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Restraint and self-injury in people with intellectual disabilities

A review

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Abstract  Most of the recent debate concerning the ethics of physical interventions has focused on the management of aggressive and destructive behaviours, neglecting the management of self-injurious behaviour. This is an important omission, given the extremely serious consequences that can arise from this form of challenging behaviour. The present article reviews types of restraint used to manage self-injury, prevalence of use, and main and side effects of restraint use. It describes some good practice standards and highlights the need for further research and debate in this complex area.

Keywords  restraint; self-injury
Introduction

Murphy (1999) has defined self-injurious behaviour (SIB) as any behaviour initiated by the individual that directly results in physical harm to that individual. Self-injury in people with intellectual disabilities is a heterogeneous class of responses that have multiple topographies with numerous causes and effects (Schroeder et al., 1980). Its common characteristics include repetitive movements of various body parts that produce physical damage or potential damage if repeated frequently. Thompson and Caruso (2002) have suggested that this behaviour occurs in two principal forms. First, it may present in discrete, brief bouts lasting no longer than a few seconds; it is proposed that brief episodes of this type are environmentally determined. Alternatively, it may consist of very protracted episodes lasting for several hours with only very brief pauses; whilst SIB of this type may be precipitated by environmental events, once started, it is maintained by neurological factors.

Oliver et al. (1998) have stated that between 4 and 14 percent of people with intellectual disabilities self-injure. SIB is often persistent, difficult to treat and, when untreated, has serious consequences. The latter can include major injury that can result in permanent tissue damage and secondary problems such as infection, sensory and neurological impairment and even death (Emerson, 1992).

Therapeutic interventions for SIB have most typically employed either pharmacological or behavioural methods, although more psychodynamic interventions have also been undertaken (Simpson and Miller, 2004). Some forms of psychotropic medication, notably the typical neuroleptics, have been used to treat SIB but with little evidence of therapeutic effectiveness, other than general sedation affecting all forms of behaviour (Brylewski and Duggan, 2001; DeLeon et al., 2002). A potentially promising development in recent years has been the use of opiate antagonists, such as naloxone or naltrexone, to block the effect of endogenous opiates that are produced by repeated self-injury, thereby effectively reducing the behaviour itself (Emerson, 1992; Murphy, 1999; Oliver et al., 1987; Thompson and Caruso, 2002). Whilst this form of pharmacological intervention appears effective for some, interventions based on applied behaviour analysis are still generally considered the most proven treatments for self-injury, especially when based on detailed functional analysis (Carr et al., 1990a; 1990b; Emerson, 1992; Horner and Carr, 1997; Kahng et al., 2002a; 2002b; Schroeder et al., 2002; Scotti et al., 1996; Thompson and Caruso, 2002). Optimum intervention may well involve combined bio-behavioural treatment where, for example, opiate antagonists are used functionally in direct response to the results of behavioural analysis of SIB (DeLeon et al., 2002;
Thompson et al., 1994). However, despite the continued promise of effective intervention, available data suggest that most people with SIB (and indeed challenging behaviour in general) in the UK are unlikely to receive effective evidence-based treatment (Emerson et al., 2000; Harris and Russell, 1989; Oliver et al., 1987; Qureshi, 1994; Robertson et al., 2005).

Even with successful intervention, complete elimination of self-injury is a rare phenomenon. Given the risks that this behaviour poses, there is a clear need therefore to devise effective reactive strategies to manage self-injurious episodes in combination with proactive strategies for behaviour change. Over the last decade, virtually all of the ethical debate, policy development and staff training concerning reactive strategies has focused on managing externally directed behaviour, most notably aggression (Allen, 2001, 2002; British Institute of Learning Disabilities, 2001; Department of Health and Department for Education and Skills, 2002; Harris et al., 1996). In contrast, very little attention has been paid to the reactive management of self-injury. The present article is therefore devoted to this topic. The existing literature is reviewed, and information on the types of restraint employed to manage self-injury, their frequency of use, and primary and secondary effects are described. Some good practice points are then identified and future research issues discussed.

