THE UNIVERSITY OF HULL

Interpersonal factors influencing self-injury in people with learning disabilities: expressed emotion and attributions in residential care staff

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Overview

The portfolio has three parts: a systematic literature review, an empirical study and a set of Appendices.

Part one is a systematic literature review entitled 'The Experiences of People with Mild-Moderate Learning Disabilities who Self-Injure: A Critical Review,' in which empirical literature relating to the experiences of people with mild-moderate learning disabilities who self-injure is reviewed and critically evaluated. It aims to present an understanding of why people with learning disabilities self-injure, and what they find useful from services in relation to their self-injury.

Part two is an empirical paper entitled 'Expressed Emotion and Attributions in relation to Self-Injury in People with Learning Disabilities,' which used quantitative methodologies to explore whether the level of expressed emotion in residential staff affects their perceptions of severity of self-injury in people with mild-moderate learning disabilities, and whether the staffs' attributions also contribute to the perceived severity of self-injury. To achieve this, adult staff working in residential homes completed measures of expressed emotion, attributions and perceived severity of self-harm with the main researcher, which were analysed using Pearson Product Moment Correlations and non-parametric statistical tests. The results of this analysis are discussed in relation to current theories on self-injury, as well as the wider social and political context. The clinical implications and methodological limitations are also discussed and areas requiring further research are identified.

Part three comprises of Appendices relating to the research, including a reflective statement on the process of conducting the research.

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Part one: Systematic Literature Review

The Experiences of People with Mild-Moderate Learning Disabilities who Self-Injure:

A Systematic Literature Review

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Abstract

Keywords: self-injury, review, perceptions, mild, moderate

In recent years, a body of literature has emerged detailing the lived experience of people with mild-moderate learning disabilities who self-injure. This paper is a systematic literature review which aims to synthesise this information, with a view to discussing the reasons why people with learning disabilities self-injure, as well as placing the literature within a social and political context. A search was conducted of major databases to produce a total of six studies which were analysed in a narrative format. All of these studies used qualitative methodology to interview people with mild-moderate learning disabilities about their self-injury, and three broad themes were elicited, namely 'functions of self-injury,' 'choice' and 'relationships.' These studies are placed in a context with Nock's (2009, 2010) model of self-injury, with a discussion of utilising the therapeutic relationship and ways in which staff can work more effectively with people with learning disabilities who self-injure.

Introduction

Over the past decade, a large body of literature has been produced discussing selfinjurious behaviour in people with learning disabilities. Prevalence rates for this behaviour in people with profound and multiple learning disabilities range from 4% to 24% (Oliver et al., 1998; the National Institute of Health and Clinical Excellence, There are no reliable estimates for people with mild-moderate learning 2004). disabilities, as the majority of this literature does not distinguish between mild-moderate and severe learning disabilities, and so much of the literature refers to people with profound and multiple learning disabilities and investigates the genetic and behavioural correlates for this behaviour (see, for example, Kahng, Iwata & Lewin, 2002). In people with profound and multiple learning disabilities, for example, genetic syndromes such as Smith-Magenis syndrome and Cri du Chat syndrome may play a part in selfinjurious behaviour (Greenberg et al., 1991; Collins and Cornish, 2002). Other factors, such as lack of speech and level of autistic spectrum disorder (ASD), are still hotly debated (see Baghdadli et al., 2003 and Cooper et al., 2008, for contrasting viewpoints), but are widely seen to be behavioural correlates for self-injurious behaviour. Indeed, the main evidence-based intervention for self-injury is positive behavioural support, which has a behavioural approach at its core (although there are few long-term follow up studies on the effectiveness of this approach; see Prangnell, 2009, for a review of behavioural interventions for self-injurious behaviour). However, research indicates that there is a failure rate of up to 25% for behavioural and medication-based approaches over a period of 5 years (Symons & Thompson 1997). This suggests that a more holistic approach needs to be taken to self-injury in people with learning disabilities, potentially considering factors such as low ability to express emotions and low self-esteem, which have been found to influence self-injury in the general population (Fliege et al., 2009).

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Definitions of self-injurious behaviour in people with learning disabilities are reasonably narrow, and concern direct physical behaviours, such as the following definition of self-injurious behaviour as "non-accidental behaviours which produce temporary marks or reddening of the skin or cause bruising, bleeding or other temporary or permanent tissue damage" (Oliver et al., 2003, p55). In this definition, there is no discussion of intent – that is, this behaviour could be suicidal in nature. In people without learning disabilities, self-harm is the term generally used, which appears to refer to a greater variety of behaviours, such as "An act with a non-fatal outcome, in which this definition refers to cutting, ingesting substances in excess of prescribed amounts, or ingesting non-ingestible objects" (Hawton et al., 2002). This clearly demarcates the outcome of the self-harm from suicidal behaviour and, implicitly, intent, as the act is non-fatal. It is interesting to note that in neither of these definitions is it suggested that there may be a function to this behaviour. Additionally, Turp (2003) has produced the idea of CASHAS (Culturally Acceptable Self-Harming Activities) which include a range of behaviours that are seen to be socially acceptable, including tattooing and body-piercing. It is difficult to see how this may apply to people with learning disabilities, who may find it difficult to do these things, however it may be the case that someone with a learning disability who was, for example, depriving themselves of sleep, would not be seen as self-harming. Indeed, self-injury in people with learning disabilities often comes under the umbrella of challenging behaviour (Lovell, 2007), which gives little information about intent or, indeed, what this behaviour may be trying to accomplish other than being confrontational or 'challenging' for carers.

Lovell (2007) suggests that the distinction between self-injurious behaviour (in people with learning disabilities) and self-harm (in people without learning disabilities) is false, as some of the same contributors to self-harm can be found in self-injurious behaviour. For example, there is a high level of sexual abuse committed against people

with learning disabilities (Senn 1988), and subsequently there is a increased likelihood of self-injury occurring (Burke & Bedard 1995). This is consistent with research into the general population, which supports a link between childhood sexual abuse and selfharm (Warner, 2000). Additionally, research into people without learning disabilities who self-harm suggests that those who are insecurely attached are more likely to display this behaviour (Hallab & Covic, 2010). As people with learning disabilities have been found to have a higher prevalence of insecure attachment than those without learning disabilities (Van Ijzendoorn et al., 1999), it has been suggested that self-injurious behaviour can serve as a way of coping with stress for people with profound learning disabilities when attachment has been lacking (Janssen, Shuengel & Stolk, 2002). As the term self-injury is beginning to be used more consistently in research relating to the general population (see Nock, 2009; 2010), and to avoid creating the same demonstrably false distinction, this review shall use the term self-injury to refer to this behaviour across all populations from this point.

Taking one step further from arbitrary definitions of self-injury, it can be argued that the concept of learning disability *in itself* is arbitrary; a distinction made between statistical levels of intelligence and social functioning that could be changed to fit with the dominating social ideals of the time (see Sleeter, 1986). This is not to say that the concept in itself is not useful in providing social and functional support to vulnerable members of society, however the concept can also be used to exclude and distinguish people in a negative manner. Lovell (2007) provides a compelling case for the functions of self-injury in those with multiple and profound learning disabilities being similar to those of the general population. It is therefore plausible that the functions of self-injury in those with mild-moderate learning disabilities are even closer to those of the general population; however research has only begun to explore this idea in the last decade, with research before 2002 tending to focus on more behavioural explanations. It may therefore be more accurate to view learning disability as a continuous variable, rather than a series of discrete categories. However, there is a clearer rationale for trying to distinguish between mild-moderate and severe-profound learning disabilities; that within certain genetic syndromes occurring most frequently in the severe-profound learning disabled population, there are behavioural phenotypes which take the form of self-injury. For example, Lesch-Nyhan Syndrome, an inherited disorder caused by mutations on the X chromosome, causes self-injurious behaviours (particularly lip and finger biting; Anderson & Ernst, 1994) and is commonly found in those with severe and profound learning disabilities. As this behaviour has a clear genetic cause, it is argued that it can be distinguished from self-injury that is more a product of the environment.

This review aims to synthesise research looking at the factors influencing selfinjury in people with mild-moderate learning disabilities, and includes those studies where the perspective of the person engaging in self-injury has been sought. A cursory review of the literature reveals that there is a small body of literature devoted to the perspectives of people with mild-moderate learning disabilities, and how they view their self-injury, which will form the focus of this review. There are a number of studies looking at the perspectives of those without learning disabilities who self-injure (see Sinclair & Green, 2005, or Lindgren et al., 2004, for a flavour of this research), and so a review into the experiences of those with learning disabilities was justified. As well as providing a comprehensive overview of recent research, the review will attempt to put the current body of literature into context by discussion of research conducted with people without learning disabilities, in particular Nock's (2009; 2010) model of selfinjury. This model refers to self-injury as a multifaceted coping strategy, and takes into account several hypotheses produced by a number of authors as to why self-injury occurs. The research questions were therefore: how do people with mild-moderate learning disabilities make sense of their self-injury, and what factors may influence this behaviour.

Method

Search strategy

A search of electronic databases up to and including April 2012 was undertaken. Databases covering a range of disciplines were searched for research into factors influencing people with learning disabilities who self-injure. The databases included in the search were PsycINFO, CINAHL and Web of Science, and hand searches were carried out of six journals related to learning disabilities. As no review has previously been done in this area, a cut-off date was not employed. The search terms used were, broadly speaking, related to learning disabilities or self-injury; the terms 'mild' or 'moderate' were not included in the final search strategy due to zero results being produced when these terms were included. The final search terms are provided in Appendix C.

All combinations of the search terms were systematically entered into each database to retrieve articles that contained these terms in their abstract, title or keywords. Relevant articles were ascertained from their titles, and the selection criteria were applied to the abstract, or the full article if it was unclear from the abstract whether the selection criteria would be fulfilled. As it became clear that there were very few articles in this area, manual searches of the reference sections of the articles included were undertaken. Three key authors in this field were also contacted and asked if they were aware of any further papers that had not been identified by the search strategy detailed above, which led to one additional paper being identified.

Selection criteria:

The selection criteria were developed from the research questions and were refined using data provided by the scoping searches. For inclusion in the review, articles had to meet all of the inclusion criteria, as well as meeting none of the exclusion criteria. The rationale for using these particular inclusion and exclusion criteria can be found in Appendix D.

Inclusion criteria:

- Participants in the study must be adults (age 18+) with a mild to moderate level of learning disability.
- Participants must have engaged in, or currently be engaging in, self-injurious behaviour.
- The research must either report the direct experiences of the person engaging in self-injury (through self-report, qualitative methodology, etc) or establish factors that may be influencing the participant's decision to self-injure (through quantitative methodology, etc).
- The research must feature in, or be in the process of being submitted to, a peer-reviewed journal.

Exclusion criteria:

- Studies where the participants have learning difficulties, such as dyslexia, or developmental difficulties such as autistic spectrum disorders without also having a learning disability.
- Studies referring to violent or aggressive behaviour directed towards others, gestures which are clearly suicidal rather than self-injurious, or studies where 'challenging behaviour' is referred to without explicit identification of what this behaviour involves.
- Literature reviews or other non-empirical papers.
- Studies which are not written in English.

- Studies where it is not possible to ascertain the participants' level of learning disability.
- Articles which include people with both mild-moderate and multiple and profound learning disabilities, but do not discriminate between these groups in the results section (i.e. population studies which include people with learning disabilities as an homogeneous group).

Study Quality Assessment

As the literature base for this review was small, the decision was made not to exclude studies on the basis of quality ratings. This allowed for the reviewer to provide a thorough critique of the literature, as well as making informed judgements as to the strength of the research findings and how future research into this area can be conducted and improved.

As all the studies identified for inclusion in the review adopted a qualitative framework, a quality checklist produced for qualitative studies was employed by the reviewer (Spencer et al., 2003; see Appendix E). The framework was developed, in part, by reviewing the 29 existing frameworks developed in the fields of health and medicine, and by in-depth interviews carried out with government workers, academics and practitioners involved in qualitative research. This framework is based around four guiding principles; namely that qualitative research should be contributory in advancing knowledge or understanding, defensible in design, rigorous in conduct and credible in claim. The framework itself consists of 18 appraisal questions, designed for in-depth interviews, observational studies, documentary analysis and focus groups. As all the studies in this review employed in-depth interviews, this was felt to be the most appropriate checklist to use. There is an absence of scores or marks accompanying the framework as Spencer et al (2003) argue that arbitrary scoring systems can be

prescriptive, emphasising the developmental nature of the framework and that flexibility is an essential component of the checklist. However, in order to aid discussion in this review, a 0-3 scale has been utilised, which is dependent on the rater's subjective interpretation of the rating scale. In this instance, a scale of Omitted (0), Poor (1), Good (2), Excellent (3) was utilised, as a simple way of discriminating between studies.

Data Extraction

Data was extracted using a form that was specially designed for this review. For the full data extraction form, see Appendix F. A total of six articles were included in the review.

Data Synthesis

As the studies in this review all utilised qualitative methodology, statistical analyses of outcome were not appropriate. Data collected from the studies has been reported in a qualitative style, which has allowed for rich descriptions of the studies included.

