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Richards, Caroline; Oliver, Christopher; Nelson, L; Moss, Joanna

DOI:
10.1111/j.1365-2788.2012.01537.x

Document Version
Early version, also known as pre-print

Citation for published version (Harvard):
Richards, C, Oliver, C, Nelson, L & Moss, J 2012, 'Self-injurious behaviour in individuals with autism spectrum disorder and intellectual disability', *Journal of Intellectual Disability Research*, vol. 56, no. 5, pp. 476–489. https://doi.org/10.1111/j.1365-2788.2012.01537.x

UNIVERSITY OF BIRMINGHAM

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Richards, C., Oliver, C., Nelson, L. and Moss, J.

Cerebra Centre for Neurodevelopmental Disorders,

School of Psychology,

University of Birmingham

Please use this reference when citing this work:

Richards, C., Oliver, C., Nelson, L. and Moss, J. (2012). Self-injurious behaviour in individuals with autism spectrum disorder and intellectual disability. Journal of Intellectual Disability Research. 56, 476-489. DOI: 10.1111/j.1365-2788.2012.01537.x

The Cerebra Centre for Neurodevelopmental Disorders,
School of Psychology, University of Birmingham, Edgbaston, Birmingham, B15 2TT
Website: www.cndd.Bham.ac.uk **E-mail**: cndd-enquiries@contacts.bham.ac.uk

Acknowledgements

This research was funded by Research Autism and Cerebra. We are grateful to the parents and carers who completed the questionnaires with such diligence. Michelle Hooker contributed to collecting data on the Fragile X syndrome group. The Fragile X Syndrome Society, the Down Syndrome Association and the National Autistic Society gave significant administrative support to the project.

Abstract

Background: Autism spectrum disorder (ASD) has been identified as a risk marker for self-injurious behaviour. In this study we aimed to describe the prevalence, topography and correlates of self-injury in individuals with ASD in contrast to individuals with Fragile X and Down syndromes and examine person characteristics associated with self-injury across and within these groups.

Method: Carers of individuals with ASD (N=149; mean age=9.98, SD=4.86), Fragile X syndrome (N=123; mean age=15.32, SD=8.74) and Down syndrome (N=49; mean age=15.84, SD=12.59) completed questionnaires relating to the presence and topography of self-injury Information was also gathered regarding demographic characteristics, affect, autistic behaviour, hyperactivity, impulsivity and repetitive behaviour.

Results: Self-injurious behaviour was displayed by 50% of the ASD sample; a significantly higher prevalence than in the Down syndrome group (18.4%) but broadly similar to the prevalence in Fragile X syndrome (54.5%). Self-injury was associated with significantly higher levels of autistic behaviour within the Down and Fragile X syndrome groups. Within the ASD group, the presence of self-injury was associated with significantly higher levels of impulsivity and hyperactivity, negative affect and significantly lower levels of ability and speech.

Conclusions: Self-injurious behaviour is prevalent in individuals with ASD and the presence of ASD phenomenology increases the risk of self-injury in individuals with known genetic disorders but without a diagnosis of idiopathic autism. Person characteristics associated with self-injury in ASD indicate a role for impaired behavioural inhibition, low levels of ability and negative affect in the development of self-injurious behaviour.

Keywords: autism spectrum disorder, self-injury, fragile x syndrome, down syndrome, prevalence, hyperactivity, impulsivity

Introduction

Prevalence estimates for self-injury range from 4% to 12% in individuals with intellectual disability and 33% to 71% in autism spectrum disorder (ASD) (Cohen *et al,* 2010; Cooper *et al.,* 2009; Oliver *et al.,* 1987; Dominick *et al.,* 2007; Murphy *et al.,* 2009; Shattuck *et al.,* 2007; Baghdadli *et al.,* 2003; Bartak & Rutter, 1976). Variability in estimates is due to differing definitions of both ASD and self-injury and variability in degree of ability within cohorts. Within individuals with intellectual disability, ASD has been identified as a risk marker for self-injury and is associated with both persistence and severity (Emerson *et al*., 2001; Baghdadli *et al.,* 2003; Bodfish *et al.,* 2000). In a meta-analytic study McClintock *et al.* (2003) found that those with autism were approximately six times more likely to engage in self-injury than those without autism. Finally, within populations with ASD, self-injury is associated with increased severity and quantity of autistic characteristics (Bhaumik *et al.,* 1997; Matson & Rivet, 2008). In summary, both the presence and severity of ASD are associated with self-injury..

In order to better understand the phenomenology and prevalence of self-injury in ASD, it is important that degree of intellectual disability is assessed, as both ASD and a greater degree of intellectual disability are associated with a higher prevalence of self-injury (McClintock *et al.,* 2003). Previous studies have compared individuals with ASD to groups of individuals with intellectual disability of heterogeneous aetiology (Ando & Yoshimura, 1979; Bhaumik *et al.,* 1997). However, the use of this comparison group may be problematic due to the presence of unknown levels of ASD and genetic syndromes associated with a higher prevalence of self-injury (Arron *et al.,* 2011). In order to delineate self-injury in ASD, comparison groups need to be homogenous. The use of standardised measures across multiple homogeneous groups with known characteristics would strengthen conclusions.