**Method**

Preliminary electronic literature searches were conducted in the Medline and PsycINFO databases using various combinations of search terms. PsycINFO proved to be the most productive: a search using the terms ‘mental retardation and self-injurious behaviour and restraint’, limited to peer review journals, identified 52 papers. Similar combinations substituting ‘restraint’ with ‘behavioural management’ identified one unpublished dissertation; substitutions using ‘reactive strategies’ and ‘reactive management strategies’ identified no papers. Searches using the terms ‘mental retardation and autism and self injurious behaviour’ yielded four papers that were all included in the list of 52 papers previously identified. Substituting ‘learning disabilities’, ‘intellectual disabilities’, ‘self-harm’, ‘autistic spectrum disorder’, ‘triad of social impairment’ and testing different combinations did not identify any additional papers. In a number of these papers, restraint was employed as a punitive consequence in a behavioural intervention rather than as a reactive strategy per se. A total of 34 papers were finally included in the review.
Types of restraint employed to manage self-injury

There is clearly great variation in the type of restraint used to manage self-injury. Mechanical restraints, for example, can range in their form of restrictiveness and degree of restrictiveness from almost complete immobilization using objects such as beds (Tate, 1972) or chairs, to the use of wrist cuffs that bring the SIB under stimulus control but which do not restrict movement (Oliver et al., 1998). The way in which terminology is used can also be confusing. Although the term 'mechanical restraint' implies a greater degree of restriction than the term 'protective device', they are often used interchangeably, which makes differentiating between protection and restraint problematic. For example, the joint guidance from the Department of Health and Department for Education and Skills (2002, p. 10) briefly mentions mechanical restraint and defines the use of a protective helmet to prevent self-injury as non-restrictive and the use of arm cuffs or splints to prevent self-injury as restrictive. However, some forms of 'protective device', such as orthotic helmets that cover the entire face, could be more restrictive than some forms of mechanical restraint, such as wrist cuffs that allow a considerable degree of movement. Further, some forms of physical restraint (for example, having your hands held at your side by a carer), although applied for short periods, could conceivably be more intrusive and restrictive than protective devices such as wrist cuffs that allow considerable movement but are worn continuously.

The degree of restrictiveness is a complex issue and a more objective and reliable means of measuring and describing this would clearly be useful. Duker and Seys (1997) developed the Imposed Mechanical Restraint Inventory (IMRI) to directly address some of these issues and measure restrictiveness as a dependent variable when evaluating treatment. The IMRI measures a number of dimensions in considerable detail such as: whether restraint is applied when the person is ambulant, sitting in a chair or lying in bed; the parts of the body that may be restrained; the degree of restraint applied to each body part; and a timescale to measure the duration of restraint. The IMRI is notable because it appears to be one of the only scales designed to directly address this issue; it has been found to be reliable and could be adapted to gather useful data in future studies.

Figure 1 shows responsive strategies for self-injury cited in the literature organized into a general continuum from least to most restrictive. This continuum can only be described in very general terms because the degree of restriction can vary considerably depending on the specific details of how the strategy is designed and applied in practice. Unfortunately, many studies do not describe the approach used in sufficient detail to make a precise assessment of the degree of restriction involved.
The strategies have been classified into three levels of intrusiveness. The least intrusive strategies consist primarily of distraction/defusion techniques, although a low level of physical prompting may also be sufficient to interrupt early stages of self-injury for some service users. Restrictive strategies include alterations to the physical environment, personal restraint and specific mechanical restraint devices that do not have a major impact on restricting the wearer’s movement. Finally, the most restrictive devices are those which both inhibit self-injury and place major restrictions on the wearer’s freedom of movement.