Results:

Studies were assessed using the framework provided by Spencer et al. (2003). The selection process for articles (shown in Figure 1) led to six articles being included in the review. The database search identified 633 articles considered for review; 145 of these were duplicates. 437 were removed by title, and 24 were removed after review of abstracts. This left 27 articles, 3 of which were pertaining to people with mild-moderate learning disabilities. Hand-searching relevant journals and the reference sections of these papers produced two more, and one further paper was procured by e-mailing Rebecca Fish, co-author on three of the other papers. See Appendix H for the list of studies removed by abstract.

Web of Science: 333 results

Total: 633

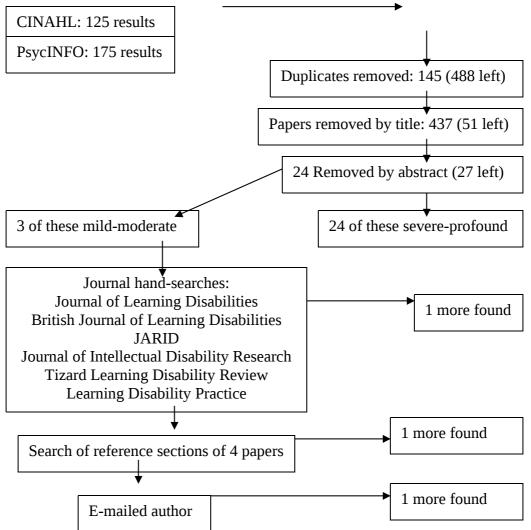


Figure 1: selection process for articles included in the review.

Quality Ratings:

As previously mentioned, the scale produced by Spencer et al. (2003) was utilised to provide quality ratings for each of the six studies. For a table of itemised quality assessment scores, see Appendix G.

Table 1: Details of studies included in review

Reference	Study Aims	Participants	Study Design	Themes Elicited (with Examples)	Quality
					Assessment
Harker-	To explore the	One woman with	Semi-structured	Themes discussed are:	
Longton &	experience of	mild-moderate	interviews lasting from	Reasons for and functions of self-injury (I	
Fish (2002)	self-injury from	learning	30-90 minutes each,	used to feel like I had to punish myself, for	
	the perspective	disabilities,	taking place over a	being dirty.)	41
	of one person,	residing in a	three-month period and	Self-help strategies (I stay calm and I say to	41
	using the	medium secure unit	analysed using a pure	myself, 'You're not going to do it.")	
	pseudonym of	in England for 4	phenomenological	Service issues (Yeah, [people want to stop me	
	Catherine	years	approach	cutting because] I may cut too deep, it's	
				dangerous.)	
				Punishment (I like having a bath on my own	
				too, but I can't. They won't let it go.)	

Duperouzel & Fish (2007)	To compare the experiences of people with mild-moderate learning disabilities who	Nine people with mild-moderate learning disabilities (four men, five women) and nine staff	In depth interviews with participants, analysed using a pure phenomenological approach	Individual service provision (They should have a positive attitude, about self- injury.) Common themes between staff and service users: Understanding (all I want is the staff to understand a bit more about people who self-harm and why they do it.) Communication (I think there should be a	40
	self-injure with	members (four nursing assistants	epp-ouen	lot more done: counselling, teaching	
	the experiences	and five qualified		peoplehow to talk things through)	
	of the staff who	nurses)		Control (They punish me by putting me on	
	support them			a higher supervision level)	
				Who's to blame? (They've said their job	
				would be on the line if they continually let	

Fish &	Discusses	Same	Pure phenomenological	Themes are:	
Duperouzel	Duperouzel &	participants as in	approach used	Negative aspects of the staff/client	
(2008)	Fish (2007)	Duperouzel &		relationship: (I feel that nobody cares, and	
	with specific	Fish (2007)		when you talk to them, it's 'Oh wait a	
	reference to the			minute.) (Sometimes they say 'Go and play	
	therapeutic			with your toys.') (I wanted to go to a	27
	relationship			meeting that's discussing my(a)nd they	37
				said no, clients are not allowed.)	
				Helpful relationships: (if the staff I like are	
				with me yeah it's all right) (I don't know	
				whether it's her personality or what I think	
				she's fantastic.) (I think they give you	
				aspects of life to think aboutgiving you	
				goals to aim for)	
Brown &	To explore the	Nine participants	Semi-structured	Themes are:	

Beail (2009)	experiences of	(five men, four	interviews undertaken,	Self-harm in an interpersonal context (I	
	people with	women) with mild	analysed using	always scratch meself when house is un,	
	learning	learning disabilities	Interpretative	when house in't stable)	
	disabilities		Phenomenological	Self-harm as an emotional experience (Well	
	living in secure		Analysis	when I bang me head it keeps me happy	
	accommodation			because then I know that I'm getting the	46
	who self-injure,			frustration out)	
	and to explore			Managing self-harm: internal (I say to myself	
	their			no cuts, done it, no cuts) and external (I	
	experiences of			couldn't tell the staff because they'd put me	
	interventions			on a higher level.	
	for self-injury				
Heslop	To explore the	Twenty-five	Up to four interviews	Results are split into ways of coping, e.g.	
(2011)	views of people	people with	per person	distraction ('Best of all is if you exercise	
	with learning	learning		yourself, 'cause you're concentrating on what	

disabilities about	disabilities who	you're doing), and a discussion of this rather	
their self-injury,	self-injure (6	than actual themes, as well as what people are	27
and to discuss any	men, 19 women)	looking for in a good support, such as being a	
support that they		good listener (But she wouldn't do all the	
feel they need		talking, she would let you talk), being non-	
		judgmental (Just people not judging, yeah	
		people not judging you for it) and their ability	
		to regulate their own emotional state (If	
		somebody flaps then I'll flap because I think	
		there's something to flap about)	

Quality assessment:

As previously mentioned, the scale produced by Spencer et al. (2003) was utilised to provide quality ratings for each of the six studies. The scores ranged from 27 to 46 out of 54. All six papers were second-rated by a second marker, achieving a Cohen's kappa of 0.363. This is 'fair' according to Landis and Koch's (1977) criteria, however it should be noted that it is possible that the qualitative nature of the checklist made it more difficult to achieve consensus, as the items are intended to structure thinking rather than provide a clear yes/no template for rating studies.

In the majority of the studies there was a tendency not to discuss the limitations of the research in detail, particularly with respect to issues such as gender, issues of researcher bias, and difficulties occurring when staff members had to be present for the interview process. Brown and Beail (2009) discuss some of these issues, and Harker-Longton and Fish (2002) give a thorough account of obtaining consent and the issues around confidentiality, but no study completely discusses the biases that the researchers themselves may hold.

Harker-Longton and Fish (2002) obtained a quality assessment score of 41, which distinguishes it as a study of high quality – a mark which was obtained in no small part due to the in-depth discussion of the ethical considerations needed when interviewing participants with learning disabilities. Brown and Beail's (2009) study scored 46 on the quality checklist, the highest score in this review, indicating again that it was methodologically sound, particularly in relation to documenting the process by which the authors arrived at their conclusions from the wealth of data elicited from participants. Duperouzel and Fish (2010) obtained a score of 38 in the quality assessment ratings, due to a lack of reflection on how the researchers may have affected the results and little demographic

information on the participants; however, this score is still admirable and the 2007 synthesis study (Duperouzel & Fish, 2007) scored 40 on the quality checklist as, taken together, the studies demonstrated a good use of qualitative methodology. However, for the same authors (Fish & Duperouzel, 2008), their third paper scored 37 on the quality checklist, mainly due to lack of discussion around the researcher's own biases and a lack of clarity around who was organising the themes and who, if anyone, was checking them. Finally, Heslop (2011) scored just 27 on the quality checklist; unfortunately this was due to a lack of information in the published paper, which it is acknowledged can be found in the full Hidden Pain report. However, the checklist was utilised to assess the quality of peer-reviewed articles only, and was not applied to the full report.

Characteristics of included studies

Of the six studies included for review, four used what they termed a 'pure phenomenological approach,' one used Interpretative Phenomenological Analysis (IPA), and one did not state the method of data analysis. In total, 53 different participants were used across the six studies, with nine of these being staff members. 15 of the participants with learning disabilities were male (34%).

Results

Three themes emerged from the studies included in this review: 'reasons for and functions of self-injury,' 'relationships,' and 'choice.'

Reasons for and functions of self-injury

Most of the studies identified the reasons for and functions of self-injury in their themes. Harker-Longton and Fish (2002) focus less on the participant's

motivation, however these appear to be around coping with distressing experiences (for example "What do they mean to you those scars? What do they mean to you? (Participant)... [*long pause*] Problems. [*long pause*] Past.") and feeling as though she should be 'punished' (for example "I used to feel like I had to punish myself, for being dirty. I was dirty so I had to punish myself.). Selfinjury is seen as a way of coping with distressing experiences in many of the studies, with Brown and Beail (2009) focusing particularly on childhood abuse and loss, but this study also recognises that relationships in the present can have an effect on self-injury, which is echoed in Duperouzel and Fish's (2010) study. Self-harm is additionally seen as a form of protection for some participants (Brown and Beail, 2009; Harker-Longton and Fish, 2002).

The participants in Brown & Beail's (2009) study also discuss a range of emotions relating to self-injury, including anger and frustration beforehand, feelings of calmness during the self-injury, and guilt and regret following the act. This suggests that the positive, calming effects of the self-injury can be shortlived, and the third theme elicited from the data in this study, 'managing selfharm', shows participants discussing a number of other calming strategies they could use to regulate their emotions, such as listening to music.

When asked, most participants across all studies could clearly give reasons for how their self-injury began and how it is maintained. Exceptions to this tended to be participants who had ceased self-injuring; their experience was different as they could not always remember why they had self-injured in the past (Brown & Beail, 2009). In the aforementioned study, this was explained as the participants rejecting the old, 'bad' self in order to embrace a new way of relating to the world, of which self-injury was not a part. Many participants appear to speak matter-of-factly about their self-injury as a way of coping with experiences that are challenging (Harker-Longton & Fish, 2002). The term 'coping' appears in all the studies, and seems to be an overarching term that refers to managing all aspects of the self-injury experience, from the reasons why it occurs to the ability to talk to staff members about it, and preventing further self-injury from happening.

Relationships

Inter- and intra-personal relationships appear to be important to the participants in all the studies. In discussing their relationships with others, participants are able to clearly discuss what helps them in relation to their self-injury and what makes this behaviour worse (Fish & Duperouzel, 2008; Heslop, 2011). Staff did not appear to recognise the role their relationship played in self-injury (Duperouzel & Fish, 2007); however they were clear in that they felt that they needed more training on how to relate to people who do self-injure. Within Duperouzel and Fish's (2010) study, staff participants asked for extra training to enable them to cope with self-injury, and both sets of participants asked for greater understanding; service users from the staff team, and the staff from the policymakers who ostensibly may have service user's best interests at heart but whose policies make it difficult to create a good relationship with service users who do self-injure.

Other studies found that the loss of a relationship often precipitated the onset of self-injury (Brown & Beail, 2009) and, in one woman's case, the continual loss of relationships with staff she perceived as close to her was given as

a reason for the maintenance of self-injury (Harker-Longton & Fish, 2002). Participants in Duperouzel and Fish's (2010) study also described a difficult relationship with staff on many aspects relating to their self-injury, including staff not making time for them to talk, staff not understanding why they self-injured, and being fearful of the anger incurred when they told staff about their self-injury. The participants felt that this anger was due in part to the large amount of extra work that self-injuring caused the staff. Duperouzel & Fish (2007) found that, whilst participants who were service users felt that they should be allowed to selfinjure, the staff team participants felt that there were too many negative consequences for them in allowing this behaviour. One key theme, 'who's to blame?' picks up on this tension between being understanding and imposing controls for safety. There were also questions of trust raised; that is, the staff felt that they could not trust service users not to self-injure, and the service users did not trust staff with knowledge about their self-injury unless they felt that the staff were understanding of the behaviour.

Fish & Duperouzel (2008) focus more on the therapeutic relationship aspect of care in their latest paper, which discusses the 2007 paper with specific regard to what makes a good relationship for service users who self-injure and staff who work with them. This study found that there were many negative and positive aspects of the staff-service user relationship, with negative aspects including feeling uncared for or as though staff did not have the time to talk, or feeling out of control in that treatment is not collaborative. More positive aspects of the relationship include spending quality time with staff in a one-to-one relationship, and being encouraged to talk about feelings in a caring, non-judgmental way. This is also highlighted in Heslop (2011), who discusses that the ability to disclose self-injury is therapeutic in itself, as some people struggle to communicate the depth of their distress. Many of the qualities that service users look for in staff members are similar to those in the Fish & Duperouzel (2008) study, such as being easy to talk to and being non-judgmental, however some other specific qualities did emerge, notably the staff member's ability to keep calm and to calm down service users who were experiencing difficult emotions, and being kind and nice; concepts which the people in this study genuinely valued. Importantly, communication was regarded very highly by all participants, especially the ones for whom communication was difficult (three participants had limited verbal communication). For those participants, physical communication such as hugging was suggested to be very useful. Many of the participants also acknowledged that they found seeking help and talking to staff to be difficult, suggesting that at times participants would shy away from the thing that they wanted because they found it too difficult. It is suggested in the report that staff should be sensitive to this need.

