased levels of preoccupation, for example a preoccupation with violent weapons, difficulties with understanding others’ perspectives, higher sensory sensitivities and social difficulties. In addition, autistic people who have struggled with their diagnosis of autism, and therefore found it difficult to accept support, as well as those who received a diagnosis at an older age, may be more at risk of engaging in violent behaviour. Further individual factors found to be associated with an increased risk of violence included being male, having difficulties with sleep, and having parents who have engaged in criminal behaviour.

The new literature review suggested that the criminal justice system should aim to unpick these risk factors in order to determine the appropriate treatment plans and support that should be offered, on an individual basis. By identifying the individual risk factors relevant for each person, personalised care pathways can be determined to increase the chance of reduction in risk and increase in well-being of the individual. In addition, some of the risk factors identified in the new paper could be used for risk profiling in the community; the literature review recommends that services providing autism diagnoses in the community could be identifying risk factors, such as parental criminality and lack of acceptance of an autism diagnosis, and communicating with crime prevention services to offer support and reduce future risk of violence.

Autism does not cause violent behaviour, but by understanding more about the factors that may be associated with violent behaviour, we can consider how best to support autistic adults who do engage in violent behaviour, or who may be at increased risk.

Chapter Two: Press release

According to a new study, autistic adults report having emotional outbursts due to treatment in secure mental health services. Specialist inpatient mental health services, designed to support and rehabilitate autistic people who have experienced a mental health crisis, are not providing therapeutic environments that prioritise the wellbeing of autistic adults. New research has identified that autistic adults detained in a secure mental health hospital reported having no personal agency, living in an environment that is not therapeutic, and not feeling cared for, resulting in increased intense emotional responses and aggressive behaviours.

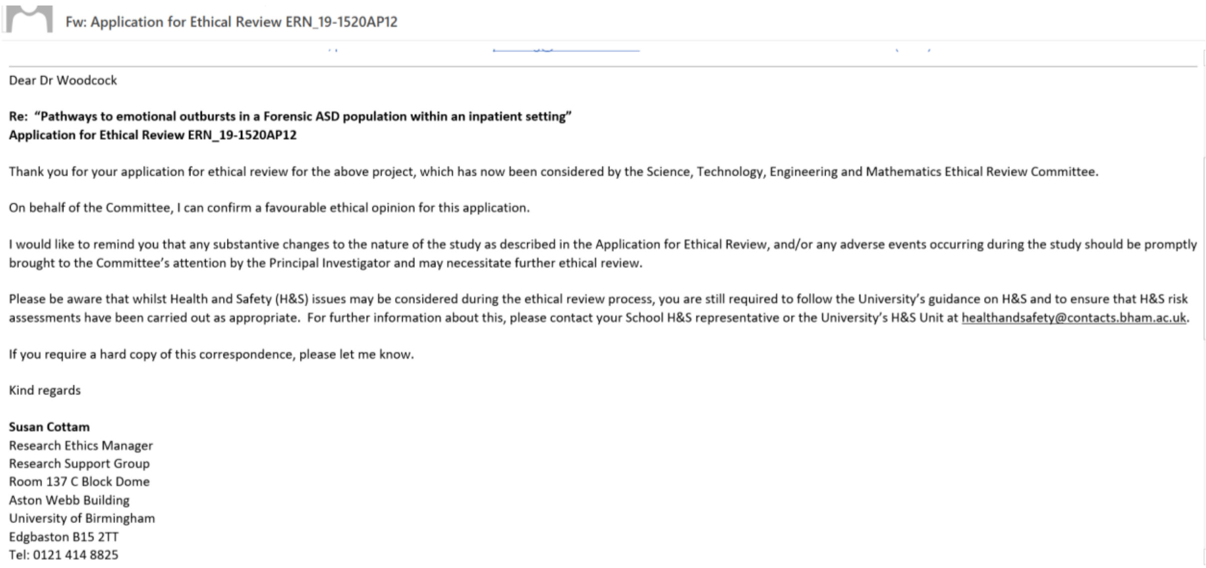
New research has explored the triggers for emotional outbursts in autistic adults living in a secure mental health hospital. Nine autistic adults engaged in interviews to identify the triggers that they had experienced since living in the hospital and explored the impact of the environment on their emotional states and responses.

