Clinical effects of sexual abuse on people with learning disability

Critical literature review

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Background There are few publications concerning the psychological reactions of people with learning disabilities to sexual abuse. Most significantly, there are no controlled studies and few which demonstrate a systematic approach to documenting the sequelae of trauma.

Aims To critically review the published research in this field.

Method A literature search in peer-reviewed psychiatry, psychology, nursing and social care journals for the years 1974 to 2001 was conducted and 25 studies were reviewed.

Results Several studies suggest that, following sexual abuse, people with learning disabilities may experience a range of psychopathology similar to that experienced by adults and children in the general population. However, because of methodological limitations, these results are not conclusive.

Conclusions Whether people with learning disabilities experience reactions to sexual abuse similar to the general population has yet to be explored by systematic research.

Declaration of interest None.

Within the general population, experience of sexual trauma or abuse is associated with psychological disturbance (Briere, 1992; Kendall-Tackett et al, 1993; Friedrich, 1998). However, there are few publications concerning the psychological reactions of people with learning disabilities to sexual abuse. Most significantly, there are no controlled studies. Furthermore, the majority of studies are single case reports, and few demonstrate a systematic approach to documenting the sequelae of trauma in this group. This dearth in the literature is surprising, given that research in the general population suggests that individual responses to abuse may be less related to the actual characteristics of the event than to developmental variables that predispose the individual to being overwhelmed by the experience (Friedrich, 1998). In addition, we know that people with learning disabilities suffer from a similar or higher rate of mental health problems compared with people in the general population (Moss, 1995; Holland & Koot, 1998; Deb et al, 2001).

It is tempting to hypothesise that sexual trauma victims both with and without learning disability would share a similar range of behavioural or psychological reactions. It might also be expected that some reactions, mediated by cognitive impairment, would not be found in the general population. These ideas have yet to be explored by systematic research, which could be a useful source of information for clinicians.

METHOD

A literature search in peer-reviewed psychiatry, psychology, nursing and social care journals for the years 1974 to 2001 was conducted. The following sources were searched: Medline, PsycLIT, CINAHL, Applied Social Sciences Index and Abstracts (ASSIA), Cochrane Library and EMBASE.

In addition, a manual search was made through relevant journals (Child Abuse and Neglect, American Journal of Mental Retardation, British Journal of Learning Disabilities, Journal of Applied Research in Intellectual Disability, Journal of Intellectual Disability Research, 1995-2001) and published books (e.g. Brown & Craft, 1989; Sinason, 1992; Sobsey, 1994), dissertation abstracts and conference proceedings. Researchers with a known interest in this or related areas were consulted regarding relevant work in progress. The search was restricted to English-language publications and publications with an English abstract.

Search strategies were conducted using variations on the following: LEARNING DISABILIT*, DISABLED PERSON, INTELLECTUAL DISABILIT*, CHILD ABUSE, DEVELOPMENTAL DISABILIT*, SEXUAL ABUSE, RETARDATION, RAPE, MENTAL HANDICAP, *ASSAULT, MENTAL* SUBNORMAL*, PTSD.

Papers were identified that presented original data and directly or indirectly addressed the question, 'What are the psychological effects of sexual abuse in people with learning disabilities?' Papers that did not directly report on the effects of abuse were excluded from this review. However, studies where effects were reported as a secondary consideration (e.g. part of a wider incidence survey) were incorporated in the comprehensive compilation of the literature. Both adult and child studies were included. There were no other inclusion criteria.

RESULTS

The 25 papers under review are presented in Table 1. No studies are known to have used control groups, and only a small number of case studies used rating scales with published psychometric properties or standardised psychiatric interviews.

The literature review identified 8 retrospective studies of clinical case material or surveys involving over 50 participants, 4 smaller quantitative studies of clinical case material, 11 descriptive reviews of clinical cases or single case studies and 2 studies that employed a qualitative methodology. The most significant of these studies are discussed in the text.

