The chronicity of self-injurious behaviour: A long-term follow-up of a total population study.

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Abstract

Background Self-injurious behaviour (SIB) is a relatively common problem for people with intellectual disabilities and it is known to be associated with various risk markers, such as degree of disability, sensory impairments and autism (McClintock et al., 2003). Less is known about its long-term course however.

Method The present study was conducted to examine quality of life and changes in behaviour for a cohort of 49 people with intellectual disabilities and self-injurious behaviours who were all part of a previous total population study conducted in the south of England by Oliver, Murphy and Corbett (1987). Assessment tools used in the original study, plus an additional quality of life measure, the Life Experience Checklist (Ager, 1990) were carried out with informants in the participant’s homes or places of day activity.

Results The results show that 84% of the sample continued to self-injure nearly 20 years on, with no significant mean changes in number of topographies or severity of SIB across the group. No one was living in hospital in this study (c.f. many individuals in the first survey) but for those who had moved out of hospital, their SIB had not reduced. More people were receiving psychological treatment; more were also receiving anti-convulsant and anti-psychotic medications, though polypharmacy had reduced somewhat. The number of people accessing full - time day activities had decreased substantially, with 44% of people only accessing structured daily activities for 2½ days per week or less.

Conclusions The results of the study add to the growing evidence of extreme chronicity for self-injurious behaviour and the relative lack of impact of treatment for
people in whom self-injury has become well-established. They imply that early intervention is essential if such behaviour is to be eliminated long term.

Introduction

Self-injurious behaviour, a behaviour that is not uncommon in people with intellectual disabilities, has profound implications for quality of life (Emerson, 1990; Murphy and Wilson, 1985; Oliver et al., 1987; Symons and Thompson, 1997). Such behaviour may result in direct physical injury being sustained (e.g., blindness, further brain damage) and it also has detrimental effects of an indirect nature, in that people with self-injurious behaviour are likely to be excluded from activity and opportunities to integrate (Oliver et al., 1987) and are likely to receive large doses of psychoactive medication, and/or protective devices to prevent serious tissue damage (Oliver et al., 1987; Emerson, 1990; Kahng et al., 2002). Self-injurious behaviour is also a major predictor of parental decisions to seek residential placements (Tausig, 1985; Emerson, 1992; Duker and Seys, 1996; Murphy et al., 1999).

Staff who care for people with self-injurious behaviour are also likely to be affected. Hastings and Remington (1993) found that self-injurious behaviour was likely to evoke feelings of sadness, disgust or despair in staff and typically resulted in the person receiving a poor service, being more at risk of abuse, and often receiving little in the way of effective treatment. Oliver et al. (1987), in their survey, found that just 2% of people with severe self-injurious behaviour, from 596 individuals surveyed, were receiving any current psychological treatment.
What is known about treatments for self-injurious behaviour is mainly based upon generalisation from small data sets. Kahng et al. (2002) found highly effective treatments covering over 700 data sets in 396 studies of self-injurious behaviours. They commented however that with published studies, treatment effects are biased towards positive outcomes and they suggested that there was relatively little longitudinal data to allow the examination of concurrent and predictive factors in relation to self-injurious behaviour.

Self-injurious behaviour has been reported as a characteristic of between 8% and 15% of people with intellectual disabilities who live in hospitals (Maisto et al., 1978; Schroeder et al., 1978; Maurice and Trudel, 1982; Griffin et al, 1986; Oliver et al., 1987) and between 2% and 12% of those living in the community, varying partly with age (Oliver et al, 1987; Emerson, 1992; Murphy, 1999). Within certain age groups, in certain settings, the prevalence figure can be over 35% (Oliver et al., 1987), especially where risk markers such as profound disabilities, sensory impairments and autism are present (McClintock et al., 2003). Previous evidence on the extent to which such behaviour is chronic, however, has been contradictory, with some studies finding high levels of chronicity and others finding low chronicity over follow-up years (Schroeder et al, 1978; Griffin et al, 1986; Windahl, 1988; Murphy et al, 1993; Emerson et al., 1996; Emerson et al., 2001; Totsika et al., 2008; Cooper et al., 2009).

The first total population study.

In 1983, the UK Department of Health funded Murphy and Corbett to conduct the first total population study into severe self-injurious behaviours in children and adults.
with intellectual disabilities, living in the South East Thames Regional Health Authority of England (population approximately 3.5 million). Initially, contact was made in writing to every intellectual disability provider in the region through psychiatrists, psychologists, paediatricians, special schools and community GP’s and subsequently to other services identified by them, including hospitals, day services, group homes and hostels (see Oliver et al, 1987). All participants were asked if anyone with intellectual disabilities in their care showed self-injurious behaviour that was sufficient to have caused tissue damage in the last four months.

Altogether 616 people met the tissue damage criterion set and data were collected for 596 of these individuals using structured assessment interviews with their staff/carers. At the time of that study (which preceded the major deinstitutionalisation movement in the late 1980s in the UK), about half of the individuals identified (51%) lived in ‘mental handicap’ hospitals, with the remainder residing in the community. The mean age of those showing SIB was 24.8 years (range 2 - 88 years), with a high number of individuals receiving psychotropic medication, and a high proportion wearing protective devices or having their environment padded (75 people and 2 people respectively) either all of the time or part of the time as a management technique to prevent tissue damage from self-injurious behaviour.

