

**A CASE SERIES TO EXAMINE WHETHER PEOPLE WITH LEARNING DISABILITIES
CAN LEARN HOW TO LINK MEDIATING COGNITIONS TO SUBSEQUENT
EMOTIONAL RESPONSES**

By

Ioanna Tsimopoulou

**A thesis submitted to the University of Birmingham for the degree of
MASTER OF RESEARCH (Clinical Psychology)**

School of Psychology
University of Birmingham
July 2015

Word count: 14747

(Excluding tables, figures, appendices and references)

UNIVERSITY OF
BIRMINGHAM

University of Birmingham Research Archive

e-theses repository

This unpublished thesis/dissertation is copyright of the author and/or third parties. The intellectual property rights of the author or third parties in respect of this work are as defined by The Copyright Designs and Patents Act 1988 or as modified by any successor legislation.

Any use made of information contained in this thesis/dissertation must be in accordance with that legislation and must be properly acknowledged. Further distribution or reproduction in any format is prohibited without the permission of the copyright holder.

Acknowledgements

I would like to warmly thank Dr Biza Stenfert Kroese, Dr Gemma Unwin and Dr Sabiha Azmi for their valuable advice, feedback and encouragement in my first placement and my summer project.

Thank you to Dr Ruth Howard, Dr Ravinder Vohra and Dr Inigo Tolosa for their guidance and help in my second placement.

I would also like to thank my family and friends for their love and belief in me.

Finally, I would like to express my sincere thanks to the Alexander S. Onassis Public Benefit Foundation for funding my master's and giving me the opportunity to realise my dream.

TABLE OF CONTENTS

Overview	1
Chapter 1: Effectiveness of Cognitive Behavioural Therapy programmes for anxiety or depression in adults with Learning Disabilities: a review of the literature	
Introduction	6
Methods	7
Results	8
Discussion	18
Reflection	22
References	25
Chapter 2: Preoperative psychological interventions for patients undergoing surgery for cancer: a systematic review	
Introduction	37
Methods	39
Results	41
Discussion	47
Reflection	52
References	54
Chapter 3: A case series to examine whether people with learning disabilities can learn how to link mediating cognitions to subsequent emotional responses	
Abstract	58
Introduction	60
Methods	65
Results	73

Discussion	86
References	92

Appendices

Appendix 1: Search terms (Chapter 1)	101
Appendix 2: Data extraction form (Chapter 1)	101
Appendix 3: Search terms (Chapter 2)	102
Appendix 4: Quality assessment of the included studies (Chapter 2)	103
Appendix 5: Characteristics of the studies included in the review (Chapter 2)	104
Appendix 6: Description of the psychological interventions (Chapter 2)	106
Appendix 7: Thorough list of post-operative outcomes (Chapter 2)	107
Appendix 8a: Female presentation cards for the ‘Cognitive mediation’ task (Chapter 3)	108
Appendix 8b: Male presentation cards for the ‘Cognitive mediation’ task (Chapter 3)	110
Appendix 9a: Female presentation cards for the ‘Linking activating event to emotions’ task (Chapter 3)	112
Appendix 9b: Male presentation cards for the ‘Linking activating event to emotions’ task (Chapter 3)	114
Appendix 10: Qualitative feedback about the video (Chapter 3)	116
Appendix 11: Application for ethical review (Chapter 3)	117
Appendix 12: Participant information sheet (Chapter 3)	131
Appendix 13: Capacity to consent assessment (Chapter 3)	144
Appendix 14: Participant consent form (Chapter 3)	145

Overview

I was born and grew up in Greece where I completed my undergraduate studies in Psychology. I have a genuine interest and love for Clinical Psychology and I came to the UK to do this master's degree and explore a career in this field. This course has been a great experience for me, as it helped me expand my knowledge and experience in qualitative and quantitative research methods, in conducting literature reviews and clinical audits. Moreover, I further developed my research, clinical and academic skills through three research placements in NHS, and my capacity to design and conduct research, critically evaluate research and act in an ethical and professional way was enhanced.

My first placement was at the Learning Disability (LD) Service of Birmingham Community Healthcare NHS Trust and required me to conduct a literature review on the effectiveness of Cognitive Behavioural Therapy (CBT) programmes for anxiety or depression in adults with LD. The review was a very interesting learning experience that taught me how to use advanced database searching techniques and improved my knowledge of the complex needs and difficulties of people with LD. Furthermore, I had the opportunity to present it in the CPD event of the Faculty of LD, an experience that helped me overcome my public speaking anxiety and improve my presentation skills.

Review findings demonstrated the need for further research on the effectiveness of CBT for people with LD and anxiety. The second aim of my placement was to participate in the design of a group CBT study for anxiety in individuals with LD and develop some session materials. In particular, I

collaborated with a Speech and Language Therapist (SLT) to develop an anxiety log. This experience improved my understanding of the stages involved in the development of a research project and my ability to develop materials accessible to people with LD. All these skills proved to be very important for my final project. In general, this placement was a great introduction to my final project, given my little previous experience with this population.

My second placement was at the Sarcoma Unit of Queen Elizabeth Hospital Birmingham (QEHB) and had two main objectives. The first was to conduct a systematic review about the effect of pre-operative psychological interventions on the post-operative outcomes of patients undergoing surgery for cancer. The second aim was to conduct a clinical audit of the records of patients who underwent an operation for retroperitoneal sarcomas. This placement gave me the opportunity to explore my interest in clinical health psychology and gain a better understanding of psychology applied to healthcare and of the role of clinical psychologists in such settings. It was also a unique chance to acquire an insight into NHS, considering that I had no previous experience of working in NHS settings.

Moreover, I collaborated with colleagues from a wide range of professions and levels of seniority -i.e. surgeons, oncologists, nurses and clinical psychologists- in order to conduct the review and the audit. This was a very interesting and challenging experience that helped me develop my communication and presentation skills further and understand the importance of a well-established MDT for the provision of high quality treatment. Finally, this placement resulted in two academic papers. The writing process and the feedback provided by my supervisors helped me a lot to improve my academic writing skills.

The knowledge and experience I acquired from my placements was exceptionally useful for my final project which examined whether adults with LD can understand the principles of CBT and especially the concept of cognitive mediation. This is the most substantial piece of research I have conducted until now and I really enjoyed the research process. Prior to conducting the study, I applied for university ethics approval, a procedure that made me very aware of the ethical implications of working with this population.

One of the goals I had set for myself when I started this course was the enrichment of my clinical skills and the further development of my communication skills. Through the delivery of the intervention and the meetings I had with the participants, I managed to accomplish these aims and I became more capable of adapting my behaviour and communication for each individual's special needs and language comprehension. Furthermore, my ability to produce accessible materials was enhanced with the development of the training intervention, although eliminating jargon and simplifying language was quite challenging in some situations.

Throughout the project, I worked independently under the supervision of three clinical and research psychologists. This helped me further develop my organisational and time management skills and improve my metacognitive skills and my capacity to reflect. In the initial stage of the study, I faced some practical difficulties with the original plan and there was a need to amend it and renegotiate its objectives with my supervisors within a tight time frame. Although this was a quite challenging process, it considerably increased my ability to tolerate uncertainty and adapt to new situations, while I also learnt how to work in a more relaxed manner and manage my anxiety more effectively. Moreover,

a delay in the recruitment process taught me that it is important to contact service managers in a timely manner, so as to allow them adequate time to request further information, decide about participation in research and notify potential participants. If I were to conduct this project again, I would have dedicated more time to planning participant recruitment.

My desire is to become a Clinical Psychologist, able to apply psychological knowledge, conduct influential research and have an impact on individuals' lives and on the society and this course brought me a step closer to it. After having completed it, I feel much more skilled at carrying out research and more suitable to undergo clinical training.

CHAPTER 1:

**EFFECTIVENESS OF COGNITIVE BEHAVIOURAL THERAPY PROGRAMMES FOR
ANXIETY OR DEPRESSION IN ADULTS WITH LEARNING DISABILITIES: A REVIEW OF
THE LITERATURE**

Introduction

People with LD suffer from mental health problems at least at the same rate as the general population (Cooper, Smiley, Morrison, Williamson & Allan, 2007; Deb, Thomas & Bright, 2001; Reid, Smiley & Cooper, 2011; Tsiouris, Kim, Brown & Cohen, 2011) with depression and anxiety being the most common disorders (Reid et al., 2011; Richards et al., 2001; Smiley, 2005). Research evidence indicates that there is variation in the prevalence rates of mental illness among this population, due to difficulties in diagnosing mental disorders in individuals with LD, and especially in those with severe or profound LD, and due to the different inclusion criteria and assessments used by most studies (Dagnan & Lindsay, 2012; Deb et al., 2001; Emerson & Hatton, 2007; Hemmings, Deb, Chaplin, Hardy & Mukherjee, 2013; Matson & Shoemaker, 2009).

The guidelines published by the National Institute for Health and Clinical Excellence in the UK (NICE, 2011; 2009) recommend that CBT is offered to individuals with depression or anxiety disorders, but there is no mention of individuals with LD. Although there is a growing body of evidence for the effectiveness of CBT for people with LD and anger regulation problems, there is still little evidence on how effective CBT is for individuals with anxiety or depression (Hamelin, Travis & Sturmey, 2013; Hassiotis & Hall, 2009; Vereenoghe & Langdon, 2013; Willner, 2005; Willner et al., 2013).

Furthermore, there is some research evidence from the anger management literature to support the effectiveness of staff-administered CBT programmes for people with LD (Willner, Brace & Phillips, 2005; Willner et al., 2013). Research also shows that individuals with anger management problems are benefited by the involvement of carers in therapy (Rose, Loftus, Flint & Carey, 2005; Rose, West & Clifford, 2000; Willner, Jones, Tams & Green, 2002), as carers reinforce the techniques learnt and support service users with homework. However, it is unknown whether staff-delivered CBT is equally effective for individuals with anxiety or depression symptoms.

Therefore, the aim of the present review is to examine the effectiveness of CBT programmes delivered by therapists or staff for individuals with anxiety or depression symptomatology.

