

Epidemiology of self-injurious behaviour in adults with learning disabilities

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Background There have been few epidemiological studies of the disabling and poorly understood disorder self-injurious behaviour among adults with learning disabilities.

Method Interviews were undertaken with the carers of adults known to the Leicestershire Learning Disabilities Register ($n=2277$). The Disability Assessment Schedule was used and information was also collected on demographic characteristics, developmental and physical status.

Results Self-injurious behaviour was present in 17.4% of the population. In 1.7% self-injurious behaviour occurred frequently and was severe. There was no gender difference between those with and without self-injurious behaviour. Both the chronological age and developmental quotient of individuals with self-injurious behaviour were lower than those of individuals without self-injurious behaviour. Autistic symptoms were more common among those with self-injurious behaviour. The association of self-injurious behaviour with a wide range of other maladaptive behaviours was highly significant. Logistic regression analysis retained age, developmental quotient, hearing status, immobility and number of autistic symptoms as explanatory variables for self-injurious behaviour.

Conclusions Self-injurious behaviour is a prevalent and disabling disorder among adults with learning disabilities.

Self-injurious behaviour has been reported to occur in 7.7–40% of people living in learning disabilities hospitals, and is known to be associated with some genetic syndromes which are aetiologically linked to learning disabilities (Deb, 1998), but there have been few community studies. Oliver *et al* (1987) studied 596 people: self-injurious behaviour in the previous four months occurred in 12% of adults resident in learning disability hospitals, and 3% of adults at a social education centre. In an Irish population study, Hillery & Mulcahy (1997) found self-injurious behaviour in 14.4% of 429 children and adults over a one-month period. Rojahn (1986) used a postal survey to study 25 872 individuals with learning disabilities: 1.7% of children and adults living in the community had had self-injurious behaviour in the previous 14 days. The present study was undertaken in order to examine the prevalence and associated features of self-injurious behaviour among people with learning disabilities living within Leicestershire.

METHOD

This study analyses the epidemiology of self-injurious behaviour in adults with learning disabilities known to the Leicestershire Learning Disabilities Register (LLDR). Self-injurious behaviour was rated in terms of its severity and frequency. Frequent self-injurious behaviour refers to episodes more than three times a week. Specific types of self-injurious behaviour were used as prompts under this item, for example, headbanging, picking sores, biting; however, where more than one type of self-injurious behaviour occurred, one combined rating for severity and frequency was made. The relationship of self-injurious behaviour to age, gender, developmental quotient, sensory impairments, seizures, mobility, autistic symptoms and other maladaptive behaviours was explored.

Details regarding the LLDR and the methodology regarding collection of information about adaptive and maladaptive behaviours have been reported in detail in a related paper (Smith *et al*, 1996). Data collection included questions about the person's skill level, similar in nature to those of the Vineland scale (Sparrow *et al*, 1984). Extrapolation from Vineland scores of 71 randomly selected cases on the LLDR enabled a developmental quotient to be calculated for the whole population. The LLDR is a comprehensive register of all adults with learning disabilities living in Leicestershire, which was established during a period of extensive and active case finding. It is regularly updated by staff employed solely for this purpose. Interviews were undertaken with the carers of the 2277 adults whose names are held on the LLDR. Questions about a variety of maladaptive behaviours, including self-injurious behaviour, were sought. Ratings of maladaptive behaviours included frequency and severity, and were in keeping with those of Holmes *et al* (1982), incorporated in the Disability Assessment Schedule (DAS). Reference was also made to other items in the DAS including the presence of autistic symptoms, which included the quality of social interaction, empathy, the presence of stereotypies, routine or obsessional behaviour and quality of speech.

The Statistical Package for the Social Sciences was used for statistical analyses. Frequency data were elicited. The null hypothesis that there was no statistically significant difference between those with self-injurious behaviour compared with those adults who did not exhibit self-injurious behaviour with regard to age, gender, developmental quotient, presence of epilepsy, sensory impairments, autistic symptoms, other maladaptive behaviours and mobility was explored using Mann-Whitney and χ^2 tests. Developmental level may be a confounder for some of these variables. Logistic regression analysis was therefore undertaken using the backward stepwise method, with variables being removed from the equation until the log likelihood decreased by less than 0.01%. In this way the contribution of the explanatory variables (age, gender, developmental quotient, epilepsy, hearing status, visual status, immobility and number of autistic symptoms) on the dependent variable (presence or absence of self-injurious behaviour) could be determined.