The closure of the institutions in the late 1980’s has meant that those individuals living in hospitals then, are now living elsewhere, i.e. in the community in ordinary housing with staff teams, and they are likely to be known to the disability services provided by the individual’s borough of origin.
This current study has been conducted approximately eighteen years after the first
survey, in order to compare, over time, the characteristics of people’s self-injurious
behaviour, the management of that behaviour and their quality of life. It was
hypothesised that, compared to the first survey:

1. There would be a reduction in self-injurious behaviours for most individuals in
terms of number of topographies and the Severity Index.
2. Fewer people would be using protective devices.
3. More people would be receiving psychological input and those receiving it
would have a lower Severity Index Rating than the rest of the sample.
4. Fewer people would be prescribed psychotropic medication.

It was also predicted that the majority of people with self-injurious behaviour
would have other challenging behaviours and they would have lower quality of life
scores on the Life Experience Checklist (LEC) than other groups of people with
intellectual disabilities.

**Method**

The original study (Oliver et al, 1987) covered the counties of Kent and East Sussex
and the London boroughs of Bromley, Bexley, Greenwich, Lewisham, Lambeth and
Southwark, which at that time made up the South East Thames Regional Health
Authority (total population approximately 3.5 million). This study was only able to
cover part of the original area surveyed, due to resource constraints, and it included
one inner and two outer London boroughs (total population 726,500), approximately
a 20% sample.
Self-injurious behaviour was defined in the original study (Oliver et al., 1987) as repeated, self-inflicted, non-accidental injury producing bruising, bleeding or other temporary or permanent tissue damage, and repetitive behaviours that had the potential to do so if preventative measures (e.g., protective devices, restraints) were not taken. The same definition was used in this study.

Prior to the start of the study, the project was reviewed and approved by NHS ethics committees covering the relevant boroughs.

Participants
Case identification had already been established in Oliver et al. (1987). The original raw data (n = 596) were trawled for links to find the borough of origin. Once an initial list of names, with the gender of the individual, dates of birth, and boroughs of origin were constructed, key professionals in health and social services within each borough were consulted to check the lists against records of people who were known to them in intellectual disability services. The local authority register in each borough was also consulted and this provided further information, identifying people who might not be receiving specialist health services, or who had died, or were placed outside of the borough.

The number of people meeting the criteria for inclusion in the first study (Time 1) was 616 from a total population of approximately 3.5 million (i.e., 1.76 per 10,000). Of these 616, data were collected on 596 (Oliver et al., 1987; Murphy et al., 1993). The total population of the three boroughs in this study (Time 2) is approximately 726,500 and 92 people from the first survey appeared to have originated from one of the
three boroughs covered in this study (1.27 per 10,000). Of these, 77 were traced through intellectual disability registers kept in each of the boroughs and through professionals in intellectual disability services. The remaining 15 were not traced despite searches on locally held registers and on the national death register. It is likely that they had moved with their families from the borough soon after the first survey took place (more recent moves would have been documented on registers and/or professionals in the services would have known the locations of families, but older moves may well have not been documented or recalled). Of the 77 people traced, 12 people had died, leaving 65 people still alive.

Of these 65 people, 64 had severe/profound intellectual disabilities, and were unable to consent for themselves. One woman had moderate intellectual disabilities but was also not able to consent for herself. So information about the study and consent forms were sent out to the next of kin (where they existed) and to carers where there was no known next of kin. Consent was gained and data collected for 49 people; the remaining 16 declined to take part.

Measures
Three types of assessment were carried out with parents, carers, or day service staff to provide information about individuals. The first assessment below was used in the original study by Oliver et al. (1987) and the next two measures were additional for this study:

1. The original assessment measure (Oliver et al., 1987), consisted of a carer/staff interview with questions regarding basic demographic information, estimated degree of intellectual disability, topographies and frequencies of
self-injurious behaviours, treatment required on the last occasion of self-injurious behaviour, any restraint or protective devices, type of help received with regards to the self-injurious behaviours, and current medication.

2. The AAMD Adaptive Behaviour Scales – Part 2 (Nihira et al., 1974). The ABS – Part 2 rates the occurrence of ‘maladaptive’ behaviours and allows comparison with normative data contained within the manual. Behaviours were rated as occurring frequently (2), occasionally (1), or not at all (0).

3. The Life Experience Checklist (Ager, 1990) is a measure designed to measure the quality of life, activities and experiences of people with disabilities. The LEC can be completed by service users who are able to read, by carers in association with service users, or by an informant. It consists of 50 questions that are sub-divided into 5 separate domains of Home, Leisure, Relationships, Freedom and Opportunities. The scores yielded can then be compared to pre-existing data, either by domain or by the total score. The informant version was used in this study due to the degree of disability of the individuals with SIB.

Procedure

Once the participants had been identified, their next of kin, where they existed, were contacted by telephone. This was followed up with an information pack, which contained a description of the study and a consent form, to be signed and returned to the researchers. Reminder letters were sent out where necessary. Once written permission was received, the main carer was contacted and the measures were conducted with either the person’s nearest relative or main carer, according to who knew the person best.
Reliability

Reliability for case identification was established by comparison of personal details currently held within registers against hard copy, and computer database, information used in the original study.

To establish reliability of informant information, for 20% of cases two informants were interviewed separately about the same person, using the assessment tool 1 above. Percentage agreement was calculated across categories and was 75%. Assessment tools 2 and 3 (the ABS and LEC) were not checked for reliability as these have established reliability levels (see Nihira et al 1974; Ager, 1990).