One possible design is to compare individuals with ASD to individuals with syndromes that have well documented aspects of behavioural phenotypes relevant to the contrasts to be made. Down and Fragile X syndromes each have comparatively well documented behavioural phenotypes. Individuals with Down syndrome evidence a relatively low prevalence of ASD (Cohen *et al.,* 2005; Moss & Howlin, 2009). In contrast, those with Fragile X syndrome show high levels of ASD characteristics (Hall *et al.,* 2008; Lewis *et al.,* 2006; Moss & Howlin;

2009; Oliver *et al.,* In Press). Additionally, a specific topography of self-injury, self-biting, is reported to be unusually common in Fragile X syndrome (Arron *et al.,* 2011; Hall *et al.,* 2008; Oliver *et al.,* In Press, Symons *et al.,* 2010). The selection of these groups enables the association between ASD characteristics and self-injury to be approached in a number of ways. Firstly, the groups have predictable characteristics of relevance. Secondly, it enables a comparison of those with high levels of ASD (ASD and Fragile X syndrome groups) to those with low levels of ASD (Down syndrome group). Finally, comparisons of topography of self-injury can be made across the groups.

The three groups defined by aetiology confer another advantage. Within group analyses of relatively homogenous samples allows investigation of factors that are associated with self-injury whilst controlling for aetiology. For example, stereotypic and repetitive behaviours are common within ASD populations and are associated with self-injury (Bodfish *et al.,* 2000). Similarly, attention deficit hyperactivity disorder (ADHD), overactivity and hyperactivity are independently associated with self-injury (Cooper *et al.,* 2009; Collacott *et al.,* 1998; Schneider *et al.,* 1996). Interestingly, recent research has indicated that in those with intellectual disability, high levels of repetitive behaviours are associated with higher levels of impulsivity and overactivity (Burbidge *et al.,* 2010) and that these variables in combination are predictive of self-injury (Oliver *et al.,* 2009; Arron et al., 2011). Investigation of these characteristics in ASD is important as they may indicate common influences on self-injury across aetiological groups.

These person characteristics are also of interest as they allude to neuropsychological influences on self-injury. It has been hypothesised that deficits in executive function and response inhibition compromise ability to control repetitive behaviours (Turner, 1999). Similarly, ADHD is hypothesised to be underpinned by delayed development of inhibition which, amongst other deficits, comprises both an inability to stop a prepotent response to a stimulus and the inability to terminate an ongoing response (Barkley, 1997). Therefore, underlying executive deficits may influence the severity and frequency of self-injurious behaviour by virtue of compromised behavioural inhibition. In some cases, it could result in an individual being less able to inhibit self-injury in response to a discriminative stimulus and\or establishing operation *and* being less able to cease self-injury once started. Preliminary

evidence to support this hypothesis comes from the observation that individuals who engage in self-injury and show high levels of repetitive behaviour actively engage in self-restraint behaviours (Hyman, *et al.,* 2002). It is plausible that an association between self-injury and impaired behavioural inhibition, exists within individuals with ASD and, if so, may be evidenced through the presence of ADHD type behaviours such as overactivity and impulsivity alongside repetitive behaviours.

A final characteristic that has been associated with self-injury is low mood (Arron *et al.,* 2011; Carr *et al.,* 2003). It is unclear whether this association arises because self-injury is a 'behavioural depressive equivalent' (Marston *et al.,* 1997) or is related to pain that has repeatedly been demonstrated to be underlying self-injurious behaviour in some people (Breau *et al.,* 2003; Carr & Owen-Deschryver, 2007; Luzzani *et al.,* 2003). Either way it is important in the first instance to establish if low mood is associated with self-injury in ASD in the same way as it is in Cornelia de Lange, Fragile X, Angelman and Prader-Willi syndromes (Arron *et al.,* 2011).

Using between and within group analysis, in this study we will delineate the prevalence, phenomenology and associated behavioural characteristics of self-injurious behaviour in ASD. Through analysing data from ASD, Fragile X and Down syndromes groups, three key areas will be addressed:

i) The prevalence of self-injury in ASD will be delineated and compared to the other groups. It is predicted that there will be a higher prevalence of self-injury in the ASD group, compared to the Down syndrome group and a comparable prevalence of self-injury to the Fragile X syndrome group. Data will be analysed to describe the topography self-injury in all groups.

ii) The association between ASD behaviours and self-injury within each of the three groups will be investigated. It is predicted that self-injury will be related to higher levels of autistic behaviour within all groups.

iii) Factors which may be associated with self-injury will be investigated within the ASD group, including repetitive behaviours, impulsivity and overactivity, affect and demographic characteristics. It is predicted that the presence of self-injurious

behaviour will be associated with lower ability and poorer speech, higher levels of repetitive behaviour, impulsivity and activity and more negative affect.

Methods

Recruitment

Participants with ASD, Fragile X and Down syndromes were recruited in the UK via the National Autistic Society, Fragile X Society and the Down's Syndrome Association respectively. 288 carers of individuals with ASD (return rate 19.63%), 144 carers of individuals with Down Syndrome (28.80%) and 212 carers of individuals with Fragile X syndrome (44%) completed the questionnaire pack.

Procedure

All carers received an information sheet, cover letter, consent form, demographic questionnaire and questionnaire pack. To avoid priming, the study was described as investigating behaviours associated with the relevant syndrome group. Carers returned completed questionnaires and consent forms in a prepaid envelope. Ethical approval for this study was obtained from the ethical review committee at the University of Birmingham.

Participants

Participants were excluded if: 1) they were under the age of four as some measures were not appropriate, 2) they did not have a confirmed diagnosis from a relevant professional, 3) a large proportion of the data (25% or more of items across questionnaires) were incomplete, 4) they had incomplete total scores on the Social Communication Questionnaire (SCQ; Berument *et al.*, 1999). All individuals in the ASD group scoring below the ASD cut off on the SCQ were also removed from the analysis. Participants who scored the maximum possible score of nine on the self help subscale of the Wessex (Kushlick *et al.*, 1973) were excluded[1]. The Wessex was used as a proxy estimate of level of ability. This was done in order to identify those individuals with an associated intellectual disability.

