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Restrictive physical intervention with people who have intellectual disabilities:

An explorative study of service users' perspectives

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Submission for Doctor of Clinical Psychology

University of Sheffield

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Declaration

This work has not been used for any other qualification or submitted

to any other institution

Thesis structure

Both the literature review and research report have been prepared in accordance with the current guidance for contributors to the Journal of Applied Research in Intellectual Disabilities. Copies of the University journal approval letter and guidelines for authors are provided in Appendix i.

Section	Word Count	
Abstract	233	
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Abstract

This thesis is divided into two main sections:

Section 1- Literature Review: The literature review critically appraises the literature on the experiences and views of service users with intellectual disabilities and their carers on restrictive physical interventions. Previous reviews which have been conducted on this topic area are discussed and both qualitative and quantitative studies are included in the review. Papers examining the experiences of service users and carers of restrictive physical interventions are reviewed together, followed by papers evaluating the views of service users and carers on specific restrictive physical intervention procedures. The review concludes that restrictive physical interventions are viewed negatively by service users and carers and there are a number of issues and ethical dilemmas raised by their use.

Section 2- Research Report: The research report concerns a qualitative study on the views of adults with intellectual disabilities on restrictive physical intervention procedures. Individual interviews and a focus group were conducted. Participants watched videos of five different restrictive physical interventions and a semi-structured interview followed each video. Thematic Analysis (Braun & Clarke, 2006) was used to analyse the data. Six overarching themes emerged, including emotional reactions to the holds, cognitive reactions to the holds, concerns about safety, restriction, reporting the incident and attempts by participants to put the holds into context. Themes were on a continuum, with views from the most to least restrictive holds represented along the continuum.

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Section 1

Literature Review

A review of the experiences and views of adults with intellectual disabilities and their carers on restrictive physical interventions

A review of the experiences and views of adults with intellectual disabilities and their carers on restrictive physical interventions

Abstract

Background: The issue of restrictive physical intervention with adults with intellectual disabilities is an important one, due to the extent to which it is used and the controversy surrounding the area. It is particularly important to understand the experiences and views of adults with intellectual disabilities and their carers on this issue.

Methods: A literature search of relevant databases was conducted using search terms associated with restraint and intellectual disabilities.

Results: A small amount of literature emerged on experiences and views of adults with intellectual disabilities and those involved in their care on restrictive physical intervention. Largely negative experiences of restrictive physical intervention were reported by service users and carers and moral and ethical issues were raised in relation to their use. Also, negative views towards restrictive physical intervention techniques were expressed.

Conclusions: There is limited research on the experiences and views of adults with intellectual disabilities and those who care for them on the issue of restrictive physical intervention and it will be important for future work to be carried out in this area.

Introduction

Definition and usage

Restrictive physical intervention, as defined by the British Institute of Learning Disabilities (BILD), is "a method of responding to the challenging behaviour of people with learning disabilities or autistic spectrum disorders which involves some degree of direct physical force which limits or restricts the movement or mobility of the person concerned" (Harris *et al.* 1996, p. 6). Restrictive physical intervention is set out into three main categories in the BILD policy framework, direct physical contact (i.e. physical restraint), use of barriers (i.e. seclusion, restricting access), and materials or equipment (i.e. mechanical or chemical restraint) to restrict or prevent movement (Harris *et al.* 1996). The term restrictive physical intervention will be used throughout this review to refer to the categories of restraint set out above and will, from now on, be referred to as RPI.

Good practice and the law dictates RPI should only be used as a last resort if someone is at risk of harming themselves or others (Matson & Boisjoli, 2009). Approximately 10-15% of people with intellectual disabilities display challenging behaviours (Emerson *et al.* 2001) and "around half of all people with learning disabilities and challenging behaviour are subject to physical interventions" (BILD, 2010). Risks are associated with RPI and it is a controversial topic in the field of intellectual disabilities (Finn & Sturmey, 2009; Jones & Stenfert-Kroese, 2007; Williams, 2009).

History of RPI

RPI arose from behavioural theory as a method for dealing with challenging behaviour. These approaches, based on operant conditioning, have evolved over the years from focussing on aversive interventions to positive behavioural support (PBS). The therapeutic model now in use, PBS, emerged from the debate on the use of aversive behavioural procedures that took place in the 1980's and early 1990's (Axelrod, 1990). During this time punitive interventions were used to manage challenging behaviour and a debate centred on the high frequency of such punitive interventions and the nature of stimuli used in such interventions (Guess et al. 1997). Something which was suggested as fuelling this situation was the lack of a values base underlying the behavioural theory (Emerson & McGill, 1989). PBS emerged to address this, combining behavioural interventions with the values base of social role valorisation and person centred planning for people with intellectual disabilities. This also enabled RPI practices to sit within current policy for people with intellectual disabilities. The central theoretical model for PBS is behavioural, but it promotes an inclusive approach to blend practice from different theoretical perspectives into an intervention model. PBS rejects aversive interventions and focuses on preventative strategies, such as altering triggers for challenging behaviour and teaching new skills.

Research on RPI

Whilst lots of research exists on the issue of RPI, most of the studies focus on adult mental health and forensic populations and are conducted in secure settings (Hawkins *et al.* 2005). Given the amount of literature on RPI, the fact

that there is a relatively sparse amount focusing on its use with adults with intellectual disability is interesting to note. Due to the degree to which RPI is used with people with intellectual disabilities and the controversy surrounding its use, the amount of literature in this area does not seem to reflect its importance. Most of the literature that does exist relating to RPI with adults with intellectual disability focuses on aspects such as policy, training, effectiveness and elimination of RPI (Deveau & McGill, 2009; Luiselli, 2009). There is only a small amount of literature focusing on the experiences and views of RPI with adults with intellectual disabilities or those who care for them. The bulk of the literature on service user and carer experiences and views of RPI have been carried out with adults with mental health problems (Hawkins et al. 2005).

Involving service users

Gaining views from adults with intellectual disabilities and their carers is important to help inform policy, training, and our understanding of organisational culture. Previously adults with intellectual disabilities have been overlooked and not given a voice (Edgerton, 1988; Lowe, 1992). Following developments in policy and legislation regarding adults with intellectual disabilities, there is now more emphasis placed on involving them in evaluating the services they receive. The white paper, Valuing People (Department of Health, 2001), provided important government guidance, promoting choice and inclusion for adults with intellectual disabilities. More recently the white paper, Valuing People Now (Department of Health, 2011), encompassing the same vision as Valuing People (Department of Health, 2001), reaffirmed that adults with intellectual disabilities are people first and

deserve the right to the same opportunities as any others and to be treated with dignity and respect. People with intellectual disabilities should be involved in evaluating their care and now a platform exists where they are being encouraged to do this (Stenfert-Kroese *et al.* 1998).

Rationale for Literature Review

There are several reasons which make this review pertinent at this time. One of the reasons is the absence of a review focusing specifically on the views of adults with intellectual disabilities on RPI and those who care for them. During the literature search, two reviews were found which discussed literature on service user views on RPI. A review conducted by Sequeira and Halstead (2002) examined the literature on service users views of RPI. However, this review only included two studies involving service users with intellectual disabilities. Another review by Stubbs *et al* (2009) included a small review of service user and staff views on RPI as part of a wider review on RPI. Although adults with intellectual disabilities were included in these reviews, along with service users and staff in adult mental health settings, no reviews have been conducted focusing solely on studies examining the views of adults with an intellectual disability or their carers.

It is important to consider adults with intellectual disabilities separately in relation to this topic for a number of reasons. People with intellectual disabilities have higher risks of physical health problems than the general population, potentially putting them at increased risk of harm from the use of RPI (Perry *et al.* 2006). Also, there is a greater likelihood of past abuse in people with intellectual disability (Perry *et al.* 2006), and the potential for re-

traumatisation after RPI is an important consideration. Also, the communication difficulties in people with intellectual disabilities may lead to them being restrained more often and for less serious behaviours (Mason, 1996). Literature in the area of mental health focuses on the use of RPI for controlling aggressive patients (Stubbs *et al.* 2009); however, for people with intellectual disabilities there is evidence that RPI is also used to prevent self-injury (Jones *et al.* 2007). Therefore, it is important to study the use of RPI specifically in relation to people with intellectual disabilities, as it has a broader use and may be understood and applied differently.

Secondly, the contentious issue of RPI, made so by the risks of injury and even death that can result from its use (Paterson *et al.* 2003), and the potential for abusive situations to arise from its misuse is currently a topical issue. Abuse of RPI involving NHS Trusts in Cornwall and Sutton and Merton in the UK has previously led to two major inquiries into the care provided at these trusts (Healthcare Commission and Commission for Social Care Inspection, 2006).

Thirdly, there has been a cultural shift in understanding on RPI in more recent years. Initially Control and Restraint (C&R) techniques developed for those in prison were applied to care settings (Hawkins *et al.* 2005). These techniques largely relied on inflicting pain. However, techniques used now in care settings for adults with intellectual disabilities have moved away from these methods. In July 2002 the first guidance, issued jointly by the Department of Health and the Department for Education and Skills, on the matter of restrictive physical intervention was published and formed part of a

national agenda on RPI. Now guidance suggests RPI for those individuals who may require them should be couched within a wider care plan, with an emphasis on proactive strategies, as opposed to reactive ones and on RPI as a last resort in circumstances where less intrusive interventions have been tried and been ineffective (Department of Health, 2002). It is important to examine the views of service users' with intellectual disabilities and those who care for them to note if there have been any shifts in their views or experiences in line with the legislative and cultural changes relating to RPI practice.

Finally, research suggests that it is not solely the degree of challenging behaviour which determines the use of RPI, but that other factors play a role including staff training, service policy, supervision and oversight (Cunningham *et al.* 2003; Allen *et al.* 2009). Reviews on causative factors and usage suggest that RPI is more frequently used in certain settings or organisations (Sturmey, 2009). Therefore, a review on service user and carer views will be important in exploring and gaining an understanding of this issue.

Method

This review presents an overview of the literature on the experiences and views of service users with intellectual disabilities and their carers on RPI. RPI has been defined broadly for the purposes of this review, according to the categories set out by Harris *et al* (1996). The literature searches were conducted in May 2011.

Search strategy

Inclusion criteria

Both quantitative and qualitative studies were included. Studies were included if they met the following criteria:

- Studies stated that service users involved had an intellectual disability or developmental disability (Service users with an additional mental health problem or forensic history were included).
 - Or, studies stated that carers involved in the study worked with those who had an intellectual disability or developmental disability. Carers were defined as either paid staff (including educational and residential care staff) or non-paid staff (including familial or parental carers).
- 2. The papers addressed the views or experiences of service users and/or carers on RPI.
- 3. The papers were published after 1995.

Exclusion criteria

Studies were excluded on the following grounds:

- 1. Papers which did not meet all the criteria above.
- Papers which focused solely on medication as a restrictive intervention.
- Papers not primarily concerned with obtaining views/ experiences of RPI.
- 4. Studies focusing on children or adolescents.

Literature searches of psychinfo and Medline databases using the following search terms were carried out:

- Intellectual disabilit*, learning disabilit*, developmental disabilit*, autism, autistic spectrum disorder, mental retardation and mental handicap.
- Restraint, restrictive physical intervention, restrictive intervention,
 physical restraint, manual restraint, seclusion and mechanical restraint.
- View*, perspective*, experience* and attitude*

These search terms, searching keywords, were combined using AND and OR accordingly. Although search terms relating to views were used, the searches were subsequently run using only terms relating to intellectual disabilities and restraint, to ensure all relevant papers were picked up due to the small amount of literature in this area.

Following the search, using only terms relating to restraint and intellectual disability, 301 papers were retrieved. Studies were screened for content relevance by title and for those with relevant titles, abstracts were read to screen for eligibility. Nine papers were found to meet the inclusion criteria. References were searched for further relevant papers, and one other paper was found.

Due to the changes to policy regarding RPI over the years, including papers from 1995 onwards was thought to be helpful to capture any changes in views or experiences, given the political and cultural shifts in the policy and

practice of RPI. Due to the shift which started to take place in the 1980's involving adults with intellectual disabilities, previously residing in institutions, moving to a community model of care, it was decided that including papers published from 1995 onwards would ensure relevance. All the papers were from peer reviewed journals and were published in the English language.

Quality control

In assessing methodological quality of the quantitative studies included in this review, an adapted version of the Downs and Black Checklist was employed (Downs & Black, 1998). As this checklist was developed for appraising studies of health care interventions, it was adapted to make it more applicable to the papers under review, assessing acceptability of RPI. The checklist included twenty-seven questions to assess methodological quality, however as many of these items were not applicable to the papers under review, only nine of the original questions were used along with three questions relating directly to the quality of the studies being assessed. This produced a profile of the methodological quality of the paper and each paper was given an overall score.

The Critical Appraisal Skills Programme (CASP) tool was utilised to assess methodological quality of the qualitative papers included in this review. The tool considered rigour, credibility and relevance and provided an overview of the quality of the paper. An overall score for quality based on the ten questions in this tool was given to each paper.

Structure of review

This review will firstly discuss the previous reviews conducted on service user and carer views of RPI. Qualitative studies focusing on the experiences of service users with intellectual disabilities and their carers of RPI will then be reviewed. These papers provide rich descriptions on the reported experience of being involved in RPI. Following this, quantitative papers which focus on views of service users with intellectual disabilities and/or their carers on specific RPI holds will be reviewed. These papers provide an insight on how particular RPI practices are viewed.