Analysis

Data were anonymised and entered onto SPSS. They were analysed using parametric statistics where this was appropriate (ie. for interval data, normally distributed); non-parametric statistics were used where data arose from rating scales and/or was not normally distributed.

Results

Assessments were conducted between August 2001 and July 2003. Data were collected for 49 individuals using the staff/carer interview and the Adaptive Behaviour Scales and for 46 individuals using the Life Experience Checklist (three sets of parents whose son/daughter still lived with them, declined to be interviewed themselves, so the LEC was not completed, but they were happy for other measures to be completed with their son/daughter’s carers at the local day centre).
Representativeness of the sample

Table 1 shows the characteristics of the total sample originally studied at time 1 (n=596), compared to the current sample at time 1 and time 2 (n=49 each time). None of the differences between the total sample and this sample at Time 1 were statistically significant and it is concluded that the sample included here was representative of the total sample.

It can be seen from the Table that at Time 2 the main changes to the characteristics of the sample were that they were of course older, fewer were living with parents, and none were living in institutions (this was due to the institutional closure programme; for those in residential homes their sizes ranged from 3 to 10 residents, with a mean of 5.8). As regards day activities, there was no longer anyone at school (all 15 were now adults) and there was a shift towards proportionately more people having part-time day activities, with somewhat fewer having no structured day activities or having full-time day activities (chi square not significant).

Changes in the number of topographies and severity of SIB

Table 1 also shows the number of topographies that people in this sample had at Time 1 and Time 2. At Time 1, 55% of the sample had more than one topography. At Time 2, although 8 people had no topographies, i.e. they were thought to have stopped self-injuring (see below for further details of this group), 59% of the sample had more than one topography.

Table 1 about here

Table 2 shows a comparison of the topographies of self-injurious behaviour reported in the original study for all cases (Oliver et al, 1987) and for this sample at Time 1
and Time 2. The most common topographies for both Time 1 (total cohort and this sample) and Time 2, were head punching/slapping, skin picking, head to object banging, and self-biting (fingers or hand).

Table 2 about here

At Time 1, those whose self-injury involved head to object banging or punching in this cohort (n = 14) had a mean number of 2.8 topographies (SD 1.12). This was similar at Time 2 (n = 15), when the mean number of topographies was 3.5 (SD 1.06). People who engaged in head to object banging or punching had significantly more topographies than other participants both at Time 1 and at Time 2 (Mann – Whitney test Z = 3.17; p = 0.002 and Z = 4.23; p = <0.001, 2 tailed, respectively) and they also had significantly higher severity indices at Time 1 and Time 2 (Mann Whitney Z = 2.89, P<0.005; and 4.78, P<001 respectively) than other participants.

Eight people (16.3%), 4 male and 4 female, had not shown any self-injurious behaviour in the 4 months period before assessment at Time 2, i.e. they appeared to have stopped self-injuring. At Time 1, seven of these eight people had single topographies of either skin picking/pinching, digit chewing, or hair removal. The other person who had not self-injured in the 4 months prior to the assessment, had engaged in hitting his body against objects and skin picking at Time 1. The ages of these eight people ranged from 10 to 49 years at Time 1 (mean 27.9, SD 13.0) and from 29 to 66 years (mean 46.2, SD 13.0) at Time 2. There was no significant age difference between this group and the rest of the sample (Mann-Whitney test Z = - .812 NS).
Figure 1 shows the changes in numbers of topographies for this sample between Time 1 and 2 \((n=49)\). A few people had large changes to the number of topographies they displayed but most people's number of topographies changed little. Numbers of topographies on the two occasions correlated highly (Spearman correlation 0.55, \(p<0.001\)). The mean change in numbers of topographies between Time 1 and Time 2 was very small (0.10 for \(n=49\)) and not significant on a Wilcoxon Signed Ranks Test.

*Figure 1 about here*

**Severity Index Rating of behaviours**

In the original study, a Severity Index was developed to rate the levels of individual's self-injurious behaviours (Murphy et al, 1993). This was based upon the frequency and the number of topographies. Topographies were rated '3' if occurring hourly or more frequently, '2' if occurring less than once per hour but at least once per week, and 1 if occurring less than once per week. Thus, if an individual had 3 topographies, each of which occurred daily, they would be given a score of 6 \((3 \times 2)\). Severity Index Ratings at Time 1 ranged from 1 to 15, and at Time 2 from 0 – 12.

Figure 2 shows the changes in Severity Index Rating for the sample between Times 1 and 2. In general Severity Indices on the two occasions were highly correlated (Spearman’s \(r = .57, p < 0.001\)). The mean change in Severity Index Rating for the group as a whole was very small (-0.30) and there were no significant differences overall in Severity Index Ratings for the group between Time 1 and Time 2 on Wilcoxon’s signed ranks test. Interestingly, the Severity Index scores at T1 and T2 were significantly negatively correlated with age both at Time 1 and Time 2.
(Spearman’s r = -0.49: p < 0.001 and r = -0.36: p < 0.05 respectively), suggesting that older people had less severe self-injury.