Methods

Three databases were searched up to 2nd November 2013 using terms related to LD, CBT, anxiety and depression (Appendix 1): Embase (1974 to 2013 Week 44), Ovid MEDLINE(R) In-Process & Other Non-Indexed Citations and Ovid MEDLINE(R) 1946 to Present and PsycINFO (1967 to October Week 5 2013). Duplicates were removed and the following inclusion criteria were used to scan the titles and abstracts:

- Population: adults with LD and anxiety or depression
- Intervention: CBT

- Outcomes: data about the effectiveness of the intervention
- Study: quantitative and qualitative studies in English published in a peer-reviewed journal

The remaining full text papers were examined and studies that met the inclusion criteria were included in the review. The references of these studies were checked to identify any missed papers. After the selection of the final studies, information was extracted using a data extraction form (Appendix 2). The methodological limitations of the included studies are presented and although some of them have important flaws, they were included due to the limited literature in this area of research. A narrative synthesis is used to report the results.

Results

Ninety seven studies were identified by the database search and six were considered appropriate for inclusion. Three more papers were identified from cross-referencing. A single paper by Lindsay (1999) reported two different studies. Two more case study papers met the inclusion criteria (Lindsay et al, 1997; Lindsay, Howells & Pitcaithly, 1993), but these were excluded as it was thought that a summary of their findings was reported in a study already included in the review. As a result, the total number of studies included in the review is ten (see Figure 1 for a description of the selection process).

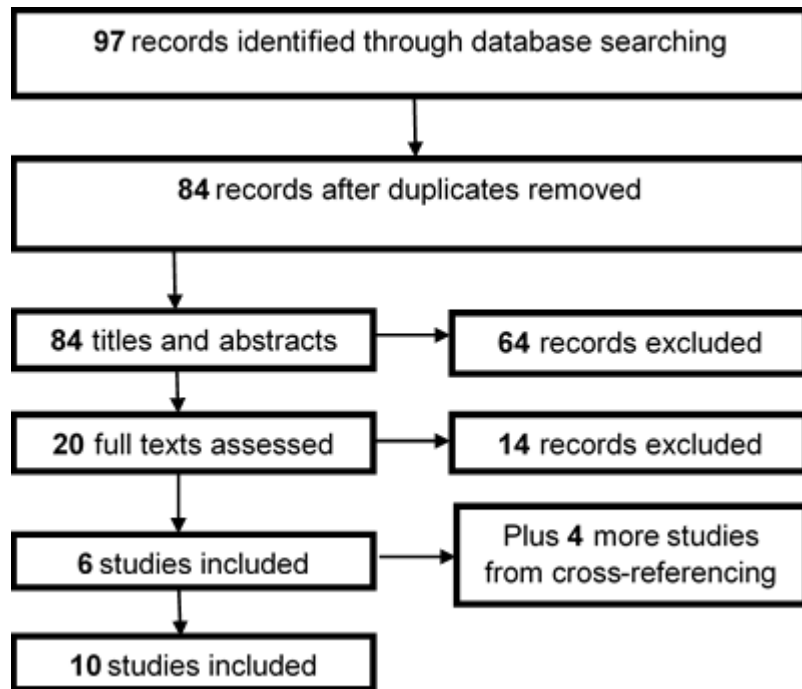


Figure 1. Study selection process

Characteristics of the studies

The methodological characteristics of the studies and their main findings are presented in Table 1.

Three studies provided CBT interventions to individuals with anxiety problems (Douglass, Palmer & O'Connor, 2007; Lindsay, 1999; Marwood & Hewitt, 2012), three to individuals with depression symptoms (Lindsay, 1999; McCabe, McGillivray & Newton, 2006; McGillivray, McCabe & Kershaw, 2008), and four studies included people with mixed clinical presentation, including anxiety, depression and/or anger (Ghafoori, Ratanasiripong & Holladay, 2010; Hassiotis et al., 2013; Pert et al., 2013; Stenfert Kroese et al., 2014). The two qualitative papers by Pert and colleagues (2013) and by Stenfert Kroese and colleagues (2014) reported data from the same group of participants.

Table 1. Methodological characteristics and main findings of the studies included in the review

	First Author (year)	Study design	Participants	Mental health condition	Intervention	Measures	Main findings
ANXIETY							
1	Douglass (2007)	Mixed methods One-group Pretest and posttest assessments Post-intervention semi-structured interviews with participants and with carers	N=7 (and one carer for each individual) Age: 22-65 2M/4F LD: mild-moderate Country: UK Interviews: N=6	Generalised anxiety	Group CBT 12 weekly, 2-hour sessions Delivered by Therapist	-GAS-ID -Structured self-rating interview -Rating scale for carers on impact of anxiety	-Decreased anxiety scores for three participants -clinically significant reduction for two -Post-intervention interviews indicated that individuals had less worries and they developed a repertoire of coping strategies -The feedback from facilitators and carers was very positive
2	Lindsay (1999)	Case series Pretest, posttest and follow up assessments	N=15 (referred between 1989-1996) LD: not mentioned Country: USA	Anxiety	Beck's Cognitive Therapy (simplified form) 23 sessions on average (range: 15-47) Delivered by Therapist	-Revised BDI or ZAS -Reported frequency of problematic cognitions	-There was a statistically significant decrease in the anxiety and the negative automatic thoughts of participants, from 75% to 49% -Results were still significant at a 6-month follow-up assessment
3	Marwood	Mixed methods One-group pretest and posttest	N=8 (and one support person for each individual)	Range of anxiety	Group CBT Anxiety Management	-QOLS	-Five out of eight participants had reduced anxiety scores –there was a clinically significant decrease for two -An improvement was observed in

	(2012)	quantitative assessments Posttest interviews (IPA)	Age: 17-73 Gender: not clear LD: mild Country: UK Interviews: N=4	problems (obsessional, social etc.)	6 weekly, 1-hour sessions (plus one last session for supporters, 90 minutes) Delivered by therapist	-GAS-ID -HoNOS-ID	the QoL and well-being scores of five individuals -Qualitative interviews showed that participants found the group helpful and enjoyed their participation
	DEPRESSION						
4	Lindsay (1999)	Case series, pre and post and follow up assessments.	N=5 (referred between 1990-1996) LD: not mentioned Country: USA	Depression	Beck's Cognitive Therapy (simplified form)	-Revised BDI or ZDS -Reported frequency of cognitions related to depression	-There was a 25% decrease in the depression scores of the participants (no statistical analysis due to the small sample size) -This decrease was maintained at the 6-month follow-up assessment
5	McCabe (2006)	RCT (quasi-independent) Pretest, posttest and follow up assessments	EG N=34 Mean age: 34 16M/18F CG N=15 Mean age: 40 6M/9F LD: mild-moderate Country: Australia	Depression (ranging from clinical depression to some depressive symptoms)	EG Group CBT Programme 5 weekly, 2-hour sessions Delivered by therapist CG Waitlist	-BDI-II -SCS -Rosenberg Self-esteem Scale (RSES) -ATQ-R	- There was a statistically significant reduction in the depression scores of participants -Individuals had a statistically significant improvement in their self-perception, less negative automatic thoughts -There was no intervention effect on their self-esteem -All these changes remained significant at the 3-month follow-up
6	McGillivray (2008)	RCT (cluster, quasi-independent) Pretest, posttest and follow up	EG N=20 Mean age:38 13M/7F CG N=27	Depression (from minimal symptoms to clinical depression)	EG Group CBT 12 weekly, 2-hour sessions Delivered by staff	-BDI-II -ATQ-R -The Social Readjustment Rating Scale (SRRS; 10 items)	-There was a significant group by time interaction effect for BDI-II, ATQ-R and SCS. No effect for SRRS -Significant decrease in the BDI-II and ATQ-R scores of the EG at post-test

		assessments	Mean age:31 19M/8 F LD: mild Country: Australia		CG waiting list	only) -SCS	-Positive intervention effects were maintained at the 3-month follow up
	ANXIETY AND DEPRESSION						
7	Ghafoori (2010)	One-group Pretest, posttest and follow-up assessments	N=8 Age: 19-22 2M/6F LD: mild-borderline Country: USA	Mood difficulties (depression, anxiety and anger)	Group CBT 9 weekly, 90-minute sessions Delivered by therapist	-Symptom Checklist 90-Revised (SCL-90-R)	-The anxiety and the depression scores of participants decreased significantly -The intervention had no effect on hostility -These changes were not maintained at the 4-month follow up
8	Hassiotis (2013)	Mixed methods RCT Pretest, posttest and follow up assessments Post-CBT interviews (content analysis)	EG N=16 Mean age: 34 5M/11F CG N=16 Mean age: 38 7M/9F LD: mild-moderate Country: UK Interviews: N=13	Mood disorder or symptoms of depression and/or anxiety	EG Manualised Individual CBT (M-iCBT) 16 weekly, 1-hour sessions Delivered by therapist CG Treatment as usual	-BDI-Youth -BAI-Youth -Manchester Short Assessment Of Quality of Life (MANSA) -Client Satisfaction Questionnaire (CSQ-8) -Client Service Receipt Inventory, adapted for this study (CSRI)	-No significant interaction or main effect on the depression and anxiety scores for both groups -There was a non-significant reduction in the depression scores of participants (no matter if they also had anxiety or not) -Participants were satisfied with the services -Individuals were unable to complete the MANSA due to its complexity -The thirteen participants who were interviewed reported that the intervention was helpful, but it did not solve all their problems. -More than half participants reported that they used in their everyday life the strategies they learnt

9	Pert (2013)	Qualitative methods Two semi-structured interviews (the first between sessions four and five, and the second between sessions nine and ten) (IPA)	N=15 Mean age:39 8M/7F ID: borderline-mild Country: UK	Anxiety (four), depression (four), anger (four), mixed presentation (three)	Individual CBT Ten weekly or fortnightly one-hour sessions Delivered by therapist		-Individuals felt that the ability to talk about their emotions and thoughts was very helpful -They stressed the importance of being carefully listened and understood by a therapist who took their problems seriously -They thought that therapy had a positive effect on their lives, although this was not considered to be stable
10	Stenfert Kroese (2014)	Qualitative methods Two semi-structured interviews with staff (the first pre-intervention and the second after session nine) (Thematic analysis)	First interview N=11 3M/8F Second interview N=9 3M/6F People with LD N=15 8M/7F LD: borderline-mild Country: UK	Anxiety (four), depression (four), anger (four), mixed presentation (three)	Individual CBT Ten weekly or fortnightly one-hour sessions Delivered by therapist		-In the first interview, the majority of participants had poor understanding of CBT and did not expect that therapy would have an impact on service users -In the second interview, most staff members observed positive changes in their clients, improved mental health and cognitive processing -They thought that these are not permanent

CBT, Cognitive Behavioural Therapy; LD, level of intellectual disabilities; N, number of participants; M, males; F, females; RCT, Randomised Controlled Trial; EG, Experimental Group; CG, Control Group; IPA, Interpretative Phenomenological Analysis

Scales: GAS-ID, Glasgow Anxiety Scale-for people with an Intellectual Disability; GDS, Glasgow Depression Scale; BAI, Beck Anxiety Inventory; ZUS, Zung Anxiety Scale; QOLS, Quality of Life Scale; HoNOS-ID, Health of the Nation Outcome Scale – Learning Disability Version; BDI, Beck Depression Inventory; ZAS, Zung Anxiety Scale; ZDS, Zung Depression Scale; SCS, Social Comparison Scale; BSI, Brief Symptom Inventory; ATQ-R, Automatic Thoughts Questionnaire - Revise

The total number of participants with LD in the studies included was 186, with 30 in studies about anxiety, 101 in studies about depression and 55 in studies where participants had a mixed presentation of mood disorders. Participants had mild LD in four studies (Marwood & Hewitt, 2012; McGillivray et al., 2008; Ghafoori et al., 2010; Pert et al., 2013; Stenfert Kroese et al., 2014), mild to moderate LD in three studies (Douglass et al., 2007; McCabe et al., 2006; Hassiotis et al., 2013), while the level of disability was not mentioned in the two studies that were reported in a single paper (Lindsay et al., 2009). No study included individuals with severe LD.