Prevalence of use
Data are sparse regarding the extent to which reactive strategies are used to manage SIB in practice and this may be related to the fact that written plans are only found in very few service settings (Oliver et al., 1987). However, despite this, it can be assumed that staff are likely to adopt various ad hoc reactive approaches, as they, quite understandably, feel guilty if they do nothing in response to SIB. Hastings (1996) investigated staff responses to a hypothetical situation involving severe SIB and found staff citing a range of strategies consistent with the continuum of restrictiveness previously described. However, notably, staff reported that they were much more likely to use physical and mechanical restraint because they needed to take immediate action to prevent service users harming themselves.
Mechanical forms of restraint have received the greatest attention in the literature on self-injury and some epidemiological studies report on the prevalence of use. A total population study of people with intellectual disabilities and challenging behaviour in one health region in the UK in the early to mid 1980s (Murphy et al., 1993; Oliver et al., 1987) showed that approximately 13 percent (75 individuals) of people with intellectual disabilities who self-injured wore protective devices or mechanical restraints. Arm splints were the most commonly used device. These people had severe SIB, were generally younger, and had greater sensory, cognitive and physical impairments than other people with SIB. They also tended to present multiple forms of challenging behaviour.

Emerson (2002) reported on a series of studies conducted over the period 1994–2000 that showed that 5 percent of children with intellectual disabilities who self-injured were ‘usually’ or ‘sometimes’ managed by mechanical restraint. The equivalent figures for adults in two separate studies were 7 and 17 percent. Although comparisons are difficult, taken overall, these figures suggest little change in the rate of mechanical restraint for self-injury in the UK over the last two decades. Given the lack of availability of effective therapeutic support alluded to earlier, this would perhaps be expected.

Although not directly related to the present article, it is important to note that it has been estimated that between 12 and 50 percent of people with intellectual impairments and SIB also engage in self-restraint. This may occur via service users folding their arms, sitting on their hands or legs, entangling themselves in clothing, requesting or positioning themselves in mechanical restraints, holding or wearing particular items (Forman et al., 2002). Whilst this is generally viewed as an attempt to prevent or escape from SIB, the precise functional relationship between SIB and self-restraint is likely to be more complex.

**Main and side effects**

There is no doubt that restraint can be very effective in reducing self-injury whilst in use, and there is also some evidence to suggest that brief personal restraint (i.e. when the person is held by others) is at least as effective as longer-term application (Harris, 1996).

Mechanical restraint can also have a number of detrimental side effects. A major concern is that the social attention that is delivered during the application can serve to positively reinforce and therefore increase rates of SIB in individuals whose behaviour is maintained by this contingency (Hastings, 1996; Spain et al., 1984). In the absence of a clear framework of guidance, training and monitoring, physical restraint may also risk injury to the client or staff involved, as well as providing contingent
attention (Harris, 1996). Harris also suggests that mechanical restraint may be safer than personal restraint, although evidence from the grey literature would appear to question this assertion (Allen, in press). Mechanical or protective devices may themselves serve to reinforce and maintain SIB, thus making the person dependent on wearing them for long periods of time (Fisher et al., 1997; Foxx and Dufrense, 1984; Spain et al., 1984). In this sense, the restraint itself assumes reinforcing properties, possibly because it represents a means of escaping compulsive self-injury. Under these circumstances, it is not unusual to see self-injury occurring at high rates in order to ‘earn’ access to restraints, and upon restraint removal in an attempt to secure reapplication. Mechanical restraint may also result in the development of other, alternative types of SIB, that replace those controlled or eliminated through using mechanical restraints (Emerson, 1992; Fisher et al., 1997; Kahng et al., 2001; Lerman et al., 1994). A not uncommon outcome is that controlling one form of self-injury (e.g. fist to head hitting) via restraint may simply result in other forms (e.g. damaging knees by hitting objects or head butting). Muscular atrophy, demineralization of bones, shortening of tendons, arrested motor development and disuse of limbs may also occur because of long-term restriction (Emerson, 1992; Fisher et al., 1997). Mechanical restraint and protective devices are also associated with disruption or prevention of opportunities to engage in activities associated with daily living, education, leisure and reduced levels of interaction with carers (Emerson, 1992; Spain et al., 1984).