Results

Two reviews were found which discussed the literature on service user views on RPI, one of which also discussed literature on carer views of RPI. The first review, by Sequeira and Halstead (2002), was conducted on UK and international studies of the views of service users with intellectual disabilities and mental health problems on RPI. This review stated that the views of service users had not previously been used to inform policy on RPI. As part of a wider review by Stubbs *et al* (2009) on RPI, a review of service users and staff views was included. Each of the reviews reported that a largely negative view of RPI is held (Sequeira & Halstead, 2002; Stubbs *et al*. 2009). The reviews reported feelings of fear, anger, powerlessness and frustration in service users. Each reported that service users experienced pain and discomfort during RPI. Also, the issue of re-traumatisation through experience of flashbacks when being restrained was highlighted by the reviews. This was of particular concern when a female service user was

being restrained by a male. The reviews also highlighted the fact that service users felt staff may have enjoyed using restraints and used them for arbitrary reasons. In the review by Stubbs *et al* (2009) RPI was referred to as 'being jumped'. Both reviews found a theme of service users feeling punished by staff when RPI was used. Also, there was a sense that RPI were counterproductive, in that it could actually provoke more anger in service users.

Stubbs *et al* (2009) also reviewed studies on staff experiences of RPI and found that nurses often had a positive view of RPI but did express concerns over potential misuse of the interventions. Re-traumatisation for staff who had been involved in untoward incidents was found to be an issue and the main theme reported was that of anxiety about being hurt. Some worrying comments were reported by staff members, including that RPI was a 'legal way to hurt a patient' and that some staff used RPI too quickly and their attitude was to 'deck them first'. These comments from staff appear to concur with some of the service user reported experiences of staff enjoying RPI and it being used in arbitrary ways, not necessarily in emergencies only.

The review by Sequeira and Halstead (2002) had a number of methodological flaws due to the search strategy and process not being clearly documented and not stating the inclusion and exclusion criteria. Also, this review failed to evaluate the quality of the selected papers. Since this review was conducted there have been significant changes to policy regarding RPI, which have affected the training and practice of RPI for adults with intellectual disabilities. Further studies have been conducted in light of

this which were not included in this review. The review by Stubbs *et al* (2009) had a number of methodological issues, including a search strategy which was not clearly described or elaborated on and the absence of assessment of quality for the papers included. This review was not systematic or a comprehensive account of the literature. Despite methodological flaws of the reviews they do offer some useful discussion on the views of service users and staff on RPI and suggest avenues for future work.

The papers included in the review will now be outlined and discussed. A summary of each of the papers included in the review is contained within in Table 1.

Table 1- Summary and quality ratings for the papers included in the literature review

Qualitative Studies

Paper	Aims	Methodology	Sample Characteristics	Summary of Outcome	Comments	Quality rating
Murphy	To interview service	Retrospective (after	26 service users with	Service users expressed	Aims of study not	
et al.	users about their	an average of four	mild intellectual	strong negative feelings	clearly set out.	8
1996	experiences of being at	and a half years)	disabilities who had	about restrictions of	Methodology not	/20
(UK)	a specialist	interviews with	committed criminal	liberty	clearly set out. How	
	assessment and	service users, set	offences and had		the interviews were	
	treatment unit	questions- some of	previously been at a		conducted and	
		which were closed	specialist hospital unit		analysed is unclear	
		questions and some				
		open questions				
Sequeira	To examine women's	Retrospective	5 women with	4 themes-	Analysis clearly	
and	experience of	individual semi-	developmental	Pain and discomfort	described and	15/
Halstead,	seclusion, manual	structured interviews.	disabilities who	Anxiety and distress	rigorously completed	20
2001	restraint and rapid	Thematic analysis	experienced emergency	Feelings of anger		
(UK)	tranquilisation	used to analyse data	interventions in a	Used to punish and		

psychiatric hospital control

Jones	To examine views of	Individual structured	10 service users with	RPI could lead to	Number of	
and	service users on RPI	interviews. Method of	mild intellectual	potentially abusive	methodological	6
Stenfert-		analysis unclear,	disabilities living in	situations. Service users	issues with this study.	/20
Kroese,		however article	secure residential units	were divided on whether	Unclear how data	
2006		states themes and		it calmed them and	were gathered and	
(UK)		key words were		whether staff enjoyed it	description of	
		highlighted			analysis essentially	
					absent	
Lunsky	To learn about	Retrospective study	4 women with	The negative impact of	Research question	
and	challenges faced by	of service users who	intellectual disabilities	RPI, not feeling	appeared vague.	14/
Gracey,	women attending	accessed	and psychiatric issues	respected, the trauma of		20
2009	emergency	emergency	who had used	RPI and punishment		
(Canada)	departments in crisis	department up to two	emergency departments	were key areas		
	and how to improve	years prior to study.	in psychiatric or	highlighted		
	crisis management	Thematic analysis of	behaviour related crises			
		data obtained from				
		focus group				
Hawkins	To examine personal	Semi structured	8 staff from community	Experiences were	Service user/staff	
et al.	impact of RPI on	interviews of service	residential houses and	intrinsically linked and	pairs were	14/

2005	service users and	user and carer pairs.	8 service users living in	the interactional nature	interviewed, however 20
(UK)	carers and their	Grounded theory	community residential	of physical interventions	the practicalities
	perspectives of the	used to analyse data	houses	was highlighted.	involved not
	impact on each other			Experience depended	discussed. Different
	and consider			on more than just the	interview schedules
	similarities and			application of the	were used for staff
	differences in accounts			techniques	and service users
Fish and	To explore the	Individual interviews	16 staff and 9 service	Staff felt incidents were	Well-constructed
Culshaw,	accounts of aggressive	with service users	users from medium	upsetting and traumatic.	study with good 17
2005	incidents and the	and carers.	secure forensic settings	Service users felt they	discussion and /20
(UK)	consequences of	Interpretative		brought back bad	recommendations
	physical interventions	phenomenological		memories, could be	
		analysis used		painful and made them	
				frustrated. Discrepancy	
				over whether used as	
				last resort with service	
				users not sure of this	

Table 1 summarises all the studies included in the review. The studies can be clearly divided into qualitative studies which focus on the experience of RPI from service user and carer perspectives and then quantitative studies which examine the views of service users and carers on specific RPI techniques. The review of the above papers will be organised in this way.

The Downs and Black checklist, which was adapted for use to assess the quality of the quantitative papers in this review, would conventionally enable a score out of 10 to be attributed to the papers, using a cut off of 6 as a marker for a quality paper. However, as this checklist was revised for the purposes of this review and the scoring was amended to reflect the adaptation, using such a cut off score was not appropriate. All of the studies found through the literature search were included in the review due to the limited amount of work on this topic, however, some of the studies rated higher than others for quality.

Qualitative studies focusing on experiences of RPI

Six studies asked service users with intellectual disabilities about their experiences of RPI, two of which also asked staff about their experiences of RPI and a single study asked about parents' experiences of using RPI with their adult son or daughter with intellectual disabilities. Firstly, the studies which examined service users' experiences of RPI will be reviewed, followed by the studies which examined experiences of carers.

Fish and Culshaw (2005), Jones and Stenfert-Kroese (2007), Lunsky and Gracey (2009), Murphy *et al* (1996) and Sequeira and Halstead (2001) all studied retrospective views of service users in secure or hospital settings. Each of these studies, with the exception of the study by Fish and Culshaw (2005) and Jones and Stenfert-Kroese (2007) asked about RPI in the broad sense, covering chemical restraint, seclusion and physical restraint. Fish and Culshaw (2005), Jones and Stenfert-Kroese (2007) and Hawkins *et al* (2005) focused specifically on physical restraint. Hawkins *et al* (2005) was the only study to be carried out on a community sample.

Service user experiences of RPI reported in these studies focus mainly on negative feelings associated with RPI. Mental distress was reported by the participants' in all the studies except the study by Jones and Stenfert-Kroese (2007), in which there was an absence of emotional content reported by participants. This may have been due to the structured interview schedule utilised in this study, which may not have allowed for participants to expand on their experiences. Negative feelings reported in the other studies included sadness, anxiety and fear. Also, helplessness and powerlessness were reported by the studies. Re-traumatisation was reported in the study by Fish and Culshaw (2005), Hawkins et al (2005) and Sequeira and Halstead (2001), with service users discussing RPI as bringing back traumatic memories. Anger was a common reaction to RPI, with it being reported by participants in the studies by Fish and Culshaw (2005), Hawkins et al (2005), Murphy et al (1996) and Sequeira and Halstead (2001). RPI was reported as causing further anger and aggression, suggesting it may be counterproductive as an intervention to reduce challenging behaviour. This concurs with the previous studies conducted in mental health settings.

In the study by Jones and Stenfert-Kroese (2006) some participants felt RPI prevented further risk while others, similar to the findings by Fish and Culshaw (2005), Hawkins *et al* (2005) and Sequeira and Halstead (2001), felt it made things worse. The fact that some participants in this study reported that RPI prevented further risk may have been due to the poor design of the study, whereby leading questions were asked to participants'. Given the likelihood of adults with intellectual disabilities to acquiesce with interviewers (Heal & Sigelman, 1995) and their greater likelihood towards suggestibility (Clare & Gudjonsson, 1993), the leading questions may have primed participants' to answer in a particular way.

Service users in the studies by Fish and Culshaw (2005), Hawkins et al (2005) and Sequeira and Halstead (2001) reported experiencing pain during RPI. The fact that pain was reported in these studies may be due to their focus on physical restraint. Whilst the study by Sequiera and Halstead (2001) did include other forms of restraint, it was reported that physical restraint was most commonly used. Physical restraint may be more likely to cause pain as it involves direct contact with the service user. Although service users in the study by Jones and Stenfert-Kroese (2007), which focused on physical restraint, did not report pain, they did report actions likely to cause pain. It may be due to its poor design which meant experiences were not properly elicited. In the studies by Fish and Culshaw (2005) and Hawkins et al (2005),

where non-aversive physical restraint techniques were evaluated, pain and discomfort were still reported, despite the approaches not intending to cause pain.

The potential for abuse was highlighted by service users in the studies carried out by Jones and Stenfert-Kroese (2007), Lunsky and Gracey (2009) and Sequiera and Halstead (2001). Service users in these studies spoke of the potential for abusive situations to arise from the use of RPI. Service users in the studies by Jones and Stenfert-Kroese (2007) and Lunsky and Gracey (2009) reported abuse which had occurred during RPI. Worryingly, in the study by Jones and Stenfert-Kroese (2007), one service user had reported the abuse but staff 'stuck together' so the police did not take further action. Also, the abuse discussed in the study by Lunsky and Gracey (2009) was ignored after it was raised through the hospital complaints procedure.

Negative feelings about staff were reported in all studies except Murphy *et al* (1996). Feelings of anger and hatred towards staff were reported by participants in studies by Fish and Culshaw (2005), Hawkins *et al* (2005) and Sequeira and Halstead (2001). Also the notion that RPI was used as punishment and that staff enjoyed being in control and hurting service users was also reported. Participants felt staff enjoyed using RPI (Fish and Culshaw, 2005; Hawkins et al. 2005; Jones and Stenfert-Kroese, 2007; Lunsky and Gracey, 2009; and Sequeira and Halstead, 2001) with participants in the study by Sequeia and Halstead (2001) and Hawkins *et al* (2005) reporting staff laughing during RPI. The studies by Lunsky and Gracey (2009), Sequeira and Halstead (2001) and Jones and Stenfert-

Kroese (2007) appear to suggest that the attitude of staff can influence how the service users view RPI. As service users viewed staff as punishing them, intending to hurt or control them, or as enjoying performing RPI, they felt anger towards staff and felt negatively about RPI being used on them.

Service users in the studies by Fish and Culshaw (2005), Jones and Stenfert-Kroese (2007) and Lunsky and Gracey (2009) reported that RPI was not always used as a last resort. Some participants in the study by Fish and Culshaw (2005) felt that RPI was sometimes unnecessary and used as punishment. All participants' in the study by Jones and Stenfert-Kroese (2007) identified alternatives to restraint, suggesting that other methods had not been tried first and that alternative methods could have calmed them. In the study by Lunsky and Gracey (2009) service users suggested restraints were used without support put in place to calm them first.

Although service users were able to state in general terms why RPI were used, they appeared to commonly report not fully understanding why or when RPI was used for them (Fish & Culshaw, 2005; Hawkins *et al.* 2005; Jones & Stenfert-Kroese, 2007; Lunsky & Gracey, 2009 and Sequeira & Halstead, 2001). Also service users reported being ignored following RPI (Fish & Culshaw, 2005; Hawkins *et al.* 2005; Jones & Stenfert-Kroese 2007), which may be unhelpful in terms of helping them understand what happened. In the study by Lunsky and Gracey (2009) service users spoke about feeling disempowered and ignored by staff, with RPI happening to them against their will and without consent.

The studies by Murphy et al (1996), Lunsky and Gracey (2009) and Sequeira and Halstead (2001) focused on various forms of emergency intervention, therefore they provide an understanding of how service users view RPI generally but not how they view specific RPI practices. Experiences may differ depending on the RPI in use. However, this cannot be established from the findings of these studies. The studies by Fish and Culshaw (2005), Hawkins et al (2005) and Jones and Stenfert-Kroese (2007) give a more in depth account of one particular form of restraint, physical restraint. The findings between the studies asking about general RPI use and specifically physical restraint do not differ greatly, suggesting that RPI generally give rise to similar negative experiences. A significant limitation of the studies by Murphy et al (1996), Lunsky and Gracey (2009), Sequeira and Halstead (2001), Jones and Stenfert-Kroese (2007) and Fish and Culshaw (2005) is that they rely on retrospective recollection, which brings the validity of the studies into question as they rely on memory recall by participants', which has been suggested to be poor in people with intellectual disabilities (Booth & Booth, 1998). Hawkins et al (2005) interviewed participants soon after incidents involving RPI. Although the findings are similar to retrospective studies, more information was given in this study suggesting that a better understanding may be gained from asking about experiences soon after the incidents. Also, the majority of studies take place in secure or hospital settings, therefore limiting their generalisability. The only exception is Hawkins et al (2005) which examines a community sample, where many adults with intellectual disabilities may now be subject to RPI. The findings across secure settings and the community setting study are similar, suggesting RPI are viewed negatively despite the setting in which they occur.