The majority of the included studies employed a quantitative research design (Lindsay, 1999; Ghafoori et al., 2010; McCabe et al., 2006; McGillivray et al., 2008) and three of them used mixed methods (Douglass et al., 2007; Hassiotis et al., 2013; Marwood & Hewitt, 2012). Three studies had a control group (Hassiotis et al., 2013; McCabe et al., 2006; McGillivray et al., 2008) and six had a follow up period that ranged between three and six months (Ghafoori et al., 2010; Hassiotis et al., 2013; Lindsay, 1999; McCabe et al., 2006; McGillivray et al., 2008). Finally, two studies used qualitative methods; one explored the experiences of individuals who received a CBT intervention (Stenfert Kroese et al., 2014) and the second the perspectives of support staff (Pert et al., 2014).

Effectiveness of CBT for anxiety and depression

Three studies examined the effectiveness of CBT for individuals with anxiety and none of them had a control group (Douglass et al., 2007, Lindsay, 1999, Marwood & Hewitt, 2012). In Douglass and colleagues (2007), a clinically significant reduction was found in the anxiety scores of two out of seven participants. Anxiety was measured using the Glasgow Anxiety Scale-Intellectual

Disability (GAS-ID; Mindham & Espie, 2003) and clinical significance was calculated according to the definition provided by Jacobson and Truax (1991). In their post-intervention interviews, participants reported that they had less worries and they learnt new coping strategies. Observation showed that they applied these coping strategies in their everyday lives.

Marwood and Hewitt (2012) used a similar design and found that the anxiety of five out of eight participants decreased following intervention. This decrease was clinically significant only for two individuals. However, the quality of life (QOLS; Andrews & Withey, 1976) and well-being scores (HoNOS-LD; Roy, Matthews, Clifford, Fowler & Martin, 2002) of five participants improved. Four participants were interviewed following intervention and they all said that the group was helpful and that they enjoyed their participation in the study, the opportunity to discuss their feelings and go out of the home. Finally, they liked the involvement of their support partners. In the study by Lindsay (1999), participants' anxiety scores (BAI; Beck, Epstein, Brown & Steer, 1988) decreased significantly and this reduction remained significant at 6-month follow up.

Three studies investigated how effective CBT is for people with LD and depression. Two of them were controlled (McCabe et al., 2006; McGillivray et al., 2008) and one adopted a case series research design (Lindsay, 1999). In the study by McCabe and colleagues (2006), there was a statistically significant decrease in the depression scores of participants who were in the intervention group (from 14.56 to 5.71), compared to those in the control group (from 13.60 to 12.80, $p < 0.001$), as assessed by Beck Depression Inventory II (BDI-II; Beck, 1996). Moreover, the intervention had a significant effect on individuals' negative automatic thoughts (ATQ-R; Kendall & Hollon, 1987) and their self-perception (SCS; Allan & Gilbert, 1995). All these changes were maintained significant at the 3-month follow up assessment. Furthermore, the feedback of

participants demonstrated that they enjoyed taking part in the research and the opportunity to express themselves in a safe and non-judgmental place. They also found the handouts they were given very useful.

In McGillivray and colleagues (2008), the CBT intervention was delivered by staff. This was the only study that examined the effectiveness of a staff-administered CBT programme for people with LD and anxiety and/or depression. Results show that depression scores were significantly reduced from 16.20 to 8.45 in the intervention group, compared to a 11.05 to 6.05 drop in the control group ($p < 0.01$). Additionally, the intervention had a significant effect on participants' negative automatic thoughts. These changes remained significant at 3-month follow up. In Lindsay (1999), the depression scores of individuals dropped by 25%, but no statistical analysis was conducted due to the small sample size ($N=5$). This reduction remained stable at the 6-month follow up assessment.

Four studies included individuals with mixed mood disorders. One used a quantitative design (Ghafoori et al., 2010), one mixed methods (Hassiotis et al., 2013) and two used qualitative methods (Pert et al., 2013; Stenfert Kroese et al., 2014). In their small pilot study, Ghafoori and colleagues (2010) found a significant intervention effect on the anxiety and depression symptoms of participants. Nevertheless, these changes did not remain significant at 4-month follow up. In Hassiotis and colleagues (2013), the manualised individual CBT programme did not affect the anxiety scores of participants, as measured by GAS-ID (Mindham & Espie, 2003). However, there was a decrease in individuals' depression scores (regardless of whether they also had anxiety or not) and although this was not significant it suggests a tendency for further improvement. Thirteen individuals were interviewed following intervention and they reported that the intervention was helpful, but did not solve all their problems. Eight individuals reported that they used the strategies

they learnt in their daily lives and they felt calmer. Finally, seven participants expressed a positive opinion about their therapist.

As already mentioned, Pert and colleagues (2013) and Stenfert Kroese and colleagues (2014) reported data from the same group of participants. The former examined the experiences of individuals who participated in CBT and the latter the perspectives of their staff/carers. Participants felt that the ability to talk about their emotions and thoughts was very helpful. What was considered important and valued most was not the technical aspects of CBT, but the sense of being carefully listened to by a therapist who understands you and takes your problems seriously. In general, they thought that therapy had a positive effect on their lives, although this was considered to be unstable. In the study by Pert and colleagues (2013), pre-intervention interviews with staff revealed that the majority had poor understanding of CBT and did not expect that therapy would impact service users. However, most of them reported positive changes in their clients in the second interview. They said that their mental health and cognitive processing improved, but they thought that these changes were not permanent.

Methodological limitations

The studies presented here have some methodological limitations. The number of participants is generally small. No study performed a power calculation, but Hassiotis and colleagues (2013) used their data to calculate the sample size needed for a future larger study. Only three studies had a control group, with two of them targeting depression (McCabe et al., 2006; McGillivray et al., 2008), and one targeting anxiety and/or depression (Hassiotis et al., 2013). Hence, the search did not identify any controlled study that targeted anxiety. Moreover, the severity of participants'

anxiety or depression symptoms varied across studies, and therefore, the profile of individuals with LD who can benefit most from a CBT intervention is not known.

Lindsay (1999) does not report any information about the demographic characteristics (i.e. age, gender) and the level of LD of participants included in his study. As a result, the generalisability of findings is limited. Furthermore, in studies where there was a follow up assessment, the period was short -it varied between three and six months. Finally, only in McGillivray and colleagues (2008) and in Hassiotis and colleagues (2013) the outcome measures were administered by an independent researcher and the researcher was blind to group allocation only in the latter. Treatment fidelity was assessed only in two studies (Hassiotis et al., 2013; Pert et al., 2013).

Discussion

This review identified ten studies examining the effectiveness of CBT for individuals with LD and anxiety or depression. Most of them have important methodological limitations, including small sample sizes, short-term follow ups and few control groups. Despite a paucity of evidence, studies indicate the feasibility of CBT and its effectiveness for people with depression. Moreover, although there is currently no robust evidence to support the effectiveness of CBT for anxiety, some studies indicate it may be useful. These findings were corroborated by a recent meta-analysis (Vereenoghe & Langdon, 2013) that demonstrated a moderate effectiveness of CBT interventions for people with LD and depression or anger symptoms, but identified no controlled study for anxiety.

There were discrepancies between quantitative and qualitative findings. In particular, varying quantitative data were reported across the studies, whereas qualitative results were more consistent. They showed that participants had a positive perception of therapy and they particularly valued the ability to discuss their thoughts and feelings and build a relationship of trust with a therapist. Moreover, individuals reported using the coping strategies they learnt in their everyday lives. An explanation for the lack of statistical significance in some studies may be that they were under powered due to their small sample sizes. Additionally, it may also be that the outcome measures used across the studies have lacked sensitivity to change.

In all studies, participants had mild to moderate LD, none of them reported the inclusion of individuals with severe LD. Hence, results cannot be generalised to people with severe or profound LD, and perhaps talking therapies -such as CBT- are not suitable for this group of people. However, no study has examined whether there is an IQ cutoff score for participation in CBT and this is an issue future research should address. Moreover, there is a need for further exploration of the mixed quantitative results to find out whether individuals with certain demographic profiles or symptomatology can benefit more from a CBT intervention.

Only one staff-administered CBT programme for people with LD and anxiety or depression (McGillivray et al., 2008) was identified by the literature search and results showed a significant decrease in participants' post-intervention depression scores. Additionally, another CBT intervention delivered by trained staff significantly decreased the anger scores of individuals with LD (Willner et al., 2013). The experiences of care staff who acted as 'lay therapists' were explored further in a qualitative study by Stimpson and colleagues (2013) where they reported that they felt that participants became more capable of managing their anger effectively and had an increased

emotional awareness after the intervention. As a result, future research should investigate whether CBT interventions delivered by staff can be also used for individuals with LD and anxiety.

Three of the studies included in this review reported the involvement of carers and/or support staff in therapy (Douglass et al., 2007; Hassiotis et al., 2013; Marwood & Hewitt, 2012). The feedback provided by the participants was very positive and they found the involvement of carers very helpful. Previous research has also highlighted the importance of engaging carers in CBT for people with anger regulation problems (Rose et al., 2005; Whitehouse et al., 2006; Willner et al., 2002). Care staff can reinforce the implementation of coping strategies and ensure the transfer of skills that participants are taught within the sessions to different situations and settings.