Results of the research suggest that the hospital did not empower the autistic people living there, leaving them feeling “voiceless and powerless”. It was reported that considerable power imbalances in the system left the service users feeling unable to question decisions made about their care, and leaving them feeling unable to meaningfully work towards progress back into the community. Participants in the new study identified that the specialist autism units did not address their sensory needs, providing spaces with bright lighting, loud noises and a lack of therapeutic activities to engage in. This resulted in service users feeling overwhelmed by the sensory input in their environments, and experiencing increased levels of boredom due to having nothing to do during the day. In addition, the autistic adults in the study reported that “no one cares about us”; saying that it was difficult to get their staffing teams to listen to their requests and preferences. Participants reported feeling disrespected by staff on the units and unsafe in the environment. Many reported having negative relationships with staff teams due to low staffing levels, disrespectful language being used by staff and their care plans being ignored. These triggers resulted in increased emotional outbursts in the hospital, including feelings of “frustration” and “anger”, as well as “shouting”, “punching stuff” and “intimidating people”.

The new study suggests that specialist autism units should aim to meet the needs of their service users through understanding the individual triggers and sensitivities of each person, and working together with the service user to create a safe and therapeutic living space. The research identifies a number of clinical recommendations including involving service users in decisions made about their care, making sure service users have all necessary information to inform these decisions and allowing choice for the service user where possible. In addition, the new findings indicate that specialist autism services should outline clear pathways for progression by working with community placement providers to increase positivity and hope for the future. Lastly, staff within the hospitals should aim to create full and enriching timetables for the service users to engage in throughout their stay to reduce levels of boredom amongst service users.

Appendices

Appendix 1. Ethical approval



Fw: Application for Ethical Review ERN_19-1520AP12

Dear Dr Woodcock

Re: "Pathways to emotional outbursts in a Forensic ASD population within an inpatient setting"
Application for Ethical Review ERN_19-1520AP12

Thank you for your application for ethical review for the above project, which has now been considered by the Science, Technology, Engineering and Mathematics Ethical Review Committee.

On behalf of the Committee, I can confirm a favourable ethical opinion for this application.

I would like to remind you that any substantive changes to the nature of the study as described in the Application for Ethical Review, and/or any adverse events occurring during the study should be promptly brought to the Committee's attention by the Principal Investigator and may necessitate further ethical review.

