Prevalence of Autism within Medium Secure Units: a feasibility study

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Word count: 4602 words

Abstract

Previous research has indicated that autism is over-represented among inpatients in forensic high secure hospitals in England. The aim of this study was to assess the feasibility of estimating the prevalence of autism without an intellectual disability in medium secure units (MSU). Male inpatients on three MSU wards were approached to participate in the study following ethical approval. Patients who met the inclusion criteria and consented were

screened for autism using the AQ (Autism Quotient), and the EQ (Empathy Quotient). Out of a total of 46 patients on these wards, sixteen individuals were ineligible to participate. Of the remaining 30, 12 (40%) subsequently consented to participate. After ruling out an intellectual disability using the Schonell Graded Work Reading Test, these individuals were screened for autism using the AQ, and completed the EQ. None of those who participated scored above screening threshold for further diagnostic testing using the AQ. However, three inpatients (of the original 46 patients on these wards) were previously diagnosed with Asperger's Syndrome suggesting a prevalence of 6.5% (95% CI 1.7-.18.9 %). The results indicate that this group is over-represented within medium secure forensic psychiatric units and highlight the difficulties in undertaking research in this population.

Background

Autism Spectrum Disorder (ASD) is characterised by specific impairments in social interaction and communication and the pursuit of rigid and circumscribed patterns of behaviour (Wing 1981). The term Asperger syndrome was previously used to describe many individuals who fell into the category of ASD without an intellectual disability, but this is no longer used as a diagnostic term.

A body of research has raised awareness that some people with a diagnosis of ASD may encounter the criminal justice system in the context of alleged unlawful behaviour. These behaviours range from relatively minor to more severe. For instance, Wing (1981) referred to a small minority of people with ASD with a history of "bizarre anti-social acts". Hippler and Klicpera (2003) identified "disciplinary problems" and conduct disorder, in half of the children originally diagnosed by Asperger (1944). Since then, a number of case studies and case series (refer to Dein and Woodbury-Smith, 2010 for a list of these) described associations between autism and offending. More recently, a systematic review of the literature by Allely and Dubin (2018) found links between ASD and the possession of child pornography. Similarly, a Swedish population-based study found an increase in violence by people with autism, but this was later explained by the comorbid diagnosis of ADHD and conduct disorder in this population (Heeramun et al., 2017). To date the area of autism and crime remains under-researched, despite the complexities involved and the significance of this issue to public health and safety as well as to individuals with autism. Further insight can be obtained from examining offender populations, including those detained in secure hospital facilities and prisons. For instance, Murphy 2011 suggested the need for an AQ (Baron-Cohen et al, 2001) forensic version after comparing AQ profiles in patients diagnosed with mental illness, personality disorder and ASD within Broadmoor high secure hospital. Whilst

previous research in forensic psychiatric hospitals has focussed on high secure facilities (Scragg and Shah, 1994, Hare et al., 1999; Hawes 2003, Murphy 2003, Murphy 2011) and autistic patients with ID (Esan et al., 2015), few papers have looked at people without an ID in the larger group of generic non-ID medium secure units.

Regarding research in high security, a study in Broadmoor Hospital by Scragg and Shah (1994) suggested that people with Asperger's syndrome (AS) made up 1.5% (CI 95%; 0.6-3.3) of the male population of this high secure psychiatric hospital in England (rising to 2.3% if those with probable AS were included). This exceeded the prevalence rate of 0.36% found in the general population (estimated on the basis of studies conducted amongst children) by using the same diagnostic criteria (Ehlers and Gillberg, 1993). Other estimates of prevalence have indicated a lower prevalence (0.46%) in Scottish secure units (Myers 2004) or an excess of well over ten times (18%) among perpetrators of severe crimes admitted for forensic psychiatric evaluations by court order in Sweden compared to the general population (1.2%; Soderstrom, 2004). Within the prison population, studies have generally indicated an excess of those with autism (Hawes 2003; Fazio et al., 2012; Underwood et al., 2016). However, Robinson et al. (2012) did not identify any cases of ASD within the Scottish prison service (n= 2458); a finding that could be attributed to the low sensitivity of the screening instrument utilised in this study (28.6%). Similarly, Myers (2004) did not attempt to screen for new cases of ASD within secure psychiatric hospitals.