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Authors	c	Туре	Psychological disturbance reported	Assessment and methodology notes (no control groups;
			to be associated with sexual abuse	unless otherwise stated, no comparison group)
Beail & Warden (1995)	22	Case series	Sexualised behaviour, emotional and behaviour difficulties, self-injurious behaviour	Retrospective analysis of clinical case notes using structured questionnaire
Bernard (1999)	9	Qualitative interviews with informants (mothers)	Anger, crying, masturbation, aggression, running away, soiling, stealing	Interviews with Black mothers of children who have experienced abuse. No clinical interview, no systematic records of behavioural data
Brown et <i>al</i> (1995)	601	Incidence survey of sexual abuse (replication of Turk & Brown, 1993, below)	72% of victims reported by staff as definitely or possibly traumatised by abuse experience	Anecdotal staff report only, no formal assessment of psychological effects
Cruz et al (1988)	^	Description of therapeutic intervention	Referred problems: overfriendly with strangers, sexually permissive, depressed, self-abusive/suicidal, hitting males when touched, crying when criticised by male	Seen individually for evaluation
Davidson et al (1994)	-	Case study	PTSD, moderate/severe depression	Systematic assessment using standardised assessment tools: Impact of Events Scale (Horowitz et al., 1979), Beck Depression Inventory (Beck, 1978). Formulation of PTSD as defined in DSM-III-R (American Psychiatric Association, 1987)
Dunne & Power (1990)	<u>n</u>	Case series	Acting out, verbal abuse, inappropriate sexual behaviour, anxiety and fearfulness, nightmares, depression	Psychiatric interview in 6 of 13 cases
Fairley et <i>al</i> (1995) Fenwick (1994)		Case study	Multiple personality disorder Inappropriate sexual behaviour, symptoms consistent with PTSD: subdued state, crying, irritability, sleep disturbance, panic behaviour	Not reported Not reported
Firth et <i>al</i> (200 I)	£	Retrospective analysis of case notes. Clinical sample of child and adolescent victims and perpetrators	PTSD not common. Perpetrators differentiated by t experience of sexual or physical abuse, both or neither. Perpetration against younger victims associated with earlier experience of multiple forms of abuse	Details of abuse history/probability of abuse occurrence/ sample characteristics reported in Balogh et al (2001)
Focht-New (1996)	_	Case study	Increased crying. Alternate displays of affection and aggression	Not reported
Johns on (2 001) Lindsay et <i>al</i> (2001)	4 4	Case studies Comparison study of 2 clinical cohorts	Dissociative symptoms, self-harm, alcohol misuse Sex offenders more likely to have experienced sexual abuse than non-sex offenders	Not reported History taken at assessment and during treatment by mental health professionals. Sex offenders, compared with nonsexual offenders in relation to history of sexual/physical abuse
McCreary & Thompson (1999)	^	Case studies	Allegations of sexual abuse. Reports of PTSD, flashbacks, paedophilia	Not reported

Table I (continued)

Authors	z	l ype	rsycnological disturbance reported to be associated with sexual abuse	unless otherwise stated, no comparison group)
Mansell et <i>al</i> (1992)	611	Survey of general sexual abuse variables	Survey of general sexual abuse variables Withdrawal, aggressive or inappropriate sexual behaviour, unspecified emotional distress or no problems	Questionnaire completed by client advocates and victims with disabilities. No control/comparison sample, no standardised
Mansell et <i>al</i> (1998)	9 8	Comparison study of 2 clinical cohorts	Children with and without learning disability displayed aggressive/dominant behaviour, inappropriate anger, poor self-esteem and nightmares	Comparison of 43 children with and 43 children without learning disability. Structured checklist completed from counselling session case notes
Martorana (1985) Rvan (1994)	- 08	Case study	Schizophreniform psychosis 51 rases of PTSD	Psychiatric evaluation (DSM-III) Clinical interview DSM-III-R used but criteria not specified
Sinason (1988)	} –	Case study	Developmental delay in response to trauma (secondary mental handicap as defence against sexual trauma)	Not reported
Sinason (1992)	m	Case studies	Hallucinations, nightmares, crying; self-injurious behaviour, public anal masturbation, depression; self-injurious behaviour. public masturbation, violence, pica	Not reported
Sobsey & Doe (1991)	162	Reports completed by people with disabilities and by advocates	Emotional, behavioural and social consequences universal: inappropriate sexual behaviour (percentage unspecified); 63% reported uncategorised emotional distress; 24.7% exhibited aggression and non-compliance;	Questionnaire completed by client advocates and victims with disabilities, no standardised measures, results for whole sample, but only 70.3% of sample presented with learning disability
Sobsey & Mansell (1994)	130	Survey (children)	Emotional distress, withdrawal, behavioural problems, temper tantrums, non-compliance, aggressive acting out, sexually inappropriate behaviours	Questionnaire completed by client advocates and victims with disabilities, no control/comparison group, no standardised measures
Turk & Brown (1993)	<u>6</u>	Incidence survey of sexual abuse	55% suffered emotional trauma or distress	Anecdotal frontline staff report only, no assessment of psychological effects
Varley (1984) Walters et <i>al</i> (1995)	ռ <u>6</u>	Case studies Retrospective analysis of suicidal behaviour in children and adolescents	Schizophreniform psychosis Study focus on suicidal behaviour (not abuse). Of 19 patients presenting with suicidal behaviour, 7 (36.5%) reported being sexually abused	Not reported Records of 90 admissions, subject to archival chart review. Information on range of variables including descriptions of suicidal behaviour (n=19), history of physical/sexual abuse and psychiatric diagnosis
Westcott (1993)	3 (9)	Qualitative	Loss of self-esteem, self-destructive tendencies, anger, perceived vulnerability (effects of sexual abuse not specifically described)	Semi-structured interview schedule, 3 sexual abuse cases (9 total including physical, sexual, emotional abuse)