Research evidence shows that training can enhance the ability of staff working with individuals with LD to identify mental health problems among their clients and improve their knowledge (Costello et al., 2007; Quigley et al., 2001) and emotional intelligence (Zijlmans et al., 2011). An interesting area of research would be to train staff to use CBT techniques in their everyday practice. In a recent study by Dodd and colleagues (2013), staff were trained in applying CBT techniques and their evaluations -especially those reported in their reflective diaries- indicated that they found training beneficial and helpful. Nurses working with people with LD have already expressed interest in CBT training (Brown & Marshall, 2006), but no action has been taken until now.

Qualitative data from the studies included in this review indicated that participants particularly valued the ability to discuss their feelings with a therapist who actively listens to and respects them. The importance of therapeutic relationship in psychotherapy has been highlighted by the existing research (Keijsers et al, 2000; Lambert & Barley, 2001). Therapists working with individuals with LD also perceive the therapeutic relationship as fundamental (Jones, 2013), while other factors that

appear to determine the effectiveness of psychotherapy include the ability of individuals to think psychologically and their motivation to engage in treatment (Jones, 2013; MacMahon et al., 2014; Willner, 2006). However, no research has been conducted yet to investigate the association between quality of relationship and therapeutic outcome (Jones & Donatti, 2009).

The present review has some limitations. The search was not exhaustive and only studies in the English language were examined, so it is possible that some papers have been missed. The included studies were assessed only informally, there was no formal quality appraisal process. Moreover, although a systematic review and meta-analysis may be useful in the future, at present, meta-analysis would be premature. There is a need for more RCTs, although the difficulties in conducting trials with this population are known. These are essential to determine the effectiveness of CBT interventions for individuals with LD.

Reflection

My first placement was in the LD service of Birmingham Community Healthcare NHS Trust and my supervisors were Dr Biza Stenfert-Kroese, Dr Sabiha Azmi and Dr Gemma Unwin. It was part of a broader project aiming to develop and evaluate a CBT anxiety management programme for people with LD delivered by staff or carers. My first placement objective was to conduct a literature review on the effectiveness of staff-administered CBT programmes for individuals with LD and anxiety. The second aim was to contribute in the development of materials and session plans for the anxiety management project.

As regards to the literature review, an initial database search identified only one relevant paper. Therefore, the search strategy was widened to capture studies which examined the effectiveness of CBT interventions, administered either by care staff or therapists, for individuals with LD and anxiety or depression problems. This review also aimed to identify the most effective methods for training care staff in managing anxiety in people with LD. However, the findings of the first question are only reported here due to the word limit.

This was my first attempt to conduct a systematic review and the learning outcomes were valuable. I learnt how to work methodically and consistently, I was taught how to use advanced database searching techniques and conduct a systematic literature search and I valued evidence-based practice even more. Furthermore, the quality assessment of the included studies, although informal, helped me develop further my design and analysis skills. This review was also a great chance to work systematically on my report and academic writing skills and improve them. This was the first time I wrote an academic report in English and I found the manuscript preparation for publication and the comments of my supervisors very helpful. I transferred all these skills to my other

placements and I will also use them in any other work setting.

My knowledge about several issues related to people with LD, and especially their mental health, increased following this placement. In particular, I gained an insight into how mental health services are delivered to this population and I understood the importance of MDT working and of accessible materials when working with people with LD. Moreover, the familiarity I acquired with the content and format of CBT programmes for individuals with LD and anxiety or depression was particularly useful for my second placement objective. This required me to develop some session materials for the anxiety management project. For example, I developed an anxiety log in collaboration with a SLT –an experience that increased my ability to produce accessible materials and proved to be valuable for my summer project.

As part of my second objective, I also needed to adapt the session plans and the training manual used in a study of CBT for people with LD and anger regulation problems (Willner et al., 2013) to the needs of our anxiety management project. For this purpose, I consulted my supervisors and a clinical psychology trainee (i.e. Natalie Smith) with experience in running anxiety management groups and I subsequently prepared a draft training manual and session plans. The ultimate aim of this project is to contribute to the production of NICE guidelines for people with LD and anxiety problems, as these individuals are not currently considered in the existing NICE guidance (2011).

The weekly meetings I had with my supervisors were extremely useful and not only helped me to improve my research skills, but also my capacity for self-reflection and self-observation. In general, supervision had a positive impact on my personal, clinical and academic skills. My ability to use the feedback of multiple supervisors in an effective manner was also improved and I managed to strike a balance between following their advice and working independently and taking initiatives.

In conclusion, my placement goals were accomplished and most importantly, my work had implications for the broader project of my supervisors. However, if I were to start this placement again, I would have done some things differently. Initially, I would have tried to find some time to acquire more insight into the inpatient and outpatient services of the Trust. This could have increased my understanding about the services that are available for people with LD and the role of clinical psychologists within the NHS. Moreover, if I conducted the review again, I would have dedicated more time to exploring the unique features of each database and learning how to utilise them more effectively. This would have really saved my time. For example, in my initial searches I was not aware of the subject headings used by some databases (e.g. Ovid Medline) and I only did some free text searching. Since I might have missed some papers, I re-conducted the searches and mapped search terms to subject headings in addition to the free text searching.

Finally, if I were to do this placement again, I would have spent more time on structuring my literature review. I did not pay a lot of attention to its structure when I initially wrote it and some sections were a bit repetitive and confusing. Some of the amendments I made when I worked again on it were a separate section for the methodological limitations of the studies and the presentation of results separately for studies which included individuals with anxiety, depression or a mixed clinical presentation.

References

- Allan, S., & Gilbert, P. (1995). A social comparison scale: Psychometric properties and relationship to psychopathology. *Personality and Individual Differences*, 19(3), 293-299.
- Andrews, F. M., & Withey, S. B. (1976). *Social indicators of well-being*. New York and London: Plenum, 20-31.
- Beck, A. (1996). Beck Depression Inventory-II (BDI-II). The Psychological Corporation. Harcourt Brace, San Antonio.
- Beck, A. T., Epstein, N., Brown, G., & Steer, R. A. (1988). An inventory for measuring clinical anxiety: psychometric properties. *Journal of consulting and clinical psychology*, 56(6), 893.
- Brown, M., & Marshall, K. (2006). Cognitive behaviour therapy and people with learning disabilities: implications for developing nursing practice. *Journal of psychiatric and mental health nursing*, 13(2), 234-241.
- Cooper, S. A., Smiley, E., Morrison, J., Williamson, A., & Allan, L. (2007). Mental ill-health in adults with intellectual disabilities: prevalence and associated factors. *The British Journal of Psychiatry*, 190(1), 27-35.
- Costello, H., Bouras, N., & Davis, H. (2007). The role of training in improving community care staff awareness of mental health problems in people with intellectual disabilities. *Journal of Applied Research in Intellectual Disabilities*, 20(3), 228-235.
- Dagnan, D., & Lindsay, W. R. (2012). People with Intellectual Disabilities and mental ill-health. In E. Emerson, C. Hatton, K. Dickson, R. Gone, A. Caine & J. Bromley (Eds.), *Clinical Psychology and people with Intellectual Disabilities* (pp. 313-338). Chichester: Wiley-Blackwell.

- Deb, S., Thomas, M., & Bright, C. (2001). Mental disorder in adults with intellectual disability. 1: Prevalence of functional psychiatric illness among a community-based population aged between 16 and 64 years. *Journal of Intellectual Disability Research*, 45(6), 495–505.
- Dodd, K., Austin, K., Baxter, L., Jennison, J., Kenny, M., Lippold, T., ... & Wilcox, E. (2013). Effectiveness of brief training in cognitive-behaviour therapy techniques for staff working with people with intellectual disabilities. *Advances in Mental Health and Intellectual Disabilities*, 7(5), 300-311.
- Douglass, S., Palmer, K., & O'Connor, C. (2007). Experiences of running an anxiety management group for people with a learning disability using a cognitive behavioural intervention. *British Journal of Learning Disabilities*, 35(4), 245-252.
- Emerson, E., & Hatton, C. (2007). Mental health of children and adolescents with intellectual disabilities in Britain. *The British Journal of Psychiatry*, 191(6), 493-499.
- Ghafoori, B., Ratanasiripong, P., & Holladay, C. (2010). Cognitive behavioral group therapy for mood management in individuals with intellectual disabilities: A pilot study. *Journal of Mental Health Research in Intellectual Disabilities*, 3(1), 1-15.
- Hamelin, J., Travis, R., & Sturmey, P. (2013). Anger management and intellectual disabilities: A systematic review. *Journal of Mental Health Research in Intellectual Disabilities*, 6(1), 60–70.
- Hassiotis, A., & Hall, I. (2008). Behavioural and cognitive-behavioural interventions for outwardly-directed aggressive behaviour in people with learning disabilities. *Cochrane Database of Systematic Reviews*, 2008(3), 1-44.
- Hassiotis, A., Serfaty, M., Azam, K., Strydom, A., Blizard, R., Romeo, R., ... & King, M. (2013). Manualised Individual Cognitive Behavioural Therapy for mood disorders in people with mild to moderate intellectual disability: A feasibility randomised controlled trial. *Journal of affective disorders*, 151(1), 186-195.

- Hemmings, C., Deb, S., Chaplin, E., Hardy, S., & Mukherjee, R. (2013). Review of research for people With ID and mental health problems: A view from the United Kingdom. *Journal of Mental Health Research in Intellectual Disabilities*, 6(2), 127-158.
- Jacobson, N. S., & Truax, P. (1991). Clinical significance: a statistical approach to defining meaningful change in psychotherapy research. *Journal of consulting and clinical psychology*, 59(1), 12.
- Jones, R. A. (2013). Therapeutic relationships with individuals with learning disabilities: a qualitative study of the counselling psychologists' experience. *British Journal of Learning Disabilities*, 42(3), 193-203.
- Jones, R., & Donati, M. (2009). The therapeutic relationship in psychological therapy for individuals with learning disabilities: a review of existing literature. *Advances in Mental Health and Learning Disabilities*, 3(1), 47-51.
- Keijsers, G. P. J., Schaap, C. P. D. R., & Hoogduin, C. A. L. (2000). The Impact of Interpersonal Patient and Therapist Behavior on Outcome in Cognitive-Behavior Therapy A Review of Empirical Studies. *Behavior Modification*, 24(2), 264-297.
- Kendall, P. C., & Hollon, S. D. (1987). Automatic Thoughts Questionnaire. In K. Corcoran & J. Fischer (Eds.), *Measures for Clinical Practice: A Sourcebook* (pp. 94-95). Free Press: New York.
- Lambert, M. J., & Barley, D. E. (2001). Research summary on the therapeutic relationship and psychotherapy outcome. *Psychotherapy: Theory, Research, Practice, Training*, 38(4), 357.
- Lindsay, W. R. (1999). Cognitive therapy. *Psychologist*, 12(5), 238-241.
- Lindsay, W. R., Howells, L., & Pitcaithly, D. (1993). Cognitive therapy for depression with individuals with intellectual disabilities. *British Journal of Medical Psychology*, 66(2), 135-141.