[1] The self-help subscale is calculated by summing three items regarding independent washing, dressing and feeding ability. Each item is scored on a three point likert scale ranging from one (not at all) to three (without help), resulting in total scores ranging from three to nine.

After applying exclusion criteria, 321 (49.84%) individuals were included in analyses. Participants were aged between 4 and 62 (mean = 12.92; SD = 8.45), 276 (86.0%) were male and 273 (85.0%) were able/partly able (score above six on the self help subscale of the Wessex Scale). 305 (95.0%) participants were fully mobile and 270 (84.1) were verbal (more than thirty words/signs in their vocabulary). Table 1 describes the characteristics of each participant group. Significant differences were found between the groups for age, gender and total SCQ score.

++++++++++ Insert Table 1 about here ++++++++++

Measures

The questionnaire pack included the following informant based questionnaire measures which are all appropriate for children and adults with intellectual disabilities.

A demographic questionnaire to collect information on gender, mobility, verbal ability and diagnosis.

The Wessex (Kushlick *et al.,* 1973) is used to assess ability in children and adults with intellectual disabilities. It comprises five subscales including: continence, mobility, self help skills, speech and literacy. For the purpose of this study, the self help subscale was used as an estimate of degree of ability, and responses to items on mobility, speech, reading, writing and counting were used to further describe the groups. The Wessex Scale has modest inter-rater reliability at subscale level for both children and adults (mean Kappa value of .62 and .54 for overall classification and item level reliability respectively; Kushlick *et al.,* 1973; Palmer & Jenkins, 1982). The Wessex has been as argued to be an effective tool for large-scale questionnaire studies (Palmer & Jenkins, 1982).

The Mood Interest and Pleasure Questionnaire – Short form (MIPQ-S; Ross & Oliver, 2003) was included to assess affect. It comprises twelve items, forming two subscales: Mood, and Interest and Pleasure. The measure has good internal consistency (Cronbach's alpha coefficients: total = .88, Mood = .79, Interest and Pleasure = .87), test-retest (.97) and inter-rater reliability (.85). Internal consistency for the subscales is good (alpha coefficient range

for subscales .84 - .94). Concurrent validity between the MIPQ and the Aberrant Behavior Checklists's (ABC, Aman & Singh, 1986) ranged from medium to strong (0.36 – 0.73; $p<.001$).

The Activity Questionnaire (TAQ; Burbidge *et al.,* 2010) was included to assess behaviours indicative of overactivity and impulsivity. The measure has eighteen items which form three subscales of Overactivity, Impulsivity and Impulsive Speech. Item level inter-rater reliability ranges from .31 to .75 (mean .56) and test-retest reliability ranges from .60 to .90 (mean .75). Inter-rater and test-retest reliability indices for subscales and total score exceed .70. Internal consistency for the subscales is good (alpha coefficient range for subscales .67 - .94).

The Social Communication Questionnaire – Lifetime Version (SCQ; Berument *et al.,* 1999) was included to assess ASD behaviours. The SCQ was developed as a tool for screening for ASD in children and adults and is based on the Autism Diagnostic Interview and asks questions about the individual's developmental history (Lord *et al.,* 1994). The measure consists of 40 items grouped into three subscales: Communication; Social Interaction and Repetitive and Stereotyped patterns of Behaviours. The authors identify a cut off score of 15 as indicative of Autistic Spectrum Disorder and a higher cut off of 22 to differentiate between individuals with autism and those with other Pervasive Developmental Disorders. The SCQ shows good concurrent validity with the Autism Diagnostic Interview and with the Autism Diagnostic Observation Schedule (Howlin & Karpf, 2004). Internal consistency is also good ($\alpha = .90$ for the total scale). The Fragile X syndrome group completed an earlier version of the SCQ (Autism Screening Questionnaire; ASQ) which had the same items and subscales, calculated using the same procedure as the SCQ. Consequently, the ASQ data for the Fragile X syndrome group are comparable to the SCQ data for the ASD and Down syndrome groups.

In calculating the total score for the SCQ, item 17 was removed from analysis ('has she/he ever injured her/himself deliberately, such as biting her/his arm or banging her/his head?') to prevent confounds in the data. Therefore, all individuals in the ASD group who were included in the analysis, scored above the cut off for ASD *without* including their score on item 17.

The Repetitive Behaviour Questionnaire (RBQ; Moss *et al.,* 2009) and the Challenging Behaviour Questionnaire (CBQ; Hyman *et al.,* 2002) were also included. The RBQ comprises five subscales: Stereotyped Behaviour, Compulsive Behaviour, Insistence on Sameness, Restricted Preferences and Repetitive Speech. Previous examination of the psychometric properties of the RBQ (Moss *et al.,* 2009) reveals that it has good inter-rater reliability coefficients (range .46 - .80), test-retest reliability (range .61 - .93; Moss *et al.,* 2009) and internal consistency (alpha coefficient range for subscales .50 - .78). Concurrent validity and content validity between the RBQ and the repetitive behaviour subscale of the ASQ is good (0.6; $p<.001$).

The CBQ (Hyman *et al.,* 2002) evaluates the presence of self-injury, physical aggression, verbal aggression, destruction of property and stereotyped behaviour in the last month. The measure also examines eight topographies of self-injurious behaviour that were adapted from Bodfish *et al* (1995). Items evaluating self-injury were used for the current study. Previous examination of the psychometric properties of the questionnaire has demonstrated good inter-rater reliability with reliability coefficients ranging from .61 to .89 (Hyman *et al.,* 2002).