In the original study, there seemed to be a raised prevalence of SIB in people in their late teens and 20s, with lower prevalence in older people (Oliver et al., 1987). As the survey at Time 1 was cross-sectional, it was not clear if people actually self-injured less as they got older or if, for example, the age-related prevalence had some other explanation (such as increased mortality in more self-injurious people). In this study, it was possible to consider whether the older people had reduced their self-injury more than the younger people. The sample of 49 were therefore split into those under and over the mean age (ie those of 43 years and over, vs those of under 43 years) at Time 2. It transpired that there were no significant differences between the younger group and the older group in terms of the changes in severity index (the same was true for changes in numbers of topographies) – Mann-Whitney test, p>0.05 in both cases.

Protective devices and severe self-injurious behaviour

In the original study, 77 people of the 596 exhibited self-injurious behaviour to a degree where protective devices (or padding) were employed in order to prevent them self-injuring or suffering tissue damage as a consequence of their behaviour. These people tended to show certain types of behaviour: head against object banging, head punching, and teeth banging. They also tended to have multiple topographies. This current study included 9 people from the original 77 who wore
protective devices (at Time 1, 5 had worn splints full- or part-time; 2 had worn gloves full-time, 1 had worn a helmet part-time and 1 had worn multiple devices full-time). Their mean age at Time 1 was 15.1 years (SD 4.86, range 6-21 years); they were significantly younger than those not wearing protective devices at Time 1 (mean age 27.7 years, SD 12.8) – t test, t=4.8, p<0.01.

At Time 2, their mean age was 33.9 years (SD 4.91, range 24 years to 41 years) and only one was still using any kind of protective device (this man had used multiple devices at Time 1; at Time 2 he simply required cushions and close supervision). Nevertheless, there was no significant change in the numbers of topographies or the Severity Index for these 9 people between Time 1 and Time 2. Only one person who had chewed his fingers at Time 1 sufficiently to have required protective devices, had stopped all self-injury by Time 2.

In the original study, this group of 9 people had a significantly higher Severity Index Rating than the other 40 people in this sample (Mann-Whitney Z = 2.57; P = < 0.05, 2 tailed) but not significantly more topographies (Mann-Whitney Z = 1.44; NS). At Time 2 there were no significant differences in the Severity Index Rating (Mann-Whitney Z = 1.68; NS) or number of topographies (Mann-Whitney Z = 1.05; NS) between this group of 9 and the other 40 people.

**Persistence of Topographies**

Further comparisons were made between the original survey and the current survey to gauge the persistence of the four most common topographies of people’s self-injurious behaviours. Of the 15 people who banged their head against a hard object
in the original survey, 10 were still doing it in this follow-up study, a persistence rate for head to hard object banging of 67%. The persistence rate for head punching was 65%; for self-biting 63% and for scratching and skin picking 53%.

For the 9 people who had sufficiently severe self-injury to require protective devices at the time of the original study, 4 people who were head banging against a hard object at Time 1 were all still doing it at Time 2, giving a persistence rate of 100%. Four out of 6 people amongst this 9 who were head punching at Time 1 were still doing it at Time 2, giving a persistence rate of 67%. Other topographies for this 9 people were not analysed for persistence, due to the small numbers.

Psychological input.

At Time 1, only 2 people (4%) were receiving any current psychological help for their self-injurious behaviour, one of these being someone in protective devices. At Time 2 this had risen to 25 people (51%). Three of the 9 people who had worn protective devices at Time 1 were among those receiving psychology input at Time 2. Those receiving psychological input at Time 2, had a higher severity index at Time 2 than those not receiving psychological input at Time 2 (though the difference in severity scores between these two groups was not significant). Typically, the psychological input included close monitoring and behavioural support plans/staff guidelines.

There was a small worsening in the mean Severity Index score (+0.52 for n = 25) and mean number of topographies (+0.24 for n = 25), between Times 1 and 2, for those receiving psychological input. For those people not receiving psychological input at Time 2, there was a small improvement in the mean Severity Index and
mean number of topographies, between Times 1 and 2 (-1.15 and - 0.04 respectively, n = 24). Those receiving psychological input had a significantly bigger change in severity index on Mann Whitney test (Z = - 2.01; p<0.05) than those not receiving such input, but this did not hold for the number of topographies.

Co-morbidity with other challenging behaviours.
The ABS - Part 2 (Nihira et al., 1974) was completed with all 49 people in this current study. Table 3 shows the percentage of people who also engaged in different types of challenging behaviours and the percentage of those who scored within the 90th percentile or above, compared to the normative samples within the ABS manual (Nihira et al., 1974)

Table 3 about here

Spearman’s correlations were conducted to test whether there were associations between self-injurious behaviours (in terms of Severity Index) and the total domain scores of the ABS Part 2. A significant correlation was found between severity of self-injurious behaviour (Severity Index) at time 2 and the raw scores on the section of the ABS for ‘stereotyped behaviours’ (r = 0.43, n = 49, p <0.01, 2-tailed). There were no other significant correlations between other ABS domains and the Severity Index.

People receiving psychotropic medication.
In this study, information about medication was obtained by reference to individual’s medication administration recording charts where people lived in group homes, or by direct examination of the person’s medication where they lived at home. Different
types of medication were classified according to the British National Formulary classification (2000). Information was available for 45 people at Time 1 and 49 people at Time 2. Comparative data were examined for the 45 people for whom data were available at both Times 1 and 2.