The studies are small scale studies and not necessarily generalisable.

Both Fish and Culshaw (2005) and Hawkins *et al* (2005) also examined staff experiences of using non-aversive RPI. Staff in these studies also reported largely negative views of RPI. In the study by Hawkins *et al* (2005) the overwhelming feeling was that of anxiety, both in the build-up to RPI and during RPI and staff reported concerns about getting hurt. Fear, anger and sadness were emotions reported across studies by staff in relation to RPI use. However, in the study by Hawkins *et al* (2005) some positive emotions were expressed by staff, which were dependent on how the incident was perceived. For example, if staff felt empathy rather than anger towards the service user, they were less likely to feel positively about the RPI.

Staff expressed ethical dilemmas concerning RPI, such as whether they are applying RPI correctly or whether they could have prevented the incident. Both studies reported staff blaming themselves for what happened. However, staff generally located the reason for aggression within individual clients and did not consider other factors which play a role.

Staff reported feeling that they have to take responsibility for clients and deescalate situations. They attribute lack of control to service users and interestingly the literature suggests service users report feeling a sense of powerlessness and helplessness, as they feel staff take control instead of enabling them to do this for themselves. Although in both studies staff suggested they were aware of the general dislike service users felt about RPI, they did not appear to recognise just how negative an experience it may be and staff in the study by Hawkins *et al* (2005) dismissed ideas that RPI may induce pain. Staff in the study by Hawkins *et al* (2005) also felt service users may intentionally disrupt in order to gain attention through RPI.

A discrepancy between service user and staff accounts concerns whether RPI is used as a last resort. Many staff in these studies stressed how RPI is always the last resort. However, Hawkins *et al* (2005) found staff suggested RPI could be used too soon and expressed concerns over this. Staff in each study discussed how debriefing was important following RPI. However, service users do not get this opportunity and many service users reported being ignored following RPI. The study by Hawkins *et al* (2005) found that staff felt they were 'walking on eggshells' following RPI as they felt service users behaviour was unpredictable and did not want to make the situation worse.

In the study by Elford *et al* (2009), which addressed parents experiences of RPI with their adult son/daughter with intellectual disabilities, 'a very fine line' represented the ethical dilemmas inherent in the use of RPI. Parents, like staff in the above studies, shared ethical dilemmas regarding the use of RPI and had a negative view of RPI. Parents expressed concerns over service cultures which may lead to greater RPI use than necessary. Also, parents felt RPI may not always be necessary but that time and staffing means RPI is used when it could be avoided at home. This appears to concur with service users views of RPI not always being a last resort. What is considered the last resort by paid care staff versus service users and families may be different.

Parents suggested that they could feel left in the dark about the RPI use with their children and discussed how RPI could be used without them being informed.

There is a scarcity of research on carer views of RPI with adults with intellectual disabilities. The above studies are small scale studies and may not be generalisable to all carers. Only one study exists focusing on parents' experiences of using RPI, and the parents in the study conducted opted in suggesting they may represent a specific group with something to share about RPI.

Quantitative studies focusing on views of RPI procedures

The quantitative studies focusing on views towards particular RPI holds will now be reviewed. The treatment acceptability of RPI has been studied through asking participants to rate videos of RPI techniques. An initial pilot study conducted by McDonnell *et al* (1993) asked students to rate three different methods of RPI and found that all holds were viewed negatively but that a chair restraint was viewed as more acceptable than two floor restraints. This pilot study has not been included in this review as it did not meet the inclusion criteria. However, since this pilot study was conducted, follow up studies have sought views of service users and carers.

Three studies which have been included in this review, which followed on from the study by McDonnell *et al* (1993), are those conducted by McDonnell *et al* (2000), Cunningham *et al* (2003) and Jones and Stenfert-Kroese (2008). Each of these studies involved asking different groups of participants to rate

three methods of RPI. The methods, selected after reviewing the literature to find representative holds to demonstrate via video sequences, included a chair restraint and two floor restraints, one where the service user is facing downwards and one where they are facing upwards.

The study conducted by McDonnell et al (2000) involved special educational staff and residential staff working with adults with intellectual disabilities along with undergraduate students. All restraints were rated negatively but the chair restraint was rated as most acceptable by all three groups. The interesting finding was students views were less polarised than the views of residential staff, as students rated the face up floor restraint as more acceptable than the carers, and the carers rated the chair restraint as significantly higher for satisfaction than the students. Cunningham et al (2003) followed on from this study, also including service users as well as carers, again finding the pattern of negative views but more favourable views towards the chair restraint, suggesting the level of negativity was dependent on the method being used. The face up restraint was viewed more favourably than face down restraint. This study also included service users and interestingly found that they rated all the restraints more negatively than the carer and student groups. Jones and Stenfert-Kroese, (2008) carried out a follow up study also asking carers and service users views on the three methods of RPI, finding the same pattern of responses. This study also asked service users about their experiences of RPI, asking them to rate their beliefs regarding RPI on visual analogue scales and found negative emotions were expressed, including feeling frightened and stressed.

The main methodological flaws, consistent across the above studies, were in relation to the sampling. The studies did not clearly state inclusion or exclusion criteria. They did not adequately describe how participants were sampled, how they were selected and contacted or how many participants who were asked agreed and opted out. However, descriptions of participant characteristics were given. The studies each described in detail the RPI techniques being shown and gave clear descriptions of the procedure of the study in relation to how the videos were shown. Each study randomised the order of the presentation of videos to prevent order effects. The study by Jones and Stenfert-Kroese, (2008) also included asking service users to rate experiences of RPI. This was not sufficiently explained and the method for analysis of this data was not described. Therefore, the information from this part of the study may not be reliable or valid.

Discussion

Summary of findings

The existing studies on service user and carer experiences of RPI suggest that on the whole RPI are viewed negatively and the findings concur with the previous reviews carried out. Drawing from the studies with high quality ratings, it can be seen that similar findings occur across studies. The studies with low quality ratings, namely, Jones and Stenfert-Kroese (2007) and Murphy *et al* (1996) do suggest similar findings to the other studies. However, they do not report as detailed information, perhaps due to the poor

design of the studies. Also, some participants in these studies report findings in contrast with the other studies. These findings have not been given as much weight due to the poor quality rating given to the studies.

The main findings, therefore, suggest that service users report feeling sadness, fear, powerlessness and anger. Staff also report negative feelings including anxiety, frustration and anger. Service users suggest that RPI can lead to further aggression and therefore may be counterproductive. The potential for re-traumatisation was highlighted by service users. Also, the experience of pain during RPI was reported, however, staff in the study by Hawkins *et al* (2005) dismiss the fact that service users experience pain. Service users suggest RPI are not always used as a last resort. Staff, on the other hand mostly stress RPI are a last resort with the exception of some staff in the study by Hawkins *et al* (2005) who did express concerns over RPI being used too soon. Negative views were expressed towards staff performing the RPI. Staff appear to lack empathy at times towards service users which can impact how they view RPI. Parents share the negative feelings and ethical concerns over RPI and worry that RPI may not be a last resort and may happen without them being informed.

In the quantitative studies, specific RPI holds were viewed negatively by service users and carers, with less restrictive holds being viewed as less negative than the more restrictive holds. Despite these studies scoring low on the quality control measure, the design of the studies were strong in that they described fully the procedure and randomised the order of presentation of the

video materials. It was the lack of information on the sampling procedure that was a weakness of the studies. Despite this, they provide valuable information on how specific RPI procedures are viewed.

Implications of review

Due to cultural shift in the understanding and practice of RPI, with nonaversive techniques now in use, couched within a therapeutic model of PBS. a change in the experience of RPI may be expected in line with this. The expectation would be that experience of RPI in more recent times may be of a less negative nature than was previously the case. However, the experiences and views of RPI as expressed by service users and carers are still largely negative despite the changes to policy and delivery of the interventions. In the study by Hawkins et al (2005), which particularly asked about service users experiences of non-pain compliant RPI, one service user who had previously experienced C&R methods did report the newer RPI were better. They stated that C&R hurt and that the prone position was used previously, which they did not like. Although this one participant in this study did make reference to this shift, and in the direction expected, whereby she felt more favourably towards the newer techniques, on the whole the negative views of RPI persisted even towards the non-pain compliance methods. Furthermore, participants' expressed that discomfort and pain was felt even with the use of the non-pain compliant techniques. This is something which needs to be addressed in practice as RPI should not induce pain.

With the shift to PBS, staff training should place emphasis on behavioural interventions, such as functional analysis (LaVigna & Willis, 2002) to work preventatively rather than reactively to manage challenging behaviour. Evidence has shown that conducting pre-intervention assessment, such as functional assessment, improves outcomes of interventions used. Therefore a data driven approach to practice is important, focusing on data collection to gain an understanding of the behaviour to then alter triggers or teach new skills to service users. Staff training could focus more on these preventative strategies, enabling staff to gain a better understanding of the behaviours presented by service users to inform their interventions. Service providers should place emphasis on these preventative, pre intervention assessment measures by providing staff with further training on such issues.

Previous studies have suggested it is not just challenging behaviour which determines RPI use but that other factors play a role (Cunningham *et al.* 2003). The organisational culture of a service has also been shown to have an impact on the use and application of RPI practice (Nunno, 1997). It is important to note that staff report perceiving the use of RPI differently dependent on how they view the service user. Staff reported if they felt empathy towards the service user this made them feel less positive about using RPI. This may impact on their decision to intervene, with some staff reporting concerns that RPI was used too soon (Hawkins *et al.* 2005) Increasing staff understanding of challenging behaviour and their empathy towards service users through further training may help in reducing RPI.

There appeared to be discrepancies between service users' experiences of RPI and staff views of RPI. In the study by Hawkins *et al* (2005) staff reported service users intentionally attempted to get restrained. Service user accounts would not verify this due to the amount of negative feelings they reported about the use of RPI, plus the fact that often they were unsure why and when RPI was used, suggesting they may not have the insight to initiate its use. Such unhelpful views and misconceptions by staff need to be addressed through further training. It may be helpful for staff to hear more on service users' views of RPI and the negative impact they can have. However, some staff did report being aware of the general dislike of RPI by service users (Hawkins *et al.* 2005 and Fish & Culshaw, 2005).

Previous studies have suggested it is not how the techniques of RPI are administered solely which determines how they are viewed but that other factors can have an impact. In the studies reviewed, service users did talk about how certain factors impacted on their experience. For example, service users valued being talked to by staff to help calm them. The perception of staff appeared to impact on service users experience of RPI, for example, in the study by Sequeira and Halstead (2001) service users reported that staff laughed when carrying out RPI, which made service users angry as they felt staff were enjoying it. It is important that staff carrying out the techniques demonstrate the correct demeanour. This is something which could be addressed by service providers during training staff to use RPI.

Relationships between service users and staff may be affected following RPI. Service users reported that staff did not talk to them following RPI procedures. Staff in the study by Hawkins *et al* (2005) described 'walking on eggshells' following RPI so not to upset or anger the service user further. Staff discussed the need for debriefing following RPI but service users do not have this opportunity and it seems are not given the opportunity to discuss the RPI after it happens. It may be useful to create more space for service users to debrief following RPI and to allow time for them to talk to staff about the experience. This may enable better understanding of RPI in service users. Service providers should ensure staff members have a responsibility to discuss RPI with service users through ensuring a route for debriefing is readily accessible following service users being involved in RPI or witness to it.

The study by Elford *et al* (2009) was the only study to examine parents' experiences of using RPI. Parents reported not knowing when RPI is used by services supporting their children. It will be important for services to be more transparent about use of RPI and open dialogue between families and professionals. A large proportion of adults with intellectual disabilities live with families (Elford *et al.* 2009) and further training and support in the use of RPI may be helpful for families. Also, the potential for abuse when using RPI which was highlighted as an issue by service users suggests the need for service providers to create clear routes of reporting available for service users and their families. The methods for reporting could be clearly outlined to service users by service providers to ensure they are aware of how to

report any wrong doing by staff. This would be a safeguarding measure which service providers could implement.

Future research

There is only a small amount of research on service user and carer experiences and views of RPI. The majority of studies focus on secure settings and further research should focus on community settings. There is only one study on parents' experiences of using RPI and this is an area where future work may be required.

The fact that pain was highlighted as being experienced by service users even with the use of non-aversive techniques, suggests they may not be being applied correctly. This is something which should be addressed in future research, to determine what exactly causes pain to service users.

The studies conducted on views of specific RPI holds found negative views but that the less restrictive hold was viewed less negatively. Future research should focus on qualitative studies of views on specific RPI holds to further our understanding of this area and gain more rich information on how service users and carers view specific RPI techniques.

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Section 2

Research Report

Restrictive physical intervention with people who have intellectual disabilities: An explorative study of service users' perspectives

Restrictive physical intervention with people who have intellectual disabilities: An explorative study of service users' perspectives

Abstract

Background: There are a relatively sparse amount of studies focusing on understanding the views of adults with intellectual disabilities on the restrictive physical intervention procedures they may be subject to. No qualitative studies exploring their views on specific physical restraint procedures have been carried out.

Materials: Five videos were shown to participants of restrictive physical intervention procedures with varying amounts of restriction. Following each video a semi-structured interview schedule was completed with participants taking part in individual interviews and a focus group interview.