The orders of the measures in the questionnaire pack were counterbalanced across each group to reduce order effects.

Data analysis

Data were tested for normality using Kolmogorov–Smirnov tests. Where data were not normally distributed ($p<.05$), non-parametric techniques were employed. To investigate the prevalence and topography of self-injury in ASD, the percentage of each group showing self-injury and specific topographies of self-injury were derived from the CBQ. Relative risk statistics were then calculated comparing the likelihood of individuals in each group showing self-injury and the specific topographies, compared to the likelihood of individuals in the other groups showing self-injury and the specific topographies.

The differences between levels of ASD behaviour in those who self-injure and those who do not within each group was investigated through a series of Mann Whitney U tests upon the presence of self-injury and SCQ subscale and total scores. Cliff's dominance (*d*) statistic

(1993) was used to calculate effect sizes for Mann Whitney U testsA *d* value of +1 would indicate that every datum point in a series is greater than every other datum point in the other series. A *d* value of -1 would indicate that every datum point in a series is less than every other datum point in the other series. Arbitrary cut offs for effect strengths were assigned as follows: .0 - .4 = weak, .4 - .8 = moderate, .8 – 1.0 = strong.

To investigate variables associated with self-injury within ASD, participants with ASD showing self-injury were compared to participants with ASD who did not display the behaviour. The difference between variables contingent on the presence of self-injury was then examined. Chi-square statistics were applied to categorical data and Mann-Whitney U tests for ordinal data.

Results

Prevalence and topography of self-injurious behaviour

In order to test the first hypothesis prevalence data and relative risk statistics were calculated to compare the likelihood of each group displaying any form of self-injury and specific topographies of self-injury compared to the other groups.

Table 2 displays the percentage of individuals showing self-injury in all groups and relative risk statistics of the likelihood of individuals in each group showing self-injury compared to the other groups. 50% of individuals in the ASD group had engaged in self-injurious behaviour in the preceding month. The ASD group was 2.67 times more likely to show self-injury than the Down syndrome group, and the Fragile X syndrome group was 2.91 times more likely to show self-injury than the Down syndrome group. There were no significant differences in the likelihood of displaying self-injury between the ASD and Fragile X syndrome groups.

++++++++++++ insert table 2 about here ++++++++++

Table 3 displays the percentage of individuals showing each topography of self-injury in all groups. Additionally, it shows the relative risk statistics of the likelihood of individuals in each group showing each topography of self-injury compared to the other groups. Individuals

in the ASD were 4.79 times more likely to show self-injury that involved hitting their own body than the Down syndrome group. Similarly, individuals with Fragile X syndrome were 4.03 times more likely to show self-hitting behaviours than individuals with Down syndrome. Individuals with ASD were 3.35 times more likely to engage in self-injury that involved hitting their own body with an object than individuals with Fragile X syndrome. Individuals in the Fragile X syndrome group were 2.52 times more likely to show self biting behaviour that individuals in the ASD group, and 7.67 times more likely to show self-biting than individuals in the Down syndrome group.

+++++++++ Insert table 3 about here ++++++++++

In summary, individuals with ASD were more likely to engage in self-injury than the Down syndrome group, but are no more likely to engage in self-injury than the Fragile X syndrome group. Individuals with ASD were more likely to engage in hitting their own body than the Down syndrome group and more likely to engage in self-hitting with an object than the Fragile X syndrome group. The Fragile X syndrome group were more likely to engage in self-biting than the ASD and Down syndrome groups.

Difference in autism spectrum disorder behaviour between those who self-injure and those who do not

In order to test the second hypothesis of the study, median scores were calculated for all subscales of the SCQ for those who self-injure and those who do not, within each group[2]. Figure 1 displays the median, maximum and minimum scores and significant differences within groups. Within all groups, those who engaged in self-injury had higher scores on all subscales and the total score of the SCQ, in comparison to those who did not engage in self-injury. At the total score level, this difference was significant for the Fragile X syndrome ($U = 2348.0$, $p = .008$, one tailed, Cliff's $d = .25$) and Down syndrome ($U = 276.0$, $p = .004$, one tailed, Cliff's $d = .57$) groups. Additionally, within the Fragile X syndrome group, individuals

[2]As above, item 17 (has she/he ever injured her/himself deliberately, such as biting her/his arm or banging her/his head?) was not included in any subscale or total score.

who engaged in self-injury had significantly higher scores on the social interaction subscale (U = 2363.5, p = .004, one tailed, Cliff's *d* = .26). Within the Down syndrome group, individuals who engaged in self-injury had significantly higher scores on the communication (U = 235.5, p = .027, one tailed, Cliff's *d* = .41), repetitive behaviour (U = 236.0, p = .038, one tailed, Cliff's *d* = .38) and social interaction subscales (U = 247.0, p = .020, one tailed, Cliff's *d* = .44). In summary, across all groups, those who engaged in self-injury had higher scores on the SCQ total score than those who did not engage in self-injury. This difference was significant for the Fragile X syndrome and Down syndrome groups.

++++++++++++ Insert figure 1 about here ++++++++++

Differences in demographic and behavioural variables dependant on presence of self-injury in autism spectrum disorder

In order to test the third hypothesis, individuals with ASD who displayed self-injury were compared to individuals with ASD who did not display self-injury on a number of demographic and behavioural variables. Table 4 shows the demographic variables for participants with ASD who engaged in self-injury and revealed that there were no significant differences in gender, age, mobility, vision or hearing between those with self-injury and those without self-injury. However, individuals who engaged in self-injury were significantly less likely to be able/partly able and verbal/partly verbal.