Lindsay, W.R., Neilson, C., & Lawrenson, H. (1997). Cognitive behaviour therapy for anxiety in people with learning disabilities. In B. Stenfert Kroese, D. Dagnan, & K. Loumidis (Eds.), *Cognitive-behaviour therapy for people with learning disabilities* (pp. 124-140). London: Routledge.

MacMahon, P., Stenfert Kroese, B., Jahoda, A., Stimpson, A., Rose, N., Rose, J., ... & Willner, P. (2014). 'It's made all of us bond since that course...'—a qualitative study of service users' experiences of a CBT anger management group intervention. *Journal of Intellectual Disability Research*.

Marwood, H., & Hewitt, O. (2013). Evaluating an anxiety group for people with learning disabilities using a mixed methodology. *British Journal of Learning Disabilities*, 41(2), 150-158.

Matson, J. L., & Shoemaker, M. (2009). Intellectual disability and its relationship to autism spectrum disorders. *Research in developmental disabilities*, 30(6), 1107-1114.

McCabe, M. P., McGillivray, J. A., & Newton, D. C. (2006). Effectiveness of treatment programmes for depression among adults with mild/moderate intellectual disability. *Journal of Intellectual Disability Research*, 50(4), 239-247.

McGillivray, J. A., McCabe, M. P., & Kershaw, M. M. (2008). Depression in people with intellectual disability: An evaluation of a staff-administered treatment program. *Research in developmental disabilities*, 29(6), 524-536.

Mindham, J., & Espie, C. A. (2003). Glasgow Anxiety Scale for people with an Intellectual Disability (GAS-ID): development and psychometric properties of a new measure for use with people with mild intellectual disability. *Journal of Intellectual Disability Research*, 47(1), 22-30.

NICE (2009). *Depression: the Treatment and Management of Depression in Adults (Update)*. NICE clinical guideline 90. Available at www.nice.org.uk/CG90 [NICE guideline].

NICE (2011). *Generalised Anxiety Disorder and Panic Disorder (With Or Without Agoraphobia) in Adults: Management in Primary, Secondary and Community Care*. NICE clinical guideline 113. Available at www.nice.org.uk/CG113 [NICE guideline].

Pert, C., Jahoda, A., Stenfert Kroese, B., Trower, P., Dagnan, D., & Selkirk, M. (2013). Cognitive behavioural therapy from the perspective of clients with mild intellectual disabilities: a qualitative investigation of process issues. *Journal of Intellectual Disability Research*, 57(4), 359-369.

Quigley, A., Murray, G. C., Mckenzie, K., & Elliot, G. (2001). Staff knowledge about symptoms of mental health problems in people with learning disabilities. *Journal of Intellectual Disabilities*, 5(3), 235-244.

Reid, K. A., Smiley, E., & Cooper, S. A. (2011). Prevalence and associations of anxiety disorders in adults with intellectual disabilities. *Journal of intellectual disability research*, 55(2), 172-181.

Richards, M., Maughan, B., Hardy, R., Hall, I., Strydom, A., & Wadsworth, M. (2001). Long-term affective disorder in people with mild learning disability. *The British Journal of Psychiatry*, 179(6), 523-527.

Rose, J., Loftus, M., Flint, B., & Carey, L. (2005). Factors associated with the efficacy of a group intervention for anger in people with intellectual disabilities. *British Journal of Clinical Psychology*, 44(3), 305-317.

Rose, J., West, C., & Clifford, D. (2000). Group interventions for anger in people with intellectual disabilities. *Research in Developmental Disabilities*, 21(3), 171-181.

Roy, A., Matthews, H., Clifford, P., Fowler, V., & Martin, D. M. (2002). Health of the Nation Outcome Scales for People with Learning Disabilities (HoNOS-LD). *The British Journal of Psychiatry*, 180(1), 61-66.

- Stenfert Kroese, B., Jahoda, A., Pert, C., Trower, P., Dagnan, D., & Selkirk, M. (2014). Staff expectations and views of cognitive behaviour therapy (CBT) for adults with intellectual disabilities. *Journal of Applied Research in Intellectual Disabilities*, 27(2), 145-153.
- Tsiouris, J. A., Kim, S. Y., Brown, W. T., & Cohen, I. L. (2011). Association of aggressive behaviours with psychiatric disorders, age, sex and degree of intellectual disability: a large-scale survey. *Journal of Intellectual Disability Research*, 55(7), 636-649.
- Vereenoghe, L., & Langdon, P. E. (2013). Psychological therapies for people with intellectual disabilities: A systematic review and meta-analysis. *Research in developmental disabilities*, 34(11), 4085-4102.
- Whitehouse, R. M., Tudway, J. A., Look, R., & Stenfert Kroese, B. (2006). Adapting individual psychotherapy for adults with intellectual disabilities: A comparative review of the cognitive-behavioural and psychodynamic literature. *Journal of Applied Research in Intellectual Disabilities*, 19(1), 55-65.
- Willner, P. (2005). The effectiveness of psychotherapeutic interventions for people with learning disabilities: a critical overview. *Journal of Intellectual Disability Research*, 49(1), 73-85.
- Willner, P. (2006). Readiness for cognitive therapy in people with intellectual disabilities. *Journal of Applied Research in Intellectual Disabilities*, 19(1), 5-16.
- Willner, P., Brace, N., & Phillips, J. (2005). Assessment of anger coping skills in individuals with intellectual disabilities. *Journal of Intellectual Disability Research*, 49(5), 329-339.
- Willner, P., Jones, J., Tams, R., & Green, G. (2002). A randomized controlled trial of the efficacy of a cognitive-behavioural anger management group for clients with learning disabilities. *Journal of Applied Research in Intellectual Disabilities*, 15(3), 224-235.

Willner, P., Rose, J., Jahoda, A., Stenfort Kroese, B., Felce, D., MacMahon, P., ... & Hood, K. (2013). A cluster randomised controlled trial of a manualised cognitive behavioural anger management intervention delivered by supervised lay therapists to people with intellectual disabilities. *Health Technology Assessment*, 17(21), 1-173.

Zijlmans, L. J. M., Embregts, P. J. C. M., Gerits, L., Bosman, A. M. T., & Derksen, J. J. L. (2011). Training emotional intelligence related to treatment skills of staff working with clients with intellectual disabilities and challenging behaviour. *Journal of intellectual disability research*, 55(2), 219-230.

CHAPTER 2:

**PREOPERATIVE PSYCHOLOGICAL INTERVENTIONS FOR PATIENTS UNDERGOING
SURGERY FOR CANCER: A SYSTEMATIC REVIEW**

The effect of pre-operative psychological interventions on the post-operative outcomes of patients undergoing surgery for cancer: a systematic review

Ioanna Tsimopoulou

Supervisors: Dr Ravinder Vohra, Dr Ruth Howard, Dr Inigo Tolosa



For my spring placement, I worked in the Sarcoma Unit of Queen Elizabeth Hospital Birmingham (QEHB) and I was supervised by Dr Ravinder Vohra, Dr Ruth Howard and Dr Inigo Tolosa.

Presentation content

- 1. Placement objectives**
- 2. Practical Experience**
- 3. Literature review & ideas for the development of an intervention**
- 4. Reflect on learning outcomes**

My presentation consists of four main parts. I will describe my placement objectives, the practical experience I gained and, most importantly, I will attempt to provide you with an overview of the literature review I conducted and its clinical implications. Finally, I will reflect on the learning outcomes I achieved.

1. Placement objectives

- A literature review of the effect of pre-operative psychological interventions on the post-operative outcomes of patients undergoing operations for cancer
- Clinical audit of the records of sarcoma patients



- **Get involved in outpatients and theatres**

In this placement, I had three primary objectives. The first was to carry out a literature review about the effect of pre-operative psychological interventions on the post-operative outcomes of patients undergoing surgery for cancer. The second was to conduct a clinical audit and the third to get involved in outpatients and theatres.

The aim of the audit was to examine whether the psychological needs of sarcoma patients who underwent surgery at QEHB had been formally assessed (Holistic Needs Assessment) and if this assessment had an impact on their post-operative outcomes. For that purpose, I extracted and analysed patient data from three sources: the Clinical Portal, the Prescribing Information & Communication System (PICS) and the Somerset Cancer Registry. I successfully accomplished this task, but will not provide further information here due to the restricted word limit.

2. Practical experience

- Involved in outpatients clinics
- Observed major surgeries
- Discussed with members of the sarcoma MDT



As part of my placement, I was given the opportunity to get involved in outpatient clinics, observe major operations and discuss with members of the sarcoma MDT the complex needs and difficulties of patients. These valuable experiences increased my awareness of the multiple physical, social and psychological issues sarcoma patients need to cope with and fortified my commitment to this project.

3. Literature review

i. Introduction

- **Cancer patients experience anxiety and depression symptoms following diagnosis and during treatment** (Krebber et al., 2014; Mitchell et al., 2011; Vehling et al., 2012)
- **The pre and perioperative period is particularly distressing** (Lehto & Cimprich, 1999; Nosarti, Roberts, Crayford, McKenzie & David, 2002)
- **Effectiveness of pre-operative psychological interventions for non-cancer surgical patients** (Devine, 1992; Nelson et al., 2013)

Aim: investigate the effect of psychological interventions delivered prior to surgery on the post-operative outcomes of patients undergoing cancer surgery

Now, I will focus on the literature review.

Cancer patients experience anxiety and depression symptoms following diagnosis and during treatment (Krebber et al., 2014; Mitchell et al., 2011; Vehling et al., 2012). A wide range of psychological therapies have been proposed in an attempt to provide cancer patients with aids to alleviate their distress, but these have been typically administered following cancer treatment. However, the pre- and perioperative period is particularly distressing for cancer patients (Lehto & Cimprich, 1999; Nosarti, Roberts, Crayford, McKenzie & David, 2002).