There are a number of possible explanations for the increased prevalence of ASD within forensic psychiatric units. Hare et al. (1999) found that the mean length of time in high secure units for patients with autism was 2 to 3 years longer than the average of 8.5 years reported for patients in a Special Hospital. This had led to Dein and Woodbury-Smith (2010)

suggesting that the longer length of stay was responsible for the "over-representation" of men with autism in secure settings. However, Esan et al. (2015) did not find a difference in the length of stay of forensic inpatients with and without autism within a forensic intellectual disability hospital. Alternatively, those diagnosed with ASD may experience a greater psychiatric morbidity leading to an increased presence within psychiatric hospitals, and forensic psychiatric hospitals as an extension of this. Davidson et al. (2014) found a raised prevalence of 3.4% of Asperger's Syndrome among patients admitted under the care of an Early Episode Psychosis team. Similarly, a recent systematic review of psychiatric hospitals suggested an increased prevalence rate of 2.4-9.9% of ASD among inpatients (Tromans et al. 2018).

Previous research has indicated a low rate of criminal offending within a community sample of people with ASD (Woodbury-Smith et al. 2016), as well as within a large Danish population samples (p=0.89; Mouridsen et al., 2008). Similarly Weiss and Fardella (2018) did not find an increased rate of criminal activity by adults with ASD when compared to non-autistic adults, despite the former having an increased rate of victimisation.

Paradoxically, Rava et al. (2017) found that nearly 20% of young males with ASD had been stopped by the police by the age of 21. Similarly Tint et al. (2017) found that 16% of individuals with ASD had some involvement with the police over a 12-18 month period. Previous research (Shiner et al. 2018; Monk, 2018) has indicated that an increase in police interest can lead to arrests, and imprisonment. Similarly, the increased prevalence of ASD in forensic settings may be attributable to the increased police interest.

Most patients within forensic psychiatric hospitals are cared for within low and medium secure psychiatric hospitals with around 3,500 medium secure in-patient beds in England (Durcan, 2011). Clearly this has several implications. Previous research has indicated that most patients with ASD in high secure units were undiagnosed prior to these investigations (Scragg and Shah, 1994; Hare et al., 1999). Medium secure units have the role of discharging mentally disordered offenders into the community, and ASD has implications for risk assessments, risk management strategies and for recidivism (Wing 1997; Hare et al., 1999; Barkham et al., 2013). Additionally, the misdiagnosis of ASD can lead to inappropriate use of psychotropic medication, and may contribute to longer stay in hospital (Murphy, 2003). Whilst Esan et al. (2015) identified 42 patients with ASD out of 138 patients within an intellectual disability medium secure unit over a 6 year period, suggesting a prevalence of 30.4% so far no published studies have estimated the prevalence of autism without an intellectual disability within generic (non-intellectual disability) medium secure units in England or Wales. The prevalence of ASD within an intellectual disability forensic unit is likely to be higher than within a generic unit, due to the significant overlap between the two conditions (Matson and Shoemaker, 2009). However, there are difficulties in undertaking this research within a forensic population. ASD is a rare condition with a prevalence of 9.8 per 1000 (95% CI 3.0-16.5; Brugha et al., 2011). It is difficult to obtain a reliable developmental history regarding an adult offender with possible ASD (Dein and Woodbury-Smith, 2010), particularly if s/he was raised by multiple carers or in foster homes. Some people with ASD may be unwilling to participate in research as they may find social situations difficult due to the ASD itself. In view of these difficulties in estimating prevalence of ASD among adult forensic populations, a feasibility study was undertaken.

Aims and Objectives

This study aimed to test the feasibility of estimating the prevalence of ASD without an intellectual disability (ID) amongst male inpatients within medium secure units (MSU). We decided to focus only on only those without an ID as the secure units we were targeting typically do not admit those with an ID. Additionally, as Mason and Shoemaker (2009) pointed out, persons with intellectual disability and ASD show considerable differences in presentation to those with ASD only.

We also decided to focus only on males because women form a much smaller proportion of the medium secure population (Coid et al., 2000) and as Hull et al (2020) point out, it is likely that women express the autistic genotype in a manner which does not meet the current diagnostic criteria.   It is therefore easier to miss this diagnosis of ASD in females, especially in the high functioning group, where the ratio of men to women with autism has been found to be as high as 9:1 (Frazier et al., 2014).   We need a better understanding of feminine autism before we can correctly estimate it's prevalence, first within the general population, and then in forensic units.

We were concerned that the difficulties inherent in the identification of women with ASD in the community, would likely be amplified in the forensic setting. There is a body of literature that has examined the phenotype among females, and it has been suggested females may be under-represented in part due to the inadequacy of current diagnostic criteria (Constantino and Charman, 2012). For example, compared to males, females with ASD require more severe symptoms, including greater behavioral and cognitive impairments, in order to receive the diagnosis (Dworzynski et al., 2012). Additionally, it has been suggested that females resort to 'camouflaging' or 'pretending to be normal' more than their male counterparts,

making them more challenging to identify (Bargiela, 2016). As a result of these confounds, we decided to focus specifically on the male population in this current study.