The numbers of people receiving the various types of medication at time 1 and time 2 are shown in Table 4. Overall, the number of people receiving psycho-active medication (either anti-psychotic or anticonvulsant medication had increased from 28 people (62%) at Time 1 to 36 people at Time 2 (80%). Altogether at Time 2, 21 people (47%) were on more than one psychoactive medication, 15 people (33%) being on two types and 6 people (13%) on three 3 types.

Table 4 about here

At Time 2, seventeen people (38%) were taking medication prescribed to regulate bowel movement and nine people (20%) were taking medication to prevent or treat ulcers. Five people (11%) were taking both. There were no comparison data from Time 1.

Quality of Life

Quality of life was measured using the LEC. LEC data were obtained for only 46 of the total sample of 49 people due to some parents not wishing to be directly interviewed (so that no LEC data were possible). Table 5, shows the LEC mean scores achieved for the total sample (n =46), for eight of the nine people who wore protective devices at Time 1 and for the remainder (n=38).
Table 5 about here

The 8 people with severe self-injurious behaviour requiring protective devices at Time 1 had lower mean scores in all domains, apart from ‘home’, compared to the rest of the sample (all LEC scorers refer to Time2). Their mean score for ‘opportunities’ was significantly lower than the remainder of the group (Mann-Whitney tests Z = 2.347; P = <0.05). There was a negative correlation between the Severity Index and scores on the LEC but it was not significant (Spearman's r = -0.18; NS).

The mean scores achieved by the total sample were lower than those for Ager’s general population sample, but broadly comparable with those of Murphy et al’s study (1996) and Wagner’s study (community-based sample - see Ager, 1990), though this sample had somewhat lower mean scores in areas of leisure and freedom.

Discussion

Self-injurious behaviour was defined as in the original study (Oliver et al., 1987) as repeated, self-inflicted, non-accidental injury producing bruising, bleeding or other temporary or permanent tissue damage, and repetitive behaviours that had the potential to do so if preventative measures were not taken. The study therefore included people whose self-injury was very clear and did not include those people who merely showed stereotyped behaviour. Analysis suggested that the (3-borough) sample followed up in this study was closely representative of the original total population sample studied in Oliver et al. (1987).
Chronicity

Evidence from this study suggested there was a high level of chronicity to SIB, for people whose behaviours were well enough established to have caused tissue damage (and thus to have been counted at Time 1). While it was hypothesised that there would be a reduction in SIB over time (hypothesis 1), it transpired that there was no overall change in the number of topographies or in the mean severity of SIB over the 18 years between Time 1 and Time 2. Fewer people were using protective devices (hypothesis 2), though this seems to have resulted more from cultural changes in intellectual disability services than from changes in participants' SIB. More people were receiving psychological input than at Time 1, but those receiving such input did not have a lower severity index, providing only partial support for hypothesis 3. There was no evidence that those people receiving psychological input had shown a reduction in SIB since Time 1. Finally it was hypothesised that fewer people would be receiving psychotropic medication (hypothesis 4) but it appeared that in fact more people were receiving such medication,

Challenging behaviours generally appear to decline with age, after a peak in early adulthood, according to cross sectional and some longitudinal studies (Oliver, 1993; Emerson, 1995; Clarke, 1998; Murphy et al, 2005). Whilst this current study did indicate a negative correlation between age and severity of self-injurious behaviour, 84% of the sample were still self-injuring after 18 years with no significant mean differences in the number of topographies or the severity (Severity Index) of their self-injurious behaviours. Despite limited data that suggests otherwise (e.g. Schroeder et al., 1978; Cooper et al., 2009), most studies, including this one, suggest that self-injurious behaviour persists for many people for many years.
(Windahl, 1988; Murphy et al, 1993; Emerson et al., 1996; Emerson et al., 2001; Totsika et al., 2008).

The data in this study also provided further evidence that the maintenance of self-injurious behaviour is not dependant upon institutional environments, since many people had moved out of hospital environments but were still self-injuring, confirming that SIB is not maintained simply by institutional environments (Oliver et al., 1987; Clarke, 1998; Deb, 1998; Halliday and Mackrell, 1998; Nøttesdat and Linaker, 2001; Thompson and Caruso, 2002). Rather it may be the personal characteristics of individuals, such as impaired mobility, severe epilepsy, communication impairments, autism, lower developmental abilities that put them at risk of developing SIB (Murphy et al., 1999; Nøttesdat and Linaker, 2001; Emerson et al., 2001; McClintock et al., 2003), as well as the reactions of carers to the behaviours in the individual’s social environment that maintain it (Hastings and Remington, 1993(a); Hastings, 1995; Murphy et al., 1999; Nøttesdat and Linaker, 2001; Oliver et al., 2005).

**Topographies**

In this study, the most common self-injurious behaviours were skin picking, self-biting, hand to head banging and head to object banging, as in the previous study (Oliver et al., 1987).

Only very small changes in topographies were found, which supports others’ findings that specific topographies are relatively stable (Emerson et al., 1996). Here, there was an 81% (17 out of 21 people), persistence rate for those people who engaged in head/face contact behaviour for the sample, rising to 100% for those people who were deemed to have had severe self-injurious behaviour at Time 1 (n = 6). Only 8
people ceased all topographies of SIB and these were mainly people who had only had a single topography at Time 1.

In this current study, 51% of self-injurious behaviours were directed towards the head or face and 20% towards the body. This was largely unchanged from the time of the original study (45% and 24%). Other studies also report high incidence of behaviours either directed towards the head or hands (e.g., Berkson et al., 2001; Murphy et al., 1999; Symons and Thompson, 1997), but the percentages attributed to either head or hands appear to vary dependant upon the sampled population in terms of age and type of provision.