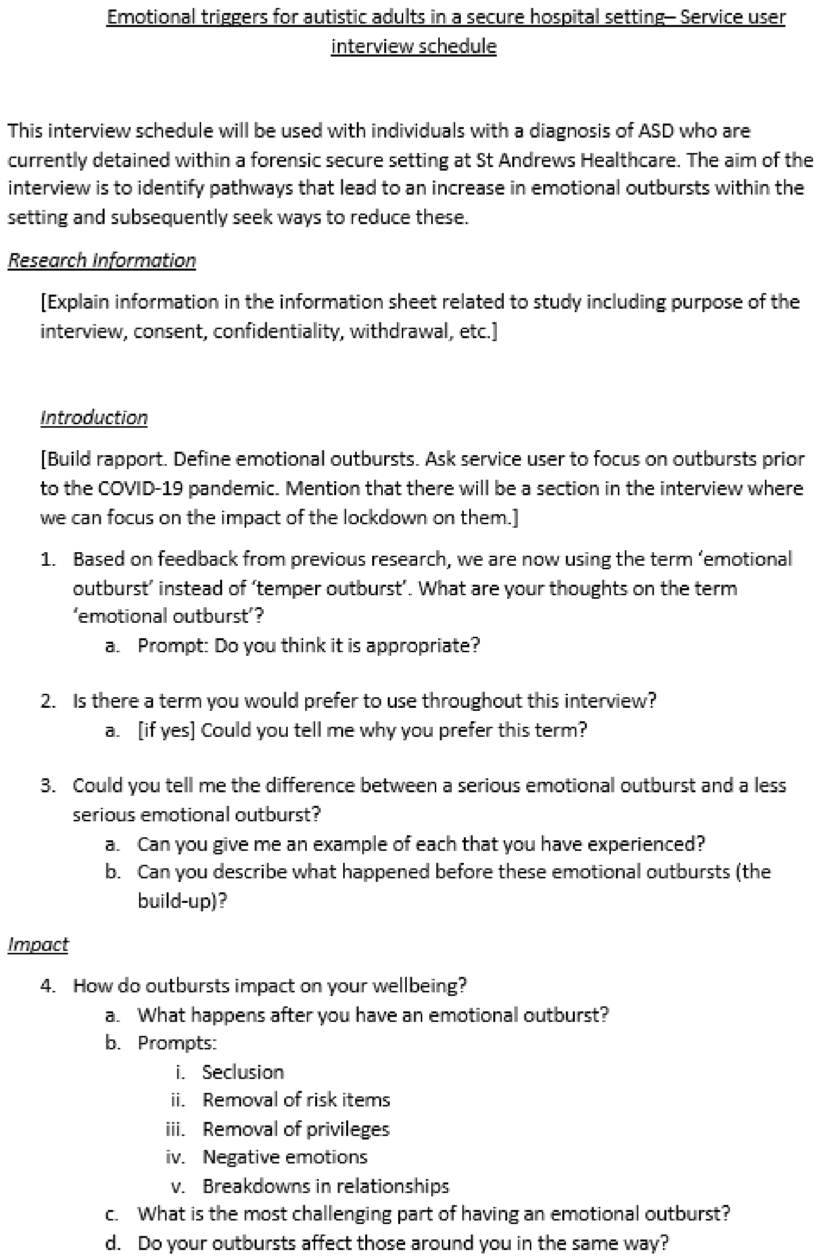
Please be aware that whilst Health and Safety (H&S) issues may be considered during the ethical review process, you are still required to follow the University's guidance on H&S and to ensure that H&S risk assessments have been carried out as appropriate. For further information about this, please contact your School H&S representative or the University's H&S Unit at healthandsafety@contacts.bham.ac.uk.

If you require a hard copy of this correspondence, please let me know.

Kind regards

Susan Cottam
Research Ethics Manager
Research Support Group
Room 137 C Block Dome
Aston Webb Building
University of Birmingham
Edgbaston B15 2TT
Tel: 0121 414 8825

Appendix 2. Interview schedule



Emotional triggers for autistic adults in a secure hospital setting– Service user interview schedule

This interview schedule will be used with individuals with a diagnosis of ASD who are currently detained within a forensic secure setting at St Andrews Healthcare. The aim of the interview is to identify pathways that lead to an increase in emotional outbursts within the setting and subsequently seek ways to reduce these.

Research Information

[Explain information in the information sheet related to study including purpose of the interview, consent, confidentiality, withdrawal, etc.]

Introduction

[Build rapport. Define emotional outbursts. Ask service user to focus on outbursts prior to the COVID-19 pandemic. Mention that there will be a section in the interview where we can focus on the impact of the lockdown on them.]

1. Based on feedback from previous research, we are now using the term 'emotional outburst' instead of 'temper outburst'. What are your thoughts on the term 'emotional outburst'?
    a. Prompt: Do you think it is appropriate?

2. Is there a term you would prefer to use throughout this interview?
    a. [if yes] Could you tell me why you prefer this term?

3. Could you tell me the difference between a serious emotional outburst and a less serious emotional outburst?
    a. Can you give me an example of each that you have experienced?
    b. Can you describe what happened before these emotional outbursts (the build-up)?