++++++++++ Insert table 4 about here ++++++++++++++

Secondly, scores on measures of mood, repetitive behaviour and activity level were compared between those with ASD who show self-injury and those who do not. Table 5 shows the median scores and Mann Whitney statistics for measures of affect, repetitive behaviour and activity level. Those who engage in self-injury have significantly higher overactivity, impulsivity and impulsive speech scores than those who do not engage in self-injury, although these differences have weak effect sizes. Those who engage in self-injury have significantly lower mood and interest and pleasure scores than those who do not engage in self-injury, although again these differences have weak effect sizes. There was no difference in repetitive behaviour between the two groups.

++++++++++++++++ insert table 5 about here ++++++++++++

In summary, those who engage in self-injury are significantly more likely to be less able and non-verbal. Additionally, individuals who self-injure have significantly higher overactivity, impusivity and impulsive speech scores and more negative affect.

Discussion

The prevalence and topography of self-injury in ASD were examined in this study in comparison to Down and Fragile X syndromes. ASD characteristics in the presence of self-injury were explored within each group and the characteristics of those with ASD who engaged in self-injury were also investigated. Importantly, the use of relatively homogenous groups for both within and between group analyses strengthens the internal validity of this study and the use of standardised measures across large groups allows the prevalence of self-injury across groups to be compared. Finally, the use of an ASD screen increases the internal and external validity of the study, and ensures a robust estimate of the prevalence and topography of self-injury in ASD.

Results revealed that the ASD group evidenced a higher prevalence and relative risk of self-injury than the Down syndrome group. Within all groups, those engaging in self-injury obtained higher scores on measures of autistic behaviour, with the self-injury Fragile X syndrome and Down syndrome groups scoring significantly higher on the total score for autistic behaviour. Those with ASD who engaged in self-injury had significantly higher scores on measures of overactivity and impulsivity, and significantly lower scores on measures of affect, suggesting that these factors may be associated with self-injury in ASD.

The results indicate a relatively high prevalence of 50.0% for self-injury in individuals with ASD, which is consistent with rates reported in other studies (Ando & Yoshimura, 1979; Baghdadli *et al.,* 2003; Dominick *et al.,* 2007; Shattuck *et al.,* 2007). However, the prevalence is considerably lower than that reported by Bartak and Rutter (1976) perhaps because their data were from a subset of individuals with an average IQ of 45.7, and lower ability level has been consistently associated with higher prevalence of self-injury (McClintock *et al*., 2003; Collacott *et al.,* 1998). The selection criterion employed in this study selected individuals with lower levels of adaptive behaviour, and thus is likely to have resulted in a sample with a

greater degree of intellectual disability, although this sample may still have a higher ability level than the sample included in Bartak and Rutter's study (1976). The results of this study are comparable to those from previous research showing self-injurious behaviour to occur in between 40-50% of individuals with ASD. Importantly, this study extends prior research by calculating the heightened risk of self-injury in ASD. The ASD group were 2.67 times more likely to engage in self-injury than the Down syndrome group, supporting previous research indicating a heightened risk of self-injury in ASD (McClintock *et al,* 2003). Interestingly, the results also revealed that individuals with ASD were 4.79 times more likely to engage in self hitting with their own body than individuals with Down syndrome. Similarly, individuals with ASD were 3.35 times more likely to engage in self-hitting with an object than individuals with Fragile X syndrome. These findings require further investigation, to determine whether these differences are related to homogeneity of topography of self-injury in the ASD group or a low prevalence of these topographies in the Down and Fragile X syndrome groups.

Consistent with previous research, 54.4% of individuals with Fragile X syndrome engaged in self-injury and were 2.91 times more likely to self-injure than individuals with Down syndrome. Consistent with findings in other studies, individuals with Fragile X syndrome were significantly more likely to engage in self-biting than both the ASD and Down syndrome groups (Hall *et al.*, 2008), suggesting a specificity to their self-injury. This finding is clinically relevant and suggests both a quantitative and qualitative difference in self-injury in these two groups. Finally, in line with previous research, the prevalence of self-injury in Down syndrome was substantially lower than the prevalence in either of the two other groups at 18.4%. The Down syndrome group included significantly fewer males than the ASD and Fragile X syndrome groups. However, previous research has demonstrated that gender is not associated with self-injury (McClintock *et al,* 2003). Therefore, the lower prevalence of self-injury in the Down syndrome group is assumed to reflect a true group difference. The reported prevalence figure of 18.4% is comparable to that identified in the general intellectual disability population, and consequently reinforces the utility of making comparisons between these three groups and using the Down syndrome group to benchmark comparisons.

In addition to the heightened risk of self-injury within the ASD group, the association between autistic characteristics and self-injury was explored across all three groups.

Supporting findings from previous research, the individuals in all groups who engaged in self-injury attained higher total scores on the SCQ (Baghdadli *et al.,* 2003; Bhaumik *et al.,* 1997; Matson & Rivet, 2008). However, this difference was only significant for the Fragile X syndrome and Down syndrome groups. The non-significant finding within the ASD group may be due to the screening process employed within this study. Nonetheless, the trend for all groups was for higher total scores being associated with self-injurious behaviour. This result suggests that the concept of ASD *diagnosis* as a risk marker for self-injury needs to be broadened and re-conceptualised. Supporting findings in individuals with rare genetic syndromes, it is the presence of high levels of ASD type behaviour, rather than only a diagnosis of ASD, appears to be associated with self-injury (Arron *et al.,* 2011). This distinction has clinical utility when considering risk for self-injury within non-ASD populations, such as those with genetic syndromes.