The relationship that the participants have with themselves, which appears to be related to their self-esteem and perceptions of themselves, is also presented in a number of the accounts. Some participants are given negative messages by others (Brown & Beail, 2009), which may be reacted to with an angry selfinjurious response. Additionally, participants who are repeatedly given negative messages may internalise these, becoming self-injurious as 'punishment' for their perceived deficits (Harker-Longton & Fish, 2002; Duperouzel & Fish, 2010).

Choice

The majority of participants in these studies seem to feel strongly that the decision to self-injure is a choice that they make at certain times, and that they should be allowed to make that choice without suffering repercussions (Duperouzel & Fish, 2007, 2010; Harker-Longton & Fish, 2002). This is similar to literature from the general population, in which participants express the same strong feeling of choice (Fortune, Sinclair & Hawton, 2008). Many of the studies discuss participants who feel that such measures are punitive (e.g. Duperouzel & Fish, 2010) however two participants in Brown and Beail (2009) felt that the external controls of restraint and medication change were useful to them. Some participants in this study found it difficult if staff did not understand, or were perceived to be acting in a deliberately provocative manner, for example by withholding medication.

Notably, in Duperouzel and Fish (2010), being kept in a medium security facility was seen by some participants as contributing to their self-injury, and all the participants saw self-injury as a choice that they made. They felt that it was their right to make that choice, and that staff should not try to stop them. The participants also felt that, as in the previous studies discussed, special measures taken to prevent them from self-injuring were negative, using words such as 'degrading' and 'violated' to describe this experience. This was seen as punitive and ultimately futile, as participants also stated that they would still find a way to self-injure, even with extra precautions being taken. Due to this, Duperouzel & Fish discuss a harm minimisation approach, emphasising that expecting people to simply stop self-injuring is not helpful and that access to other coping methods

needs to be available for people to feel safe enough to contemplate reducing or stopping self-injury. However, the staff group interviewed in Duperouzel & Fish's (2007) study highlighted some of the difficulties in allowing service users to self-injure, namely the culture of blame that makes them feel guilty about this behaviour and the policies in place which suggest that their goal should be to stop self-injury.

Discussion

This review aimed to summarise and synthesise information from a variety of articles about how people with mild-moderate learning disabilities perceive their self-injury, and what factors may influence this behaviour.

As shown, the papers included in this review have common themes, which can be placed under the headings 'reasons for self-injury', 'choice' and 'relationships', which are also points that appear in the literature pertaining to people without learning disabilities (Harris, 2000; Warm, Murray & Fox, 2002). This suggests that people with learning disabilities should not be treated differently with respect to self-injury than those without, and would support Lovell's (2007) position of a false dichotomy between those with learning disabilities and those without in respect of self-injury. However, it is acknowledged that in medium secure and residential settings, where self-injury is less likely to be a private affair, the reaction to this behaviour is usually to put into place sanctions to 'stop' self-injury occurring. In those situations where sanctions are put into place for self-injurious behaviour, some participants in these studies felt that they were being punished (Harker-Longton & Fish, 2002).

When trying to place these papers into a theoretical context, it is useful to consider Nock's (2009, 2010) model of self-injury. Nock's model makes three

main propositions: namely, that self-injury is engaged in because it enables people to regulate themselves affectively or cognitively, or that it enables people to exert influence and control over their relationships and social environment; that the risk of a person self-injuring is increased by difficulties that a person may have in regulating their environment or affective state, such as difficulties in communication, poor social skills, or low distress tolerance; and that the risk of self-injury is increased by a number of factors that lead a person to this type of behaviour instead of another coping method, such as social modeling or a desire to be punished (Nock, 2010). As shown in the papers included for review, some participants have difficulties in both communication and relationships (Heslop, 2011) and childhood maltreatment is described by many (Brown & Beail, 2009), which may increase vulnerability to inter- and intra-personal difficulties, making it more likely that a person will choose self-injury as their coping mechanism. It is important to note that Nock (2010) does not suggest that childhood abuse will lead to self-injury per se, rather that it increases vulnerability to difficulties that may lead to people using self-injury to cope.

There are a number of different hypotheses about the uses of self-injury, which Nock (2010) explores in some detail. The studies included in this review provide support for these hypotheses being appropriate for those with learning disabilities, and this will now briefly be discussed.

Bandura (1977) first provided evidence for the idea that we learn from those around us (social learning hypothesis), and it is known that our peers can have a strong effect on the behaviours that we engage in (Prinstein et al. 2009). It is suggested that, in an environment such as a secure residential facility, people with learning disabilities may be exposed to behaviours that may be classified as challenging and self-injury more than those people who do not live in such an environment. One disruptive resident will doubtless have an effect on the other residents, and this may be how some people come to understand that self-injury may work for them as a coping strategy, as they see it working to help others cope with difficult situations. For example, in Brown and Beail's (2009) study, one participant stated "I always do scratch meself if its...I always scratch meself when house is un, when house in't stable" (p506), suggesting that the disruptive behaviour of others does have an effect, and another participant was mindful of the effect their self-injury may have on others, stating "I used to think to meself, well I don't want to do it in front of other residents, cos it will upset them" (p507). This shows awareness of the effect that this behaviour will have on others.

Nock & Prinstein (2005) proposed an opiate hypothesis after they found that people engaging in self-injury reported feeling little or no pain when doing so. In the studies in this review, some participants also reported feeling no pain (e.g. Duperouzel & Fish, 2010), suggesting that this hypothesis is also valid for this population. There is some suggestion that the endorphins released during self-injury have an analgesic effect, and that opiate antagonists can reduce selfinjury, however this finding is not consistently replicable (Plener et al. 2009) and is little understood at present.

Additionally, it has been proposed that people may self-injure because they are not able to adequately express themselves in other ways – described by Nock as the social signaling hypothesis. People who self-injure have been found to struggle when generating words (Photos & Nock, 2006), which may suggest difficulties in conveying messages to others. People with a learning disability, it is hypothesized, would be particularly vulnerable to this, as many people struggle with word-finding and communication (Heslop, 2011).

Nock's (2009, 2010) model appears to be a useful addition to research on self-injury, however within the field of learning disabilities there are other considerations to make, namely issues around choice and people's relationships with staff members and with each other. It is notable that all participants appeared to view self-injury as a choice, and that attempts to moderate this behaviour were seen as oppressive. It has been suggested that high levels of self-injury in people with learning disabilities is reflective of the severity and nature of oppression they experience (Jones, Davies & Jenkins, 2004), and that people without learning disabilities have explicitly identified organizational processes (such as restraint and observations) as re-confirming traumatic experiences, leading to increased self-injury (Motz, 2009).

Areas for future study:

Much of the research included in this review pertains to the lived experience of people residing in medium secure settings. Whilst this raises interesting issues around power and control, particularly in relation to policies such as continued observation, it may not accurately reflect the experiences of people with mildmoderate learning disabilities who live in residential care homes. In addition, as a number of studies have indicated that people with learning disabilities who selfinjure find procedures such as continued observation to be oppressive and abusive at times, further research should aim to produce ways of managing risk without increasing distress.

Limitations of the current review:

As the current review only looked at behaviour explicitly classified as self-injury, there may have been studies that were missed, particularly those around 'challenging behaviour' of which self-injury may be a component. Additionally, by excluding studies which were not written in English, it is possible that studies from non-English journals were missed. There may also be studies focusing on children and how they make sense of their experience, or factors contributing to their self-injury, which were missed, as it is unclear from the literature reviewed here how much the population of people with learning disabilities mirrors the general population in that self-injury is more common in adolescents in the latter (see Hawton et al., 2002).

Conclusion

When discussing the reasons why people with learning disabilities self-injure, the literature to date clearly points to reasons which are not dissimilar to those expressed by people without learning disabilities. Furthermore, models which have been used thus far with people without learning disabilities (i.e. Nock 2009, 2010) appear to be able to be utilized with people with learning disabilities. This suggests that, when discussing the best way in which to support a person with a learning disability who self-injures, staff should be aware that their motives appear to be no different to those who do not have learning disabilities. Staff in the papers included in this review expressed their wishes for greater training with respect to self-injury, which it is felt should incorporate some aspect of normalization of the behaviour, as pathologising self-injury and increasing restrictions are felt by service users to be ineffective ways of supporting them.

Finally, it is recommended that further research be undertaken into the lived experience of people with mild-moderate learning disabilities who self-injure, in settings other than medium secure facilities, to facilitate further discussion of this behaviour and potentially discover other effective ways in which to support people who engage in self-injury.

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Part 2: Empirical Paper

Psychosocial Factors Affecting Staff Perceptions of Self-Injury in a Learning Disabled Population

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Abstract

Keywords: Expressed Emotion, attributions, self-injury, learning disabilities Aspects of the psychosocial environment may influence self-injury in people with learning disabilities, with both expressed emotion (EE) and attributions being a part of this environment. This study aimed to look at whether self-injury was correlated with EE in residential care staff working with people with mildmoderate learning disabilities, whilst also taking into account attribution theory and its relationship with EE. This study also investigated level of learning disability as a moderating variable. A total of 42 staff completed measures of self-injury and EE, and undertook a ten-minute interview, which was analysed for attributions using the Leeds Attributional Coding Scale (LACS). Level of learning disability was assessed using the ABAS-II. A series of correlations revealed no significant relationship between any facet of EE or attributions and self-injury, however level of learning disability was significantly correlated with self-injury. Post-hoc non-parametric tests were also undertaken. The results of this study are analysed with relation to Weiner's attributional model and models of prosocial and helping behaviour.

Introduction

One of the most challenging aspects of working within the learning disabilities community is working with individuals who self-injure, defined as "nonaccidental behaviours which produce temporary marks or reddening of the skin or cause bruising, bleeding or other temporary or permanent tissue damage" (Oliver Prevalence rates for this behaviour in people with and Petty, 2002, p55). profound and multiple learning disabilities range from 4% to 24% (Oliver et al., 1998; the National Institute of Health and Clinical Excellence, 2004). There are no reliable estimates for people with mild-moderate learning disabilities, as the majority of this literature does not distinguish between mild-moderate and severe learning disabilities, however, a study undertaken by Wisely et al. (2002), reported a prevalence rate of 22% for people with learning disabilities living in residential care homes. Self-injury in people without learning disabilities can cause significant distress for staff members working with them, with feelings such as helplessness and irritability reported (Arnold, 2005, Pompili et al., 2006). Therefore, it is reasonable to assume that staff working with people with learning disabilities who self-injure also experience these emotions, and research confirms this, with staff working with 'challenging behaviour' reporting feelings such as anger, fear and disgust (Bromley & Emerson, 1995).

When staff report such strong emotions about working with people without learning disabilities who self-injure, the psychosocial environment in which the relationship occurs may be affected. There is a wealth of literature on the link between different aspects of this environment and the effects this has on clients, particularly in relation to carers of people with schizophrenia and other mental disorders (Amminger et al., 2011; Sundquist, Frank & Sundquist, 2004; Alloy et al., 2005). Of these psychosocial factors, the concept of expressed emotion (EE) is seen as a useful way of conceptualising difficulties in relationships, typically between family members (Brown, Birley & Wing, 1972). EE is defined as how often family members express hostile, critical, or emotionally over-involved attitudes towards the patient, and has received surprisingly little attention within in the learning disability literature, and even less in relation to self-injury in both learning disabled and non-learning disabled populations. As adolescents often report that self-injury is precipitated by conflicts related to family interactions (Lowenstein, 2005), recent research has looked at expressed emotion in adolescents without learning disabilities who self-injure, and suggests that EE could be an important factor in predicting adolescent self-injurious behaviours. Wedig and Nock (2007) found that high parental EE was associated with selfinjurious thoughts and behaviours, as well as suicidal ideation, plans and attempts. Further analysis revealed that one specific component of EE (parental criticism) was strongly associated with self-injurious behaviour, whereas emotional overinvolvement was not. Santos et al. (2009) report that high EE is associated with repeated parasuicidal behaviours, and that high EE families were characterised mainly by emotional over-involvement, which, as this study was undertaken in Portugal, may reflect cultural differences. However, these are currently the only two studies that exist in this area, although there are a number of studies looking at EE within the context of suicidal behaviour (Pollard, 1996; Tarrier et al., 2004), which conclude that certain facets of EE (such as criticism and hostility) are related to suicide attempts and feelings of depression.

The research into people with learning disabilities and EE focuses mainly on challenging behaviour. For example, Weigel et al. (2006) looked at EE within

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staff members when discussing a client with challenging behaviours which included "screaming (and) throwing objects and items of furniture" (p208) or discussing a client without challenging behaviours, and found that higher levels of EE were reported by staff towards the client with challenging behaviour. Cottle et al. (1995) also reported that staff working with clients with learning disabilities reported higher levels of EE following a violent incident. There has been no research into self-injurious behaviours in people with learning disabilities in relation to EE. However, there has been research into another facet of the psychosocial environment which may be related to EE; namely, the attributions made by staff and family members as to the behaviour. Attribution theory suggests that people search for reasons why behaviour occurs, pertaining to dimensions of locus of control (internal or external), stability (stable or unstable), and controllability (controllable or uncontrollable; Heider, 1958). These attributions may then influence behaviour on the part of the person making them, and research suggests that some attributions may lead to inconsistent care, or may actually increase challenging behaviours (Dunne, 1994). As Weigel et al. (2006) suggest, this may impact work done to intervene with behaviours that cause damage, such as self-injury.