Mansell et al (1998)

A notable study of the sequelae of sexual abuse is that of Mansell et al (1998), who reported the effects of sexual abuse for two clinical samples of sexually abused children (43 with learning disabilities and 43 without learning disabilities). The authors did not meet with the children or informants directly but used notes from counselling sessions and meetings with counsellors to complete a customised information record. The record included, among other victim and offender variables, seven broad categories of reported sexual abuse sequelae: school/academic/work activities; personal relationships; sexuality; bedtime; hygiene; behavioural/emotional problems; medical/clinical findings. The face and content validity of this assessment is reported to be adequate. However, there are no data on reliability or discriminative validity and there was no use of standardised measures to assess the presence or absence of behavioural or emotional problems.

Overall, Mansell et al found that clinical symptoms recorded in reports from counselling sessions for children with learning disabilities were similar to those in the non-learning-disability group. Both groups of children exhibited aggressive and dominant behaviours, inappropriate anger, poor self-esteem and nightmares. The authors reported statistically significant differences between the groups, including poor sense of personal safety and little sexual knowledge among children with learning disabilities. However, they acknowledge that these factors may be more accurately described as risk factors, or reflect deficiencies in education rather than the effects of abuse. The authors also identified several non-significant differences between the groups, including a higher frequency of self-abuse and a higher frequency of withdrawal into fantasy among the children with learning disabilities, and suggested that these might represent different kinds of response to abuse. Unfortunately, there is no clear description of how these phenomena were defined or how they were assessed.

The authors acknowledged a number of limitations in their study, in particular the lack of a control group of non-abused children. Without such a control group the effects of sexual abuse cannot be determined. The presenting problems in the children with learning disabilities might be due

to factors associated with the cognitive impairment *per se* or other life events and not necessarily the experience of sexual abuse. A further limitation was the use of a clinically referred sample of children, who might be expected to be presenting with either behavioural or emotional difficulties. It is therefore possible that the sample was biased towards children with mental health problems and not representative of children who were not referred to treatment.

Mansell et al (1992)

Earlier studies by the same research team also attempted to address the question of clinical effects of abuse. Mansell et al (1992) studied 119 victims of sexual abuse with learning disabilities. Information was obtained from family members, service providers and in some cases the victims themselves. The study focused on whether the sexually abused person experienced any social, emotional or behavioural injury and the nature and extent of such trauma. It was reported that 9.8% of the sample with mild and moderate disabilities and 17.7% of those with severe and profound disabilities experienced withdrawal; 19.6% of the group with mild and moderate disabilities and 31.1% with profound disabilities were reported to show aggressive and/or other behavioural problems such as inappropriate sexual behaviour. Only 3.9% of respondents with mild and moderate disabilities reported no social or emotional problems, and all those with more severe learning disabilities showed difficulties in these areas. Without a non-abused control group, however, it is difficult to be certain whether the reported difficulties would have been present regardless of the abuse.

Sobsey & Mansell (1994)

In a further paper, Sobsey & Mansell (1994) reported that 98.5% of 130 sexually abused children with a wide range of disabilities reported emotional distress, withdrawal or behavioural problems. Specific problems included tantrums, non-compliance, aggressive acting out or sexually inappropriate behaviours. Unfortunately, no validity or reliability data are provided for the measure used; terms such as emotional distress are not defined and the proportion of the sample presenting with learning disabilities is not specified. This study, like its predecessor, lacked a non-abused control group.