Method

Study Design

We set out to undertake a cross-sectional design across multiple sites to examine the feasibility study across medium secure psychiatric facilities across England and Wales, with the aim of examining the prevalence of ASD. Unfortunately, our response rate was poor, despite several attempts to connect with key personnel at each site. Consequently, our final sample was opportunistic.

Setting

Mentally disordered offenders within England and Wales are managed within secure psychiatric hospitals that are divided into three levels of security – high, medium and low. Around a third of the medium secure care provision is within the private sector (Durcan, 2011). We obtained ethical approval from the National Research Ethics Service (NRES) Committee - London Westminster (Ref 11/LO/0199) to conduct a feasibility study in a limited number of medium secure units.

Participants and Recruitment

KD initially contacted by email the research department of St Andrews' healthcare (a private healthcare provider) based in Northampton, UK and Birmingham, UK as well as the John

Howard Centre, one of the largest government providers of medium secure psychiatric care. The hospitals were forwarded confirmation of ethical approval along with a short summary of the study, participant information leaflets and a letter to the responsible clinician.

Following approval by the research department at St Andrews, clinicians who were identified as working within the medium secure wards were contacted by email and were asked if they would be willing to support the research through identifying individuals under their care who met the inclusion criteria. We contacted a total of 7 clinicians. The majority did not respond (n=4), and therefore their reasons for not doing so remain unclear. Three clinicians responded positively, but only two clinicians working across three wards on two different sites, one in Northampton (AR) and the other in Birmingham (RS) subsequently identified participants who met the inclusion and exclusion criteria as described below. The third clinician cited a busy schedule as a reason for not approaching patients. The John Howard Centre had a more complex process for obtaining permission from the local research department, that led to significant time delays, and therefore plans to approach this hospital were aborted.

The participant inclusion criteria were:

    1. Male inpatients aged 18 years or above on male medium secure wards.

The exclusion criteria were:

    1. ASD specific wards within the hospital (the purpose of the study was to estimate the prevalence of ASD on generic MSU wards);

    2. Female inpatients;

    3. Inpatients with an intellectual disability;

4. Inpatients with a sensory impairment, such as deafness;

5. Patients who could not speak English fluently.

Participants who met the inclusion criteria were screened using the instruments described below.

Measures

The Autism Spectrum Quotient (AQ; Baron-Cohen et al., 2001) is a brief 50 item self-administered screening questionnaire designed for adults that identifies the degree to which an adult of normal intelligence might have features of autism. Eighty per cent of the adults with autism without an intellectual disability scored 32+, versus 2% of controls (Baron-Cohen et al., 2001). The Autism Spectrum Quotient (AQ; Baron-Cohen et al., 2001) was validated within a forensic population by Murphy (2011). This study data collection began in 2011, and therefore did not make use of the AQ10 (Allison et al, 2012) that was published the following year.

The Empathy Quotient (EQ; Baron-Cohen and Wheelwright, 2004) is a self-report questionnaire developed for measuring empathy, for use amongst adults of normal intelligence. It is used as a screening instrument for AS. Of adults with autism without an intellectual disability, 81% scored equal to or fewer than 30 points out of 80, compared with only 12% of controls (Baron-Cohen and Wheelwright, 2004).

The Schonell Reading Test (Shearer et al., 1975) is a standardised, reliable and valid single word reading assessment. It assesses premorbid cognitive functioning capacity based on the premise that reading abilities are related to general intellect.

Data

All continuous outcomes were tested for normality of distribution using the Shapiro-Wilk test for normality. Where normality was established, independent samples t-tests were used p =test for differences between the sample and established norms from other settings (e.g. the community and other levels of security).

To account for multiple pairwise testing, a Bonferroni correction was adopted to the alpha threshold for significance. The adjusted alpha was α 0.05/4 = 0.0125, and only p values below this level were taken to indicate statistical significance.

Results

The data were gathered from two medium secure wards in April 2012 and from the third in January 2014. At the time of the study, the total population of these three wards was 46 patients with 14 patients on one ward, 15 on another and 17 on a third. Out of a total of 46 inpatients, 16 were excluded according to the criteria set out above. Of the participants identified, a proportion (n=10, 21.7%) were acutely unwell, and were not therefore approached for research purposes, being deemed unable to participate. As the instruments utilised in the research were validated for use, primarily among English speakers, one patient was therefore excluded due to his lack of fluency in English (n=1, 2%). Of those who met the inclusion criteria (n=30), half (n=15) declined to participate, without citing reasons.