At a subscale level, again the trend was for higher scores on all subscales to be associated with self-injury across all groups with significant results for the Down syndrome group for all subscales and for the Fragile X syndrome group for the Social Interaction and Communication subscales only. This result differs from the results reported by Matson and Rivet (2008), who demonstrated that restricted and repetitive behaviour was significantly associated with self-injury in an ASD population. This difference in findings may be due to the screening of the ASD population in this study. The results of this study suggest that for the ASD population, none of the triad of impairments is specifically associated with self-injury. This is interesting with regard to repetitive behaviour, given the empirical evidence of a temporal association between stereotyped behaviours, proto-injurious behaviour and self-injurious behaviour (Petty, Allen & Oliver, 2009; Richman & Lindauer, 2005). The lack of difference in repetitive behaviour between those who self-injure and those who do not may reflect a progression from stereotyped and repetitive behaviours, towards self-injurious behaviours that are more reliably reinforced and rewarded by caregivers (Guess & Carr, 1991). Within this model, stereotyped and repetitive behaviours would reduce in frequency as self-injury became more functionally efficient within an individual's behavioural repertoire. This interpretation is consistent with the absence of difference in repetitive behaviour found in this study.

A within group analysis between those with ASD who self-injure and those who do not was conducted, in order to reveal associated variables that may contribute to the high prevalence of self-injury in ASD. The results revealed that individuals with ASD who engaged in self-injury had significantly higher scores on measures of impulsivity, overactivity and impulsive speech. These findings support previous studies that associated overactivity, impulsivity and self-injury (Cooper *et al.,* 2009; Collacott *et al.,* 1998; Oliver *et al.,* 2009; Schneider *et al.,* 1996) and provide tentative evidence for a potential role for executive dysfunction in aetiological models of self-injury. The elevated levels of impulsivity and overactivity in individuals with self-injury found in this study may constitute behavioural indicators of impaired inhibition. However, the analysis also revealed an association between lower speech and ability levels and self-injury within the ASD group. Consequently it is plausible that the differences in overactivity and impulsivity are simply a reflection of differences in ability levels.

The study also demonstrated that individuals with ASD who engaged in self-injury had significantly lower scores on measures of mood and interest and pleasure. This finding supports results identified in individuals with genetic syndromes, where self-injury was also associated with low mood (Arron *et al.,* 2011). However, these results do not fully evaluate the causal associations between low mood and self-injury. It is plausible that both self-injurious behaviour and low mood are depressive equivalents although evidence for this interpretation is weak. However, lower mood may be reflective of untreated pain that may have precipitated the self-injury, or in fact, be a direct result of it (Ross & Oliver, 2002). Further investigation of this is required.

A caveat that must be considered when interpreting these findings is that all individuals were recruited via parent support groups, with relatively low response rate. It is possible that this may have induced a recruitment bias, as those who are in contact with support groups may have more challenging children, and consequently be more in need of support. However, as all groups were recruited in the same way, the bias should be consistent across groups, and consequently comparisons remain valid. This validity is supported by the prevalence figures for self-injury in the ASD (Baghdadli *et al.,* 2003), Down syndrome and Fragile X syndrome (Hall *et al.,* 2008) groups being comparable to those previously reported in the literature.

Additionally, key findings relating to overactivity and impulsivity, rely upon the use of the Wessex (a measure of adaptive behaviour) as a proxy measure of ability.

Taken as a whole, these results indicate that individuals with ASD are more likely to engage in self-injury than those with Down syndrome. The results also show that individuals who engage in self-injury show significantly more behaviours indicative of ASD. Finally, the results reveal that impaired impulse control and overactivity are potentially associated with self-injury in ASD, and leads to the possibility that impairments in executive functioning may contribute to the high prevalence of self-injury in ASD. Similarly, it is possible that low mood associated with self-injury in ASD might be indicative of unresolved pain.

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Table 1 Mean age (standard deviation) and range, percentage of males, percentage of participants who were able, mobile and verbal, mean SCQ total score (standard deviation) and range for between group analyses.

		ASD	**Down Syndrome**	**Fragile X Syndrome**	**F/χ^2**	**Df**	***p* value**	**Post hoc analyses (Scheffe/chi square)**
N		149	49	123				
Age	Mean (*SD*)	9.98 (*4.86*)	15.84 (*12.59*)	15.32 (*8.74*)	18.76	2	<.001	DS, FraX>ASD
	Range	4-39	4-62	6-47				
Gender	% male	88.6	42.9	100.0*	96.50	2	<.001	FraX>ASD>DS
Self Help	% partly able/able	83.2	85.7	87.0	0.773	2	.679	N/A
Mobility	% mobile	95.3	91.8	95.9	-**	-**	.506	N/A
Speech	% verbal	82.4	85.7	86.2	.794	2	.672	N/A
SCQ total score	Mean (*SD*)	26.46 *(5.46)*	12.80 *(7.85)*	21.36 *(6.32)*	92.41	2	<.001	ASD>FraX>DS
	Range	15 - 38	2 - 33	1 – 38				

* Only male participants with Fragile X syndrome were recruited for the study
** Fishers exact T revealed calculated as one cell had expected count < 5.