Impact

4. How do outbursts impact on your wellbeing?
    a. What happens after you have an emotional outburst?
    b. Prompts:
        i. Seclusion
        ii. Removal of risk items
        iii. Removal of privileges
        iv. Negative emotions
        v. Breakdowns in relationships
    c. What is the most challenging part of having an emotional outburst?
    d. Do your outbursts affect those around you in the same way?

        i. If not, can you explain why not?
    e. The goal of this research is to identify what is increasing the likelihood of you having an emotional outburst and try to reduce these. Could you describe what could be changed/improved to reduce your emotional outbursts?
        i. In the environment
        ii. In the therapies/interventions offered

Contextual pathways

5. What are the most important things that you think cause your outbursts? [if they used words such as *trigger* – use this word for questioning]

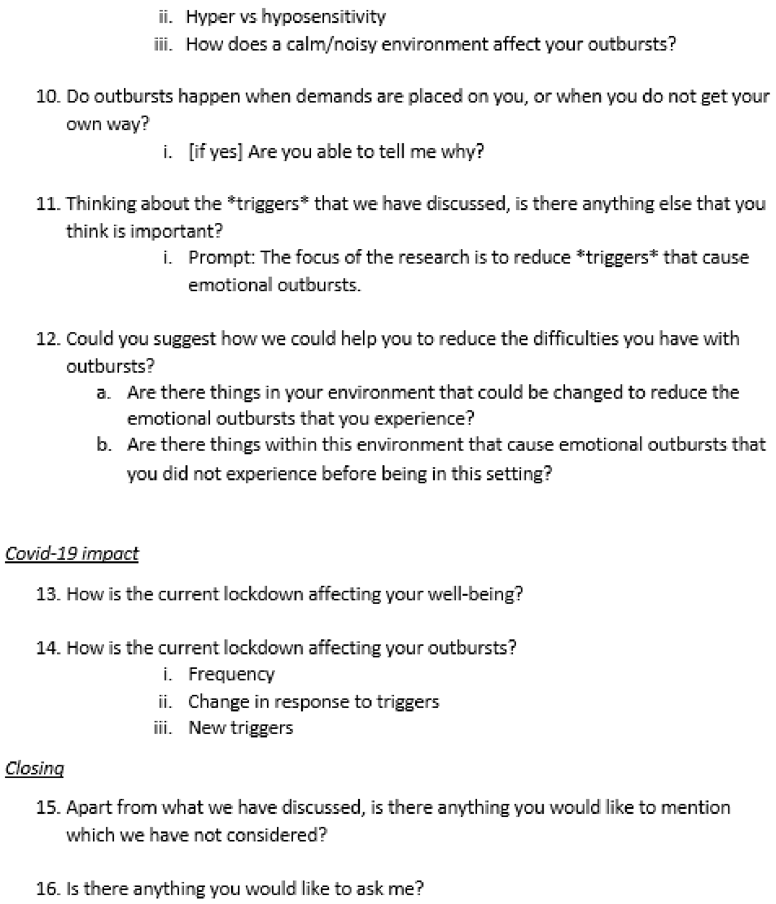
[Explain how background factors/setting factors can influence how we respond to *triggers* e.g if we are in a good mood, we might not experience an emotional outburst when faced with a *trigger*. However, if there are negative background/setting factors we might be likely to respond with an emotional outburst. Most people feel more on edge when they are tired. Everybody has different factors that might make them more or less vulnerable to an emotional outburst.]

6. What are the most important background factors or settings that might make emotional outbursts more likely to happen?
    i. Where you are
    ii. Who you are with
    iii. How you are feeling
        - Use prompt cards if appropriate
    iv. What you are doing e.g. Structured activity/down time

7. Can you think of a time when you have been exposed to an important *trigger* and you have not had an emotional outburst?
    a. [if yes] Why do you think this was?
    b. [if yes] What were the background factors?

8. Do you think being in a secure setting affects your outbursts?
    a. [If yes] In what way do you think this?
    b. Can you think of a time before you were in secure services that you experienced an emotional outburst?
    c. What were the background factors?