RESULTS

Prevalence

Of the 2277 adults with learning disabilities known to the LLDR, complete data were ascertained for 2101 individuals (92.2%). Self-injurious behaviour of varying degrees of severity and frequency was present in 17.4% of the population with learning disabilities. An additional 2.5% of the population had a past history of self-injurious behaviour (but did not present with it in their current environment). In all, 19.9% of the Leicestershire population with learning disabilities had a present or past history of self-injurious behaviour. In 1.7% of individuals their self-injurious behaviour was severe in nature and frequent in occurrence (at least three times per week), while in 2.9% of individuals self-injury was frequent but less severe in nature. In 3.5% of individuals self-injury, although severe, did not occur frequently. In 9.3% of the population self-injury was a lesser management problem.

Demography

The mean chronological age of all individuals with current self-injurious behaviour was 33.56 years (s.d.=12.67 years) which was lower than the mean of 38.36 years (s.d.=14.97 years) for those without self-injurious behaviour ($z=-5.77$; $P<0.001$). There was a decline in the percentage of individuals with self-injurious behaviour in older age cohorts. Of those with self-injurious behaviour 56.9% were male, being similar to that of the population without self-injury in whom 56.8% were male ($\chi^2=0.003$, d.f.=1, $P=0.96$). This is shown in Table 1. In addition the developmental quotient was significantly lower for those individuals with self-injurious behaviour at a mean of 22.38 (s.d.=12.98) compared with a mean of 30.88 (s.d.=14.29) in those without self-injurious behaviour ($z=-10.76$; $P<0.0001$). Table 2 shows the distribution of level of developmental quotient for the people with self-injurious behaviour and those without.

Sensory impairments, mobility and epilepsy

Of those individuals with self-injurious behaviour, 21 (5.5%) were blind and 40 (10.4%) had poor or partial sight compared with 3.2% and 9.9% respectively among those without self-injurious behaviour. This is of borderline statistical signifi-

Table 1 Percentage of adults with self-injurious behaviour in differing age-gender groups

Gender	Age group (years)					All ages
	20–29	30–39	40–49	50–59	60+	
Male	21.3	20.5	16.1	7.3	7.8	17.5
Female	21.1	18.4	16.1	11.3	10.5	17.4

Table 2 Distribution of level of developmental quotient for adults with and without self-injurious behaviour

	Self-injurious behaviour (n=372)	No self-injurious behaviour (n=1729)
Profound learning disabilities (%)	177 (47.6)	363 (21.0)
Severe learning disabilities (%)	127 (34.1)	616 (35.6)
Moderate learning disabilities (%)	55 (14.8)	608 (35.2)
Mild learning disabilities (%)	13 (3.5)	142 (8.2)

cance ($\chi^2=5.72$, d.f.=2, $P=0.058$). Among individuals with self-injurious behaviour, 3.9% were recorded as deaf and 5.0% had poor or partial hearing, compared with 1.8% and 5.9% respectively among those without self-injurious behaviour ($\chi^2=7.48$; d.f.=2; $P=0.024$). Mobility was rated on a seven-point scale and was found to be significantly different between individuals with and without self-injurious behaviour ($\chi^2=41.02$; d.f.=6; $P<0.00001$). There was no difference in the prevalence of epilepsy or of seizure frequency (coded in the categories of seizures once or more per month; occasionally; none) between those individuals with and those without self-injurious behaviour ($\chi^2=2.36$; d.f.=1; $P=0.13$).

Autistic symptoms

Autistic symptoms were more prevalent among individuals with self-injurious behaviour than in those without, and are shown in Table 3. Individuals with self-injurious behaviour had a significantly poorer quality of social interaction ($\chi^2=93.63$; d.f.=3; $P<0.002$). Regarding empathy, there was less awareness or concern about other people's feelings in those with self-injurious behaviour ($\chi^2=112.14$; d.f.=2; $P<0.001$). Stereotypic movements were more common in those with self-injurious behaviour ($\chi^2=136.60$; d.f.=1; $P<0.001$). Obsessional behaviour was more common in those with self-injurious behaviour ($\chi^2=28.85$; d.f.=2; $P<0.001$).

Expressive language was minimal or absent in 41.5% of those with self-injurious behaviour compared with 15.5% of those without it ($\chi^2=134.15$; d.f.=1; $P<0.001$). Among those with sufficient conversational speech to rate, 16.5% with, compared with only 6.1% without self-injurious behaviour, showed a markedly repetitive quality to their speech ($\chi^2=31.29$; d.f.=1; $P<0.001$).