**Co-variance with challenging behaviours**

In this study, using the ABS - Part 2, 88% of the sample had ‘violent and/or destructive behaviours’ with almost half of the sample scoring at the 90th percentile or above for these behaviours, compared to the normative data (Nihira et al., 1975). These findings are similar to those of Read (1998) and Griffin et al (1986). However, there was no significant correlation found between the severity of people’s self-injurious behaviours (Severity Index) and behaviours that could be described as hostile, supporting the findings of Nøttesdat and Linaker (2001).

This study also found a high positive correlation between the level of stereotyped behaviours and the level of self-injurious behaviour. A number of studies have suggested that self-injurious behaviour develops early on in children’s lives, often originating as a stereotyped behaviour (e.g. Guess and Carr, 1991; Murphy et al, 1999; Schneider et al., 1996; Berkson et al., 2001; Petty et al., 2009). Others have
also found that there is a high correlation between stereotyped and self-injurious behaviours (e.g. Rojahn, 1984).

**Pharmacology**

The efficacy of chemical treatments for challenging behaviour has, for a long time, been a subject of debate. Occasional studies have indicated positive outcomes of psychoactive medication for certain behaviours (e.g. Markowitz, 1992; Lewis et al., 1995) but under scrutiny a substantial number of studies that promote the efficacy of pharmacological approaches are characterised by methodological limitations (Schroeder, 1995; Matson et al., 2000; Kahng et al., 2002) and others cast doubt on the ability of anti-psychotic medication to change specific individual challenging behaviours (Gringras, 2000). The overall sedative effect that medication may produce is also frequently accompanied by extra-pyramidal symptoms, which can be debilitating, and are likely to require further medication to reduce them (Oliver et al., 1987; Clarke, 1999; Gringras, 2000). Moreover Schaal and Hackenberg (1994) suggested that up to 30% of people receiving psychotropic medication may suffer from tardive diskenesia, a movement disorder that can be permanent.

The recognition of the severity of side-effects has led to a reduction in the use of some anti-psychotic medications e.g. haloperidol, used to reduce stereotypies, reduce aggression and stabilise mood (Campbell et al., 1996) and the recognition of biological abnormalities associated with self-injury, some have argued, has allowed a more rational selection of treatment (Clarke, 1998). However, the use of medication is hard to evaluate for methodological and ethical reasons. Despite tighter controls both here in Britain and the USA, designed to limit the prescribing of drugs to
particular diagnostic criteria and make experimentation with potentially dangerous
drugs less likely (Gringrass, 2000), Clarke (1998) claimed that treatment often
involved the use of unlicensed medication, rather than specifically developed drugs
for self-injurious behaviour.

Reiss and Aman, 1997, have reported that in large residential settings the use of
psychotropic medication ranged from 30% to 50% of the population, and
anticonvulsant medication from 25% to 35% of the population, so that between 45%
and 67% of people received some kind of psychoactive medication. For the
community population the range for psychotropic medication was between 25% and
40%, anticonvulsants 20% to 30% and a combined total prevalence of between 35%
and 48%.

This study focused upon people with self-injurious behaviours most of whom were
now living in staffed houses within the community. The prevalence of the use of
medication for this sample was approximately 15% higher than that quoted for large
residential settings in all three categories. Emerson (1990) highlighted concern that
between 40% and 50% of people with self-injurious behaviour were receiving
psychoactive drugs. In this study, 80% of people were receiving some kind of
psychoactive medication and 11% of people were still receiving more than one kind
of antipsychotic medication despite there being no valid scientific or clinical
justification for the practice of ‘polypharmacy’ (Reiss and Aman, 1997).

One type of medication that has been convincingly demonstrated as effective in
reducing self-injurious behaviour is Naltrexone, a beta-endorphin antagonist. Over
40 studies of the effect of naltrexone on self-injury have been published, and in a selection of 27 of them, Symons et al (2004) found 80% of participants showed an improvement in self-injury. However, Naltrexone appears to be rarely used: none of the people in this study were on this type of medication despite the chronicity of their SIB and the fact that 28% of people engaged in head to object SIB.

**Quality of Life**
Ager (1990) has suggested that the Life Experience Checklist can be read as a service response to the ideas of normalisation (Wolfensberger, 1983), to gauge the extent to which people enjoy experiences common to other members of the population. Whilst Ager (1990) points out the problems regarding the subjective interpretation of ‘valued experiences’, Felce et al. (2002) have shown that quality of life is strongly associated with abilities. This is reflected within this sample where the scores achieved on the Life Experience Checklist tended to be lower across domains where individuals’ levels of ability were more likely to limit their access to activities and experiences enjoyed by more independent people. Those people with more severe behavioural challenges are also likely to be further restricted in accessing valued activities and socialising, even at a basic level of experiencing different environments with different people. The results of this study suggest that the provision of day-activities for this group, most often through attendance at day centres, has improved slightly in that fewer people had no day activities, but nevertheless the majority of people still received 2½ days a week or less of structured activity (and fewer people had full-time day activities than previously).

This study does have some strengths and some limitations:
1. The follow-up period of 18 years exceeds those of previous long term studies of SIB, so that a real view of the long term outcome of SIB is possible.