9. Does sensory sensitivity affect your outbursts?
    i. Explain how hyper/hyposensitivity to sensory stimuli is related to a diagnosis of ASD
    a. Could you describe how your sensory sensitivity is related to your outbursts?
        i. Different senses



    ii. Hyper vs hyposensitivity
    iii. How does a calm/noisy environment affect your outbursts?

10. Do outbursts happen when demands are placed on you, or when you do not get your own way?
    i. [if yes] Are you able to tell me why?

11. Thinking about the *triggers* that we have discussed, is there anything else that you think is important?
    i. Prompt: The focus of the research is to reduce *triggers* that cause emotional outbursts.

12. Could you suggest how we could help you to reduce the difficulties you have with outbursts?
    a. Are there things in your environment that could be changed to reduce the emotional outbursts that you experience?
    b. Are there things within this environment that cause emotional outbursts that you did not experience before being in this setting?

Covid-19 impact

13. How is the current lockdown affecting your well-being?

14. How is the current lockdown affecting your outbursts?
    i. Frequency
    ii. Change in response to triggers
    iii. New triggers

Closing

15. Apart from what we have discussed, is there anything you would like to mention which we have not considered?

16. Is there anything you would like to ask me?

Appendix 3. Information sheet

Participant Information Sheet

Title of Study: Pathways to emotional outbursts in individuals with a diagnosis of ASD within a forensic inpatient setting.

Name of Researcher: Martha Platt **Name of Chief Investigator:** Kate Woodcock

You are invited to take part in our research study.

Before you say yes or no, this form will tell you what the research is and what it means if you take part. Please ask if there is anything that does not make sense, or if you have any questions.

What is the purpose of the study?

To see why people with an ASD diagnosis have emotional outbursts. We would like to see if there are things in hospital that might make this worse and see how we can improve this.

Why have I been invited to take part?

You are being invited to take part because you have a diagnosis of ASD and you are in hospital. Your clinical team thought you would be able to take part in this study.

Do I have to take part?

No. You do not have to take part in the study. If you decide you do not want to take part, this will not affect any elements of your care.

What will happen to me if I take part?

If you do decide to take part, you will be given this information sheet to keep and be asked to sign a consent form. The researcher will then organise a time to come and complete an interview with you, the interview will look at some of your risk behaviours and things that might lead to these behaviours on the unit. The researcher will also look at some RiO data regarding your risk behaviours.

What happens if I change my mind about being in the study?

If you change your mind, you can tell us that you no longer want to take part in the study. You can change your mind at any time, without giving a reason – your care and legal rights will not be affected. If you withdraw we will remove your information from the study.

What are the possible disadvantages and risks of taking part?

The interview will look at some of your risk behaviours and situations that make you feel upset or distressed. This might make you feel upset or distressed. If you do, you can stop the interview and return to the ward. The researcher will let the nursing staff know, so that they can support you.

What are the possible benefits of taking part?

The researcher cannot promise the study will help you, but the information from this study may help other patients in the future. The results of the study can be shared with you, and your clinical team to help provide the best care on the ward.

What happens after all the information has been collected?

The information will all be collected together and compared to find any patterns about why participants experience emotional outbursts.

What if there is a problem?

If you have any problems, please talk to your clinical team who can ask the researcher to come and see you, or you can ask the researcher directly.

Will my taking part in the study be kept confidential (private)?

Yes. Your information provided during the interview will be kept **strictly confidential**. Only the people doing the research study can look at it. On the consent form you can choose whether your results are shared with your clinical team.

The researcher will let your clinical team know that you have participated in the study. Although what you say to is confidential, should you disclose anything which puts you or anyone else at any risk this will need to be discussed with your clinical team. The researcher will let you know if it occurs.

What happens at the end of the study?

Your contact information will be kept by the University of Birmingham for 12 months after the end of the study so that the research is able to contact you about the findings of the study (unless you advise us that you do not wish to be contacted). Everything you say in the interview will be confidential and kept separately from your contact details.

In line with the University of Birmingham's policies, the research data may be shared with researchers in other Universities and organisations, including those in other countries, for additional research in healthcare.