Methods: Thematic Analysis (Braun & Clarke, 2006) was used to analyse the data. Analysis of individual interviews and the focus group interview were conducted separately and each of the five holds were analysed separately.

Results: Six overarching themes emerged, including emotional reactions to the holds, cognitive reactions to the holds, concerns about safety, restriction, reporting the incident and attempts to put the holds into context. Each theme can be represented a continuum, with the most restrictive holds being at one end of the continuum and the least restrictive holds at the other end.

Conclusions: The themes which emerged can be related back to the literature on service users' views and experiences of restrictive physical intervention. The importance of involving service users in their care plans is emphasised.

Introduction

Definitions of restrictive physical interventions

Restrictive physical interventions (RPI), as defined by the British Institute of Learning Disabilities (BILD), are "a method of responding to the challenging behaviour of people with Learning Disabilities or Autistic Spectrum Disorders which involves some degree of direct physical force which limits or restricts the movement or mobility of the person concerned" (Harris *et al.* 1996, pg. 6). RPI is divided into three main categories in the BILD policy framework: - direct physical contact, use of barriers, and materials or equipment to restrict or prevent movement (Harris *et al.* 1996).

For the purposes of this paper, RPI will be used to refer to the category of 'direct physical contact', as set out by Harris *et al* (1996). In other words, techniques requiring direct contact to restrict the movement of the person concerned. Whilst literature has focused on the use of seclusion, mechanical restraint and chemical restraint as well as physical restraint, it is physical restraint which appears to be favoured in the UK, being the most commonly used intervention for the management of challenging behaviours for people with intellectual disabilities (Emerson *et al.* 2001; Sturmey, 2009). Therefore, it is this category which this study will focus on.

Extent of RPI use

Studies of the rates of restraint of adults with intellectual disability are scarce (Jones *et al.* 2007). It has been suggested that approximately 10-15% of people with intellectual disabilities will display challenging behaviours

(Emerson *et al.* 2001) and "around half of all people with learning disabilities and challenging behaviour are subject to physical interventions" (BILD, 2010). Severe challenging behavior, defined by Emerson *et al* (1987) is "behaviour of such an intensity, frequency or duration that the physical safety of the person or others is likely to be placed in serious jeopardy, or behaviour which is likely to seriously limit or delay access to and use of ordinary community facilities".

History and abuses of RPI

RPI, derived from behavioural practices took the form of aversive interventions in the 1980's and 1990's (Axelrod, 1990). Initially Control and Restraint (C&R) techniques developed for those in prison were applied to care settings (Hawkins et al. 2005). These techniques largely relied on inflicting pain. However, techniques used now in care settings for adults with intellectual disabilities have moved away from these methods. Following debate around the punitive nature of the early interventions, Positive Behavioural Support (PBS) emerged as a therapeutic model to manage challenging behaviour. This model incorporates a value base to guide the application of techniques derived from applied behavioural analysis (Emerson & McGill, 1989) This model states that RPI should be non-aversive and used as a last resort, with the emphasis placed on preventative strategies and the use of the behavioural techniques, such functional analysis to understand and alter challenging behaviours (Allen et al. 2009). The understanding now is that RPI should only be integrated as part of a comprehensive behaviour support plan (Luiselli, 2009).

The abuse of RPI has been seen in major inquiries, involving NHS trusts in Cornwall and Sutton and Merton in the UK (Allen, 2009). Controversy has surrounded certain RPI procedures, for example prone holds which involve taking the service user to the floor and holding them face down, which carry risks of injury and even death (Paterson *et al.* 2003). McDonnell (2000) argues for the abolition of prone holds and states that "the views of consumers do appear to be underrepresented in the national debates about training standards".

Policy and guidance on RPI

In July 2002 the first guidance, issued jointly by the Department of Health and the Department for Education and Skills, on the matter of RPI was published. The guidance, entitled 'Guidance on Restrictive Physical Intervention for People with Learning Disabilities and Autistic Spectrum Disorder, in Health, Education and Social Care Settings' (Department of Health, 2002) formed part of a national agenda on RPI. This guidance used the definition set out by Harris et al (1996) when referring to RPI. The purpose of the guidance was to ensure RPI were used as infrequently as possible, that they were used in the best interests of the service user and that, when necessary to use, everything is done to prevent injury and to maintain a person's sense of dignity. The guidance stated that risk assessments with individuals who might require RPI should be carried out and, if interventions are required, only techniques outlined in an individual's care plan should be used. The guidance also outlined that RPI may be used

in emergencies. The guidance focused on the need for policies, procedures and training for staff.

BILD and the National Autistic Society (NAS) produced a policy framework for good practice, covering aspects associated with the use of RPI (Harris *et al.* 1996). BILD's accreditation scheme for training providers of RPI, established in 2001 and discussed in the government guidance on RPI, is the only one of its kind in the UK. The accreditation scheme means that training providers have to demonstrate they meet certain criteria before they can be accredited by BILD. However, the accreditation scheme does not consider the actual interventions taught by the training providers, which means BILD has no influence on what interventions are taught to staff for use with people with intellectual disabilities. Also, it is a voluntary code, meaning that training providers do not require accreditation from BILD to offer their services.

Service users' views on RPI

The literature on the perspectives of service users with intellectual disabilities on RPI is still relatively sparse and requires further study to gain a better understanding of this. Qualitative studies have been conducted asking people with intellectual disabilities about their experiences of RPI (Fish & Culshaw, 2005; Hawkins *et al.* 2005; Jones & Stenfert-Kroese, 2007; Lunsky & Gracey, 2009; Murphy *et al.* 1996; Sequeira & Halstead, 2001). These studies report largely negative experiences of RPI from the service users' perspectives. However, these studies largely rely on retrospective data, (Fish & Culshaw, 2005; Jones & Stenfert-Kroese, 2007; Lunsky & Gracey, 2009; Murphy *et al.* 1996; Sequeira & Halstead, 2001) which brings their validity

into question as they rely on memory recall. Also, they have mainly been carried out in secure or hospital settings, rather than community settings (Fish & Culshaw, 2005; Jones & Stenfert-Kroese, 2007; Lunsky & Gracey, 2009; Murphy et al. 1996; Sequeira & Halstead, 2001). With more people with intellectual disabilities living in the community and the management of challenging behaviours taking place more in the community (Hawkins et al. 2005), it is important that views of adults with intellectual disabilities living in the community on RPI are sought. Few of the studies conducted focus on more recent non-pain compliant techniques (Fish & Culshaw, 2005; Hawkins et al. 2005; Jones & Stenfert-Kroese, 2007), with the rest studying C&R techniques (Sequiera & Halstead, 2001; Murphy 1996), and many do not ask specifically about physical restraint but focus on RPI in the more general sense (Lunsky & Gracey, 2009; Sequiera & Halstead, 2001; Murphy et al. 1996). Fish and Culshaw, (2005), Hawkins et al. (2005) and Jones and Stenfert-Kroese, (2007) all focus specifically on the category of RPI relating to physical restraint and focus on non-pain complaint techniques, however, Hawkins et al (2005) is the only qualitative study asking about the experiences of RPI in the community.

These qualitative studies do provide some useful findings in relation to the emotions experienced by adults with intellectual disabilities as a result of RPI, such as anxiety and anger (Fish & Culshaw, 2005; Hawkins *et al.* 2005; Jones & Stenfert-Kroese, 2007; Lunsky & Gracey, 2009; Murphy *et al.* 1996; Sequeira & Halstead, 2001), and issues which arise and need to be considered when using RPI, for example the potential for re-traumatisation (Fish & Culshaw, 2005; Hawkins *et al.* 2005). Also, the studies found that

service users reported pain and discomfort associated with the RPI holds, even the non-pain complaint holds now in use (Fish & Culshaw, 2005; Hawkins et al. 2005). The studies also report interesting findings in terms of service users views on the staff performing RPI, including service users thinking staff enjoy using RPI (Jones & Stenfert-Kroese, 2007; Sequeira & Halstead, 2001), use it as a method of punishment (Fish & Culshaw, 2005; Sequeira & Halstead, 2001) and that they are not always used as a last resort (Fish & Culshaw, 2005; Lunsky & Gracey, 2009), and have the potential to lead to abusive situations (Jones & Stenfert-Kroese, 2007; Lunsky & Gracey, 2009; Sequeira & Halstead, 2001). However, these studies are concerned with service users experiences of being involved in RPI and do not enquire about the views of people with intellectual disabilities on RPI per se. That is, their opinions of the specific techniques which are used. Studies have been conducted to examine the social acceptability of specific techniques, to gather information on the opinions people hold of the particular techniques (Cunningham et al. 2003, Jones & Stenfert-Kroese et al. 2008; McDonnell et al. 2000).

A study by Cunningham *et al* (2003) asked undergraduate students, residential care staff and service users with intellectual disabilities living in the community to rate three different methods of RPI, two floor restraints, one involving the service user facing downwards and one facing upwards, and a chair restraint. Each involved two members of staff restraining the service user. The RPI were demonstrated to participants through video footage of actors carrying out the techniques. All the RPI techniques were rated negatively by each group. However, all the RPI techniques were rated more

negatively by the service user group. The chair method of restraint was rated less negatively than the two floor restraints by all groups. Jones and Stenfert-Kroese (2008) carried out a follow up study asking 16 service users with mild intellectual disabilities, who were inpatients in secure units, and 20 nursing staff, who worked in residential units for people with mild intellectual disability, about their views on the same three RPI. Again, both groups rated the chair restraint as being more acceptable than the two floor restraints. In each of the studies service users rated the face up floor restraint as less negative than the face down floor restraint.

The studies conducted on the social acceptability of RPI have so far all employed quantitative methodology, involving Likert scale ratings of the RPI techniques and forced choice methodology. Therefore, the information is limited to gaining an understanding of preference through numerical numbering. No qualitative studies have explored the opinions or views of adults with intellectual disabilities living in community settings on RPI techniques. A qualitative enquiry into the opinions of service users on particular RPI techniques is important in furthering our understanding on RPI techniques. It is important that the views of adults with intellectual disabilities are heard, in a culture in which adults with intellectual disabilities are being more involved in evaluating the interventions and services they receive (Baker, 2003).

Present study

Service users with intellectual disabilities living in the community may have RPI procedures built in as part of a care plan to maintain safety. RPI may also be used (in an unplanned way) as a reactive strategy in response to a persons' challenging behaviour, an intervention which may then become integrated into that persons care plan. Therefore, it is important that their views on the RPI techniques they may be subject to are heard.

This study takes forward the research previously conducted by Cunningham et al (2003) and Jones and Stenfert-Kroese (2008) to further explore the views of adults with intellectual disabilities in community settings on RPI procedures. This study looks at views of five RPI techniques of varying restriction, adding two further RPI holds to the ones included in the previous studies.

This study will expand on the previous studies, using qualitative methodology to explore in more depth service users' perspectives in relation to video footage of RPI techniques. The aim of this study is to qualitatively examine the opinions of people with intellectual disabilities on RPI procedures they may be subject to.

Method

Design

A qualitative approach was used due to the exploratory nature of the study. To gain the perspectives of service users on five different RPI techniques, semi-structured interviews were used. It was decided that both individual interviews and a focus group would be conducted with the data from each being analysed separately as a quality control measure.

It was decided that the study would focus on a small number of participants for the individual interviews to gain an in-depth understanding into their views on the RPI techniques. The focus group aimed to involve between six to twelve participants, as literature identifies this as the optimal size range for focus groups, providing enough participants to raise discussion but still being small enough so subgroups do not begin to form (Millward, 2006). The focus group has been identified as a useful forum for people with intellectual disabilities as it can encourage them to express themselves and learn from others (Gibbs *et al.* 2008). Therefore, it was seen as a useful tool to gather further information whilst providing a method of quality control, acting as a form of triangulation to check the integrity of inferences drawn from the data (Spencer & Ritchie, 2012).

Thematic analysis was decided upon as the most appropriate qualitative methodology to analyse the data. This method was chosen as the aim of the study was to gain an understanding of the views of service users with intellectual disabilities on specific RPI techniques. Therefore, this study was not concerned with lived experience of participants, as Interpretative Phenomenological Analysis would be, nor was it concerned with generating theory, as Grounded Theory would be, rather it was a general enquiry into the opinions on specific RPI techniques. As this is an under-studied area, themes which reflected 'the surface of reality' and gave a reflection of the entire data set were thought to be most useful to gain an understanding of the issue, which thematic analysis allows (Braun & Clarke, 2006).

Participants

Of a total of fifteen participants initially approached by the interviewer, two declined to participate and one was unable to see the video material clearly due to an eye condition affecting vision. Therefore, twelve interviews were conducted; however, one was unable to be included due to a technical fault which meant the interview was not recorded and one was excluded due to lack of understanding of the topic matter by the participant. Therefore, a total of ten interviews were completed and able to be analysed. Those who were available and volunteered to take part in the focus group on the day it was being run all decided to go ahead with the focus group. A total of seven participants took part in the focus group interview.

Ten participants with intellectual disabilities who were in receipt of social care provision in a Yorkshire town took part in individual interviews and seven took part in a focus group.

In the individual interviews, six male and four female participants, ranging in age from twenty-five to fifty-seven, took part. All participants had a diagnosis of intellectual disability and attended day-centres either full or part-time. Six participants resided with family members and four lived in supported living arrangements. Most participants stated they had not previously watched or experienced RPI, although some thought they may have seen it happen to others and two spoke about their experiences of RPI.

Four male and three female participants, ranging in age from twenty to fifty, took part in the focus group. All had a diagnosis of intellectual disability and

attended day-centres on a full or part-time basis. Five of the participants lived with family members and two lived in supported living arrangements. Participants stated they had no experience of RPI but later discussed how they had witnessed RPI.