Table 2 Percentage of individuals showing self-injury in each group. Relative risk statistics and 95% confidence intervals are shown to demonstrate the likelihood of individuals in each group showing self-injury compared to the other groups. Bold text indicates a significant difference ($p<.05$)

Test Group	N	Percentage showing SIB	RR compared to ASD (95% CI's)	RR compared to Down syndrome (95% CI's)	RR compared to Fragile X syndrome (95% CI's)
ASD	148	50.0	-	**2.67 (1.45 – 4.91)**	0.92 (0.73 – 1.15)
Down syndrome	49	18.4	**0.38 (0.20 – 0.69)**	-	**0.34 (0.19 – 0.63)**
Fragile X syndrome	123	54.5	1.09 (0.87 – 1.37)	**2.91 (1.58 – 5.35)**	-

Table 3 Prevalence of topographies of self-injury for each group. Relative risk statistics and 95% confidence intervals to demonstrate the likelihood of individuals in each group showing a specific topography of self-injury compared to the other groups. Bold text indicates a significant difference ($p<.05$).

	Hits self with body	Hits self against object	Hits self with object	Bites self	Pulls self	Rubs/ scratches self	Inserts
Prevalence of topographies (%)							
ASD	29.5	15.4	10.7	18.8	11.4	16.8	6.0
Down syndrome	6.1	8.2	0.0	6.1	4.1	10.2	10.2
Fragile X syndrome	25.2	11.4	3.3	48.0	14.6	14.6	8.1
Relative Risk Statistics compared to Down syndrome group (95% confidence intervals)							
ASD	**4.79 (1.56 – 14.73)**	1.88 (0.68 – 5.16)	-	3.05 (0.97 – 9.58)	2.78 (0.67 – 11.58)	1.63 (0.66 – 4.03)	0.59 (0.21 – 1.67)
Fragile X syndrome	**4.03 (1.29 – 12.57)**	1.37 (0.47 – 3.94)	-	**7.67 (2.53 – 23.31)**	3.51 (0.85 – 14.56)	1.40 (0.55 – 3.57)	0.78 (0.28 – 2.17)
Relative Risk Statistics compared to Fragile X syndrome group (95% confidence intervals)							
ASD	1.19 (0.80 – 1.76)	1.37 (0.74 – 2.55)	**3.35 (1.15 – 9.75)**	**0.40 (0.27 – 0.58)**	0.79 (0.43 – 1.47)	1.16 (0.67 – 2.03)	0.75 (0.32 – 1.79)
Down syndrome	**0.25 (0.08 – 0.77)**	0.73 (0.25 – 2.11)	-	**0.13 (0.04 – 0.40)**	0.28 (0.07 – 1.18)	0.71 (0.28 – 1.81)	1.28 (0.46 – 3.55)
Relative Risk Statistics compared to ASD group (95% confidence intervals)							
Down syndrome	**0.21 (0.07 – 0.64)**	0.53 (0.19 – 1.46)	-	0.33 (0.10 – 1.03)	0.36 (0.09 – 1.50)	0.61 (0.25 – 1.51)	1.70 (0.60 – 4.83)
Fragile X syndrome	0.84 (0.57 – 1.25)	0.73 (0.39 – 1.35)	**0.30 (0.10 – 0.87)**	**2.52 (1.72 – 3.69)**	1.27 (0.68 – 2.35)	0.86 (0.49 – 1.50)	1.33 (0.56 – 3.16)

- = incalculable due to an empty cell

Figure 1 Median, maximum, minimum and inter-quartile range of SCQ subscale and total scores indicating level of autistic behaviour for those who engage in self-injury and those who do not, for all groups. Significant difference in subscale score between those who engage in self-injury and those who do not are highlighted in bold ($p < .05$).