[Table 1 about here]

Of the remaining 30 patients, 13 (43%) consented to participate, and were screened for ASD. The AQ and EQ results were unavailable for one patient. The remaining 12 patients (40%) completed all the questionnaires.

Reading Ability

Schonnell Graded Reading Test Score results (Figure 1) for those who were included in the study (n=13) suggested a pre-morbid verbal intelligence quotient ranging from 86 to 111, with a mean of 99.0 (standard deviation 7.68). A Shapiro-Wilk test for normality obtained a non-significant result of 0.949 (p = 0.59) suggesting that the results were normally distributed.

[FIGURE 1 ABOUT HERE]

EQ results

Empathy Quotient results (Figure 2) for participants (n=12) ranged from 26 to 72, with a mean 44.8 (standard deviation 9.04). Only one patient scored below the screening threshold of 30. Shapiro Wilk test obtained a non-significant result of 0.983 (p=0.99) suggesting that the results were normally distributed.

[FIGURE 2 ABOUT HERE]

AQ results

Autism Quotient results (Figure 3) for participants (n=12) ranged from 13-26, with a mean 19 (standard deviation 4.88). A Shapiro Wilk test obtained a non-significant result of 0.89 (p=0.11) suggesting that the results were normally distributed. There was no significant correlation between the variables.

[Figure 3 about here]

s Table 2 indicates, there was no statistical difference when compared to the AQ scores in the general population (Ruzich et al., 2015) using an independent samples t-test (t (882) = 0.63, p=0.95). Independent sample t-testing suggest that the AQ results for our study sample (mean 19, standard deviation 4.88) were comparable to that of the mental illness group (mean 20.8, standard deviation 6.6, t(79) = 0.9, p = 0.370) and the personality disorder group (mean 20.5, standard deviation 6.5, t(34) = 0.7, p = 0.486), but considerably different to the ASD group (mean 30.5, standard deviation 5.8, t(25) = 5.25, p<0.001) described by Murphy (2011) within Broadmoor high secure hospital.

[Table 2 about here]

None of the patients scored over the screening threshold of 32, and no new cases of autism were identified through screening. Three patients who did not participate in the study were previously diagnosed with autism, suggesting a prevalence of 6.5% (95% CI 1.7 to 18.9). Two of these patients did not consent to participate and the third was considered too unwell to be included in the study. Table 1 summaries the results.

[FIGURE 3ABOUT HERE]

Discussion

Feasibility in relation to researching offenders with ASD

The researchers had originally planned to conduct a study exploring prevalence within all the medium secure units within England and Wales. Ethical approval for a small, feasibility study was obtained after three attempts. While the nature of the research was non-invasive, there were several concerns raised regarding the vulnerability of the potential participants

who were detained within coercive psychiatric facilities. For instance, the ethics committee was concerned that asking potentially disturbing questions could lead to a worsening of psychiatric symptomatology, and/or violence within this population. They were conscious of the power differences that exist between health professionals and patients detained within forensic units for lengthy periods; that patients would believe that non-participation in research would impact negatively on their treatment especially as the lead researcher was a consultant forensic psychiatrist. These valid concerns were addressed by clarifying the benign nature of the content of questionnaires, the significant experience of the lead researcher in undertaking forensic patient interviews and the service user's right to refuse consent was emphasised within the information leaflets using simple English. Additionally, it was agreed that local clinicians would make the initial approach to potential participants, instead of the lead researcher.

The feasibility study identified the significant difficulties in estimating the prevalence of autism within medium secure units. Several clinicians working within four MSUs within the NHS (a government-funded facility) and the private sector were initially approached. There was little appetite to support research by clinicians (Srivastava et al., 2013), possibly due to their busy work schedules. Indeed, only three clinicians out of the original seven who were contacted to support this research offered to make the initial contact with participants, and only two of these approached their patients.

The response rate to the survey was low, at around 50%. As discussed above, people with ASD may refuse to participate in research due to finding social situations (especially novel ones) difficult due to autism itself. Similarly, in a study by Allen et al. (2008) of people with ASD without an intellectual disability, only 16 (48%) of the total number of potential

candidates (n-=33) consented to participate. None of those who participated met the threshold for further diagnostic testing.