2. The study includes many people whose living environment has changed substantially over the years and illustrates the persistence of SIB in the face of such changes.

3. Whilst some information was gathered on whether people were receiving psychological input, detailed questions were not asked (to gauge the exact nature and outcome of the input provided, for how long it had been provided, or any past input and the results of that input). This information would have been valuable but difficult to collect.

4. The Adaptive Behaviour Scale Part 2 (1974) results should be viewed with caution firstly, as the scoring system fails to take account of the relative severity of behaviours (Qureshi, 1994) and secondly, because the scale has been criticised at times for its poor mean inter-rater reliability generally (Phi coefficient of .57), though we would argue that other measures of challenging behaviour have similar problems.

5. Statistical results for the sub-sample of 9 people who had severe self-injurious behaviour and used protective devices at the time of the original study should be treated with caution due to the small number of people involved.

It is difficult not to be disheartened by this study. The research literature abounds with demonstrations of the efficacy of applied behaviour analysis for people with self-injury and yet this study appears to show extreme chronicity for SIB, with concomitant risks to the individuals in relation to their quality of life and likely subjection to psychoactive medication. Berkson et al. (2001) and others have
suggested that intervention success may be age related, with interventions being less successful when the individual’s behaviours have become well established, and therefore difficult to eliminate. Certainly the limited data available in this study on the small number of people who stopped self-injuring would seem to support this, in that most of those who ceased SIB had only had one topography of self-injury at time 1.

It is also possible that intensive interventions of the kind that result in reductions in SIB (and research publications) are either not widely available or they are not well-sustained over the years. We suspect that both are true. The implication is that we need to intervene early, intervene intensively and plan to sustain the input if we are to make a real difference in the lives of people with self-injury.
References


Table 1. Characteristics of the total sample at Time 1 and of this sample at Time 1 & 2.

<table>
<thead>
<tr>
<th></th>
<th>Total sample at Time 1 (n=596)</th>
<th>This sample at Time 1 (n=49)</th>
<th>This sample at Time 2 (n=49)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Gender</td>
<td>346 (58%) 250 (42%)</td>
<td>27 men (55%) 22 women (45%)</td>
<td>27 men (55%) 22 women (45%)</td>
</tr>
<tr>
<td>Age</td>
<td>24.9 yrs (SD 13.0)  Range 2-88</td>
<td>25.3 yrs (SD 12.7) Range 5-64 yrs</td>
<td>43.5 yrs (SD 12.5) Range 24-82 yrs</td>
</tr>
<tr>
<td>Living situation</td>
<td>51% in institutions 28% in hostels or group homes 21% with parents</td>
<td>61% in institutions 16% in hostels or group homes 22% with parents</td>
<td>0% in institutions 90% in group homes or similar 10% with parents</td>
</tr>
<tr>
<td>School attendance (% of whole sample)</td>
<td>32% at school</td>
<td>31% at school</td>
<td>0% at school</td>
</tr>
<tr>
<td>Day activities (% of adults in sample)</td>
<td>37% no day activity 17% part-time day activity 46% full-time day activity</td>
<td>38% no day activity 15% part-time day activity 47% full-time day activity</td>
<td>29% no day activity 45% part-time day activity 27% full-time day activity</td>
</tr>
<tr>
<td>Number of topographies of SIB</td>
<td>0 – 0% 1 – 46% &gt;1 - 54% 5 or more – 3%</td>
<td>0 – 0% 1 – 44.9% &gt;1 – 55.1% 5 or more – 4%</td>
<td>0 – 16.3% 1 – 24.5% &gt;1 – 59.2% 5 or more – 6%</td>
</tr>
<tr>
<td>Mean severity of SIB</td>
<td>3.6 (SD 2.6)</td>
<td>4.1 (SD 3.2)</td>
<td>3.8 (SD 3.2)</td>
</tr>
<tr>
<td>Wearing protective devices or using cushions or padding</td>
<td>77 (13%) - 75 with protective devices - 2 with cushions /padding only</td>
<td>9 (18%) - 9 with protective devices - 0 with cushions /padding only</td>
<td>1 (2%) - 0 with protective devices - 1 with cushions /padding only</td>
</tr>
</tbody>
</table>
Table 2

<table>
<thead>
<tr>
<th>Topographies</th>
<th>Oliver et al. (1987) (n = 596) % of cases*</th>
<th>Follow up cohort (n = 49)</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Time 1 %*</td>
<td>Time 2 %*</td>
</tr>
<tr>
<td>Skin picking</td>
<td>39</td>
<td>35</td>
</tr>
<tr>
<td>Self biting</td>
<td>38</td>
<td>33</td>
</tr>
<tr>
<td>Head punching/slapping</td>
<td>36</td>
<td>35</td>
</tr>
<tr>
<td>Head to object banging</td>
<td>28</td>
<td>31</td>
</tr>
<tr>
<td>Body to object banging</td>
<td>10</td>
<td>10</td>
</tr>
<tr>
<td>Other SIB</td>
<td>10</td>
<td>12</td>
</tr>
<tr>
<td>Hair removal</td>
<td>8</td>
<td>16</td>
</tr>
<tr>
<td>Body punching</td>
<td>7</td>
<td>14</td>
</tr>
<tr>
<td>Eye poking</td>
<td>6</td>
<td>8</td>
</tr>
<tr>
<td>Skin pinching</td>
<td>4</td>
<td>4</td>
</tr>
<tr>
<td>Tool cutting</td>
<td>2</td>
<td>2</td>
</tr>
<tr>
<td>Anal poking</td>
<td>2</td>
<td>0</td>
</tr>
<tr>
<td>Other poking</td>
<td>2</td>
<td>0</td>
</tr>
<tr>
<td>Tool banging</td>
<td>2</td>
<td>2</td>
</tr>
<tr>
<td>Lip chewing</td>
<td>1</td>
<td>0</td>
</tr>
<tr>
<td>Nail removal</td>
<td>1</td>
<td>0</td>
</tr>
<tr>
<td>Teeth banging</td>
<td>1</td>
<td>2</td>
</tr>
</tbody>
</table>
Table 3.