**Good practice guidelines**

Just as has been the case with the reactive management of aggression (Harris et al., 1996), a set of good practice guidelines that could form the basis for clear standards regarding the management of SIB would be useful in improving service provision. This section will list some of the key points that emerged from the literature that could form the basis of a set of more comprehensive guidelines informed by further research and debate.

First, given that SIB is a heterogeneous class of responses that have multiple topographies which may be maintained by social, environmental and biological factors, all interventions should be based on functional analysis of SIB and follow the least restrictive alternative approach. There should be clear written behavioural management plans and treatment programmes in place, and their implementation regularly monitored and reviewed (Emerson, 1992; Hamad et al., 1983; Kahng et al., 2002a; 2002b; Spain et al., 1984). Multifaceted interventions should involve strategies both for behaviour change and for situational behaviour management; where
appropriate, the former should consist of combined pharmacological and behavioural intervention as described above.

The clearest and most comprehensive good practice guidelines regarding the management of SIB were set out by Spain et al. (1984) and these continue to be relevant, especially concerning the use of protective devices. The enduring relevance of these guidelines highlights the lack of focused attention given to this issue over the last two decades. Spain et al. (1984) emphasize that protective appliances may be of considerable value in the management and treatment of SIB, but that they should be used with caution and only as part of a general behavioural programme aimed to treat SIB and replace it with alternative behaviour. They recognized the need to balance the danger of a person becoming dependent on the protective device against the possible detrimental effects of the unprotected severe SIB. They suggested that the following type of key question should always be asked:

Is there any alternative way of preventing damage; which would be non-reinforcing of the SIB; which would allow the person to engage in other activities; and which would be feasible in practice, given actual staffing levels?

If the answer to this question is 'No', then protection may be the only alternative to prevent tissue damage, and they make a series of straightforward recommendations:

• Protection could include physical holding (depending on staffing levels). However, it may be preferable to use material restraints since physical contact may, in itself, be a powerful reinforcer in maintaining SIB. Appliances should also be easy to put on and take off, avoiding prolonged physical contact, for the same reason.
• No one should be left unattended when wearing an appliance.¹
• There are no standard appliances as such; suitably skilled and experienced therapists need to adapt and make them according to individual needs.
• Attempts should always be made to make the appliance look as ordinary and as pleasing as possible to promote social acceptability and positive self-image. Adapting ordinary clothing should always be considered – e.g. wearing a hat over a helmet.
• Shorter periods of use of appliance are found to be generally more effective than longer periods. (However, there are notable exceptions to this, such as people with Lesch–Nyhan syndrome).
• It may be justifiable to provide a suitable mechanical protective appliance to be only used in emergencies, mainly to allay staff anxiety. This is because staff may be more willing to implement reinforcement-based
behavioural treatment programmes in the knowledge that they can use an appliance if the SIB becomes too severe.

- Ideally, it should always be possible for the person wearing the appliance to engage in other activities for a large part of the day and be strongly rewarded.
- Consideration should be given from the outset as to how the use of the appliance can be gradually faded over time.