Difficulties in using the AQ (Baron-Cohen et al., 2001) were previously noted by Ashwood et al. (2016) who found that a significant proportion, as many as 64%, of those who scored negatively, were false negatives. They also observed that generalized anxiety disorder could mimic autism, leading to false positives.   These issues were further compounded within secure units . For instance, while Murphy (2011) validated the AQ (Baron-Cohen et al., 2001) within a forensic population , he found that the 'attention to detail and imagination subscales' had little discriminative validity within this group where the need for a predictable regime, susceptibility to change, as well as difficulties in understanding the perspective of other and a lack of empathy, were not infrequent outside of the ASD populace. Additionally, this instrument was developed using a sample of scientists and mathematicians. Hence a number of the screening questions are not relevant to offenders who are mainly derived from socially-deprived backgrounds (Caruso, 2017). For instance, the participant's agreement is sought regarding various social scenarios, for example "I would rather go to the library than a party" (item 13) or "I would rather go to the theatre than a museum" (item 24).

Studies of families of people with autism indicate that non-autistic relatives show a "genetic liability" for ASD expressed in a milder form that is sometimes referred to as the "broader autism phenotype" (Piven et al., 1997). Although, the mean AQ score in our sample of patients was 19 (SD 4.88), 7 patients scored above 20, suggesting that they fell into the category of the broader autism phenotype (BAP) as defined by Wheelwright et al. (2010). In comparison to this, within a high secure psychiatric hospital in England, 8 out of 12 men with ASD (66.6%) scored over the screening threshold of 32, using the AQ (Baron-Cohen et al.,

2001) as did 4 patients out of 69 diagnosed with a mental illness (5.8%) and one patient (4.2%) out of 24 with a personality disorder (Murphy, 2011).

Although one patient scored below the screening threshold using the EQ, his AQ score was 25 (below the screening threshold). While the EQ is as sensitive as the AQ, it is not as specific, and 12% of individuals without autism will score below 30 (Baron-Cohen and Wheelwright, 2004).

This study would have failed to identify any patients with ASD within the medium secure units, if it were not for support of local clinicians (a consultant psychiatrist of considerable experience and an assistant psychologist) who observed that three patients who did not participate, were previously diagnosed with ASD. Additionally, our findings suggest that the prevalence of ASD on these three MSUs was 6.5% (95% CI 1.7-.18.9 %). This is over six times the prevalence of ASD in the general population that was estimated as 9.8 per 1000 (95% confidence interval 3.0-16.5) by Brugha et al. (2011). Both the hospitals included in the study had medium secure wards allocated to men with autism. This may have impacted on the number of patients with autism on generic wards, likely reducing this number. Therefore, the actual prevalence of autism within ordinary medium secure units is likely to be still higher. The findings were in line with previous research within high secure units (Scragg and Shah 1994; Hare et al., 1999). Scragg and Shah (1994) estimated that the prevalence of ASD without an intellectual disability was 1.5-2.3% of the male population of Broadmoor (high secure forensic) hospital. Similarly Hare et al. (1999) found that 21 people within the three high secure units in England (n=1305) met the criteria for Asperger's Syndrome, suggesting a prevalence of 1.6%. These findings were at least five time the prevalence of the same condition in the community estimated using the same diagnostic criteria, namely 0.36%

(Ehlers and Gillberg, 1993). As expected, the prevalence of ASD was much lower than in a medium secure unit for people with intellectual disability (Esan et al., 2015).

Strengths and Limitations of the study

This is the first study to our knowledge that has estimated the prevalence of autism within MSUs in England. However, this was a small feasibility study covering a few private medium secure wards. The results of this study may not be representative of secure units within England. The findings may suggest a lack of state-funded facilities that cater to the needs of this population, leading to their overcrowding within privately-funded units. The low response rate to this research by both clinicians and inpatients highlights the difficulties in undertaking research within these settings.

Conclusion

This study suggests that the best way to estimate the prevalence of ASD is through undertaking a service evaluation of medium secure units, with arrangements made to screen and diagnose all the patients for autism. A similar approach was successfully utilised by Esan et al. (2015) within a forensic unit for people with intellectual disabilities. Developing autism-specific screening tools and designing studies that can accurately estimate prevalence of autism within women's secure units are key challenges for prospective studies. Future research should investigate the possible reasons for the increased prevalence of autism in medium secure units as described earlier in this paper. Undiagnosed ASD can be disguised as a difficult to discharge group of patients. Treatment in MSUs is a burden on the health economy, accounting for a one-tenth of the mental health budget and 1% of all NHS funding (Vollm et al., 2016). It would therefore benefit commissioning bodies to work in partnership

with researchers to identify and estimate accurately the size of this group the forensic inpatient population in order to map out viable discharge pathways outside of coercive treatment facilities.

Declaration of Interest

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