Ryan (1994)

A study by Ryan (1994) examined 310 persons who presented to a consultation service for people with learning disabilities in Colorado, USA. The average degree of learning disability in the sample was within the moderate range and half were reported to be non-verbal. All presented with complicated behaviours. Ryan reported that of the 310 referrals almost all had suffered significant abuse or trauma. She indicated that trauma most frequently included sexual abuse by multiple assailants, but unfortunately does not indicate the numbers who had experienced sexual abuse compared with other sources of trauma. All reports of trauma were confirmed by outside sources.

Of the 310 referrals, Ryan determined that 51 (16.5%) met the DSM-III-R (American Psychiatric Association, 1987) criteria for post-traumatic stress disorder (PTSD). Although this is an important finding, it must be noted that the sample was drawn from a clinical population and it is unclear whether this is representative of the wider population of people with learning disability who experience trauma. It is possible that this sample was biased towards those people presenting with clinical symptoms.

Ryan reported that persons who are non-verbal typically reported the history and current symptoms through drawing or gestures. The DSM-III-R criteria on which the PTSD diagnosis was made in each case were not reported. This is a crucial omission, because it could be argued that several of the diagnostic criteria for PTSD DSM-III-R require a verbal response.

Firth et al (2001)

In contrast to Ryan's finding, Firth et al (2001) found that post-traumatic symptoms were not common in a sample of victims and perpetrators of sexual abuse with learning disabilities. From a retrospective review of 43 cases (21 victims only, and 22 perpetrators of whom 16 were also victims), only 1 case of PTSD was identified. It is possible that the difference in the findings between this study and Ryan's is due to the different natures of the populations studied. For example, Firth et al examined British children and adolescents across the whole range of disability, in contrast to Ryan, who reported on adults from the USA (average age 33 years and average degree of mental retardation moderate). Although both studies were of in-patient populations, there is insufficient detailed information provided (e.g. gender, proportion of sample in each ability range) to draw any firm conclusions on this point.

Beail & Warden (1995)

The importance of stating the nature of the population studied is highlighted by Beail & Warden (1995), who suggest that gender may affect the response to abuse. The authors reported on 22 cases of people with learning disabilities who had experienced sexual abuse and who received psychoanalytic psychotherapy in a clinical psychology service over a 4-year period. They found that 19 of the 22 cases were male, which is at odds with other reports of sexual abuse of people with learning disability (Turk & Brown, 1993; Sobsey et al, 1997) and also with the wider literature on sexual abuse, where the majority of sexual abuse victims are female (Watkins & Bentovim, 1992).

Beail & Warden noted that the men in the study were referred for behavioural problems or sexualised behaviour that had potential to cause problems for their families or carers. In contrast, two of the three women victims did not present with severely challenging behaviour; the third woman presented with self-injurious behaviour. The authors note that this might suggest that men and women with learning disabilities cope with abusive experiences in different ways.

The study used a questionnaire developed by Dunne & Power (1990). This questionnaire covers the background of the survivor and the perpetrator, the type of abuse, how disclosure occurred, investigations, treatment and the effects of the abuse. The psychological impact of sexual abuse is examined in limited depth by this instrument. The study was limited by retrospective assessment, the absence of psychometric measures and reliance on case notes. Nevertheless, its design was presented in a structured and thorough manner that could be replicated in future work.

Lindsay et al (2001)

A further study worthy of note is of 46 sexual and 48 non-sexual offenders by Lindsay *et al* (2001). They report that 38% of the sexual offenders had experienced sexual abuse, compared with 12.7% of non-sexual offenders. They suggest that sexual abuse is a significant variable in the history of sexual offenders, but that

the cycle of abuse is neither inevitable nor an adequate explanation of future offending.

Clinical effects

All the studies reviewed above attempted to use a systematic approach to document the psychological effects of sexual abuse in people with learning disabilities. Other studies identified in Table 1 include smallscale or single case studies or studies where the clinical effect of abuse was not the primary focus (e.g. Brown et al, 1995). As can be seen from Table 1, a range of clinical effects were reported. These include: PTSD and depression (Davidson et al, 1994); loss of self-esteem, self-destructive tendencies and anger (Westcott, 1993); schizophreniform psychosis (Martorana, 1985); multiple personality disorder (Fairley et al, 1995); and dissociative symptoms, self-harm and alcohol abuse (Johnson, 2001).