Weiner's attributional model of helping behaviour (Weiner, 1986) suggests that attributions related to controllability and stability will influence the potential for observers to offer care or help, in that carers may be more willing to help if behaviours are seen as uncontrollable by the client (that is, due to external factors such as epilepsy or learning disability) and unstable (events that do not always occur). A number of studies have tested this model (Bailey, Hare, Hatton & Limb, 2006; Wanless & Jahoda, 2002; Dagnan & Cairns, 2005; Dagnan,

Trower & Smith, 1998; Jones & Hastings, 2003; Hill & Dagnan, 2002; Sharrock, Day, Qazi & Brewin, 1990) looking mainly at challenging behaviour, but results have been mixed within the learning disability population, and specifically when studies focus on self-injury. For example, Snow et al (2007) measured types of attribution using vignettes of hypothetical clients with a learning disability exhibiting self-injury with staff carers, and found that staff tended to give uncontrollable, unstable attributions for this behaviour. However Stanley and Standen (2000) suggest that behaviours such as self-injury are associated with stability and increased willingness to help. As Snow et al (2007) also note, there are methodological difficulties with many studies in that they tend to employ vignettes of fictitious clients, which may reduce ecological validity in studies.

The current research aimed to preliminarily investigate whether there is a link between EE and self-injury in staff working within residential homes with people with mild-moderate learning disabilities. People with mild-moderate learning disabilities were chosen to attempt to exclude genetic conditions such as Lesch-Nyhan Syndrome and Cri du Chat Syndrome, where there is a particular behavioural phenotype for the behaviour. However, in practice it was difficult to achieve this differentiation (see results and discussion sections) and may have been unnecessary given the continuum stance towards learning disabilities held by the researcher.

The hypotheses for the current study were that firstly there will be a relationship between EE and severity of self-injury, and secondly that if there is a relationship, critical comments and hostility will be more related to self-injury than emotional overinvolvement. This is based on research by Schreiber, Breier and Pickar (1995). The third hypothesis is that attributions will relate to expressed emotion in that people who are high in expressed emotion will perceive the self-harm as stable and uncontrollable (in line with the results of Weigel's 2006 study and with Hooley's (1985) attributional model). This is hypothesised to increase severity of self-harming behaviour. Finally, it is suggested that if there is a relationship between expressed emotion and severity of self-harm, it cannot be accounted for by level of learning disability as a moderating variable (this is informed by Wedig and Nock's 2007 study).

Method:

Design: The study employed a cross-sectional, within-group design with a nonrandom sample of participants.

Participants: Participants were recruited from residential care homes across the Yorkshire, Humber and North Lincolnshire area, and care home managers were contacted first by letter and then by telephone to ask if they would like to take part. A total of 70 care homes were contacted, of which 13 agreed to take part. Five of these care homes did not meet the criteria for inclusion in the study (four care homes were for people with severe and profound learning disabilities, and one did not have any residents who self-injured), leaving a total of eight residential care homes in the final study. From these care homes, ten residents were identified who engaged in self-injury, with behaviours such as head banging, biting, and ingesting paracetamol. Care staff were invited to participate from these eight care homes, and a total of 42 staff were included in the study.

As the prevalence of self-harm within the learning disability population has recently been predicted to be around 3% (Cooper et al., 2008), only a relatively

small total sample size was realistic for this study. To answer the primary research question, a sample size of 60 would give 80% power for detecting a correlation of 0.35. A sample of 60 participants was therefore justified for this study; however, due to staffing issues a final sample of 42 participants was obtained, giving 80% power for detecting a correlation of 0.43 (Statistical Package for the Social Sciences, 2010).

Exclusion and inclusion criteria: Residential home staff were invited to participate on the basis of being over 18 years of age, and being in contact with a resident with a mild-moderate learning disability who self-injured. No participants were excluded on the basis of these criteria, however one potential participant declined to take part.

Ethical approval was granted by the Postgraduate Medical Institute at the University of Hull (please see Appendix J for a copy of the approval letter).

Materials (Appendix K):

The Challenging Behaviour Interview (Oliver et al., 2003). The CBI was developed as an assessment of the severity of challenging behaviour, and is divided into two parts. Part one identifies the occurrence of five forms of challenging behaviour, of which self-harm is one. Part two assesses the severity of these behaviours, measuring the frequency and duration of episodes, effects on the individual and others and the management strategies used by carers. For this study, only the severity component of the CBI was utilized. The CBI has good psychometric properties (kappa index of 0.91, Oliver et al., 2003), which make it useful for measuring perceived levels of self-injurious behaviour.

The Level of Expressed Emotion Scale (LEE; Cole and Kazarian, 1988). The LEE is a self-report questionnaire used to ascertain an individual's level of

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expressed emotion. It consists of four sub-scales: lack of emotional support, intrusiveness, irritation and criticism. The 'relative' version was administered for this study, as there are no specific measures to use with residential staff that measure EE. It does correlate well with the Camberwell Family Interview (Van Humbeeck et al., 2002), which is said to be the "gold standard" of assessing EE in research, and which could not be used in this study due to participants not being family members.

A 10-minute semi-structured interview coded using the Leeds Attributional Coding System (LACS; Stratton, Hanks, & Davidson, 1988) was used to assess attributions. The LACS was developed in order to code causal beliefs as they are expressed during natural discourse. Although the system was developed to understand and describe the cognitions of families and individuals in therapy, it has also proved to be a useful tool in research interviews (Beese & Stratton, 2004). As with other qualitative methods of generating information, the authors recognize that quantitative concepts of validity and reliability do not apply directly. Instead they stress the need for the coding to be consistent, and annotated so that it is interpretable (Stratton et al., 1988). The LACS uses a coding system based around five axes, however, the above review of the literature suggests that two axes may be related to EE; namely, controllable-uncontrollable and stableunstable. The LACS suggests that stable factors are things that will not change about a situation, or that will continue to affect the behaviour in the future (e.g. being unable to communicate). Unstable factors are therefore those which do not influence behaviour into the future (e.g. being bored, or seeking attention). The controllability dimension relates to how much an individual is perceived to be able to influence an outcome, therefore controllable factors would be those that a person can "significantly influence...in the absence of exceptional effort or circumstance" (Stratton et al., 1988, p29). Uncontrollable factors would be related to events out of the person's control, such as having a learning disability. The Adaptive Behaviour Assessment Scale. (ABAS-II; Harrison & Oakland, 2003). The ABAS-II assesses all 10 areas of adaptive behaviours as specified by the DSM-IV in relation to learning disabilities: communication, community use, functional academics, home living, health and safety, leisure, self-care, self-direction, social and work. It also gives these scores as an indicator of the three domains of adaptive behaviour, and provides a global score which would be the one of most use in this study. As such it is widely used in learning disabilities services, and is anticipated to be familiar to care staff. For each resident, the residential care home manager completed the ABAS-II.

Analysis of results: A series of Pearson Product Moment Correlations were planned to investigate the correlation between self-injury and the different facets of EE. Correlational analysis was also undertaken to investigate potential links between types of attributions and EE, with Wilcoxon Signed Ranks test being used to discover whether one type of attribution was used significantly more than the other (e.g. significantly more stable attributions given than unstable attributions). Exploratory non-parametric (Mann-Whitney U) tests were then used to examine within-group differences, which will be explained later in this study.

Results:

Description of the sample

Participants: The majority of participants were female (82%), which is reflective of national statistics (Brietenbach & Wasoff, 2007), and working in a local authority residential home (86%; the rest of the participants stated that they worked in a private residential home, however it is interesting to note that some staff felt that their place of work was private when it was actually local authority-run, and vice versa). Most participants worked full-time (86%) and had an average of 8.3 years of experience working with people with learning disabilities (s.d. 6.76, range 1-25).

The mean level of EE of participants in this study was 7.2 (range 2-21, s.d. 3.6). As the questionnaire goes up to 60, it can be said that the sample as a whole were low in EE. The sample produced significantly more controllable, unstable attributions (see table 1, which shows the frequencies and percentages for each type of attribution, with a Wilcoxon Signed Ranks Test to show significance).

Dimension	Total	Percentage	Wilcoxon Signed Rank Test
	Frequency		
Stable	39	18	Z = -5.000, p = 0.000*
Unstable	174	82	
Controllable	193	91	Z = -5.097, p = 0.000*
Uncontrollable	20	9	

Table 1: Frequencies of attribution and Wilcoxon Signed Rank Test

Service users: Ten service users were identified who were felt by service managers to have a mild-moderate learning disability and to be engaging in selfinjury. These service users were predominantly male (70%) and had a mean age of 37 (s.d. 9.48, range 24-54). As it can be argued that ABAS-II scoring and IQ scoring are reasonably equivalent ways of establishing functioning levels for the purpose of this study (Moss and Hogg, 1997), and as IQ scores were unable to be established (not least because at least 50% of the service users were non-verbal), scores of over 55 on the ABAS-II were assumed to be equivalent to a mild-moderate learning disability. Unfortunately, only three of the service users actually fell into this bracket, accounting for 12 of the participants in this study (mean ABAS-II scaled score 51.1, range 40-65). This would make any interpretation based on an understanding of participants as having mild-moderate learning disabilities difficult. The average score on the challenging behaviour inventory for these service users (scored out of 56) was 19.95 (range 7-43, s.d. 10.1).

Hypothesis 1: Self-injury will be correlated with EE in that the higher the level of EE, the greater the level of self-injury.

The relationship between expressed emotion and perceived level of selfinjury was examined using correlation analysis (Pearson's Product-Moment Correlation Coefficient). Expressed emotion was not found to be significantly correlated with perceived level of self-injury (r = 0.137, p = 0.388, NS). See Appendix L for a graphical illustration of this.

Hypothesis 2: If there is a relationship between self-injury and EE, critical comments and hostility will be more related to self-injury than emotional overinvolvement.

A regression analysis was undertaken, with self-injury as the dependent variable and the different facets of EE as factors in the regression model. It was hypothesised that critical comments and hostility would account for more of the variance, and so they were entered after emotional overinvolvement. The regression found no correlation between self-injury and the different facets of EE (see table 2).

Facet of EE	T-value	Significance
Emotional Overinvolvement	1.429	0.161
Hostility	0.86	0.932
Criticism	-1.691	0.335
Intrusiveness	0.976	0.099

Table 2: Regression analysis of components of EE.

Hypothesis 3: The higher the level of EE a person displays, the more stable the attributions that they produce will be. Similarly, the higher their level of EE, the more controllable the attributions that they produce will be.

This hypothesis was tested by further Pearson's Product Moment Correlations between EE and stable, controllable attributions. For discussion of how the attributions were coded and rated, as well as examples of each attribution type, see Appendix O.

A total of 213 attributions were produced across the 42 transcripts, 18% (39) of which were stable and 91% (193) of which were controllable. However, higher levels of EE were not correlated with more controllable attributions (p = 0.71, NS) or with more stable attributions (p = 0.007, NS).

Hypothesis 4: If there is a relationship between expressed emotion and severity of self-harm, it cannot be accounted for by level of learning disability as a moderating variable.

Level of learning disability was entered into the previous regression analysis as a further independent variable. In an initial correlational analysis, level of learning disability was found to be moderately positively correlated with severity of self-harm (r = 0.420, p=0.006), and this was still found to be the case even when EE was controlled for (t = 2.843, p=0.007).

Discussion

The current study did not find a link between self-injury and expressed emotion in staff carers of people with learning disabilities. As this study was the first to specifically investigate self-injury and EE, there is no precedent for these results; however this contradicts research within non-learning disabled populations (Wedig and Nock, 2007; Santos et al., 2009) and the pilot study undertaken by Greedharry in 1987, which suggested that those who care for with people with learning disabilities had similar levels of EE to other groups of carers. When broken down into factors, none of the factors of EE were significantly correlated with self-injury. Additionally, participants tended to produce attributions which were unstable and controllable by the client, which contradicts previous research into attributions (Hooley, 198; Weigel et al., 2006). Finally, although there were only 12 participants who met the criteria for discussing a client with a mildmoderate learning disability, further analysis did not reveal any significant differences in this population when compared to the 30 participants who discussed a client with a severe learning disability, on either levels of EE or types of attributions made. The reasons for the lack of results in the expected direction will be discussed below. However, it is important to note that level of learning disability was correlated with perception of self-injury, which is in line with other studies measuring IQ and severity of challenging behaviour (Collacott, 1998) and suggests that both objectively and subjectively this may be the case. This also lends support to the study undertaken by Moss and Hogg (1997) which suggests that IQ scores can be accurately predicted from measures of adaptive functioning, and suggests that there is a robust link between adaptive measures of ability and IQ scores, which has also been suggested by other authors (See Moss and Hogg, 1997, for a discussion of the degree of association between adaptive behaviour and IQ).