Sampling

Many staff are trained to use RPI for use in community services (Sturmey, 2009). Therefore, this study recruited people who were accessing services, as it is possible that RPI may be used on them or those around them if necessary. Therefore, the only inclusion criteria for participants was that they had intellectual disabilities and were supported within community settings, as the aim of the study was to gain an understanding of the views of people with intellectual disabilities on the RPI they may be subject to. Although participants did not have to have previously watched or experienced restrictive physical intervention to take part in the study, they were asked about their own experiences of RPI at the start of the interview. Participants were required to answer open ended questions so therefore were required to have a level of verbal ability that enabled them to do this.

The sample was a convenience sample, as participants were recruited from day centres, and therefore recruitment of participants was dependent on who was attending on the days the interviews took place. A focus group was also conducted, following the same procedure as the individual interviews. This was also a convenience sample, dependent on who was available at the time the focus group was run.

Selection and procedure

Service leaders for social care provisions in a Yorkshire town were contacted with information about the study to recruit participants Identified possible participants were given information about the study by carers at the daycentres they attended and then approached by the researcher if they consented to this, as reported by carers. The interviews took place at day centres as literature suggests that a relaxed, familiar and non-threatening environment can aid responsiveness and reduce bias (Simons et al. 1989). The information sheets, which were provided to carers and potential participants (see appendix iv.) prior to being approached by the researcher, were also used to discuss the study with potential participants' by the researcher prior to the interviews. The information sheets were not given in isolation but along with a verbal explanation to help explain the study more clearly to participants. Also, an explanation of what was meant by RPI was given to service users verbally before the interviews began. Consent was obtained from participants prior to interview and it was made clear to participants that they could withdraw from the study at any point without consequence (see appendix iv.). There was no reason to believe any of the participants lacked the capacity to consent to participation, under the terms of the Mental Capacity Act (2005). Confidentiality and anonymity was discussed explicitly with service users before the interviews began. Due to the nature of the focus group and issues around confidentiality that arise from this, at the start and end of this interview a conversation about confidentiality was held to make this explicit to participants.

Participants were shown five video clips of RPI techniques where actors demonstrated the moves. Participants were informed that the clips were of actors. Each of the five video clips showed a different technique, each with varying degrees of restriction. The RPI demonstrated were chosen as they were found to be representative of the spectrum of physical restraint techniques in use, following a review of relevant literature. The videos of the RPI procedures were prepared for the purposes of this study and were approved by a representative of BILD. The video clips included only physical intervention, for example holding requiring direct contact with the service user, and not other forms of restraint such as chemical or mechanical restraint. After each video clip service users were interviewed about what they thought of the RPI procedure from the clip. The video was paused to show a freeze frame of the procedure being discussed to aid participants in their responses. The participants were able see the video clip more than once if necessary; however this only was necessary on one occasion. The order of presentation of video clips was randomised to prevent order effects.

The initial interview acted as a pilot for the interview schedule, and as this pilot was successful the interview schedule did not require amendment. The interviews lasted for approximately forty five minutes. The focus group followed the same procedure and lasted for approximately one hour. During the interviews responses were reflected back to participants as a quality control measure to check understanding. All service users were asked at the end of the interview if they would be willing to be contacted at a later date to discuss the themes that arise from the analysis as a quality control measure,

to check the themes represented what they said. All participants agreed to this.

Materials

Five video clips of RPI procedures, with varying restriction were shown to participants. All five videos were of actors, the same three men were in each video. The same two men were always the ones doing the restraint moves, so the same man was restrained each time for continuity. The videos included the following RPI procedures: A walking restraint, with the two 'restrainers' holding the 'restrainee' by each arm. A seated restraint, involving the restrainers holding the restrainees arms at each side and bowing so the restrainee sits down with them on a chair. Another seated restraint, involving the same procedure but also involving the restrainers placing their legs over the restrainee to secure his feet. A floor restraint, involving taking the restrainee to the floor and facing him upwards, with one restrainer holding his arms behind his back and holding his head and the other holding his legs. And another floor restraint, this time with the restrainee face down, where the two restrainers bring him to the floor, using their knees to secure his arms. with one restrainer holding his head and shoulder and the other, at the opposite side, securing his shoulder and lower back. The videos were played on a laptop with the volume turned off. The videos did not involve any talking or struggle, but just demonstrated the RPI techniques clearly. Each video clip was approximately fifteen seconds long.

The interview schedule covered demographic information and then focused on the views of the service users on the RPI procedures (see appendix iii.). The interview schedule was developed following consultation of the literature on service user experiences and views on RPI. The methods of gathering data used in the previous quantitative studies on views of RPI were taken into consideration when developing the interview schedule for the current study. The principles of Smith (1995), regarding the use of open, neutral and non-leading questions were kept in mind. Also consideration was given to the fact that the interviews were being conducted with people with intellectual disabilities. Therefore, questions were kept brief, using simple language to aid understanding. Also, the interview schedule was designed with consideration to some of the issues highlighted in the literature on conducting interviews with people with intellectual disabilities (Clare & Gudjonsson, 1993; Heal & Sigelman, 1995), for example to avoid acquiescence and problems with suggestibility.

Ethical considerations

Ethical approval was obtained from the relevant local Social Care Ethics Committee (see appendix ii.).

The area of RPI is an emotive one and therefore procedures were required to be put in place to address any concerns or complaints. The information given to service leaders and verbally to service users outlined the possible disadvantages of taking part in the study, particularly the emotional aspects associated with the area. The service users were given information about how to make complaints about any aspect of the research or researcher.

A protocol was put in place for if service users should discuss any malpractice during the interviews, involving in the first instance directing them to someone who could help them to make a complaint, with safeguarding adults procedures to be followed as appropriate. This was not an issue which arose during the interviews.

A protocol was also in place for if service users experienced distress during the interview when discussing restraint or their own experiences of restraint, involving calming the participant in the first instance and directing them to the correct route of support or complaint if necessary. In the first instance the interviewer would offer support to the participant and the interview would be stopped if the participant was too distressed. Although some participants did find the material upsetting and expressed feelings of sadness and anger, their distress was managed within the interview and through discussion with the interviewer. All participants were given the opportunity to debrief following the interview.

Analysis and quality control

All the interviews were recorded and transcribed verbatim. The analysis took place in a number of stages. Each tape was listened to and the transcript checked for accuracy. Each of five the RPI techniques were analysed separately to draw out themes relating to each individual hold. The transcripts from the individual interviews were analysed first, followed by the transcripts from the focus group. These were two independent analyses, allowing for triangulation. Therefore, a total of ten analyses were conducted on the data.

Thematic analysis was carried out on each of the data sets to draw out themes from the responses. Braun and Clarke (2006) provide an explicit step-by-step account of how to analyse data using thematic analysis, which is outlined below:

- Familiarising oneself with the data: Involving reading and re-reading the responses on the transcripts and generating a list of initial ideas.
- Generating initial codes: Involving coding interesting features of the data systematically across the data set and collating data relevant to each code.
- 3. <u>Searching for themes</u>: Involving collating codes into potential themes and gathering all data relevant to each potential theme.
- Reviewing themes: Involving checking if themes work in relation to the coded extracts. This involves producing a thematic 'map' of the analysis.
- 5. <u>Defining and naming themes:</u> Involving on-going analysis to refine each theme, generating clear definitions and names for themes.
- 6. Producing the report: Involving selecting extracts to highlight themes.

The analysis took an inductive approach, whereby themes identified were strongly linked to the data, and the analysis was therefore essentially data driven. The analysis drew out a rich description of the overall data set, giving an accurate representation of the entire data set. This was important as the

area is understudied so themes which gave a reflection of the entire data set were most useful to gain an understanding of the issue (Braun & Clarke, 2006).

Following stage four of the Braun and Clarke (2006) framework, a summary of emergent themes was verbally given to a selection of the participants who took part in the study to gain member validation as a quality control measure. Feedback was sought from three of the participants who were available and consented at the time the researcher went to feed back. The three participants' felt the themes were a true reflection of the content of the interview and an accurate interpretation. Also, following this stage, as a quality control measure, a colleague checked transcripts for agreement of coded data and checked the process of the analysis to ensure themes generated were directly related to the data.

As themes were refined through on-going analysis and reviewing (as described at stage five of the model above), the data from the ten analyses were drawn together and overarching themes were mapped from this data to represent the analyses of the five holds.

Throughout the data collection and analysis a reflexive diary was kept by the researcher as a quality control measure, meaning an awareness of the researcher's impact on the data and analysis was observed to reduce bias in this process. Also, a peer support group of others carrying out qualitative

research provided support throughout the process and enabled discussions about researcher position and reflexivity.

Results

The data from the individual interviews and focus group interview were analysed separately. However, there was overlap of themes between these two, as expected. Therefore, although analysed separately, the analyses for each of these were merged together for the purposes of clarity and reporting. Also, although data for each of the five holds was analysed separately, the themes which emerged from each were sufficiently similar that they could be collapsed together. Through the process of on-going analysis and refinement of themes, as outlined in the Braun and Clark (2006) model, six overarching themes emerged which could be drawn from the themes identified for each of the RPI procedures. These overarching themes are best represented on a continuum, whereby for each theme there were a range of responses along the continuum in line with the restrictiveness of the hold under analysis. The most restrictive RPI technique was represented at one end of the continuum and the least restrictive RPI procedure at the opposite end of the continuum.

The themes are outlined below and quotes from the interviews illustrate the continuum of responses along each theme.

Theme 1- Emotional reactions

RPI are emotive events and all participants described a range of emotions felt when watching the video and in response to the RPI holds demonstrated. Although the RPI provoked mainly negative reactions in participants, there were some more positive reactions to the less restrictive holds. The continuum for this theme can be represented as moving from strong negative emotional reactions to positive emotional reactions as the holds become less restrictive.

Strong negative emotional reactions

The face down floor restraint evoked the strongest negative emotions from participants, with more negative emotions reported and more strong negative emotions than for the other holds.

"Like I say (I was) frightened" (individual Interview 1, face down restraint)

"Frightened, angry, sad" (individual Interview 6, face down restraint)

"Frightened, het up" (individual Interview 7, face down restraint)

"Scared" (individual Interview 10, face down restraint)

The face up floor restraint also evoked strong negative emotional reactions from participants.

"Frightened you know, like I didn't want owt happening" (individual interview 4, face up restraint)

"Nervous, them people grabbing you and pulling you back and pinning your legs down and holding your arm" (individual interview 5, face up restraint)

Negative emotional reactions

The emotional responses became less negative in assertion and less emotionally loaded as the RPI became less restrictive. Therefore, participants expressed more strong negative emotions about the floor holds than the seated holds and the walking holds respectively. Whilst strong negative emotions were still reported for the face up floor restraint, many of the comments were noticeably less negative than those for the face down restraint. The comments for the seated restraints and walking restraints were even less negative in connotation.

"I'm sad a bit, I'm sad" (individual interview 1, face up restraint)

"I think I were nervous" (focus group, face up restraint)

"Embarrassed if it happened" (focus group, seated restraint with leg hold)

"Made me a bit upset" (individual interview 4, seated restraint without leg hold)

"Bit sad, sad watching it" (individual interview 2, seated restraint without leg hold)

"Upsetting me a bit" (individual interview 10, walking restraint)

"I wouldn't be happy, cos I'm shy" (focus group, walking restraint)

Positive emotional reactions

As the RPI became less restrictive some more positive emotional reactions were expressed by some participants. It was only for the walking hold that participants expressed some positive emotions.

"Felt brilliant" (focus group, walking restraint)

"Happy" (individual interview 3, walking restraint)

"Alright, felt alright" (individual interview 9, walking restraint)

"I'm happy with it cos they are walking" (individual interview 8, walking restraint)

Anger emerged as a subtheme and the majority of participants expressed feeling anger about the RPI. Anger was an emotion experienced towards the RPI holds that was most commonly mentioned by participants. The emotions expressed relating to anger could also be seen on a continuum with more comments relating to this for the more restrictive holds and less for the less restrictive holds.

"I'd give them what for. It's just watching this making me feel I want to get hold of somebody and give them what for" (individual interview 1, face down restraint) "Making me feel angry" (inididual interview 3, face down restraint)

"You will kick people" (individual interview 6, face down restraint)

"Made me feel mad" (individual interview 8, face down restraint)

"I felt my fists go like that (clenched)" (individual interview 5, face up restraint)

"I was feeling a bit mad" (individual interview 4, seated restraint with leg hold)

"I was holding my head cos I was a bit mad" (individual interview 4, seated restraint)

"Pulling him back, makes you angry" (individual interview 3, walking restraint)

Also physical reactions to the RPI holds emerged as a subtheme and were mentioned by several participants. Again, this was on a continuum with more strong physical reactions being reported for the more restrictive RPI holds.

"I was feeling sick when I saw it" (individual interview 1, face down restraint)

"Making my stomach felt churning" (individual interview 7, face down restraint)

"Shivering a bit, shivering" (focus group, face down restraint)

"(Felt) like burning inside me, you know like" (individual interview 6, seated restraint with leg hold)

"A bit my stomach was churning" (individual interview 4, seated restraint with leg hold)

"Stomach gets churned up, not much but a bit" (individual interview 9, walking restraint)

Theme 2- Cognitive reactions

This theme encompasses the reactions or opinions expressed in relation to the RPI holds. The reactions under this theme are cognitive ones, in that they are thoughts the participants express in relation to the holds. Similar to the previous theme, the continuum for this theme can be represented as moving from strong negative cognitive reactions to positive cognitive reactions as the holds become less restrictive.

Strong negative cognitive reactions

The cognitive reactions of participants to the face down restraint were particularly negative. Many of the participants voiced strong negative opinions, whilst the video was still playing and there was a sense from several participants that this restraint was wrong.