What will happen to the results of the research study?

The research will be written up for the Researcher's Doctorate in Forensic and Clinical Psychology. The research may also be published in a journal or at a conference. Your name and contact information will not be used or published.

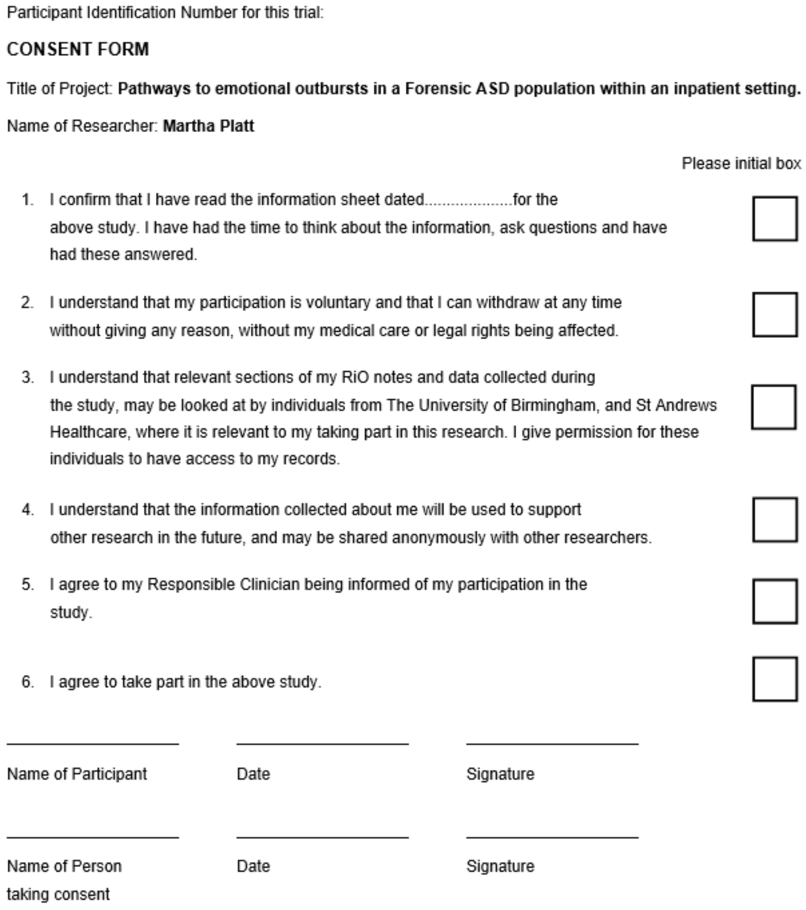
Further information and contact details

Contact details of the researcher, chief investigator and Head of School, will be given to your clinical team, who can also make contact with them on your behalf.

Thank you for taking the time to read this Information Sheet.

If you would like to take part in this research, please ask your clinician to contact the Researcher.

Appendix 4. Consent form



Participant Identification Number for this trial:

CONSENT FORM

Title of Project: **Pathways to emotional outbursts in a Forensic ASD population within an inpatient setting.**

Name of Researcher: **Martha Platt**

Please initial box

1. I confirm that I have read the information sheet dated....................for the above study. I have had the time to think about the information, ask questions and have had these answered. ☐
2. I understand that my participation is voluntary and that I can withdraw at any time without giving any reason, without my medical care or legal rights being affected. ☐
3. I understand that relevant sections of my RiO notes and data collected during the study, may be looked at by individuals from The University of Birmingham, and St Andrews Healthcare, where it is relevant to my taking part in this research. I give permission for these individuals to have access to my records. ☐
4. I understand that the information collected about me will be used to support other research in the future, and may be shared anonymously with other researchers. ☐
5. I agree to my Responsible Clinician being informed of my participation in the study. ☐
6. I agree to take part in the above study. ☐

____________________	____________________	____________________
Name of Participant	Date	Signature
____________________	____________________	____________________
Name of Person taking consent	Date	Signature