Percentage of people (n = 49) showing other challenging behaviours and comparison with normative data (Nihira et al., 1975)

<table>
<thead>
<tr>
<th>ABS Domain*</th>
<th>No. of people displaying behaviours in this sample</th>
<th>No. of people scoring within 90th percentile or above (compared to normative data).</th>
</tr>
</thead>
<tbody>
<tr>
<td>Violent/destructive behaviour</td>
<td>43 (88%)</td>
<td>24 (49%)</td>
</tr>
<tr>
<td>Antisocial behaviour</td>
<td>37 (76%)</td>
<td>11 (22%)</td>
</tr>
<tr>
<td>Rebellious behaviour</td>
<td>38 (78%)</td>
<td>21 (43%)</td>
</tr>
<tr>
<td>Withdrawn behaviour</td>
<td>42 (86%)</td>
<td>11 (22%)</td>
</tr>
<tr>
<td>Stereotyped behaviour</td>
<td>36 (74%)</td>
<td>25 (51%)</td>
</tr>
<tr>
<td>Inappropriate interpersonal behaviour</td>
<td>21 (43%)</td>
<td>13 (27%)</td>
</tr>
<tr>
<td>Unacceptable vocal habits</td>
<td>36 (74%)</td>
<td>32 (65%)</td>
</tr>
<tr>
<td>Unacceptable or eccentric behaviour</td>
<td>46 (94%)</td>
<td>34 (69%)</td>
</tr>
<tr>
<td>Hyperactive tendencies</td>
<td>25 (51%)</td>
<td>18 (37%)</td>
</tr>
<tr>
<td>Sexually aberrant behaviours</td>
<td>20 (41%)</td>
<td>12 (24%)</td>
</tr>
<tr>
<td>Psychological disturbances</td>
<td>44 (90%)</td>
<td>12 (24%)</td>
</tr>
</tbody>
</table>

* 'Untrustworthy behaviour' was not rated as it was inappropriate for the participants, given their level of ability; ‘self-abusive behaviour’ and ‘medication’ were not included as they had been considered separately already.
### Table 4

Percentage of people (n = 45) prescribed medication at the two time points

<table>
<thead>
<tr>
<th>Type of medication</th>
<th>No. of people T1 (n=45)</th>
<th>No. of people T2 (n=45)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Any anti-psychotic medication</td>
<td>20 (45%)</td>
<td>28 (62%)</td>
</tr>
<tr>
<td>More than one kind of anti-psychotic</td>
<td>7 (16%)</td>
<td>5 (11%)</td>
</tr>
<tr>
<td>Other cns medication, eg anti-cholinergics, to reduce side-effects of anti-psychotics</td>
<td>10 (22%)</td>
<td>18 (40%)</td>
</tr>
<tr>
<td>Anti-convulsants</td>
<td>9 (20%)</td>
<td>21 (47%)</td>
</tr>
<tr>
<td>Stimulants</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>Anti-depressants</td>
<td>2 (4%)</td>
<td>4 (9%)</td>
</tr>
<tr>
<td>Hypnotics</td>
<td>1 (2%)</td>
<td>1 (2%)</td>
</tr>
<tr>
<td>Anxiolytics</td>
<td>2 (4%)</td>
<td>1 (2%)</td>
</tr>
</tbody>
</table>
Table 5. Life Experience Checklist Scores (n = 46)

<table>
<thead>
<tr>
<th>LEC Domain</th>
<th>Total sample (n=46)</th>
<th>Severe sample (n=8)</th>
<th>Less severe sample (n=38)</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>score &amp; range</td>
<td>score &amp; range</td>
<td>score &amp; range</td>
</tr>
<tr>
<td>Home</td>
<td>7.6 (5-10)</td>
<td>8.3 (7-9)</td>
<td>7.5 (5-10)</td>
</tr>
<tr>
<td>Leisure</td>
<td>3.1 (0-7)</td>
<td>2.4 (0-5)</td>
<td>3.3 (0-7)</td>
</tr>
<tr>
<td>Relationships</td>
<td>5.1 (4-7)</td>
<td>4.6 (4-6)</td>
<td>5.2 (4-7)</td>
</tr>
<tr>
<td>Freedom</td>
<td>5.4 (1-9)</td>
<td>4.1 (1-7)</td>
<td>5.7 (2-9)</td>
</tr>
<tr>
<td>Opportunities</td>
<td>6.1 (2-9)</td>
<td>4.9 (3-7)</td>
<td>6.4 (2-9)</td>
</tr>
<tr>
<td>Total</td>
<td>27.2 (16-37)</td>
<td>24.3 (20-32)</td>
<td>27.8 (16-37)</td>
</tr>
</tbody>
</table>