"Uh huh oh no, no, no I don't like that, no I don't like that no, no, no I don't like that" (individual interview 1, face down restraint)

"I thought it were disgusting, absolutely disgusting" (individual interview 1, face down restraint)

"Definitely a no, no" (individual interview 3, face down restraint)

"I think it's wrong" (individual interview 8, face down restraint)

"(It's like) when you watch them on telly being violent on the police.

But this is (supposed to be) helping people with learning disabilities

(and) I'm sorry about that" (individual interview 7, face down restraint)

"It's no good hold" (individual interview 2, face down restraint)

The face up floor restraint received strong negative comments from the majority of participants.

"Now that is the one I didn't like and I still don't, no" (individual interview 1, face up restraint)

"It's disgusting, I'm appalled (because of) the way, way they have got him" (individual interview 1, face up restraint)

"I think it's blooming awful, awful" (individual interview 4, face up restraint)

"Awful, because there are two people holding onto one and there shouldn't be, there shouldn't be. It's awful" (individual interview 6, face up restraint)

Negative cognitive reactions

The negative comments towards the hold become less loaded as the holds become less restrictive

"Not nice they are doing that" (individual interview 4, seated restraint with leg hold)

"Wouldn't want it to happen to me" (individual interview 9, seated restraint)

"They should be talking to him" (individual interview 1, seated restraint)

"Not ok" (focus group, seated restraint)

"Should slack off him a bit" (individual interview 1, walking restraint)

"Should be more soft" (individual interview 9, walking restraint)

Positive cognitive reactions

As the RPI holds became less restrictive, the seated and walking restraints, participants became more positive about the holds, with several participants giving positive reactions.

"Good that one, cos just have to hold his arms (individual interview 10, seated restraint)

"Like this one, oh yeah, sitting him down" (individual interview 2, seated restraint)

"That was good that, not too rough on him" (individual interview 1, seated restraint)

"I think that's alright" (individual interview 4, seated restraint)

"Friendly, cos they are linking arms (focus group, walking restraint)

As the holds become less restrictive several positive comments were made about them in relation to the more restrictive moves, suggesting that the level of restriction affected participants view on the holds. The videos of RPI were shown in different orders to different participants', and it was prevalent across all interviews that participants' compared the RPI.

Whilst strong negative reactions were directed towards the face up floor restraint, some participants expressed that they thought the face up restraint was more acceptable than the face down restraint.

"It's good in it, he held like that-better than face down" (individual interview 3, face up restraint)

"Happy if it's that way you know (face up) it's ok" (individual interview 6, face up restraint)

The seated hold without the leg hold was viewed more positively than the seated hold with the staff members also securing the service users feet. Several comments were made by participants about the feet being used to hold the service user. It appeared that the extra level of restriction was viewed negatively.

"It's a bit wrong that cos he is putting his feet there" (individual interview 5, seated restraint with leg hold)

"Alright sitting him down, but not feet (on him)" (individual interview 6, seated restraint with leg hold)

"I don't like the one with legs too but I like this one" (focus group, seated restraint)

"That's better-because it doesn't hurt his legs" (focus group, seated restraint)

There were several general comments made suggesting the less restrictive holds were better in relation to the more restrictive holds

"Better than others" (individual interview 9, seated restraint)

"That's more like it" (individual interview 4, walking restraint)

"Better because he is not on the floor" (individual interview 10, walking restraint)

"That better, that walking" (individual interview 3, walking restraint)

"I'm not used to seeing people mishandled like that (on the floor) but this one is helping somebody" (individual interview 7, walking restraint)

"Better (than being on floor) because he is calming down now" (individual interview 8, walking restraint)

Whilst many participants stated they felt the less restrictive holds were better, and even had some positive comments towards them, the majority of participants still voiced negative comments about them and made clear that they wouldn't want the RPI techniques to be used on them.

"Wouldn't like them do me" (individual interview 3, seated restraint, with leg hold)

"I wouldn't like it, not one bit" (individual interview 1, seated restraint)

"Wouldn't want it to happen to me" (individual interview 4, seated restraint)

"Ok for someone else" (individual interview 10, walking restraint)

The majority of participants also expressed reactions to the two staff members carrying out the holds. Again, the comments made in relation to this can be seen on a continuum with more negative views towards staff, moving towards less negative views as the holds become less restrictive and more positive views of the least restrictive hold.

Negative cognitive reactions to staff

"They were not nice to do that" (individual interview 1, face down restraint)

"He got nasty" (focus group, face down restraint)

"Need sacking and get a new one" (individual interview 3, face up restraint)

"They are mean to him" (individual interview 4, seated restraint with leg hold)

"Tell them to get out of the house, not nice carers" (individual interview 7, seated restraint with leg hold)

"I don't like them two, the man in the middle is alright. The other two are getting up to mischief" (focus group, seated restraint)

Positive cognitive reactions to staff

"I felt they were there to help" (individual interview 4, walking restraint)

"Staff helping him" (individual interview 7, walking restraint)

"They are there to help out" (individual interview 5, walking restraint)

Several participants commented that the staff were happy to be carrying out the holds on the service user.

"He is happy him the one holding his head" (individual interview 1, face down restraint)

"They were feeling happy" (individual interview 4, face down restraint)

"Feeling happy (the ones holding him)" (individual interview 10, seated restraint with leg hold)

"The two holding him feel happy because they are goading him without saying owt" (individual interview 5, seated restraint)

Theme 3- Concerns about safety

The majority of participants expressed concerns about the safety of the RPI procedures. This theme can be represented on a continuum moving from concerns about pain and injury for the more restrictive holds to feeling of safety for the less restrictive holds.

Pain/Injury

"Shouldn't have him like that if it hurts his neck they are to blame" (individual interview 4, face down restraint)

"He won't be able to breathe" (individual interview 6, face down restraint)

"I didn't know, when they were pushing him down, I didn't know if they were hurting him" (individual interview 5, face down restraint)

"There's going to be an accident" (focus group, face down restraint)

"If he doesn't move his hand he can damage his eye as well cant he" (individual interview 8, face up restraint)

"Cos they can, they can, if they want they can go like that and stand on his feet and break his toe" (individual interview 3, seated restraint with leg hold)

I'd want to see if they had bruises" (individual interview 7, seated restraint with leg hold)

As the holds became less restrictive, several participants felt that they would not cause injury or pain and that they were safer.

Safety

"I knew he wouldn't get hurt" (individual interview 7, seated restraint)

"By holding him he's safe" (individual interview 4, seated restraint)

"I don't think it hurt him" (individual interview 5, seated restraint)

"That's good, that's safe" (individual interview 3, walking restraint)

Theme 4 – Reporting the incident

There was a feeling that RPI should be reported and that if it was witnessed or used on participants, they would want to report it. More comments relating to reporting the incident were made for the more restrictive holds and less for the less restrictive holds. As the holds became less restrictive the comments became more about alerting someone to what had happened rather that reporting it to the police.

"Report it to the people there then to the police" (individual interview 1, face down restraint)

"Phone support staff, support staff phone police" (individual interview 4, face down restraint)

"Phone manager, our manager. And they would phone police" (individual interview 7, face down restraint)

"Ring police" (focus group 10, face down restraint)

"Report it, police" (individual interview 3, face up restraint)

"I might report it to er the police or somebody" (individual interview 5, face up restraint)

"I would tell one of the staff at home (they'd) sort it" (individual interview, 3 seated restraint with leg hold)

"Tell one of the carers tell the carers, they tell police after" (individual interview 8, seated restraint with leg hold)

"If it happened to me, tell somebody" (individual interview 9, seated restraint)

"Get somebody" (focus group, walking restraint)

"Tell somebody" (individual interview 1, walking restraint)

There was a sense given by several participants of wrong doing for the most restrictive holds. Several participants commented that the holds should not be used and also many participants felt the staff would get in trouble for using the holds.

"He would have got those two in trouble" (individual interview 1, face down restraint)

"Get into trouble for holding them by head" (individual interview 3, face down restraint)

"Aren't allowed to use it" (individual interview 10, face down restraint)

"Tell them, police would tell them off" (individual interview 7, face down restraint)

"They are not allowed to do that to his neck" (focus group, face up restraint)

"It's a bit naughty" (focus group, seated restraint with leg hold)

Theme 5 – Restriction

An overarching theme of restriction emerged from the analyses. The nature of RPI is that there is some degree of restriction involved for the service user. The majority of participants commented on this restriction and spoke about it in terms of being controlling or preventing freedom. This overarching theme of restriction was on a continuum, with the more restrictive holds being represented at one end of the continuum as control and restriction and the less restrictive holds at the other end of the continuum, expressed as freedom and restriction.

Control and restriction

"It's telling people how to behave. They are there to train, to make him behave" (individual interview 7, face down restraint)

Now that is too much because now they have got him like that he can't retaliate back off them (individual interview 1, face down restraint)

"If he wants to do owt he can't, if he wants to scratch his nose then I think he can't" (individual interview 4, face up restraint)

"He can't move anywhere and if he wants to go to the toilet he can't go" (individual interview 5, face up restraint)

I don't go to my other half and say 'right I'm sitting you down and you are having something to eat' (individual interview 1, seated restraint with leg hold)

It's like if you say 'ok I need to go to the bathroom, ok well, I'm afraid you can't go cos you have got to stay where you are' (individual interview 4, seated restraint with leg hold)

Bet they don't let him go, bet they don't let him go to the toilet, legs are like that (stopping him). I bet they are following him (individual interview 3, seated restraint with leg hold)

Freedom and restriction

"Just let him have some freedom" (individual interview 1, seated restraint)

"Looks like he was stuck like superglue, when he sits down they both sit down" (individual interview 9, seated restraint)

"They were a bit too close together" (individual interview 4, seated restraint)

"Couldn't move when he wanted to" (individual interview 6, walking restraint)

"They should let him walk on his own" (focus group, walking restraint)

"He wanted freedom and they wouldn't let him have it" (individual interview 10, walking restraint)

"They won't let him have a bit of freedom- everyone should have a bit of freedom" (individual interview 2, walking restraint)

Theme 6- Attempts to put RPI into context

The majority of participants attempted to put the RPI viewed into some sort of context, this involved trying to make sense of what was happening or telling a story about what was happening. As the holds became less restrictive, participants moved from trying to make sense of what was going on to being clearer on giving an explanation of what was happening.

Making sense

"He was either angry or sad. In case people walk past him" (individual interview 8, face down restraint)

"It's like trouble makers go fighting and police are there to stop him" (individual interview 1, face down restraint)

"You see police doing that" (individual interview 3, face down restraint)

"Is it illegal, no its not is it" (individual interview 5, face down restraint)

"It's like in sport" (individual interview 6, face down restraint)

"In the police force when they were holding arms, when they are back, it's easy to arrest him" (individual interview 2, face up restraint)

"I can't stand to watch that, films, er cowboy type films. Has anyone seen anything like this?" (focus group, face up restraint)

"It's happened in somebody's house" (individual interview 3, seated restraint with leg hold)

"Somebody starts fighting and it's like when police get hold of you" (individual interview 9, seated restraint)

Explanations

"I imagine because he is too excitement. (individual interview 3, face up restraint)

"Perhaps he didn't know to sit down" (individual interview 5, seated restraint with leg hold)

"(he was) Kicking and spitting" (focus group, seated restraint with leg hold)

"He might have grabbed them lads" (individual interview 6, seated restraint)

"Not to fall down and hurt themselves, helping him sit on couch properly" (focus group, seated restraint)

"Might be to stop him rolling off in case he slides off" (individual interview 1, seated restraint)

"Just restraining in case they hurt someone" (individual interview 8, seated restraint)

"Might be to stop them going like that (hitting) with their arms" (individual interview 2, walking restraint)

"Might be to linking arms, not, not falling" (individual interview 7, walking restraint)

"Holding so he won't fall down" (individual interview 2, walking restraint)

"Restraining him from hurting anybody" (individual interview 6, walking restraint)

Discussion

This study furthers previous work enquiring about service users' perspectives on RPI they may be subject to and is the first study to explore this using qualitative methodology. Due to the limited work in this area, this study represents a significant step towards a better understanding of service users' views of specific RPI which may be used to manage challenging behaviour. The findings of the study show that restraint is generally viewed negatively, as suggested by previous research. It shows that service users appear to view RPI on a continuum with more restrictive holds being viewed more negatively than less restrictive holds. This continuum of views held true as the majority of service users viewed restraints negatively, needing to be reported, as perhaps causing pain or injury and as controlling or preventing freedom, with these views being more strongly represented for the more restrictive holds and less so as the holds became less restrictive.

The findings from this study support the earlier studies conducted by Cunningham *et al* (2003) and Jones and Stenfert-Kroese (2008) who found that, whilst all restraint was viewed negatively, a chair method of restraint was viewed as less negative than two floor restraints. In these studies, service users viewed the restraints more negatively than other groups of participants.

The findings from the present study can be related back to existing literature on service users' experiences of being involved in RPI. All participants expressed negative emotions in relation to the holds. This was constant across all the holds; however, there was a notable shift in the connotations of the comments made as the holds became less restrictive, with the negative comments not as emotive. Previous research on the experiences of service users subject to RPI reported that there was a largely negative impression of RPI (Stubbs *et al.* 2009).

Anger was the most commonly reported emotion by participants, supported by findings from previous studies which suggest that RPI exacerbate service users' anger and aggression (Fish & Culshaw, 2005; Hawkins *et al.* 2005; Murphy *et al.* 1996; Sequeira & Halstead, 2001) This raises the question of whether RPI are effective as an intervention to prevent harm or injury and to manage challenging behaviour. If the RPI only serve to perpetuate anger, they may be counter-productive. Participants in this study reported feeling angry and some mentioned wanting to express their anger. This was after watching RPI via video, which suggests being involved in RPI may create a

higher degree of anger. Previous research has highlighted that service users' report pain during RPI (Hawkins *et al.* 2005; Sequeira & Halstead, 2001). There is an established link between pain and anger (Seligman, 1975), suggesting that pain can induce aggression. Considering pain during RPI may be important in helping reduce anger experienced.