It may be suggested that care staff working in residential homes are a complex sample. On the one hand, as they are essentially working in a caring role there appears to be no reason why they would not be subject to the same cognitive processes as family members who have a caring role; however, on the other hand it may be important to remember that care staff are paid to perform a role, and therefore could be expected to be less emotionally involved with clients than they would be with family members (Barrowclough et al., 2001). This means that they are subject to pressures, not only from the demanding and complex nature of their work, but also from external forces, such as managers and policy-makers. Due to recent events, there has been a political drive to ensure that individuals who live in residential homes – both those for people with learning disabilities and those for older adults who may have dementia - are well cared for and not subjected to abuse (such as Valuing People Now, DoH 2010). The low response rate of residential homes contacted for this study may reflect the conflicting demands placed on both managers and staff working in an environment which has recently been under scrutiny and reluctance to potentially distress staff further by discussing an emotive topic such as self-injury. Additionally, staff may have been reluctant to answer the questionnaires in a manner that they felt may portray them in a 'negative' light, and many of the interviews consisted mainly of a discussion of best practice rather than the question of why they felt that the client selfinjured. See Appendix M for an example transcript highlighting this issue. It must also be remembered that EE is only one facet of the psychosocial environment which may have an impact on behaviour; it may be that there are other facets of the environment which impact upon self-injury in residential care homes more than the EE exhibited by staff members.

The above study does not provide support for Weiner's attributional model of helping behaviour in that this model would predict that attributions which are unstable and uncontrollable would increase willingness to help. Other studies have also found no support for Weiner's model in relation to staff working with people with learning disabilities who display challenging behaviour (Bailey et al., 2006). This may reflect the situation, as highlighted by Dagnan, Trower & Smith (1998) in that staff are paid to provide care, so this may be a greater motivator for helping behaviour than their cognitions; that is, it does not matter how they view the self-injury, they are paid to help the person regardless. There are a number of other models that may better explain these results in the context of helping behaviour, which will be briefly discussed below.

The negative-state relief model (Schaller & Cialdini, 1988) suggests that individuals will help in specific situations to reduce the negative impact of the situation on their own mood and to make themselves feel better. For example, seeing a person whom you care about self-injuring is likely to produce strong negative emotions; by helping that person to stop this behaviour the staff member feels as though they have done something worthwhile, thus improving their own mood. This basic model has been challenged over the years since its conception, and some of the additions can be linked to EE. For example, it has been observed that participants who are low in EE are higher in empathy (Hooley & Hiller, 2000) and that those people expressing high empathy are more likely to help an individual in distress regardless of their mood or the possibility of mood enhancement (Batson et al., 1989). This model is known as the empathy-altruism hypothesis (Batson, 1991). In this particular instance, we could suggest that the participants in this study are all generally low in EE as there were no scores higher than 21/60, and so may be highly empathic towards the clients they work with. If this is the case, then they would be motivated to help clients who self-injure because relieving their suffering is important, not because there is a secondary gain of mood improvement from it. There are a number of studies investigating staff attributions, optimism and willingness to help based around Weiner's attributional model (Dagnan, Trower & Smith, 1998, Snow et al., 2007), however as the current study did not take a measure of staff emotional reaction to selfinjury it would be difficult to compare with these studies directly. Many studies have also employed a forced-choice questionnaire when measuring attributions, which may not allow for full expression of the reasons individuals attribute to clients' self-injury. Additionally, Weisman et al. (1993) suggest that factors such as controllable attributions in themselves are not harmful; it is the excessive nature of these in high EE individuals that may cause difficulties. Thus, in the context of their research, those individuals who cope well "may be those who maintain a delicate balance between perceiving some control while recognising that some of the odd or disruptive behaviour is an inevitable side effect of a genuine illness" (Weisman et al., 1993, p606).

Another reason why the study may have found results that go against what would be expected may be down to the actual levels of EE recorded by the LEE. A median split could potentially differentiate between 'high' and 'low' EE within this study, however in terms of a more global outlook it could be said that the participants in this study displayed low levels of EE due to their scores on the LEE. It could be hypothesised that, in contrast to people who are high in EE expressing stable, uncontrollable attributions, that people who are low in EE would express unstable, controllable attributions. If this is the case, then the study lends at least partial support to models of interaction between EE and attributions. It is also worth remembering that participants in this study are not family members, and their caring role does not extend to 24 hour care of one particular person; indeed, a staff member may care for many different people over the course of a shift. It may be that there are simply too many different people to focus on, meaning that staff restrict their role to one of caring only, in adherence to the medical model, and do not actively think about the reasons for self-injury.

Limitations of the current study

A clear limitation of the study is that it did not achieve one aim that it originally set out to achieve; namely, only 29% of the participants were actually discussing a client with mild-moderate learning disabilities. This is interesting given that the criteria for inclusion were clearly articulated to participants; however it may be that the theoretical definitions of learning disability applied by researchers and professionals to this population do not match the lived experience of staff working with individuals in a residential care setting. Whereas research employs a cut-off point for different levels of learning disability, either through a formal IQ test such as the WAIS-IV Wechsler, 2008) or a measure of adaptive functioning such as the ABAS-II (Harrison & Oakland, 2000), staff working within this context may only be able to compare each individual client to others in the same setting. This may mean that participants work with several people, all of whom would meet the criteria for severe and profound learning disabilities, but that because there is a certain amount of variation between each person, an individual who is at the higher end of the severe/profound criteria may be judged to have a mildmoderate learning disability by staff. This can be discussed within a social model of disability (Oliver, 1983) which would suggest that it is society's views which can further impair people with both physical and learning disabilities, by virtue of the additional social barriers and constraints placed on people who are disabled in some way. It may be that the staff completing the ABAS-II were not concerned with how objectively diffcult it was for the client to complete certain tasks, but rather how severe a learning disability they perceived the client to have. Conducting the ABAS-II assessment before interviewing participants would negate this effect, as it would be clear from the beginning whether or not each person met the criteria for a mild-moderate learning disability; however in the current study, due to the low reported rate of self-injury in the residential care homes approached, this would have led to only 12 participants being acquired in total.

It is also important to consider that the sample size of mild-moderate clients may be so small due to the number of clients with a mild-moderate learning disability living in residential care homes. Emerson et al (2001) state that 63% of adults with a learning disability live in private households, usually with their families. Of the 37% who live in supported housing and residential care homes, it is reasonable to suggest that the majority may have more severe learning disabilities, as their care would be more specialist and having 24 hour care may be more of a necessity. There have been some studies looking at EE within families of children with learning disabilities (Lam, Giles and Lavander, 2003; Datta, Russel and Gopalakrishna, 2002), but none looking at adults or looking specifically at self-injury, which would both be interesting areas for future research.

A further limitation of the study appears to be that the LEE may not be appropriate to use with residential care staff. The questions which were most endorsed by participants in this study were around the Intrusiveness construct, which consists of items such as 'I often check up on him/her to see what he/she is doing' and 'I don't pry into his/her life' (reverse scored). Anecdotal evidence suggests that some participants saw this as part of their jobs as carers, rather than it necessarily being overly intrusive. Further research is needed to produce a version of the LEE which is sensitive to the type of EE exhibited by residential staff; however, research has shown that measures such as the Five Minute Speech Sample can also be used effectively with staff carers (Langdon, Yaguez & Kuipers, 2007; Weigel et al., 2006).

Conclusions:

Whilst this study did not find a link between expressed emotion and attributions in relation to staff carers of people with mild-moderate learning disabilities who selfinjure, a link was found between severity of learning disability as measured by the ABAS-II and severity of self-injury. This suggests that there may indeed be some equivalency between adaptive measures of disability and more traditional intelligence tests. Further research should take into account the difficulties in staff accurately identifying individuals with mild-moderate learning disabilities, and also how measures which are normed for one population may not translate to different populations. Facets of the psychosocial environment other than expressed emotion and attributions should also be taken into account, such as staff stress levels, organisational changes led by policy, and the emotions elicited in staff by the self-injury of clients in their care.

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Appendices

Appendix A: Reflective statement

Choice of topic and development of research idea:

After developing skills at undergraduate level in an area of research not directly related to clinical psychology (transcranial magnetic stimulation and the effects of adaptation on the motor cortex) I was looking forward to producing a piece of research with 'real-world' applications. I have been interested in self-injury for a long time, and was initially looking to do research into self-injury in people without learning disabilities; however I struggled to find a supervisor due to this being an emotive area of research that had been historically difficult to find participants for. I began to look into self-injury in different client groups, and was struck by how self-injury has been portrayed so differently in the learning

disabled population. After finding a supervisor who was willing to take up a project in this area, I realised that I had made my task even more difficult; not only was I looking at a very emotive subject, I was also looking to use a client group that is perceived as incredibly vulnerable! During the initial development of my research idea, the process of continuous revision and presentation of ideas within the Department of Clinical Psychology and the research expertise of my supervisor were invaluable to me as a relatively inexperienced researcher.

Systematic Literature Review

Having never undertaken a systematic literature review before, I vacillated between anticipating a vast amount of work needing to be done and minimising the amount of actual input that would be needed to complete the review. The end result of this was that I had much more time than I actually needed to complete the literature review, as there was not as much literature on the topic I had chosen as I had anticipated. Topics that would have yielded more literature had been covered in published reviews recently, which was frustrating but allowed me to concentrate on an area that had never been covered by review. Equally, finding just six articles for inclusion in my review initially led to panic, as I wasn't sure that this number was large enough for a review at all, but the small number of articles allowed me to look at each one in more detail, which was very interesting and allowed me to frame my ideas more clearly for my empirical paper. Indeed, when the review was finished, it was over the word limit for all learning disability journals, and it was felt by both myself and my supervisor that trying to remove 800 words from the review would be incredibly difficult and would not allow for the richness of description that choosing a journal with a higher word count, albeit one not specifically focused on learning disabilities, would provide.

Empirical Paper

I found the initial stages of planning the empirical paper quite difficult, as selfinjury within learning disabilities was a new area for me, and as there are very few comprehensive theories of self-injury that could be tested within a learning disabled population. Initially I thought that it would be interesting to do a qualitative study interviewing people with learning disabilities, but when thinking about the amount of time it would take to complete the ethics process, I decided it would be more sensible for a doctoral-level project to use residential home staff as participants instead. This made the process of going through the ethics review quite easy, as the staff were not NHS participants.

Data collection was frustrating at times, due to difficulties in communication and the fact that none of the homes I approached had been asked to do research before. Due to national news stories presenting residential homes in a negative way, the staff were understandably suspicious as to my motives, and a number of sites did not want anything to do with my project. This was upsetting and frustrating, but again the optimism of my supervisor and the fact that I had done a reasonable amount of forward planning meant that there was a large pool of sites to contact, which was expanded to include Scunthorpe due to the practicality of my being there two days a week on placement. A number of managers also misunderstood the definition of 'mild to moderate' learning disability, which was not revealed until the analysis of data took place and again left me feeling frustrated. However, this allowed me the freedom to write extensively on how this research could have been done differently. With hindsight, many pitfalls can be identified, such as the questionnaire used to measure expressed emotion not being sensitive enough, or the measure of learning disability not accurately reflecting the sample, many of whom were non-verbal. These issues, which to a certain degree could not have been predicted pre-data collection, enabled me to focus on descriptive analysis of my results rather than statistical significance; a shift which felt appropriate given the rich data given to me by the staff who had taken part.

Attribution theory

Whilst writing this statement, I began to reflect on how attribution theory could be applied to the process of producing a thesis. Whilst recruiting participants and collecting data I was acutely aware of relying on the fundamental attribution error (Ross, 1977) to explain some of the difficulty in collecting data; that is, that if something went wrong it was easier to attribute difficulties to the residential home managers being disinterested (personality-based attributions) rather than their general levels of stress at managing a residential home and having other things to do than my research (situational attribution). Likewise, if I struggled to meet a deadline, it was easier to blame situational factors (such as being tired, or having lots to do) rather than personality-based ones (the fact that I tend to procrastinate is one that has been revealed to me slowly over the last few years!). In this way I have learned how important cognitive biases can sometimes be when trying to simply function in the world, and how difficult they can be to challenge at times.

Conclusion

When thinking about the whole process of producing a thesis, many analogies spring to mind. Anecdotally, many of my colleagues have spoken about it as metaphorically running a marathon, or giving birth – the feeling seems to be that it is something physically painful and demanding which is incredibly rewarding at the end. Looking back on my thesis as a learning experience, I feel that it fully incorporates all the stages of Kolb's (1984) learning cycle and that now, moving from the reflective observation stage into the abstract conceptualisation stage (i.e. concluding and learning from the experience) I can say that the whole research process has been one which I would like to repeat in the future, to further our understanding of complex psychological topics.