There is some evidence to support the effectiveness of pre-operative psychological interventions in patients undergoing non-cancer surgery (Devine, 1992; Nelson et al., 2013). For example, pre-

operative mind-body and psycho-educational interventions on patients undergoing coronary bypass graft surgery have significantly reduced length of hospital stay, anxiety and depression scores (Arthur, Daniels, McKelvie, Hirsh and Rush, 2000; Dao et al., 2011). In addition, other studies have shown that similar pre-operative psychological interventions effectively decreased cortisol levels (Manyande et al., 1995) and enhanced wound healing following abdominal surgery (Broadbent et al., 2012).

However, the role of pre-operative psychological interventions in patients undergoing major surgery for cancer is unclear. The aim of the present review was to investigate the effect of psychological interventions delivered prior to surgery on the post-operative outcomes of patients undergoing cancer surgery.

ii. Methodology

Searched:

embase

MEDLINE

PsycINFO

Search terms: related to cancer and general surgery, psychological interventions and post-operative outcomes

Table 1. Inclusion criteria

Population: individuals who underwent surgery for cancer

Intervention: preoperative psychological interventions

Outcomes: post-operative surgical outcomes, (e.g. complications, mortality, immune function), psychological outcomes (e.g. anxiety, depression), quality of life outcomes and somatic symptoms

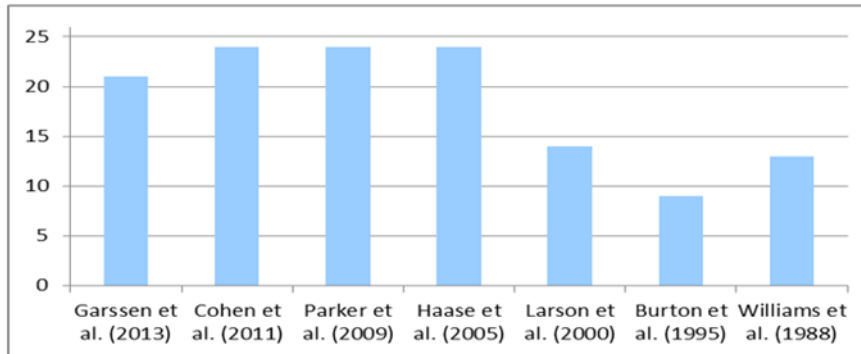
Study: any study from a peer-reviewed journal in the English language

I searched three electronic databases: Embase (1974 to 2014), Medline (1946 to 2014) and PsycInfo (1967 to 2014). Search terms are shown in Appendix 3. Briefly, I used three groups of terms: 1) terms related to cancer and general surgery; 2) terms related to psychological interventions -including the assessment of patients' psychological needs; and 3) terms related to post-operative outcomes. Finally, the search terminology varied due to the differences between the aforementioned databases.

Inclusion criteria are reported in Table 1.

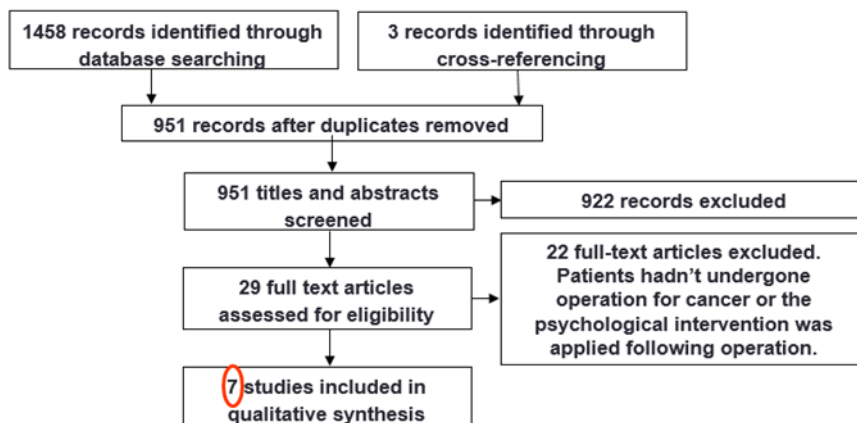
ii. Methodology

Quality assessment: Standard quality assessment criteria for evaluating primary research papers from a variety of fields (Kmet, Lee and Cook, 2004)



To assess the quality of the included studies, I used the assessment criteria provided by Kmet, Lee and Cook (2004). Four studies were assessed to be good quality (Cohen et al., 2011; Garssen et al., 2013; Haase et al., 2005; Parker et al., 2009), two moderate (Larson et al., 2000; Williams et al., 1988) and one poor quality (Burton et al., 1995) (Appendix 4). Poor quality studies were not excluded due to the small number of relevant literature in this area.

iii. Results



- **All studies were RCTs, except one** (Williams et al., 1988)
- **Included patients with breast, gynaecological, colorectal and prostate cancer** (Burton et al., 1995; Garssen et al., 2013; Larson et al. 2000; Williams et al., 1988) (Williams et al., 1988) (Haase et al., 2005) (Parker et al., 2009)
- **Interventions varied between studies**

Seven studies were considered eligible as the flow diagram shows. All were Randomised Controlled Trials (RCTs), except one (Williams et al., 1988). Four were conducted in patients with breast cancer (Burton et al., 1995; Garssen et al., 2013; Larson, Duberstein, Talbot, Caldwell and Moynihan, 2000; Williams et al., 1988) and other studies included patients with gynaecological cancer (Williams et al., 1988), colorectal cancer (Haase et al., 2005) and prostate cancer (Parker et al., 2009). The characteristics of the included studies are listed in Appendix 5.

Interventions varied between studies. They included stress management training (Cohen et al., 2011; Garssen et al., 2013; Parker et al., 2009), a psychosocial intervention (Larson et al., 2000), training to guided imagery or progressive muscle relaxation via recordings (Haase et al., 2005), a brief psychotherapeutic intervention along with an interview (Burton et al., 1995) and a structured teaching programme that prepared and informed women regarding the planned surgery (Williams

et al., 1988). In five studies, one or two sessions were also administered following the operation – typically on the second post-operative day (Cohen et al., 2011; Garssen et al., 2013; Haase et al., 2005; Parker et al., 2009; Williams et al., 1988). Detailed description of psychological interventions is provided in Appendix 6.

iii. Results

- Traditional surgical and immunological post-operative outcomes

Surgical outcomes

- Length of hospital stay
- Complications
- Analgesic consumption
- Mortality

No intervention effect

Immune outcomes

- Proinflammatory cytokines
- Natural killer cell cytotoxicity

**-There was a significant intervention effect
-Some findings were conflicting**

Several outcomes were investigated here and were grouped into two main categories: ‘traditional’ surgical and immunological post-operative outcomes and patient-reported outcomes e.g. psychological, quality of life (QoL) outcomes and somatic symptoms. A comprehensive list of outcomes included in each study has been reported in Appendix 7.

Results show that the intervention had no effect on ‘traditional’ surgical outcomes such as length of hospital stay, complications, analgesic use or mortality (Burton et al., 1995; Haase et al., 2005; Parker et al., 2009; Williams et al., 1988). However, the immunological function of patients improved following the intervention (Cohen et al., 2011; Larson et al., 2000). Levels of proinflammatory cytokines, such as IL-12p70, IL-1 β , TNF- α , and IFN- γ were significantly higher in the intervention groups compared to the controls. This increase suggests a better immune

response. However, outcomes about levels of natural killer cell cytotoxicity (NKCC) -a different indicator of immune response- were conflicting.

iii. Results

- Traditional surgical and immunological post-operative outcomes

Psychological outcomes

- Depression
- Anxiety

QoL outcomes

- Physical component
- Mental health component

Somatic symptoms

- Fatigue

-There was a significant intervention effect
-Some findings were conflicting

Studies investigating patient-reported outcomes showed much heterogeneity in their results.

Regarding psychological outcomes, a significant decrease was found in the depression and mood disturbance scores of participants (Burton et al., 1995; Garssen et al., 2013; Parker et al., 2009).

However, outcomes about anxiety were contradictory (Burton et al., 1995; Garssen et al., 2013).

Two studies examined the effect of pre-operative interventions on post-operative quality of life (QoL) outcomes. Results show that psychological interventions had a significant effect on the physical aspects of patients' QoL (Garssen et al., 2013; Parker et al., 2009), but no effect on its mental health components.

Regarding somatic symptoms, the evidence of intervention effects on fatigue is mixed (Garssen et al., 2013; Haase et al., 2005).

iv. Discussion

- Only **seven** studies have examined the effect of preoperative psychological interventions on the post-operative outcomes of cancer patients
- The interventions appear to affect **immunological function** and **certain patient-reported outcomes**
- **Stress management training** appears to be the most effective among the interventions that have been investigated

Relaxation
training

Guided
imagery

Problem
solving

Coping
strategies

Audio
CD

Only seven studies have examined the effect of preoperative psychological interventions on the post-operative outcomes of cancer patients. Despite a heterogeneous range of preoperative psychological interventions investigated, the different assessed outcomes and the different outcome measures used, the interventions appear to affect immunological function and certain patient-reported outcomes.

Based on the existing evidence, stress management training appears to be the most effective among the interventions that have been investigated. It comprises relaxation training, guided imagery (to prepare patients for the operation), problem solving strategies, coping strategies and an audio CD. The effectiveness of relaxation interventions has also been demonstrated both for non-cancer surgical patients (Nelson et al., 2013) and for cancer patients receiving a non-surgical treatment (Luebbert, Dahme & Hasenbring, 2001; Redd, Montgomery & DuHamel, 2001).

iv. Discussion

- **Limitations to the studies presented here**

- underpowered to detect a significant effect
- non-blinding of researchers to group assignment
- females with breast cancer; average age from 55 to 60 years old

- **Limitations of the review**

- only studies in the English language
- quality assessment was conducted only by me

There are limitations to the studies presented here. Blinding is an issue in these types of studies. Researchers were blinded to group assignment in only three studies (Cohen et al., 2011; Haase et al., 2005; Parker et al., 2009). In addition, the majority of the studies were conducted in females with breast cancer and their results may not be generalisable to other cancer populations. The studies presented here are all underpowered to detect a significant effect difference in the surgical outcomes such as length of stay, discussed. In three studies, no power analysis was reported (Burton et al., 1995; Larson et al., 2000; Williams et al., 1988). Meta-analysis cannot overcome this lack of statistical power. Outcomes in these studies have been assessed using a variety of measures thus limiting the possibility of summarizing the available results with meta-analysis.