In this study, for the more restrictive holds, concerns were also raised about inflicting pain, consistent with previous research. This is a real concern when using RPI and further work needs to be done to establish whether RPI cause pain. As RPI approaches have moved away from C&R, it is not expected that the RPI procedures in use cause pain to service users. Studies conducted on staff experiences of using RPI suggest that staff dismiss the idea that the holds would cause any pain (Hawkins *et al.* 2005).

Through the comments made regarding pain and injury, there was a sense that there was potential for abuse to occur from these RPI holds. Some participants stated that the staff could do things to inflict pain, for example one person said "cos they can, they can, if they want they can go like that and stand on his feet and break his toe" (individual interview 3). The potential for abuse which can arise from RPI has been highlighted in previous studies (Jones & Stenfert-Kroese, 2007; Lunsky & Gracey, 2009; Sequiera & Halstead, 2001). This potential for abuse must be monitored and therefore policies and procedures for organisations should be clear on the issue of RPI. Nunno (1997) discussed toxic organisations, which produce risk, negative outcomes and maltreatment. RPI is more common and supervision

and staff training is less prevalent in such organisations. Also, organisational climate, the psychological interaction of the individual to the organisational culture, can impact on how staff perform (Glisson & Hemmelgarn, 1998). Therefore, the importance of staff being well supported and trained and for RPI to be monitored is apparent. Potential toxic organisations, which may include a high level of restraint (Nunno, 1997), could be detected and monitored through audit of recorded data on RPI. However, RPI may not always be recorded or recorded accurately.

All participants commented that they would want to report the incident or tell somebody what happened. As RPI can be used in emergencies to manage challenging behaviour, this requires consideration. Participants expressed a sense of wrong doing in relation to the most restrictive holds. The fact that most participants felt they would contact the police to report the RPI suggests that there was not a full understanding about why such RPI are used or a clear distinction between when it is acceptable to use and when not. It is important that service users are empowered to understand what is and is not acceptable. Also, there is a need for effective routes to be established for people with intellectual disabilities and their families to use for reporting misuse of RPI or abusive practices.

RPI are clearly very emotive events and some participants in the study did express distress over watching the holds. This distress was managed by the researcher and through debriefing following the interview. Also, some participants discussed their own memories of RPI when watching the videos.

It appeared that watching the RPI for some triggered memories of previous incidents. One participant remembered being restrained at the dentist and said this had upset them at the time. Re-traumatisation following RPI has been discussed in previous research (Fish & Culshaw, 2005; Sequeira & Halstead, 2001). Using a trauma informed care model (Elliott *et al.* 2005) to engage those who have experienced trauma and acknowledge the impact it may have on their life may be helpful and the use of RPI in their care plan should be thoroughly considered. The appraisal process of service users should be considered when thinking about the physiological impact of RPI, as cognitive processes can impact on our feelings (Novaco, 1978) and those with backgrounds of abuse, may view neutral stimuli as threatening (Adshead & Mezey, 1997).

Negative cognitive reactions were reported in relation to the RPI holds. Participants expressed strong negative reactions to the most restrictive holds. The face down, prone hold, was viewed most negatively, with several participants stating that the other holds were better in comparison. This finding is supported by the research conducted by Cunningham *et al* (2003) and Jones and Stenfert-Kroese (2008), who also found the prone hold was rated most negatively. The prone restraint has attracted the most controversy, with campaigns to abolish it from practice (McDonnell, 2000). However, BILD have not made recommendations on the use of the prone restraint as it is in the seated restraint that most deaths have been reported (Paley, BILD RPI accreditation scheme manager, personal communication, 2011). However, it is interesting to note that several organisations contacted

regarding this study stated they would not want to demonstrate the prone hold even for research purposes, as they do not advocate its use.

Negative cognitive reactions to those performing the RPI were also expressed. This is in keeping with previous research, where negative reactions to staff performing RPI were discussed (Stubbs *et al.* 2009). The participants spoke about the people performing the restraints in the videos as 'staff' rather than 'restrainers', suggesting an awareness of staff using such interventions. The fact that such negative reactions to 'staff' were reported by participants in this study, despite no struggle or dialogue taking place, suggests that if RPI happened to them, or someone else there would need to be support put in place to manage these negative reactions. However, had there been some supportive dialogue from staff in the videos this may have altered service users views of the RPI in a more positive manner.

Many participants commented on the staff being happy or enjoying carrying out the RPI in the videos. This is supported by previous research (Stubbs *et al.* 2009). Some participants in this study thought staff were scary, shouting and swearing and angry. It is interesting that participants in this study ascribed emotions and actions to the staff in the videos, who were neutral in their attitude. Given the neutral stance taken by all actors in the video, it was interesting that different language emerged to describe the actors. For example, the two who were restraining were most often referred to as 'men', whilst the person being restrained was more often referred to as 'boy',

despite the three actors being of similar ages. This suggests a power imbalance in the dynamic.

Whilst participants expressed negative emotions and negative cognitive reactions in relation to the RPI holds, there did appear to be some level of confusion whereby participants, for some of the less restrictive holds, stated negative reactions alongside positive comments. It appeared that many participants were not able to imagine RPI may happen to them, stating the holds were ok for others but not them. It appeared that many participants lacked the theory of mind (Baron-Cohen, 1995) to imagine that another person would feel the same as they would. However, some participants did express some empathy towards the person being held.

The fact that RPI can be a controlling measure or form of preventing freedom and independence was highlighted by participants. Policy and guidance states that the least restrictive measures should be used first before stepping up to use more restrictive measures if necessary (Department of Health, 2002). There is an ethical issue about restriction and freedom which is present when considering the use of RPI (Luiselli, 2009). In previous studies participants outlined alternative approaches that could have been used and also reported they felt staff used RPI arbitrarily and not always as a last resort (Fish & Culshaw, 2005; Hawkins *et al.* 2005; Jones & Stenfert-Kroese, 2007; Lunsky & Gracey, 2009). The power imbalance which exists between adults with intellectual disabilities and staff who support them is important to consider. Service users being involved in their own care plan and

collaborating more with staff could help to reduce the power imbalance and promote empowerment in service users. Behavioural interventions should form part of the care plan and given the outcome data to support the use of such interventions for adults with intellectual disabilities (Didden *et al.* 1997) the figures for RPI are concerning (Allen *et al.* 2009). More should be done to promote preventative strategies to help reduce RPI use.

The area of RPI is one which service users appear unclear on. Previous research of service users experiences suggest that many are unsure about why it is used and what it is used for (Fish & Culshaw, 2005; Hawkins *et al.* 2005; Jones & Stenfert-Kroese, 2007; Lunsky & Gracey, 2009 and Sequeira & Halstead, 2001). The fact that participants in this study tried to put context around what was happening in the videos and search for meaning suggests that it is not very clear to participants what RPI is and when it is used. Despite participants appearing to understand RPI when it was explained to them and making comments about the person in the video being restrained to stop them from hurting themselves, their search for meaning suggested it was not clear to them what was happening. The area of restraint is not clear cut or straightforward, it is fraught with ethical and moral dilemmas and perhaps this lack of clarity expressed by participants is a reflection of what is a very complex topic. The RPI were likened to several things by participants, including sport, cowboy films and police documentaries.

As a quality control measure a summary of the findings was fed back to a selection of participants who agreed to this. The participants remembered the

research well and had clear memories of the RPI procedures they had seen. It was the more restrictive holds that participants demonstrated a clear memory of. This is interesting to note. A study which asked service users to draw their experience of being in a secure hospital found that one third of those asked drew a picture of restraint to represent their experience of hospital (Wadeson & Carpenter, 1976). Restraint may be such a salient and poignant memory that it is retained by those who experience it or watch it happen to others.

Limitations

This is a small scale study based on the views of a small number of participants. The aim of the study was to qualitatively examine the opinions of people with intellectual disabilities on RPI procedures they may be subject to. Therefore, the participants were selected based on the fact that they were accessing services, as RPI may be used in these settings, either as part of a care plan or as an emergency measure. However, none of the participants interviewed currently had RPI as part of their care plan, nor had they been subject to any recent RPI. The participants did appear to suggest some experience of RPI, however this group may not be reflective of other adults with intellectual disabilities who do have RPI as part of a care plan or who access different services and see it taking place on a regular basis. However, the fact that both individual interviews and a focus group interview took place, involving a separate group of service users at a different time point, with the findings being similar across both, adds to the potential validity of this study.

The sample was a convenience sample based on who was available at the time of the interviews. Participants, however had agreed to meet with the researcher, and those who agreed to this may have represented a specific group. Also, the participants that did take part had levels of verbal ability that allowed them to participate and may not be representative of people with intellectual disabilities.

The participants' reaction to the researcher is important to note, as this may have been different if it had been somebody familiar to the participants. The researcher was not known to the participants and made clear that they were not involved in the participants care or with the day centres they attended. Participants' responses may have been different if the interviews were being carried out by someone known to them or a carer who may use RPI with them.

The videos were of actors who were not known to the participants. This may have affected the way the RPI holds were viewed by participants. As this study aimed to obtain general opinions from service users about specific RPI moves, it was the moves themselves which were the focus of the videos so importance was placed on demonstrating these in a clear way. Therefore there was no struggle shown in the video, or dialogue between any of the parties. The person in the videos being restrained did not have an intellectual disability, nor were the care staff identified as such by wearing badges or uniforms. This is a rather artificial demonstration of RPI, as it would look very different in practice. Some participants did state that the staff were not

wearing badges and some participants stated that they were only actors, with one participant stating "they are only acting, it's ok cos they are only acting, but if it were real..." (individual interview 1) Therefore, it would be interesting to carry out this research using more 'real' videos or live examples of RPI. However, there would be even greater ethical considerations to take into account.

Whilst the order of presentation for the videos was randomised to control for order bias, it was clear that previous videos may have impacted on the way service users viewed the subsequent videos. For example, when the most restrictive video was shown first it had the potential to create such emotion and negativity that this tinted the rest of the videos watched, or to create the effect whereby less restrictive moves were not seen to be as bad. This order effect was controlled for as far as possible by randomisation.

As this research was a qualitative investigation carried out with adults with intellectual disabilities, there are challenges inherent in this. Literature suggests that adults with intellectual disabilities may be suggestible when interviewed (Clare & Gudjonsson, 1993). This was controlled for by the absence of leading questions. Also people with intellectual disabilities may be more likely to be acquiescent, which was controlled for by asking open questions. The responses by participants' during interviews were short, which may be due to their limited verbal ability. Prompting was required to enable participants to elaborate on points made. Although there are challenges in carrying out research with people with intellectual disabilities which may bring

into question the validity of responses, studies have shown that people with intellectual disabilities can provide valuable contributions (Stenfert-Kroese *et al.* 1998).

Implications for practice

There are a number of clinical implications from the findings of this study.

Firstly, it is important that service users who may be subject to RPI or may witness RPI happening to someone else are properly informed about it. They should be informed about why and when it might be used. This is important as the findings from this study suggest that it can cause distress to watch RPI procedures. Also, negative views towards the staff involved may be felt and service users may feel that something wrong or illegal has taken place. This could affect their sense of trust in the staff and their on-going relationships with them. Therefore, education for service users on this topic is important. It is feasible that someone may enter a service and have RPI as part of their care plan. The findings from this study suggest that other service users', who may then be witness to RPI, should be provided with some information on this to reduce any negative reactions and confusion. This could be an important safeguarding procedure which could enable service users to know when RPI is being misused so they can report it if this is the case. However, staff may also require support in talking to service users about this topic, as it is a sensitive area which staff may not feel confident in approaching with service users.

Also, as negative emotions may be experienced by service users after witnessing RPI, such as anxiety and fear, it is important that service users are aware they can discuss their feelings with staff. Therefore, it may be useful in community settings to establish routes of support for service users who may be involved in, or witness to RPI. Also, given the fact that negative reactions towards the staff carrying out the RPI may be experienced, it may be important to have a system which allows this to be explored in order to maintain good relationships between service users and staff. Staff often have the option of debriefing to help them manage their feelings or reactions following an incident, however this is not as readily available for service users (Fish & Culshaw, 2005; Hawkins *et al.* 2005. Service providers should create a clear and open system for service users to use for debriefing following RPI, for example, by nominating members of staff to provide debriefing sessions.

Another implication for practice, highlighted by the findings of this study, is the need for clear routes in place for reporting misuse of RPI. One of the themes which emerged from the study was that of reporting the incident. This is something which should be considered by service providers, so that service users know who they should report wrong doing to and how they can report it. Systems for reporting need to be in place and made clear to service users to prevent potential abuse going undetected. Enabling clear routes for service users to report misuse of RPI would be empowering for service users and could provide a safeguarding measure against possible abuse.

Another implication for practice comes from the finding that anger was a feeling commonly reported by participants watching the RPI clips. Therefore, the witnessing of such an incident could have repercussions. Staff may need to be mindful of this and consider how this could be managed. This should be considered in individual care planning. It may be necessary to consider whether RPI is the best option if it is likely to increase anger and agitation.

Further training for staff on RPI may be beneficial. To ensure a healthy organisation, which decreases risk, produces positive outcomes and well-being (Nunno, 1997), continued training and support for staff is important. Training on more preventative strategies, such as behavioural interventions to reduce challenging behaviours is important as without proactive therapeutic support, RPI will inevitably rise (Allen *et al.* 2009).