DISCUSSION

The strength of the case-study method is that a great deal of information can be conveyed which might be lost to survey. However, in terms of scientific evidence it is relatively weak because it cannot demonstrate causality. Furthermore, few of the case studies reviewed provided information on how the purported psychological effects of sexual abuse were assessed. This information is vital to adequate evaluation of any research in this area and, without it, the validity and reliability of data must be questioned. Therefore, the reports reviewed in this paper can only be taken as indicators that people with learning disabilities experience a range of symptoms, psychopathology and behavioural difficulties following sexual abuse, similar to that experienced by adults and children in the general population. There is a lack of hard evidence for an association between specific challenging behaviours and diagnoses made in people who have been sexually abused, such as PTSD, depression or anxiety disorders, as defined in DSM-IV (American Psychiatric Association, 1994) or ICD-10 (World Health Organization, 1992).

Assessment of symptoms using validated measures

The interpretation of existing research is hindered by a lack of clear descriptions of the symptoms under focus. Therefore, future study should aim to document symptoms in a systematic and reliable way, preferably using validated measures. Many tools have been validated for assessing psychopathology and challenging behaviour in people with learning disabilities (O'Brien *et al*, 2001), but no standardised diagnostic instrument is known to exist that specifically assesses the effects of trauma in this population. It is important that assessment should cover a wide range of possible disturbances and not just the post-traumatic symptoms known to occur in the general population.

Communication difficulties and assessment of psychiatric symptoms

The major difficulty in research involving people with more-severe learning disabilities is one of communication. A person may not be able to report on symptoms according to the respondent measures used with more able clients. Many researchers have relied on informant measures (completed with parents or keyworkers) but such reports are inevitably incomplete: informants cannot be totally aware of the internal subjective experience of a client or of non-visible autonomic symptoms that could be crucial to making a correct diagnosis. The diagnostic criteria for psychiatric disorders for use with adults with learning disability/mental retardation (DC-LD) (Royal College of Psychiatrists, 2001) are an attempt to address this problem by proposing symptom clusters to assist the clinician in making a diagnosis. Studies of self-reports in people with more severe learning disabilities using drawing or gestures may be more suited to qualitative research methods.

Definitions of sexual abuse and certainty of abuse occurrence

Further study should define the criteria used for sexual abuse. Without knowing the operational definition of sexual abuse being used, we cannot be sure what types of experience we are looking at. It is also important to specify whether unsubstantiated cases of abuse are being included. This is vital information in the interpretation of any findings and, unfortunately, the vast majority of the studies reviewed do not report on the certainty of abuse having occurred. A system for classifying the degree of certainty/uncertainty in

abuse cases is suggested by Brown & Turk (1992). This system could be usefully employed in further studies in this field.

Research relevant to people with learning disabilities

Mental health practitioners receive frequent referrals of clients who have both learning disabilities and a known history of sexual abuse. So that therapeutic work may be effective, practice must be grounded in research that takes account of the cognitive, emotional, social and developmental factors that are an integral part of the psychopathology of people with intellectual disabilities. It is not sufficient to apply the established findings relevant to other client groups, such as children or adults in the general population, because factors associated with cognitive impairment will undoubtedly mediate the impact of sexual trauma

As this review has demonstrated, factual knowledge regarding the possible clinical sequelae of sexual abuse in this population is sparse. Research is needed to establish the range of psychological and behavioural effects of sexual abuse in people with a learning disability, employing standardised measures. Studies should use community samples that are not necessarily biased towards clients presenting with psychological disturbance (as in clinical samples). Most crucially, studies should compare findings for abused samples with non-abused control or comparison samples.

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CLINICAL IMPLICATIONS

- Following sexual abuse, people with learning disabilities may experience a range of psychopathology similar to that experienced by adults and children in the general population. However, this is inconclusive from the evidence reviewed.
- Psychiatric symptomatology is suggested by some studies. This includes traumatic stress reactions, depression and anxiety.
- Behavioural problems are suggested by some studies. These include aggression, self-injury and sexual behaviour problems.

LIMITATIONS

- No controlled studies are known to exist in this area.
- The criteria used to report sexual abuse are inadequately or inconsistently defined in the studies reviewed.
- Few of the studies reviewed have used standardised assessments or samples from non-clinically referred sources.

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