Studies that are more recent confirm and suggest some further developments in line with these recommendations. Coaching staff in positive behavioural support strategies can reduce levels of personal and mechanical restraint (Sturmey, 2002). Similarly, the possible counter-therapeutic effect of restraint application acting as a social reinforcer can be reduced by ensuring that high densities of social reinforcement are delivered non-contingently throughout the person’s day (LaVigna and Willis, 2002). Where restraints are impractical (for example, the person refuses to wear a device), altering the environment to make it safer (by removing sharp corners, padding targeted areas, etc.: Harris et al., 1996; Mental Welfare Commission for Scotland, 2002) may represent a better option. Oliver et al. (1998) highlight as good practice that reduction strategies for fading mechanical restraints should be based on a functional analysis whenever possible, otherwise SIB or self-restraint may be inadvertently reinforced, causing physical and emotional distress to service users. However, in some cases, functional analysis using experimental analogue conditions may not be possible because the SIB may not vary in line with manipulations, or free responding is too dangerous to allow. In these cases, they recommend that mechanical restraints be designed so that they can be easily faded in more than one way or parameter, e.g. size, pressure, and degree of flexion. Arm splints were faded in experimental evaluation with very positive results for two out of three participants including both a significant reduction in SIB, a reduction in overall restriction, no increase in distress and no detrimental effect on social contact and engagement in activities. The results showed that stimulus control over the absence of SIB could be maintained after restraints were faded in size, and so that 100 percent flexion was allowed. The arm splint used provided a considerable degree of control over flexion and had a modular design so it could be faded in size easily by removing sections. Thus, if stimulus control was lost, resulting in a return of SIB, it could quickly and easily be restored to optimum size, avoiding the risk of high frequency SIB returning whilst waiting for a new splint to be made.

The need for an individualized approach is clear in the literature and highlighted by the repeated emphasis on functional assessment. Oliver et al. (1998) suggested that the parameters of stimulus control are likely to vary
between individuals, and their approach could support the point made by Murphy (1999) that the use of interview/questionnaire-based functional analysis (e.g. O’Neill et al., 1997) in combination with natural observations may play a useful part in deciding the most appropriate management approach. Although less robust and reliable than the type of experimental analogue functional assessment approaches described by Iwata et al. (1982), they may be appropriate when either practical constraints, or the nature of SIB itself, prevent or severely limit analogue assessment.

Conclusions

Whilst many positive changes may have occurred over the last two decades in the management and treatment of challenging behaviour, the reactive management of SIB seems to have received little attention. In the mid 1980s, several authors argued that the management of SIB should be given greater attention because restraint appeared to be quite frequently used in practice and that people with SIB were at risk because treatment was either unavailable or ineffective (Griffin et al., 1986; Richmond et al., 1986; Spain et al., 1984). These key things appear not to have changed and the provision of this attention is now long overdue.

Treatment and management are both necessary components of positive behavioural support. The provision of any kind of reactive intervention to challenging behaviour is ultimately indefensible on ethical grounds in the absence of parallel, proactive intervention strategies. The ‘solution’ to self-injury amongst people with learning disability lies in the latter rather than the former. However, as previously stated, even when treatment is effective, complete elimination of SIB may be elusive. It is therefore equally unethical not to consider ways of making service users safe, and in ways that maximize their opportunities for living a full life whilst limiting potentially negative side effects.

A clear set of guidelines and standards reflecting some of the advances made in the positive behavioural management of aggressive and destructive behaviours would be very helpful in relation to SIB. Spain et al.’s (1984) account is useful because it contains detailed descriptions and illustrations of the types of devices that are discussed, making it understandable, relevant and of practical use to practitioners; any future guidelines should share these characteristics. Good practice guidelines, in themselves, will not solve the issues, and indeed are likely to raise questions of service deficits in many areas, such as access to specialists who can make bespoke appliances, the general absence of behavioural inputs and the need for staff to be effectively managed as well as trained. However, debating and agreeing standards is a useful first step in improving quality. Standards are
more likely to be valid if the debate engages those key stakeholders (e.g. researchers, service providers, staff, the various multidisciplinary professionals, relatives and people with SIB themselves) who, despite the lack of academic attention given to the issue in recent years, have been continually dealing with the reality of managing SIB in practice.

Note
1 This is particularly critical, as many deaths in restraint with other user groups have occurred when people have asphyxiated as a result of being entangled in their restraints.

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