This review included only studies in the English language and quality assessment was conducted only by me.

iv. Discussion

- **Recommendations for future research**

- adequately powered RCTs
- investigate the effectiveness of interventions across several types of cancer with more generalizable cohorts
- compare the effectiveness of different interventions
- target high risk groups

More high quality research is needed. The conduct of adequately powered RCTs should be a research priority. Furthermore, there is a need to investigate the effectiveness of interventions across several types of cancer with more generalizable cohorts e.g. wider age ranges and more male participants. Future research should compare the effectiveness of different interventions and investigate the possibility that interventions might be more effective among patients with increased levels of distress pre-operatively.

iv. Discussion

- **Ideas for the development of an intervention**

- initially, explore the experiences of individuals who have undergone an operation for cancer
- potential components of such an intervention:
 - ✓ stress management training
 - ✓ relaxation training: guided imagery, progressive muscle relaxation, mindfulness techniques
 - ✓ cognitive-Behavioural skills: problem solving, coping strategies
 - ✓ preparation for operation: concerns and fears, information about the process
 - ✓ materials: a guide for stress management, audio recordings for relaxation techniques
- some booster sessions

Through this systematic review and the practical experience I acquired, I had some ideas for the development of a pre-operative psychological intervention. Initially, the engagement of individuals who have undergone an operation for cancer and the exploration of their experiences through a qualitative study would be essential.

And these are some ideas about the potential components of such an intervention:

- Stress management training
- Relaxation training: guided imagery, progressive muscle relaxation, mindfulness techniques
- Cognitive-Behavioural skills: problem solving, coping strategies
- Preparation for operation: concerns and fears, information about the process

- Materials: a guide for stress management, audio recordings for relaxation techniques

Furthermore, some booster sessions could possibly improve the effectiveness of the intervention further.

4. Reflection on learning outcomes

- Explored my interest in psycho-oncology
- My research skills were enhanced
 - Systematic literature reviews
 - Clinical audits
 - Formal quality appraisal
- Collaborated with a MDT
- Acquired work experience in the NHS
- Improved my academic and report writing skills
- Implications for the work of my supervisors

This placement provided me with the opportunity to explore my research interest in psycho-oncology and in health psychology, expand my knowledge and acquire valuable experience.

Furthermore, my research skills were enhanced and I became more capable of conducting literature reviews and clinical audits. The systematic review process was quite demanding as my supervisors had not determined the exact purpose of the review and I needed to define it in collaboration with some sarcoma MDT members. Additionally, an interesting and simultaneously challenging process was the formal quality appraisal of the included studies. This has greatly helped me become more critical when appraising a research article and increased my awareness of quality issues.

Although I had previous experience of working in teams, this was the first time I collaborated with a MDT. In particular, I co-operated very effectively with a number of surgeons, clinical psychologists and nurses in order to define the scope of review questions and conduct the audit.

This was a great experience that increased my understanding about the role of colleagues from different professions and helped me improve my communication and interpersonal skills.

Through this placement, I also achieved two of the goals I had set for myself before starting this course, i.e. to acquire work experience in the NHS and improve my academic writing skills. I had the chance to gain an insight into NHS, see how psychology is applied to health care and understand better the role of clinical psychologists within the NHS. Additionally, my academic and report writing skills were actually enhanced by the journal manuscript I prepared and the useful comments and feedback I received by my supervisors.

Finally, I am really happy that my placement had implications for the work of my supervisors. The literature review demonstrated the limitations of the existing studies and the need for high quality research and my supervisors aim to design and conduct a study that examines the effectiveness of a pre-operative psychological intervention for patients who undergo surgery for sarcomas.

References

- Arthur, H. M., Daniels, C., McKelvie, R., Hirsh, J., & Rush, B. (2000). Effect of a preoperative intervention on preoperative and postoperative outcomes in low-risk patients awaiting elective coronary artery bypass graft surgery. A randomized, controlled trial. *Annals of Internal Medicine*, 133(4), 253-262.
- Broadbent, E., Kahokehr, A., Booth, R. J., Thomas, J., Windsor, J. A., Buchanan, C. M., ... & Hill, A. G. (2012). A brief relaxation intervention reduces stress and improves surgical wound healing response: a randomised trial. *Brain, behavior, and immunity*, 26(2), 212-217.
- Burton, M. V., Parker, R. W., Farrell, A., Bailey, D., Conneely, J., Booth, S., & Elcombe, S. (1995). A randomized controlled trial of preoperative psychological preparation for mastectomy. *Psycho-Oncology*, 4(1), 1-19.
- Cohen, L., Parker, P. A., Vence, L., Savary, C., Kentor, D., Pettaway, C., ...& Radvanyi, L. (2011). Presurgical stress management improves postoperative immune function in men with prostate cancer undergoing radical prostatectomy. *Psychosomatic medicine*, 73(3), 218-225.
- Dao, T.K., Youssef, N.A., Armsworth, M., Wear, E., Papatheopoulos, K.N. & Gopaladas, R. (2011). Randomized controlled trial of brief cognitive behavioral intervention for depression and anxiety symptoms preoperatively in patients undergoing coronary artery bypass graft surgery. *The Journal of Thoracic and Cardiovascular Surgery*, 142(3), 109-115.
- Devine, E. C. (1992). Effects of psychoeducational care for adult surgical patients: a meta-analysis of 191 studies. *Patient education and counseling*, 19(2), 129-142.
- Garssen, B., Boomsma, M. F., Jager Meezenbroek, E., Porsild, T., Berkhof, J., Berbee, M., ...& Beelen, R. H. (2013). Stress management training for breast cancer surgery patients. *Psycho-Oncology*, 22(3), 572-580.

- Haase, O., Schwenk, W., Hermann, C., & Müller, J. M. (2005). Guided imagery and relaxation in conventional colorectal resections: a randomized, controlled, partially blinded trial. *Diseases of the colon & rectum*, 48(10), 1955-1963.
- Krebber, A. M. H., Buffart, L. M., Kleijn, G., Riepma, I. C., Bree, R., Leemans, C. R., ... & Verdonck-de Leeuw, I. M. (2014). Prevalence of depression in cancer patients: a meta-analysis of diagnostic interviews and self-report instruments. *Psycho-Oncology*, 23(2), 121-130.
- Larson, M. R., Duberstein, P. R., Talbot, N. L., Caldwell, C., & Moynihan, J. A. (2000). A presurgical psychosocial intervention for breast cancer patients: psychological distress and the immune response. *Journal of Psychosomatic Research*, 48(2), 187–194.
- Lehto, R. H., & Cimprich, B. (1999). Anxiety and directed attention in women awaiting breast cancer surgery. *Oncology nursing forum* 26(4), 767-772.
- Manyande, A., Berg, S., Gettins, D., Stanford, S. C., Mazhero, S., Marks, D. F., & Salmon, P. (1995). Preoperative rehearsal of active coping imagery influences subjective and hormonal responses to abdominal surgery. *Psychosomatic Medicine*, 57(2), 177-182.
- Mitchell, A. J., Chan, M., Bhatti, H., Halton, M., Grassi, L., Johansen, C., & Meader, N. (2011). Prevalence of depression, anxiety, and adjustment disorder in oncological, haematological, and palliative-care settings: a meta-analysis of 94 interview-based studies. *The lancet oncology*, 12(2), 160-174.
- Nelson, E. A., Dowsey, M. M., Knowles, S. R., Castle, D. J., Salzberg, M. R., Monshat, K., ... & Choong, P. F. (2013). Systematic review of the efficacy of presurgical mind-body based therapies on post-operative outcome measures. *Complementary therapies in medicine*, 21(6), 697-711.

Nosarti, C., Roberts, J. V., Crayford, T., McKenzie, K., & David, A. S. (2002). Early psychological adjustment in breast cancer patients: a prospective study. *Journal of Psychosomatic Research*, 53(6), 1123-1130.

Parker, P.A., Pettaway, C.A., Babaian, R.J., Pisters, L.L., Miles, B., Fortier, A., Wei, Q., Carr, D.D., and Cohen, L. (2009). The Effects of a Presurgical Stress Management Intervention for Men with Prostate Cancer Undergoing Radical Prostatectomy. *Journal of Clinical Oncology*, 27(19), 3169-3176.

Vehling, S., Koch, U., Ladehoff, N., Schön, G., Wegscheider, K., Heckl, U., ... & Mehnert, A. (2012). [Prevalence of affective and anxiety disorders in cancer: systematic literature review and meta-analysis]. *Psychotherapie, Psychosomatik, medizinische Psychologie*, 62(7), 249-258.

Williams, P. D., Valderrama, D. M., Gloria, M. D., Pascoguin, L. G., Saavedra, L. D., De la Rama, D. T., ... & Zaldivar, S. B. (1988). Effects of preparation for mastectomy/hysterectomy on women's post-operative self-care behaviors. *International journal of nursing studies*, 25(3), 191-206.

CHAPTER 3:

**A CASE SERIES TO EXAMINE WHETHER PEOPLE WITH LEARNING
DISABILITIES CAN LEARN HOW TO LINK MEDIATING COGNITIONS TO
SUBSEQUENT EMOTIONAL RESPONSES**

Abstract

Background:

People with learning disabilities (LD) have increased mental health needs. Although Cognitive Behavioural Therapy (CBT) is recommended for the treatment of a number of mental disorders among the general population, the ability of individuals with LD to understand CBT concepts and engage in CBT has been questioned.

Aims:

To examine whether specific prerequisite skills for CBT can be taught to people with LD using a newly developed training intervention and to investigate the acceptability of the intervention.

Methods:

The study adopted a within-subjects case series research design. Quantitative assessment methods were used to evaluate the CBT skills of six adults with mild to moderate LD pre-intervention, following intervention and at one-week follow up. Participants were also asked to provide some qualitative feedback about the intervention.

Results:

The cognitive mediation skills and the ability of most participants to link activating events to emotions increased following intervention training and this improvement was maintained for most of them at follow up. However, the training had no effect on the capacity of individuals to

discriminate among feelings, thoughts and behaviours. The feedback of participants regarding the process and content of the task demands was positive and useful.

Conclusions:

Study outcomes suggest that people with LD can learn some of the skills considered necessary to participate in CBT, such as cognitive mediation. However, further and more robust research is required to substantiate these findings.

Introduction

There is considerable variation in prevalence rates of mental health problems among people with learning disabilities (LD) due to the diagnostic criteria applied in each study, the assessments and sampling methods used (Cooper, Smiley, Morrison, Williamson & Allan, 2007; Dagnan & Lindsay, 2012; Emerson & Hatton, 2007) and the inclusion or exclusion of individuals with comorbid conditions such as ASD, dementia and challenging behaviour (Cooper et al., 2007; Deb, Thomas & Bright, 2001). Collectively, studies report that people with LD suffer from mental health problems at least at the same and most probably at a higher rate than the general population (Borthwick-Duffy, 1994; Cooper et al., 2007; Tsiouris, Kim, Brown & Cohen, 2011), with depression and anxiety as the most common disorders (Reid, Smiley & Cooper, 2011; Richards et al., 2001; Smiley, 2005).