This study suggests that the move towards PBS from previous more aversive behavioural strategies is in the right direction, as participants report mainly negative reactions to the RPI procedures, particularly the more restrictive ones. This suggests that continuing to promote PBS will be important for service providers. Moving away from restrictive practices and towards preventative practices, such as employing functional analysis to understand behaviour, is the direction which services should be moving towards.

Future research

As this is an under studied area, more research is needed to provide a better understanding of RPI to inform theory and practice. This study could be extended by using more 'real' example of RPI and asking more people with intellectual disabilities their views on RPI. Asking service users who frequently have RPI used on them what they think about particular holds could provide useful information to further inform our understanding of RPI procedures. Also, following on from McDonnell (2000), Cunningham *et al* (2003) and Jones and Stenfert-Kroese (2008) who asked staff to rate RPI procedures as part of their studies, using a quantitative approach, asking staff their views on RPI holds using qualitative methodology may add to our understanding, as previous research suggests in certain respects they may think differently than service users about this topic (Fish & Culshaw, 2005; Hawkins *et al.* 2005).

This study found that service users viewed RPI negatively but that the more restrictive the intervention, the more negatively it was viewed. Further study is required to learn more about the specific RPI in use. The prone hold is specifically a controversial technique. Service users' express strong negative views on this hold and concerns over pain and injury arising from it.

Conclusion

The findings of this study suggest RPI are viewed negatively and this appears to be along a continuum whereby as holds become less restrictive, they are viewed less negatively. The findings concur with previous research on the experiences and views of adults with intellectual disabilities on RPI. Similarly, negative emotions and negative reactions to staff were expressed, concerns regarding safety and the need to report incidents were raised and restrictiveness of RPI was discussed. Also participants appeared to be unsure as to why RPI is used.

More needs to be done to further our understanding of the use of RPI. This is a particularly controversial topic in the field of intellectual disabilities, and given the ethical and legal dilemmas that can arise from this, it is important that this area is understood. Central to this is gaining an understanding from those who are involved in RPI. Also, it will be important to promote service users as active participants in care planning, as this can lead to empowerment.

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Section 3

Appendices

Appendices

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Appendix i: Formats

- University letter of approval for specified journal
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Journal of Applied Research in Intellectual Disabilities

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TopAuthor Guidelines



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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.

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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.

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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.

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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,

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- -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

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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.

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Appendix ii: Ethical approval

• Ethics committee approval letter



Research Governance Social care
Social Services Directorate
Wellington House
Barnsley S70 1WA

15 July 2010

Lisa Bilsborough Clinical Psychology Unit Department of Psychology University of Sheffield Western Bank Sheffield S10 2TD

Dear Lisa

Re: Proposed activity/ Research title: Restrictive Physical Intervention with People Who have Intellectual Disabilities: An Explorative Study of Service Users Perspectives.

Thank you for submitting the above research project for consideration by Barnsley RGGC.

The Research Governance Social Care system considered the project and I am pleased to confirm that they agreed to approve this project.

In acting as Principal Investigator for Barnsley on this project, you must comply with the informed consent and procedures approved by the Ethics Committee for your project and conduct your research in accordance with the principles of the Department of Health Research Governance Framework for Health and Social Care.

You must also comply with the policies and procedures of the host organisation with regard to Health and Safety, Equal Opportunities, Information Security and Confidentiality, the recording and reporting of adverse incidents, and, if applicable, the Financial Regulations.

The RGSC Committee and Lead Officer must be notified immediately of any changes in protocol or new information that would raise questions about the continued conduct of the research. They must also be notified of any adverse incident.

Basic information about the project will be entered into the RGSC & Alliance Research database and may be submitted to National Research Registers.

I should be grateful if you could provide a brief annual report on the progress of the research to the Lead Officer RGSC, including reference to any publications that have arisen from the research.

This report should be submitted to RGSC during January 2011.

Yours sincerely

Michael

Michael Stanley Professional Development & Support Manager (Lead Officer RGSC)

Cc: Research Governance Alliance Office, BNHFT.

Appendix iii: Measures

Interview schedule

Interview Schedule

Demographic Information to be collected:
Gender:
Age:
Ethnicity:
Diagnosis:
Living situation:
Service provisions
used:
Has the participant watched restrictive physical interventions take place?
Has the participant themselves experienced restrictive physical intervention?
Questions following each video clip:
1. What did you think of that method of restrictive physical intervention?
2. Why do you think it would be used/that would happen?
3. How did it make you feel watching it?

4. What reactions did you have when you saw the move?

- 5. What would you think/how would it make you feel if that happened to you?
- 6. Why does it make you think that way/feel that way?
- 7. How do you feel about that method being used? (on you, on others)
- 8. What would you do if you saw that happen or if it happened to you?
- 9. What did you think about the people in the video?

Prompts used to elicit further information.

Appendix iv: Other

- Example of audit trail
- Participant information sheet (individual interview)
- Participant information sheet (focus group)
- Staff information sheet
- Consent form

Information Sheet

For Participants (To be read out by staff member)

Research Project Title:

Restrictive Physical Intervention with people who have intellectual disabilities: An explorative study of service users' perspectives

The researchers name is Lisa Bilsborough. Lisa is doing a project at university and she would like to find out if you want to take part.

You will need to know what the project is about and what you will have to do so you can decide if you want to take part.

What is the project about?

The project is looking at the views of service users on physical intervention (which is also called restraint).

By asking you what you think about five different methods of restraint we can learn more about your views on them.

Do I have to take part?

You do not have to take part.

It is up to you if you want to take part or not.

You can stop being part of the research at any time and do not have to give any reason for this.

What do I have to do if I take part?

Lisa will arrange a time with you when you can meet.

Lisa would like to meet with you for about an hour.

You will be asked to watch five video clips showing different restraint methods.

The video clips are of actors. They are re-enacting (pretending to do) the restraint.

You will be asked questions after each video.

Lisa will tape the time you spend talking so she can listen to it again later. No one outside of the project will hear the tape.

You will be asked at the end of the interview if Lisa can contact you again when she has done the analysis to tell you about the results of the study and check if you think it is right.

Confidentiality

Your name will not be recorded so no one will know who you are.

What you say will not be shared with staff members. Your name will not be used but staff members may be able to guess who you are from what you say.

If you tell Lisa something that makes her worry about your safety or anyone else's safety she will have to tell someone about this.

Complaints

If you have any complaint about how you were treated in this research then you can contact the University.

You can also make a complaint to Professor Nigel Beail.

If you want to take part you will be asked to sign a consent form. This will be kept safe and separate from your interview answers.

Thank you for your time.

Information Sheet

For Participants (To be read out by staff member)

Research Project Title:

Restrictive Physical Intervention with people who have intellectual disabilities: An explorative study of service users' perspectives

The researchers name is Lisa Bilsborough. She is doing a project at university and she would like to find out if you want to take part.

You will need to know what the project is about and what you will have to do so you can decide if you want to take part.

What is the project about?

The project is looking at the views of service users on physical intervention (which is also called restraint).

By asking you what you think about five different methods of restraint we can learn more about your views on them.

Do I have to take part?

You do not have to take part.

It is up to you if you want to take part or not.

You can stop being part of the research at any time and do not have to give any reason for this.

What do I have to do if I take part?

Lisa will be asking a group of service users to watch five video clips of restraint methods and talk about what they thought about them.

You would be part of this group of about 6 to 12 people.

Lisa would like to meet with you all for about an hour.

Lisa will ask you all to watch five video clips showing different restraint methods.

The video clips are of actors. They are re-enacting (pretending to do) the restraint.

Lisa will ask you questions after each video and ask you all to discuss your answers

Lisa will tape the time you spend talking so she can listen to it again later. No one outside of the project will hear the tape.

You will be asked at the end of the interview if Lisa can contact you again when she has done the analysis to tell you about the results of the study and check if you think it is right.

Confidentiality

Your name will not be recorded so no one will know who you are.

What you say will not be shared with staff members. Your name will not be used but staff members may be able to guess who you are from what you say.

If you tell Lisa something that makes her worry about your safety or anyone else's safety she will have to tell someone about this.

Complaints

If you have any complaint about how you were treated in this research then you can contact the University.

You can also make a complaint to Professor Nigel Beail.

If you want to take part you will be asked to sign a consent form. This will be kept safe and separate from the tape of the group interview.

Thank you for your time.

Information Sheet

For staff

Research Project Title:

Restrictive Physical Intervention with people who have intellectual disabilities:

An explorative study of service users' perspectives

Service users' with intellectual disabilities living in community settings are being invited to take part in a research project.

Please read the following information, and discuss it with others if you wish, so you can decide if any service users might be able to take part in this project. It will be important that you have a full understanding of what this research project involves so that any service users who might take part can discuss the project with you if necessary.

Ask me if there is anything that is not clear or if you would like more information.

Thank you for reading this.

Who is carrying out the research?

My name is Lisa Bilsborough and I am a Trainee Clinical Psychologist. I will be carrying out the research under the supervision of Prof. Nigel Beail.

What is the project's purpose?

This project is looking into restrictive physical intervention, which is sanctioned by policy and guidance for use with service users with intellectual disabilities and challenging behaviour. Not much research has been done on service users' views of this practice. Very few studies look at the views of people with intellectual disabilities and those that do often ask people in inpatient, secure settings rather than in community settings. Also the studies often ask service users to remember past experiences rather than ask about what they think about restrictive physical intervention methods per se.

The aim of this study is to explore, using an interview, perspectives of service users on five different restrictive physical intervention methods. Video clips of each method will be shown, demonstrated by actors, and after each clip the service user will be asked questions about what they thought of and how they felt about the method.

Service users will be asked to take part in an interview lasting approximately one hour, which will involve questions being asked after each video clip shown.

Why have we been chosen?

You have been chosen to ask service users to take part in this project as we aim to find out the views of service users with intellectual disabilities who are living in the community.

We will ask for more service users' with intellectual disabilities living in the community to take part as we would like to speak to 10 people to ask their views.

Do the service users have to take part?

The service users do not have to take part. It is up to them to decide whether or not to take part. They may require help from you or another staff member to make this decision. If they do decide to take part they will be given information on the study and be asked to sign a consent form. They can still withdraw at any time throughout the study without it affecting any benefits that they are entitled to in any way. They do not have to give a reason to withdraw from the study.

What will happen if someone takes part?

If a service user decides to take part we will arrange a time when they can meet with me to watch five video clips of physical intervention methods and then talk about them. I would talk to them for about an hour in total. After each video clip I would ask some questions about what they thought of it. I would tape the time we spend talking about this so that I can listen again to analyse themes from what we talk about. I would contact the service user again if they agree to this to tell them about what I have found from the analysis and check if they think it sounds right.

What do service users have to do?

Service users taking part would be asked to participate in a one hour meeting where I would show video clips of physical intervention methods and then ask some questions after each clip. Service users would be asked to talk about what they thought of the physical intervention methods and how they felt about them.

Will service users be recorded, and how will the recorded media be used?

The audio recordings of participants activities made during this research will be used only for analysis and for illustration in conference presentations and lectures. No other use will be made of them without participants' written permission, and no one outside the project will be allowed access to the original recordings.

What other information will be collected?

Other information I would collect would be the gender, age, ethnicity, diagnosis, living arrangements, involvement in services, and experience of physical interventions of the participants.

What are the possible disadvantages and risks of taking part?

The video clips are of actors showing five different physical intervention moves. Service users may find these hard to watch or they may cause feelings of sadness or anger. When talking about the methods they may find this upsetting and it may bring up emotions from past experiences.

What are the possible benefits of taking part?

Whilst there are no immediate benefits for those people participating in the project, it is hoped that this work will give us more of an understanding on service users' views of physical intervention to inform our work with them.

What if something goes wrong?

If the service user has any cause to complain about any way they have been approached or treated during the course of this study they are able to make a complaint to the Principal Supervisor. If they feel their complaint is not handled to their satisfaction they are able to contact the University's Registrar and Secretary. Service users are also able to make a complaint to the Barnsley local authority

Will service users taking part in this project be kept confidential?

All the information collected about the service users during the course of the research will be kept strictly confidential. They will not be identified in any reports or publications.

What will happen to the results of the research project?

When the information from the interviews from all participants has been analysed I will contact the participants to ask if they would agree to discuss with me the themes that have arisen from the analysis to check if they agree with them.

I will provide a copy of the final piece of work for the service so the service users can be informed of the results from the study.

The results from the study will be fed back to the British Institute of Learning Disabilities (BILD) and will be fed back through BILD to the accreditation team who are involved in the accreditation process for service providers offering restrictive physical intervention packages.

The results of this study will also be disseminated through the Physical Intervention annual conference.

Who is organising and funding the research?

The University of Sheffield is the organisation organising and funding this research.

Who has ethically reviewed the project?

This project had been ethically reviewed by Social Care Ethics.

Contact for further information

For further information about this study you can contact:

Lisa Bilsborough

If service users agree to take part they will be given an information sheet about the study, which can be read to them by a staff member and which the service user can keep. They will also be asked to sign a consent form.

Thank you for taking the time to read this information sheet.

Consent Form

Project Title:

Restrictive Physical Intervention with people who have intellectual disabilities:				
An explorative study of service users' perspectives				
Researcher:				
Lisa Bilsborough				
Trainee Clinical Psychologist, University of Sheffield				
Participants' identification number				
have read and understood the information sheet. I have had time to ask questions and decide if I want to take part				
understand that I can stop being part of the research at any time and do not have to give a reason for this				
agree to being taped as part of the research and for quotes from the tapes to be used in the research report and at research presentations				
understand what this project is about and I agree to take part				
Name of participant participant)	Date	Signed (by		
Name of researcher researcher)	Date	Signed (by		