Maladaptive behaviours

Self-injurious behaviour was not present in isolation. Individuals with self-injurious behaviour also demonstrated higher rates of other maladaptive behaviours, including aggression ($\chi^2=18.237$, d.f.=1, $P<0.001$), antisocial behaviour ($\chi^2=12.73$, d.f.=1, $P<0.001$), destructiveness ($\chi^2=188.07$, d.f.=1, $P<0.001$), disturbing other people at night ($\chi^2=101.66$, d.f.=1, $P<0.001$), continuous eating or drinking ($\chi^2=24.75$, d.f.=1, $P<0.001$), pica ($\chi^2=50.57$, d.f.=1, $P<0.001$), scattering of objects ($\chi^2=119.567$, d.f.=1, $P<0.001$), attention seeking ($\chi^2=93.08$, d.f.=1, $P<0.001$), sexually aberrant behaviour ($\chi^2=10.90$, d.f.=1, $P<0.001$), faecal smearing ($\chi^2=40.83$, d.f.=1, $P<0.001$), spitting ($\chi^2=33.60$, d.f.=1, $P<0.001$), temper tantrums ($\chi^2=143.32$, d.f.=1, $P<0.001$), uncooperative behaviour ($\chi^2=145.01$, d.f.=1, $P<0.001$), self-induced vomiting ($\chi^2=17.45$, d.f.=1, $P<0.001$), wandering ($\chi^2=32.45$, d.f.=1, $P<0.001$), overactivity ($\chi^2=98.97$, d.f.=1, $P<0.001$), excessive noisiness ($\chi^2=228.31$, d.f.=1, $P<0.001$), swearing ($\chi^2=10.50$,

Table 3 Prevalence of autistic symptoms in adults with self-injurious behaviour compared with those without

	Self-injurious behaviour (n=372)	No self-injurious behaviour (n=1729)
Quality of social interaction		
Aloof/interacts only to obtain needs (%)	17.8	6.5
Passive interactions (%)	11.0	5.7
Sociable (%)	58.2	80.5
Empathy		
No awareness/concern of other's feelings (%)	41.6	20.1
Limited awareness/concern (%)	24.5	17.6
Awareness/concern unaffected (%)	33.9	62.3
Stereotypic movements (%)	32.6	9.9
Obsessional behaviour		
Elaborate routines (%)	6.5	2.2
Minor routines (%)	25.8	20.2
Minimal or no routines (%)	67.6	77.6
Speech		
None (%)	41.5	15.5
Repetitive speech (%)	16.5	6.1

d.f.=1, $P < 0.005$) and untruthfulness ($\chi^2=5.71$, d.f.=1, $P < 0.02$). Of all maladaptive behaviours examined the only behaviour which did not have an increased prevalence among those with self-injurious behaviour was hoarding rubbish. The differences between the two groups remained even after the degree of learning disabilities between the groups was taken into account.

Logistic regression

Logistic regression provided a model which accurately predicted the classification of 82.3% of subjects into the groups with and those without self-injurious behaviour. Explanatory variables were removed using the backward stepwise method until the log likelihood decreased by less than 0.01%. The explanatory variables entered into the analysis were age, gender, developmental quotient, presence or absence of epilepsy, visual status, hearing status, immobility and number of autistic symptoms. Epilepsy was the first variable to be removed, followed by gender and then visual status. The remaining variables were included in the final equation. This model gives an improvement in likelihood from a model containing none of the ex-

planatory variables equivalent to $\chi^2=245.9$, d.f.=1, $P < 0.0001$.

DISCUSSION

Study design

The strength of this study is that it includes the whole population of adults with learning disabilities living in Leicestershire, as far as can be ascertained. As such, it contributes new information regarding the prevalence of self-injurious behaviour and its associations, and provides further information in areas where previous findings have been conflicting. The LLDR is a comprehensive, regularly updated register, which was established following a process of active case finding coordinated by one of the authors (C.M.). As Leicestershire is a large county, the number of people with learning disabilities (therefore included in this study) is high. The main drawback of the study is the measurement of behavioural characteristics (e.g. self-injurious behaviour) without relating these to psychiatric diagnosis. For example, in some cases self-injurious behaviour may be a symptom of depression or anxiety, without being a 'maladaptive behaviour' *per se*.