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Appendix B: Author Guidelines for Clinical Psychology Review:

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Appendix C: List of search terms:

(factor* OR variable*)

AND (learning disabilit* OR intellectual disabilit* OR intellectual impairment OR mental* retard* OR mental* handicap* OR developmental disability OR mental deficiency)

AND (self-injurious behavio* OR self-harm*)

Appendix D: Rationale for inclusion and exclusion criteria:

Inclusion criteria:

- Participants in the study must be adults (age 18+) with a mild to moderate level of learning disability (as the review is looking at adults with mild to moderate learning disabilities; there may be separate issues pertaining to self-injury in children)
- Participants must have engaged in, or currently be engaging in, selfinjurious behaviour (as the review is looking at self-injurious behaviour)
- The research must either report the direct experiences of the person engaging in self-injury (through self-report, qualitative methodology, etc) or establish factors that may be influencing the participant's decision to self-injure (through quantitative methodology, etc) (to investigate the hypothesis as to the experiences of people with mild-moderate learning disabilities who self-injure)
- The research must feature in, or be in the process of being submitted to, a peer-reviewed journal (as peer reviewed journals are indicative of academic rigour)

Exclusion criteria:

- Studies where the participants have learning difficulties, such as dyslexia, or developmental difficulties such as autistic spectrum disorders without also having a learning disability (as participants must have a learning disability to be included in the review)
- Studies referring to violent or aggressive behaviour directed towards others, gestures which are clearly suicidal rather than self-injurious, or studies where 'challenging behaviour' is referred to without explicit identification of what this behaviour involves (*as the behaviour identified for review is specifically self-injury*)

- Literature reviews or other non-empirical papers (to maintain an academic standard for the papers included)
- Studies which are not written in English (as no other languages are spoken to a high degree by the author)
- Studies where it is not possible to ascertain the participants' level of learning disability (as the hypothesis pertains to people with mildmoderate learning disabilities only)
- Articles which include people with both mild-moderate and multiple and profound learning disabilities, but do not discriminate between these groups in the results section (i.e. population studies which include people with learning disabilities as an homogeneous group) (as people with learning disabilities are not an homogeneous group and the review is specifically focused on those with mild-moderate learning disabilities)

Appendix E: Quality Assessment Scale

Appraisal	Quality indicators (possible features	Notes on study	Score
questions	for consideration)	being appraised	(0-3)

Ń]
1) FINDINGS	How credible are the findings?	Findings/conclusions are supported by data/study evidence (<i>i.e. the reader can</i> <i>see how the researcher arrived at his/her</i> <i>conclusions; the 'building blocks' of</i> <i>analysis and interpretation are evident</i>) Findings/conclusions 'make sense'/have a coherent logic Findings/conclusions are resonant with other knowledge and experience (<i>this</i> <i>might include peer or member review</i>) Use of corroborating evidence to support or refine findings (i.e. other data sources have been used to examine phenomena; other research evidence has been evaluated: see also Q14)	
2) FINDINGS	How has knowledge/ understand ing been extended by the research?	Literature review (where appropriate) summarising knowledge to date/key issues raised by previous research Aims and design of study set in the context of existing knowledge/ understanding; identifies new areas for investigation (for example, in relation to policy/practice/ substantive theory) Credible/clear discussion of how findings have contributed to knowledge and understanding (e.g. of the policy, programme or theory being reviewed); might be applied to new policy developments, practice or theory Findings presented or conceptualised in a way that offers new insights/alternative ways of thinking Discussion of limitations of evidence and what remains unknown/unclear or what further information/research is needed	
3) FINDINGS	How well does the evaluation address its original aims and purpose?	Clear statement of study aims and objectives; reasons for any changes in objectives Findings clearly linked to the purposes of the study – and to the initiative or policy being studied Summary or conclusions directed towards aims of study Discussion of limitations of study in meeting aims (e.g. are there limitations because of restricted access to study	

		settings or participants, gaps in the	
		sample coverage, missed or unresolved areas of questioning; incomplete analysis; time constraints?)	
S	Scope for	Discussion of what can be generalised to	
4) FINDINGS	drawing wider	wider population from which sample is drawn/case selection has been made	
4) FI	inference – how well is this explained?	Detailed description of the contexts in which the study was conducted to allow applicability to other settings/contextual generalities to be assessed	
		Discussion of how hypotheses/ propositions/findings may relate to wider theory; consideration of rival explanations	
		Evidence supplied to support claims for wider inference <i>(either from study or from corroborating sources)</i>	
		Discussion of limitations on drawing wider inference (e.g. re-examination of sample and any missing constituencies: analysis of restrictions of study settings for drawing wider inference)	
5) FINDINGS	How clear is the basis	Discussion of how assessments of effectiveness/evaluative judgments have been reached (<i>i.e. whose judgments are</i> <i>they and on what basis have they been</i> <i>reached?</i>)	
	of evaluative appraisal?	Description of any formalised appraisal criteria used, when generated and how and by whom they have been applied	
		Discussion of the nature and source of	
		any divergence in evaluative	
		appraisals	
		Discussion of any unintended consequences of intervention, their impact and why they arose	
(9			
		Discussion of how overall research	
		strategy was designed to meet aims of	
	How defensible is the	study	

	research design?	Discussion of rationale for study design Convincing argument for different features of research design (e.g. reasons given for different components or stages of research; purpose of particular methods or data sources, multiple methods, time frames etc.) Use of different features of design/data sources evident in findings presented Discussion of limitations of research design and their implications for the study evidence	
7) SAMPLE	How well defended is the sample design/ target selection of cases/ documents	Description of study locations/areas and how and why chosen Description of population of interest and how sample selection relates to it (<i>e.g.</i> <i>typical, extreme case, diverse</i> <i>constituencies etc.</i>) Rationale for basis of selection of target sample/settings/documents (<i>e.g.</i> <i>characteristics/features of target</i> <i>sample/settings/documents, basis for</i> <i>inclusions and exclusions, discussion of</i> <i>sample size/number of cases/setting</i> <i>selected etc.</i>) Discussion of how sample/selections allowed required comparisons to be made	
8) SAMPLE	Sample compositio n /case inclusion – how well is the eventual coverage described?	Detailed profile of achieved sample/case coverage Maximising inclusion (e.g. language matching or translation; specialized recruitment; organised transport for group attendance) Discussion of any missing coverage in achieved samples/cases and implications for study evidence (e.g. through comparison of target and achieved samples, comparison with population etc.) Documentation of reasons for non- participation among sample approached/non-inclusion of selected cases/documents Discussion of access and methods of approach and how these might have affected participation/coverage	
9) ДАТА		Discussion of: • who conducted data collection • procedures/documents used for collection/recording • checks on origin/status/authorship of	

	1		
<u> </u>	How well was the data collection carried out?	documents	
COLLECTION		Audio or video recording of interviews/discussions/conversations (if not recorded, were justifiable reasons given?) Description of conventions for taking field notes (e.g. to identify what form of observations were required/to distinguish description from researcher commentary/analysis) Discussion of how fieldwork methods or settings may have influenced data collected Demonstration, through portrayal and use	
		of data, that depth, detail and richness	
10) ANALYSIS	How well has the approach to and formulation of the analysis been conveyed?	were achieved in collection Description of form of original data (<i>e.g.</i> <i>use of verbatim transcripts, observation or</i> <i>interview notes, documents, etc.</i>) Clear rationale for choice of data management method/tool/package Evidence of how descriptive analytic categories, classes, labels etc. have been generated and used (<i>i.e. either through</i> <i>explicit discussion or portrayal in the</i> <i>commentary</i>) Discussion, with examples, of how any	
		Discussion, with examples, of how any constructed analytic concepts/typologies	
		etc. have been devised and applied	
11) ANALYSIS	Contexts of data sources – how well are they retained and portrayed?	etc. have been devised and appliedDescription of background or historical developments and social/organizational characteristics of study sites or settingsParticipants' perspectives/observations placed in personal context (e.g. use of case studies/vignettes/individual profiles, textual extracts annotated with details of contributors)Explanation of origins/history of written documentsUse of data management methods that preserve context (i.e. facilitate within case description and analysis)	

12) ANALYSIS	How well has diversity of perspective and content been explored?	Discussion of contribution of sample design/case selection in generating diversity Description and illumination of diversity/multiple perspectives/alternative positions in the evidence displayed Evidence of attention to negative cases, outliers or exceptions Typologies/models of variation derived and discussed Examination of origins/influences on opposing or differing positions	
		Identification of patterns of association/linkages with divergent positions/groups	
13) ANALYSIS	How well	Use and exploration of contributors' terms, concepts and meanings Unpacking and portrayal of	
13) A	has detail, depth and complexity (i.e.	nuance/subtlety/intricacy within data	
	richness) of the data been	Discussion of explicit and implicit explanations	
	conveyed?	Detection of underlying factors/influences Identification and discussion of patterns of	
		association/conceptual linkages within data	
		Presentation of illuminating textual extracts/observations	
14) REPORTING	How clear are the	Clear conceptual links between analytic commentary and presentations of original data (<i>i.e. commentary and cited data</i> <i>relate; there is an analytic context to cited</i> <i>data, not simply repeated description</i>)	
	links between data, interpretati on and	Discussion of how/why particular interpretation/ significance is assigned to specific aspects of data – with illustrative extracts of original data	
	on and conclusion s – i.e. how well can the route to any conclusion s be seen?	Discussion of how explanations/theories/conclusions were derived – and how they relate to interpretations and content of original data <i>(i.e. how warranted)</i> ; whether alternative explanations explored	
		Display of negative cases and how they lie outside main proposition/theory/hypothesis etc.; or how	

		proposition etc. revised to include them	
DN N		Demonstrates link to aims of	
) REPORTING	How clear and	study/research questions Provides a narrative/story or clearly constructed thematic account	
15)	coherent is the reporting?	Has structure and signposting that usefully guide reader through the commentary	
		Provides accessible information for	
		intended target audience(s)	
		Key messages highlighted or summarised	
REFLEXIVITY AND NEUTRALITY	How clear are the assumption	Discussion/evidence of the main	
EUT	s/ theoretical	assumptions/hypotheses/theoretical	
	perspective s/ values that have	ideas on which the evaluation was	
Y Al		based and how these affected the	
XIVIT	shaped the form and	form, coverage or output of the	
FLEY	output of the	evaluation (the assumption here is	
) RE	evaluation?	that no research is undertaken without	
16)		some underlying assumptions or	
		theoretical ideas)	
		Discussion/evidence of the ideological perspectives/values/philosophies of research team and their impact on the methodological or substantive content of the evaluation (again, may not be explicitly stated)	
		Evidence of openness to new/alternative ways of viewing subject/theories/assumptions (e.g. discussion of learning/concepts/ constructions that have emerged from the data; refinement restatement of hypotheses/theories in light of emergent findings; evidence that alternative claims	
		have been examined) Discussion of how error or bias may have	

		arisen in design/data collection/analysis and how addressed, if at all Reflections on the impact of the researcher on the research process	
17) ETHICS	What evidence is there of attention to ethical issues?	Evidence of thoughtfulness/sensitivity about research contexts and participants Documentation of how research was presented in study settings/to participants (including, where relevant, any possible consequences of taking part) Documentation of consent procedures and information provided to participants Discussion of confidentiality of data and procedures for protecting Discussion of how anonymity of participants/sources was protected Discussion of any measures to offer information/advice/services etc. at end of study (i.e. where participation exposed the need for these) Discussion of potential harm or difficulty through participation, and how avoided	
18) AUDITABILITY	How adequately has the research process been documente d?	Discussion of strengths and weaknesses of data sources and methods Documentation of changes made to design and reasons; implications for study coverage Documentation and reasons for changes in sample coverage/data collection/ analytic approach; implications Reproduction of main study documents (e.g. letters of approach, topic guides, observation templates, data management frameworks etc.)	

Appendix F: Data Extraction Form

Pro-forma for data extraction

Title of paper:

Authors:

Year:

Research

question/aims

Study design

(quantitative, qualitative,

mixed?)

Quality score

Participants' level of

learning disability

Gender ratio

Age range (and mean)

Geographical location

Any other relevant

participant information

Definition of self-harm

(if used)

Recruitment method

Inclusion/exclusion

criteria

Number of excluded

participants

Procedure

Interview process

Number of interviews

Length of interviews

Interviewer's relationship

to participant

Analysis of data

Themes identified

(with relevant quotes)

Discussion and

conclusion

Links to theory or

key literature

Implications

Limitations of

study

Other notes:

Study	Harker-	Brown	Duperouzel	Duperouzel	Fish &	Heslop
and	Longton	& Beail	& Fish	& Fish	Duperouzel	(2011)
score	& Fish	2009	(2008)	(2010)	(in press)	
	(2002)					
Question						
1	3	3	3	3	3	3
2	3	3	2	2	3	3
3	2	3	3	2	2	2
4	3	3	3	1	1	2
5	3	3	2	1	1	0
6	2	3	3	2	2	1
7	2	3	2	3	2	1
8	1	2	1	2	2	3
9	2	3	2	2	2	0
10	3	3	2	3	3	0
11	1	1	1	2	1	0
12	0	2	2	1	2	3
13	2	3	2	2	2	2
14	3	3	3	3	3	3
15	3	3	3	3	3	3
16	2	2	2	1	2	1
17	3	1	2	2	2	0
18	3	2	2	3	1	0

Appendix G: Table of quality assessment scores

Appendix H: list of studies excluded by abstract

Authors	Date	Title	Journal	Reason for Exclusion
Berkson, G., Tupa, M., and Sherman, L.	2001	Early development of stereotyped and self-injurious	American Journal of Mental Retardation	Participants are children
		behaviours I: incidence Self-injurious behaviour in	Research in	
Danis, J., Van Den Noortgate, W., and Maes,	2011	people with profound	Developmental	Review of interventive studies
B.		intellectual disabilities: a meta- analysis of single case studies	Disabilities	
		Self-injurious behavior:	School Psychology	
Durand, M., and Carr, E.G.	1985	Motivating conditions and	Review	Focuses on children
		guidelines for treatment. Identifying the variables	Journal of Autism and	
Durand, M., and Crimmins, D.B	1988	maintaining self-injurious	Developmental	Focuses on children
		behavior	Disorders	