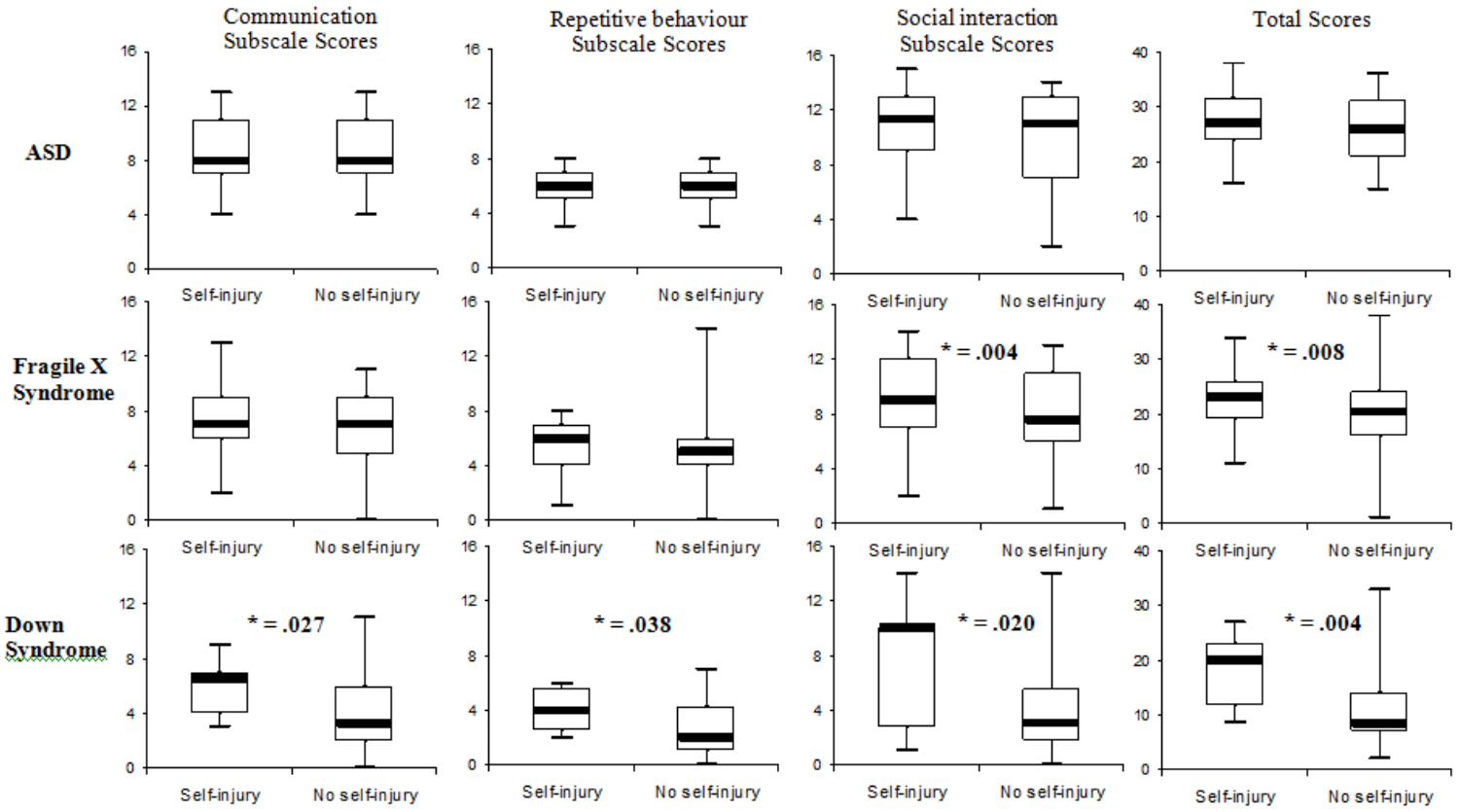

Table 4 Demographic variables for ASD participants with and without self-injury. Chi square statistics for comparison on demographic variables for ASD participants with and without self-injury. Significant differences (p<.05) are highlighted in bold; all tests are two tailed apart from level of ability and speech).

		Percentage of individuals with self-injury *(N)*	**Percentage of individuals without self-injury *(N)***	**Chi-square**	***P* value**
Gender	Male	87.8 *(65)*	89.2 *(66)*	0.066	.797
	Female	12.2 *(9)*	10.8 *(8)*		
Age	≤11 years	63.0 *(46)*	74.0 *(54)*	-*	.218
	12-18 years	28.8 *(21)*	23.3 *(17)*		
	≥ 19 years	8.2 *(6)*	2.7 *(19)*		
Ability	Able/ Partly Able	77.0 *(55)*	89.2 *(66)*	**3.899**	**.024**
	Not Able	23.0 *(17)*	10.8 *(8)*		
Speech	Verbal/ Partly verbal	80.8 *(59)*	94.6 *(70)*	**6.487**	**.006**
	Non-Verbal	19.2 *(14)*	5.4 *(4)*		
Mobility	Mobile	87.7 *(64)*	94.6 *(70)*	2.185	.139
	Non-mobile/ Partly mobile	12.3 *(9)*	5.4 *(4)*		
Vision	Normal	93.2 *(69)*	98.6 *(73)*	-*	.209
	Poor Vision/ Blind	6.8 *(5)*	1.4 *(1)*		
Hearing	Normal	93.2 *(69)*	98.6 *(73)*	-*	.209
	Poor Hearing/ Deaf	6.8 *(5)*	1.4 *(1)*		

* Fishers exact T was calculated

Table 5 Median scores and Mann-Whitney statistics for measures of affect, repetitive behaviour and activity levels for ASD participants with and without self-injury. Bold text indicates a significant difference (p<.05, one tailed).

Measure Subscale	**Median scores *(interquartile range)***		**U score**	***P* value**	**Cliff's *d***
	With self-injury (N = 74)	Without self-injury (N= 74)			
MIPQ-S					
Mood	18.50 *(16.00 – 21.00)*	19.00 *(18.00 – 21.00)*	**2249.00**	**.030**	**-.18**
Interest and Pleasure	14.00 *(11.00 – 16.00)*	15.00 *(12.00 – 18.00)*	**2241.00**	**.028**	**-.18**
RBQ					
Stereotyped behaviour	9.50 *(5.00 – 12.00)*	8.00 *(4.00 – 11.00)*	3061.00	.106	-
Compulsive behaviour	9.00 *(3.32 – 16.25)*	6.00 *(3.00 – 14.00)*	3076.50	.097	-
Insistence on sameness	4.50 *(3.00 – 7.00)*	4.00 *(2.00 – 7.00)*	2906.00	.133	-
Restricted preferences*	4.00 *(1.50 – 8.50)*	5.00 *(3.25 – 8.00)*	1710.00	.276	-
Repetitive language*	7.00 *(4.00 – 10.00)*	7.00 *(3.25 – 11.00)*	1886.50	.372	-
TAQ					
Overactivity	23.00 *(16.00 – 29.00)*	18.00 *(10.00 – 28.25)*	**3331.50**	**.012**	**.22**
Impulsivity	20.00 *(16.00 – 22.00)*	18.00 *(11.50 – 21.00)*	**3177.00**	**.022**	**.19**
Impulsive Speech*	7.00 *(4.00 -10.00)*	4.00 *(3.00 – 9.00)*	**2290.50**	**.008**	**.26**

* Subscales only calculated for verbal participant