Comparison with previous studies

The finding of 17.4% of adults with self-injurious behaviour is very similar to the prevalence described in the study of Hillery & Mulcahy (1997), which studied a similar population, although included children as well as adults. The lower rate of 1.7% described by Rojahn (1986) probably relates to the stricter criteria employed (self-injurious behaviour occurring within the previous 14 days which is repetitive, of identical form and causes physical damage), which may bear a closer resemblance to those classified as having frequent self-injurious behaviour in this study. Additionally the study did not include people living in institutions, who may have higher rates of self-injurious behaviour. Our finding that self-injurious behaviour is unaffected by gender concurs with other studies (Schroeder *et al*, 1978; Griffen *et al*, 1986; Rojahn, 1986; Hillery & Mulcahy, 1997) but not all (Oliver *et al*, 1987). The relationship between self-injurious behaviour and younger age has also been previously reported (Schroeder *et al*, 1978; Griffen *et al*, 1986; Rojahn, 1986; Oliver *et al*, 1987), although such an association was not found in the study of Hillery & Mulcahy (1997). Like the present report, most studies have also found an association between self-injurious behaviour and lower developmental ability (Schroeder *et al*, 1978; Griffen *et al*, 1986; Rojahn, 1986; Oliver *et al*, 1987; Hillery & Mulcahy, 1997).

Interpreting results

A younger age range is also a common finding in people who exhibit aggressive and destructive behaviours (Sigafos *et al*, 1994). As with aggressive behaviours, this trend could have two possible explanations. Either self-injurious behaviour is a disorder of younger adults which reduces the maturity and experience of life, or alternatively people with self-injurious behaviour have a shorter life span than those without it. Reid & Ballinger (1995) claimed that self-injurious behaviour is a chronic condition. Wieseler *et al* (1995) did not find a statistically significant difference in life span of those with self-injurious behaviour compared with those without, when level of learning disabilities, gender and epilepsy were controlled for. However, life span is shorter for people with more severe learning disabilities (Jacobson *et al*, 1985), who

are also the group more likely to have self-injurious behaviour.

Poor communication skills, elaborate routines, repetitive speech, stereotypies and lack of empathy are core symptoms of autism (Wing, 1981; Gillberg, 1993). In our study, adults with self-injurious behaviour were more likely to have these autistic symptoms than those without, and the number of autistic symptoms was retained as an explanatory variable in the logistic regression equation. These findings suggest that there may be links between the cause of autism and the cause of self-injurious behaviour or alternatively, the presence of autism may act to maintain this behaviour. The development of purposeless routines and an obsessive desire for sameness are part of the syndrome of autism. Where self-injurious behaviour occurs it may be that this becomes incorporated in such rituals.

Self-injurious behaviour has been previously reported to be associated with poor vision and hearing (Wieseler *et al*, 1995). Such associations have also been found between autism and sensory impairments (Steffenburg, 1991). In our study, statistical modelling demonstrated the role of hearing, but not vision, as predictors for self-injurious behaviour. These differences between studies probably relate to the confounding effect of developmental level on visual status.

The association of self-injurious behaviour with a wide range of other maladaptive behaviours suggests that these behaviours are not discrete diagnostic categories. Others (Schroeder *et al*, 1978; Griffen *et al*, 1986; Sigafos *et al*, 1994) have previously noted the coexistence of self-injurious behaviour with aggression, destruction and stereotypies. The nature of behaviour disorders is poorly understood, but attempts have been made to understand the coexistence of maladaptive behaviours and associated characteristics, by the use of cluster analysis (Reid *et al*, 1978; Smith *et al*, 1996). Read (1998) has drawn attention to the association between self-injurious behaviour and physical aggression, and proposes the underlying mechanism of high levels of psychophysiological arousal. From this basis, he proposes a rationale for the prescription of psychotropic drugs, which then enables psychological techniques to be used more effectively. The psychopharmacology of self-injurious behaviour, including pharmacotherapeutic approaches, and psychological treatments

CLINICAL IMPLICATIONS

- Self-injury occurs in 17% of adults with learning disabilities.
- Self-injury is associated with lower developmental quotient, younger age, autistic symptoms, hearing impairment and immobility.
- Self-injury is associated with a wide range of other maladaptive behaviours.

LIMITATIONS

- Self-injury was identified without regard to psychiatric diagnosis.
- Measurement of behaviour was through carer interview, rather than direct observation.
- There are no agreed standard diagnostic criteria to define self-injurious behaviour, which limits comparisons with other studies.

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for self-injurious behaviour have both been reviewed in detail (Clarke, 1998; Halliday & Mackrell, 1998).

Self-injurious behaviour is a highly significant disorder in terms of the level of distress it causes to sufferers and their carers. It is also cited as a cause for families to request residential care for their relative. This study has demonstrated that self-injurious behaviour is also a common disorder among adults with learning disabilities. As such, further research to establish a better understanding of its scientific basis, and treatment outcome studies are required.

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