Fahmy, V., and Jones, R.S. 199	Theories of the aetiology of self-injurious behaviour: A review.	Irish Journal of Psychology	Review article
Fehlow, P. 198	Causes and incidence of self- 9 mutilation in severely mentally		Article in German
Hall, S., Oliver, C., and Murphy, G. 200	handicapped patients Early development of self- injurious behavior: an empirical study Evaluation of relations	Psychologie American Journal of Mental Retardation	Focuses on children
Harding, J., Wacker, D.P., Berg, W.K., 200 Barretto, A., and Ringdahl, J.	stimuli and self-injury during functional analysis conditions	American Journal of Mental Retardation	Focuses on children
Hastings, R. P., Tombs, A., Monzani, L. C., & 200 Boulton, H.	3 Determinants of negative emotional reactions and causal beliefs about self-injurious	Journal of Intellectual Disability Research	Focuses on children

		study		
			Psychiatic and	
		Self-injurious behaviour and	behavioural disorders	
Hillery, J.	1999	people with developmental	in developmental	Book chapter
		disabilities	disabilities and mental	
			retardation	
		Self-harm by people with		
Jones, V., Davies, R., and Jenkins, R.	2004	learning difficulties: something	Disability and Society	Literature review
		to be expected or investigated? Self-injury by people with		
Ving D U	1993	mental retardation: A	American Journal of	Review article
King, B.H.	1995	compulsive behavior	Mental Retardation	Review afficie
Lerman, D.C., and Iwata, B.A.	1993	hypothesis Descriptive and experimental	Journal of Applied	Intervention included
		analyses of variables	Behaviour Analysis	

behaviour: An experimental

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maintaining self-injurious

	behavior Learning disability against				
Lovell, A.		tself: the self-injury/self-harm	British Journal of Learning Disabilities	Review article	
		conundrum Self-injurious behavior in a			
Lucavechi, T., Barberia, E., Maroto, M., and	2007	patient with mental	Quintessence	Review article; case study was	
Arenas, M	2007	retardation: review of the	International	a child	
Mendoza, Y., and Pellicer, F.	2002	literature and a case report Pain perception in self-	Salud Mental	Focuses on BPD	
		injurious syndrome Mediators' emotional		Focuses on DFD	
Mossman, D.A., Hastings, R.P., and Brown,	2002	responses to self-injurious	American Journal of	Focuses on children	
Т.	2002	behavior: an experimental	Mental Retardation	Focuses on children	
Oliver, C., and Richards, C.	2010	study Self-injurious behaviour in	Current Opinion in	Review article	
		people with intellectual	Psychiatry		

disability

Self-injurious behaviour in

Oliver, C., and Head, D.	1990	people with learning	International Review of	Review article
	1550	disabilities: Determinants and	Psychiatry	
Romer, M., and Dougherty, N.J.	2009	interventions Oral self-injurious behaviors in patients with developmental disabilities	Dental clinics of North America	Discussion paper
			Mental retardation and	
Schroeder, S.R., and 26 others		Self-injurious behavior: Gene-	developmental	Special Issue of Journal
	2001	brain–behavior relationships	disabilities research	summarising Conference
		Self-injurious behaviour and	reviews Journal of Intellectual	
Symons, F.J., and Thompson, T.	1997	body site preference	Disability Research	Focuses on body site only
Symons, F.J.	1995	Self-injurious behavior: A	Developmental	Review article
		brief review of theories and	Disabilities Bulletin	

current treatment perspectives

Self-injurious behavior and

American Journal of

Symons, F.J.

2003 sequential analysis: context

Mental Retardation

Comment in journal

matters

Appendix I: Author Guidelines for the Journal of Applied Research in Intellectual Disabilities (JARID):

Crosscheck

The journal to which you are submitting your manuscript employs a plagiarism detection system. By submitting your manuscript to this journal you accept that your manuscript may be screened for plagiarism against previously published works.

1. GENERAL

The Journal of Applied Research in Intellectual Disabilities is an international, peer-reviewed journal which draws together findings derived from original applied research in intellectual disabilities. The journal is an important forum for the dissemination of ideas to promote valued lifestyles for people with intellectual disabilities. It reports on research from the UK and overseas by authors from all relevant professional disciplines. It is aimed at an international, multi-disciplinary readership.

The topics it covers include community living, quality of life, challenging behaviour, communication, sexuality, medication, ageing, supported employment, family issues, mental health, physical health, autism, economic issues, social networks, staff stress, staff training, epidemiology and service provision. Theoretical papers are also considered provided the implications for therapeutic action or enhancing quality of life are clear. Both quantitative and qualitative methodologies are welcomed. All original and review articles continue to undergo a rigorous, peer-refereeing process. Please read the instructions below carefully for details on submission of manuscripts, the journal's requirements and standards as well as information concerning the procedure after a manuscript has been accepted for publication. Authors are encouraged to visit <u>http://authorservices.wiley.com/bauthor/</u> for further information on the preparation and submission of articles.

2. ETHICAL GUIDELINES

Acceptance of papers is based on the understanding that authors have treated research participants with respect and dignity throughout. Please see Section 2.2 below.

2.1 Authorship and Acknowledgements

Authorship: Authors submitting a paper do so on the understanding that the manuscript has been read and approved by all authors and that all authors agree to the submission of the manuscript to the journal. ALL named authors must have made an active contribution to the conception and design and/or analysis and interpretation of the data and/or the drafting of the paper and ALL authors must have critically reviewed its content and have approved the final version submitted for publication. Participation solely in the acquisition of funding or the collection of data does not justify authorship.

It is a requirement that all authors have been accredited as appropriate under submission of the manuscript. Contributors who do not qualify as authors should be mentioned under Acknowledgements.

Acknowledgements: Under Acknowledgements please specify contributors to the article other than the authors accredited. Please also include specifications of the source of funding for the study and any potential conflict of interest if appropriate.

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Suppliers of materials should be named and their location (town, state/county, country) included.

2.2 Ethical Approvals

Research involving human participants will only be published if such research has been conducted in full accordance with ethical principles, including the World Medical Association Declaration of Helsinki (version, 2002 <u>www.wma.net</u>) and the additional requirements, if any, of the country where the research has been carried out. Manuscripts must be accompanied by a statement that the research was undertaken with the understanding and written consent of each participant (or the participant's representative, if they lack capacity), and according to the above mentioned principles. A statement regarding the fact that the study has been independently reviewed and approved by an ethical board should also be included.

All studies using human participants should include an explicit statement in the Material and Methods section identifying the review and ethics committee approval for each study, if applicable. Editors reserve the right to reject papers if there is doubt as to whether appropriate procedures have been used.

Ethics of investigation: Papers not in agreement with the guidelines of the Helsinki Declaration as revised in 1975 will not be accepted for publication.

2.3 Clinical Trials

Clinical trials should be reported using the CONSORT guidelines available at <u>www.consort-statement.org</u>. A CONSORT checklist should also be included in the submission material (<u>www.consort-statement.org</u>).

The *Journal of Applied Research in Intellectual Disabilities* encourages authors submitting manuscripts reporting from a clinical trial to register the trials in any of the following free, public trials registries: <u>www.clinicaltrials.org</u>, <u>www.isrctn.org</u>. The clinical trial registration number and name of the trial register will then be published with the paper.

2.4 Conflict of Interest and Source of Funding

Conflict of Interest: Authors are required to disclose any possible conflict of interest. These include financial (for example patent ownership, stock ownership, consultancies, speaker's fee). Author's conflict of interest (or information specifying the absence of conflict of interest) will be published under a separate heading.

The *Journal of Applied Research in Intellectual Disabilities* requires that sources of institutional, private and corporate financial support for the work within the manuscript must be fully acknowledged, and any potential conflict of interest noted. As of 1st March 2007, this information is a requirement for all manuscripts submitted to the journal and will be published in a highlighted box on the title page of the article. Please include this information under the separate headings of 'Source of Funding' and 'Conflict of Interest' at the end of the manuscript.

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Submissions are now made online using ScholarOne Manuscripts (formerly Manuscript Central). To submit to the journal go to http:// mc.manuscriptcentral.com/jarid. If this is the first time you have used the system you will be asked to register by clicking on 'create an account'. Full instructions on making your submission are provided. You should receive an acknowledgement within a few minutes. Thereafter, the system will keep you informed of the process of your submission through refereeing, any revisions that are required and a final decision.

3.1 Manuscript Files Accepted

Manuscripts should be uploaded as Word (.doc) or Rich Text Format (.rft) files (<u>not</u> write-protected) plus separate figure files. GIF, JPEG, PICT or Bitmap files are acceptable for submission, but only high-resolution TIF or EPS files are suitable for printing.

To allow double-blinded review, please upload your manuscript and title page as **separate** files.

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1. Your manuscript without title page under the file designation 'main document'.

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3.2 Blinded Review

All articles submitted to the journal are assessed by at least two anonymous reviewers with expertise in that field. The Editors reserve the right to edit any contribution to ensure that it conforms with the requirements of the journal.

4. MANUSCRIPT TYPES ACCEPTED

Original Articles, Review Articles, Brief Reports, Book Reviews and Letters to

the Editor are accepted. *Theoretical Papers* are also considered provided the implications for therapeutic action or enhancing quality of life are clear. Both quantitative and qualitative methodologies are welcomed. Articles are accepted for publication only at the discretion of the Editor. Articles should not exceed 7000 words. Brief Reports should not normally exceed 2000 words. Submissions for the Letters to the Editor section should be no more than 750 words in length.

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<u>http://authorservices.wiley.com/bauthor/english_language.asp</u>. All services are paid for and arranged by the author, and use of one of these services does not guarantee acceptance or preference for publication.

5.2 Structure

All manuscripts submitted to the *Journal of Applied Research in Intellectual Disabilities* should include:

Cover Page: A cover page should contain only the title, thereby facilitating anonymous reviewing. The authors' details should be supplied on a separate page and the author for correspondence should be identified clearly, along with full contact details, including e-mail address.

Running Title: A short title of not more than fifty characters, including spaces, should be provided.

Keywords: Up to six key words to aid indexing should also be provided. *Main Text:* All papers should be divided into a structured abstract (150 words) and the main text with appropriate sub headings. A structured abstract should be given at the beginning of each article, incorporating the following headings: Background, Materials and Methods, Results, Conclusions. These should outline the questions investigated, the design, essential findings and main conclusions of the study. The text should then proceed through sections of Introduction, Materials and Methods, Results and finally Tables. Figures should be submitted as a separate file.

Style: Manuscripts should be formatted with a wide margin and double spaced. Include all parts of the text of the paper in a single file, but do not embed figures. Please note the following points which will help us to process your manuscript successfully:

-Include all figure legends, and tables with their legends if available.

-Do not use the carriage return (enter) at the end of lines within a paragraph.

-Turn the hyphenation option off.

-In the cover email, specify any special characters used to represent non-keyboard characters.

-Take care not to use l (ell) for 1 (one), O (capital o) for 0 (zero) or ß (German esszett) for (beta).

-Use a tab, not spaces, to separate data points in tables.

-If you use a table editor function, ensure that each data point is contained within a unique cell, i.e. do not use carriage returns within cells.

Spelling should conform to *The Concise Oxford Dictionary of Current English* and units of measurements, symbols and abbreviations with those in *Units, Symbols and Abbreviations* (1977) published and supplied by the Royal Society of Medicine, 1 Wimpole Street, London W1M 8AE. This specifies the use of S.I. units.

5.3 References

The reference list should be in alphabetic order thus:

-Emerson E. (1995) *Challenging Behaviour: Analysis and Intervention in People with Learning Disabilities*. Cambridge University Press, Cambridge.

-McGill P. & Toogood A. (1993) Organising community placements. In: *Severe Learning Disabilities and Challenging Behaviours: Designing High Quality*

Services (Eds E. Emerson, P. McGill & J. Mansell), pp. 232-259. Chapman and Hall, London.

-Qureshi H. & Alborz A. (1992) Epidemiology of challenging behaviour. *Mental Handicap Research* 5, 130-145

Journal titles should be in full. References in text with more than two authors should be abbreviated to (Brown *et al.* 1977). Authors are responsible for the accuracy of their references.

We recommend the use of a tool such as <u>EndNote</u> or <u>Reference Manager</u> for

reference management and formatting.

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http://www.endnote.com/support/enstyles.asp

Reference Manager reference styles can be searched for here: http://www.refman.com/support/rmstyles.asp

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5.4 Tables, Figures and Figure Legends

Tables should include only essential data. Each table must be typewritten on a separate sheet and should be numbered consecutively with Arabic numerals, e.g. Table 1, and given a short caption.

Figures should be referred to in the text as Figures using Arabic numbers, e.g. Fig.1, Fig.2 etc, in order of appearance. Figures should be clearly labelled with the name of the first author, and the appropriate number. Each figure should have a separate legend; these should be grouped on a separate page at the end of the manuscript. All symbols and abbreviations should be clearly explained. In the full-text online edition of the journal, figure legends may be truncated in abbreviated links to the full screen version. Therefore, the first 100 characters of any legend should inform the reader of key aspects of the figure.

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http://www.blackwellpublishing.com/pdf/SN_Sub2000_X_CoW.pdf

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Acrobat Reader will be required in order to read this file. This software can be downloaded (free of charge) from the following website:

www.adobe.com/products/acrobat/readstep2.html

This will enable the file to be opened, read on screen, and printed out in order for any corrections to be added. Further instructions will be sent with the proof. Proofs will be posted if no e-mail address is available; in your absence, please arrange for a colleague to access your e-mail to retrieve the proofs.

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Free access to the final PDF offprint of the article will be available via Author Services only. Additional paper offprints may be ordered online. Please click on the following link, fill in the necessary details and ensure that you type information in all of the required fields: http://offprint.cosprinters.com/blackwell Appendix J – Ethical acceptance letter

Appendix K – Materials used – Information sheet:

≝®≝***** UNIVERSITY OF **Hull**

Participant Information Sheet

We would like to invite you to take part in our research study. Before you decide we would like you to understand why the research is being done and what it would involve for you. **The researcher will go through the information sheet with you and answer any questions you have.** We suggest this should take about 5 minutes. Please ask if anything is not clear.

Expressed emotion and attributions in relation to people with learning disabilities who self harm: version 1.2

What is the purpose of the study?

Looking at relationships and emotions when working with a person who self-harms is an area that has not been well investigated. Working with people who self-harm can be a difficult and stressful experience, and can feel quite overwhelming at times. The term used to describe negative relationships and emotions is 'expressed emotion' (EE), which is rated as high or low.

This research project aims to find out whether high or low EE relates to how badly a person self-harms. The main research question being addressed is whether there is a relationship between EE and severity of self-harm. Secondary research questions also look at the different meanings people give to the self-harm (called 'attributions') and whether or not they influence self-harming behaviour.

Why have I been invited?

You have been invited to take part because you work in a residential home for people with learning disabilities. One or more of the people you work with self-harms. By 'self-harm,' we mean behaviours such as hitting or biting themselves, or more obvious behaviours such as cutting or burning. We are aiming to recruit 40-60 participants for this study.

Do I have to take part?

No, it is up to you to decide to take part. We will describe the study and go through this information sheet. If you agree to take part, we will then ask you to sign a consent form. You are free to withdraw at any time, without giving a reason.

What will happen if I decide to take part?

After you sign the consent form, you will be given a questionnaire to fill in with demographic information on it (age, gender, etc). The researcher will then talk through a questionnaire about the person's level of learning disability with you, and then there will be a questionnaire about their level of self-harming behaviour. You will then have a ten minute taped interview with the researcher, who will ask you a few questions about the person's self-harm. Finally, you will be asked to complete a questionnaire asking you about how you feel about the person who self-harms. The whole study should take between half an hour and an hour to complete

What are the possible disadvantages and risks of taking part?

Taking part in this study requires some of your time, which may be inconvenient for you. Talking about self-harm can also be distressing, and may make you feel uncomfortable. If there are any points during the interview or the questionnaires that feel difficult, please tell the researcher, who can get you the support that you may need.

What are the possible benefits of taking part?

We hope that the information we gain from this study will help improve the lives of people with learning disabilities who self-harm, and also the lives of those who care for them. Taking part will give you an opportunity to think about how you are coping with the self-harm exhibited by this person, and some people can find that helpful.

What will happen if I decide I no longer wish to take part?

After signing the consent form, you can still change your mind about taking part in the study. Even if you have already given us your completed questionnaires, if you have kept a note of your reference number, you can contact us at any time and we will remove and destroy any information you have provided to us.

What if there is a problem?

If you have a concern about any aspect of this study, you should ask to speak to the researchers who will do their best to answer your questions. There will be a chance to ask questions after reading this information sheet. There will also be a debrief following the study, where you will be able to ask questions and discuss how the study has affected you if you wish to.

If you find any aspect of this study distressing, please speak to the researcher as soon as possible. If you still feel distressed after speaking to the researcher, please speak to your line manager before you return to work, or as soon as possible.

Will my taking part in this study be kept confidential?

All data will be handled according to ethical and legal practice. All information which is collected about you during the course of the research will be anonymous. Your completed questionnaires will be given a code number which will be used throughout the analysis of the results. The coded data will be stored securely on University Departmental premises for five years after completion of the study. As stated previously, your interview will be tape recorded, and the recordings will be destroyed following completion of the study. During the study, you must not divulge any identifying information about the person that

you care for. Identifying information means their name, their date of birth, their address,

or any other information that could be used to identify the person.

What will happen to the results of the study?

The results will be written up as part of a doctoral qualification and are intended to be published in a scientific journal. You will not be personally identified in any of the results. Information about the results will be available from the researcher (Sarah Chafer) upon completion of the study in Summer 2012.

Who is organising and funding the research?

This research is being undertaken as part of a doctoral research project in Clinical Psychology at the University of Hull.

Who has reviewed the study?

This research has been looked at by an independent group of people at the Postgraduate Medical Institute (PGMI) at the University of Hull. This study has been reviewed and given favourable opinion by a Research Ethics Committee at the PGMI, which means that it has been found to be ethical.

Further information and contact details

If you have any further questions or queries, please contact Sarah Chafer either in person or on 07538870224 between the hours of 9:30am and 4:30pm.

Consent form:

Participant Identification number for this study:

CONSENT FORM

	11
UNIVERSITY OF HU	

 Title of project: Expressed emotion and

 attributions in relation to self harm in people view

 disabilities

 Name of Researcher:

<u>Please initial the</u> <u>box</u>

1. I confirm that I have read and understand the information sheet dated 22nd January 2011 (version 1.2), for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily.	
2. I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason, without any medical care or legal rights being affected.	
3. I am aware of the potential risks and benefits of taking part.	
4. I agree to take part in the above study.	

Name of participant	
---------------------	--

Date

Signature

Name of person Taking consent

Date

Signature

Demographic questionnaire:

Demographic questionnaire

Please take a couple of minutes to fill in this demographic questionnaire. The information on this questionnaire will not be used to identify you in any way.

Sex:		
Male	Female	
Please specify which type of service y	ou currently work	for:
Residential – private		
Residential – local authority		
Residential – voluntary		
Other		
Do you work part-time or full-time?		
Part time	Full time	
How many years experience do you disabilities?	ı have working w	rith people

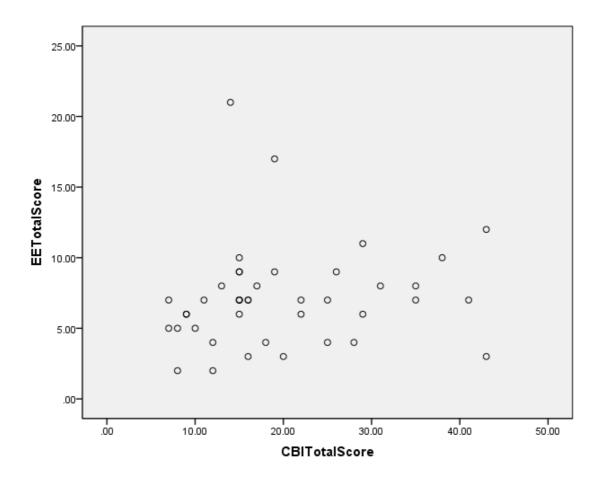
Thank you for taking the time to complete this questionnaire

with learning

Level of Expressed Emotion Questionnaire:

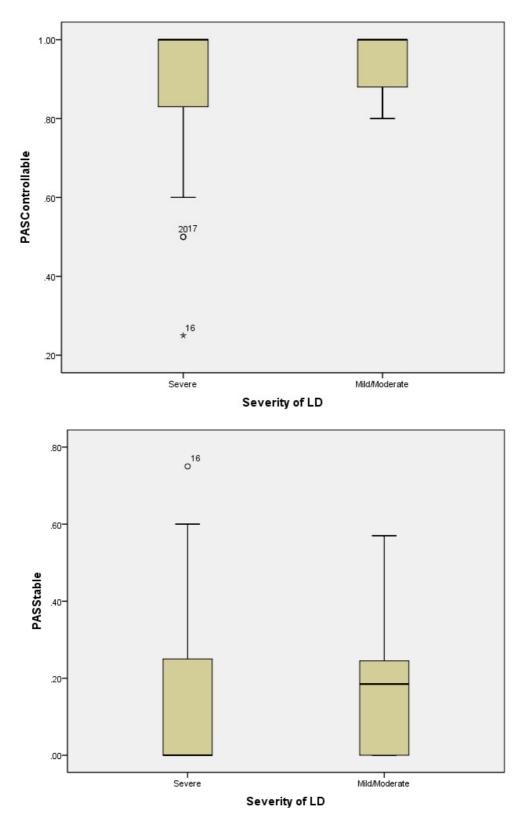
Challenging Behaviour Interview:

Adaptive Behaviour Assessment System Form:



Appendix L – Graph of EE (EE total score) vs self-injury (CBI total score)

Appendix M: Box plots of proportional attribution scores for severe and mildmoderate LD (controllable and stable shown)



Appendix N: Example Transcript:

This is the interview for participant number seventeen, so, can you tell me about the last time you remember this person self-harming, sort of what happened Erm, it was erm, it was a morning shift and I was attending to this service user's personal care and he seemed calm in himself, greeted him in his normal way following his support plan, erm, he got up, brushed his teeth, and then he started to hit his knee on his drawers which were in his bedroom, erm, I heard the bang and I was obviously in the wardrobe, turned round and just saw him, hitting the drawers, and so I asked him to stand back, calm down, erm, he sat in his chair, I gave him five minutes carried on making sure he knew where I was and I got his toiletries out, and then he erm, he comes over and he tries to touch your hand, I asked him to roll his pyjama leg up and pointed to the knee that he'd hit, erm, and we do tell him that his behaviour is not good, erm, he did try to touch my hand which is a form of communication, we don't really know what it means and I let him do it and I told him, you must not do that, you will hurt yourself, and after that short period which would have been less than ten minutes, because I left him for his cooling down period, erm, well I was still in the room but, he was fine and he just got on with his daily, daily routine, and then obviously I filled his body map in, erm, told the seniors and the other staff so they were all aware that he could be in an anxious or distressed mood but he seemed to have calmed after that, there was no trigger there was nothing that I could see that was any different, asked him if he was okay because he will tell you if there's, if he's in pain he'll point to where it is and then we just kept, you know observing him throughout the day just, I mean we knew where he was, and whereabouts, but not too, because he isn't a very interactive person he's quite withdrawn and he's quite shy, so he doesn't like that anyway but, we just made sure that we knew where he was and that he was okay, so

So what do you think causes the self-harm

Erm, I think with this service user, you're never gonna know, because, he, sometimes there'll be a situation where you'd maybe think this could maybe cause him to show behaviours, and it doesn't, and then other times when you think he might really have enjoyed it or he's enjoying himself, he can go and show a behaviour and then that's it, but I think some of it is that he can't tell us what he wants or what he doesn't like or, to a certain extent we can see by his facial expression, if he doesn't like something or his body language cos he'll back off or he'll walk out the room, or whatever, he doesn't like loud noises so if anyone else is loud or screaming he'll leave the room, or he'll try to leave the room, erm, but I just don't know whether it's just pure frustration that he can't communicate fully with us and say that's what it is, I just don't, I don't think we'll ever really know the true reason, cos sometimes there can be no trigger whatsoever, so

Appendix O: Details of attributional coding and types of attributions:

Attributions:

Participants completed a short, tape recorded interview asking two questions, 'can you tell me about the last time this person self-harmed?' and 'what do you think causes the self-harm?". These interviews were then transcribed and attributions were extracted from each interview. Extracted attributions from six transcripts were then compared with a trained rater, and a percentage agreement of 82.4% was produced. Attributions were then coded along the dimensions of stable/unstable and controllable/uncontrollable, with a further five transcripts being checked against a trained rater. Cohen's kappa for the stable/unstable dimension was 0.603. For the controllable/uncontrollable dimension, Cohen's kappa was 0.468, although the majority of the attributions here were coded as controllable (30/33), so there is not enough data to produce a conclusion about the reliability of rating. However, it can be reported that the raters agreed on 31/33 of the attributions made (94%) for the controllable/uncontrollable/uncontrollable domain.

A total of 213 attributions were produced across the 42 transcripts, 18% (39) of which were stable and 91% (193) of which were controllable. As shown by table 2, participants made significantly more attributions that were controllable rather than uncontrollable, and unstable rather than stable. Examples of attributions taken from the transcripts are as follows (outcomes are in bold type, whilst causes are underlined):

Controllable: ""So why do you think this person **self-harms**?"…I think <u>most of it</u> was to get attention, it was definitely attention seeking

Uncontrollable: ""Why do you think he used to **self-harm**?"...well, he was abused and that by his, err, family, for any wrongdoing he did and he expected to be hit or mistreated when he was carrying on if you like, and <u>if nobody else was doing it he would do it himself"</u>

Stable: "She had grazes and **she'd used a razor to cut herself on her arm**...<u>she</u> <u>feels as though she can't talk to anyone</u>"

Unstable: ""What do you think makes him **self-harm** like that?"...Sometimes <u>he</u> <u>feels rejected".</u>