Reported increased rates of mental illness have been attributed to a number of factors related to individuals' biological vulnerability, socioeconomic position and adverse life experiences (Clarke, 2003; Emerson & Hatton, 2007; Hulbert-Williams & Hastings, 2008). People with LD are more likely to have experiences of stigma and discrimination (Dagnan & Lindsay, 2012; Jahoda, Dagnan, Jarvie & Kerr, 2006; Reiss & Benson, 1984), of poverty and unemployment (Emerson, 2003; Emerson, 2007; Emerson & Gone, 2012) and of sexual and physical abuse across the life span (Lindsay, Steele, Smith, Quinn and Allan, 2006; Sequeira & Hollins, 2003). Furthermore, links have been found between dysfunctional cognitions and depressive and anxiety symptomatology (Glenn, Bihm & Lammer, 2003; Nezu, Nezu, Rothenberg & DelliCarpini, 1995). Jahoda and colleagues (2006) have stressed the important role that social experiences, such as

isolation, play in shaping people's cognitions and self-perception, thus suggesting that cognitions are more likely to mediate depression in people with LD due to their adverse life experiences.

Despite the increased mental health needs of people with LD, the development of psychosocial interventions has been slow (Hatton, 2002) and pharmacological and behavioural interventions have been the treatment of choice (Stenfert Kroese, 1997). A number of psychological therapies have emerged across the years, including CBT. CBT is a talking therapy developed by Ellis (1957, 1962) and one of its basic assumptions is that our thoughts determine our feelings and behaviours. To participate in CBT, individuals need to possess the following abilities: i) understand cognitive mediation, namely the mediating role of thoughts in emotional responses, ii) link activating events to emotions, and iii) differentiate between feelings, thoughts and behaviours. Studies have also consistently shown a significant relationship between individuals' verbal ability and CBT skills (Dagnan et al., 2000; Joyce et al., 2006; Sams et al., 2006).

Although CBT is recommended for the treatment of anxiety and depression among the general population (NICE, 2011; 2009), until recently there was a dearth of research evidence about its effectiveness with people with LD, who were perceived to lack the cognitive skills (Stenfert-Kroese, Dagnan & Loumidis, 1997) considered necessary to engage in CBT (Safran, Segal, Vallis, Shaw, & Samstag, 1993). Currently, although there is a proliferation of studies examining the effectiveness of CBT in people with LD and anger, depression or anxiety symptoms, evidence on how effective these interventions are remains modest and more rigorous and robust research is needed (Hamelin, Travis & Sturmey, 2013; Nicoll, Beail & Saxon, 2013; Unwin, Tsimopoulou, Azmi & Stenfert Kroese, 2014; Vereenoghe & Langdon, 2013; Willner, 2005; Willner et al., 2013).

McGillivray and Kershaw (2014) compared the effectiveness of CBT, cognitive and behavioural strategies in attenuating the depressive symptoms and negative automatic thoughts of individuals with mild LD. The results indicate the long-term superiority of CBT, while behavioural strategies appear to produce only short-lived effects. Existing programmes for people with mild LD and mental health problems tend to focus more on teaching participants behavioural coping strategies, and their effectiveness may be further improved if greater emphasis is given to cognitive strategies. However, there is a body of evidence that indicates the difficulty of people with LD understanding the cognitive components of CBT (Dagnan & Chadwick, 1997; Dagnan, Chadwick & Proudlove, 2000; Dagnan, Mellor & Jefferson, 2009; Joyce, Globe, & Moody, 2006; Oathamshaw & Haddock, 2006; Sams, Collins, & Reynolds, 2006) although the model has been adapted to meet their needs (i.e. use of simple language and visual aids, involvement of carers etc.) (Whitehouse, Tudway, Look & Stenfert Kroese, 2006; Willner & Gooday, 2006).

Specifically, the majority of adults with mild LD appear to be able to link specific events and emotional consequences (Reed & Clements, 1989), but have difficulties in discriminating between thoughts, feelings and behaviours (Oathamshaw et al., 2006; Sams et al., 2006) and in understanding cognitive mediation (Dagnan & Chadwick, 1997; Dagnan et al., 2000; Dagnan, et al., 2009; Joyce et al., 2006; Oathamshaw & Haddock, 2006; Sams et al., 2006). Regarding the concept of cognitive mediation, as measured by the task developed by Dagnan and Chadwick (1997; Dagnan et al., 2000), individuals found it more difficult to identify the appropriate mediating cognition when there was incongruence between the given event and the emotion (e.g., some friends do not say hello and you feel happy) compared to when the emotion matched the event.

It has been suggested that individuals who seemingly lack the prerequisite skills for CBT could possibly benefit from a pre-therapy structured intervention aiming to teach them some of CBT's core concepts, such as cognitive mediation (Dagnan et al., 2000; Sams et al., 2006). Hence, this type of training can increase a client's suitability to participate in CBT. This hypothesis is in accord with the concept of the zone of proximal development, introduced by Lev Vygotsky (1978), which suggests that it is more significant to know what someone can learn and achieve when assisted by a tutor compared to what s/he can do alone (Dagnan et al., 2000). Two studies have so far examined whether preparatory training can enhance the cognitive skills of individuals with mild to moderate LD (Bruce, Collins, Langdon, Powlitch & Reynolds, 2010; Vereenoghe, Reynolds, Gega & Langdon, 2013).

Bruce and colleagues (2010) found that individuals who received one-hour structured training in CBT skills were more capable of creating links between thoughts and feelings compared to a control group, as assessed by 'The Thought to Feeling task' (Doherr, Reynolds, Wetherly, & Evans, 2005). Individuals had a verbal IQ score of 59 or below (WASI; Wechsler, 1999). Nevertheless, training had no effect on participants' ability to discriminate among feelings, thought and behaviours, as measured by their performance on 'The Thought-Feeling-Behaviour task' (Quakley, Reynolds & Coker, 2004). Moreover, Vereenoghe and colleagues (2014) investigated the impact of computerized training on people's cognitive mediation skills, measured by tasks developed by Dagnan and Chadwick (1997) and Dagnan and colleagues (2000). Participants had an average IQ score of 53.3 (WASI-II; Wechsler & Hsiao-pin, 2011). The results indicate that the intervention was effective in increasing participants' ability to choose the appropriate feeling when they were provided with congruent pairings of events and thoughts, but had no effect on their

ability to identify the correct mediating cognition when provided with either congruent or incongruent pairings of events and emotions.

These two studies show that it is feasible to teach people with LD some of the prerequisite skills for CBT -however, both have some limitations. Initially, the two questionnaires used by Bruce and colleagues (2010) had been originally developed to assess the cognitive skills of children (Doherr et al., 2005; Quakley et al., 2004) and were subsequently adapted for use by people with LD (Sams et al., 2006). Nevertheless, no pilot was conducted to assess their suitability and acceptability among this population. Moreover, 'The Thought to Feeling task' (Doherr et al., 2005) might not be a reliable indicator of cognitive mediation and overestimate individuals' skills, as they are solely asked to identify how a fictional character would feel in specific situation-thought pairs. Their ability to correctly identify a mediating belief based on a situation-feeling pair is not assessed. Added to this, the task has only congruent situation-thought pairings, and therefore, it does not examine the effect of incongruity on individuals' ability to identify appropriate feelings. In the study by Vereenooghe and colleagues (2014), the authors acknowledge that the absence of intervention effect on the selection of appropriate mediating beliefs may be related to the nature of the intervention. Individuals were only taught how to make associations between situations and feelings based on the task by Reed and Clements (1989). They did not receive training in cognitive mediation skills, while the intervention effect on participants' ability to distinguish between thoughts, feelings and behaviours was not assessed. Finally, no follow up assessment was conducted.

This study builds on Vereenooghe and colleagues (2014) and Bruce and colleagues (2010) and adopts an idiographic approach in an attempt to gain a better insight into the capacity of people

with LD to understand the basic elements of CBT. Hence, the main aim of our study was to examine whether three of the cognitive skills considered critical to the successful implementation of CBT can be taught to people with LD using a short, cartoon-animated video. These skills are: i) the ability to identify mediating cognitions, ii) the ability to link events to emotions, iii) the ability to discriminate between feelings, thoughts and behaviours. A secondary objective was to investigate the acceptability of the intervention and the visual aids that were developed. If this simple CBT training intervention does effectively increase the cognitive skills of people with LD, this will provide important information for clinicians working with people with LD and may improve access to CBT for this population.

Methods

Design

This study employed a within-subjects case series research design to examine if people with LD can be taught some of the requisite skills for CBT. This type of design permits to explore individuals' abilities in depth and gives emphasis to individual uniqueness and complexity. Quantitative and qualitative methods were used and CBT skills were assessed at three time points: i) before the intervention, ii) following the intervention and, iii) one week after the intervention. The intervention was a video, developed by the researcher, consisting of a number of digital stories explaining the basic principles of CBT. Digital storytelling is a simple way to share a story using computer technology -including images, video clips and recorded audio narrations. The order of the administration of outcome measures was counterbalanced across participants in order to control for fatigue effects on their performance.

Participants

Sample. The recruitment target was achieved and six individuals with LD were recruited from a day centre in Birmingham. The target was decided in consultation with a research tutor due to the study design which sought in depth data. The sample consisted of four women and two men between 31 and 60 years old.

Inclusion and exclusion criteria. Participants met the following inclusion criteria: i) had mild to moderate LD, ii) were over 18 years old, iii) had English as their first language, and iv) had normal or corrected to normal vision and hearing. The level of LD was not formally assessed - suitable participants were identified by staff members. Those individuals who had been diagnosed with a severe mental health problem (such as psychosis) or were currently receiving CBT were excluded from the study.

Training intervention

A video was created by the researcher to teach people with LD about the cognitive skills considered necessary to engage in CBT. It consisted of several simple digital stories, it lasted approximately 9 minutes and was created using Pixton Comics (2014) –an online comic making tool. The idea of using this online software derived from Vereenoghe and colleagues (2014) who originally used it in their study and shared their idea and valuable suggestions with us. The video was accompanied by a voice-over which was created with the assistance of my supervisors.

The video has 4 main parts. In the first part, the three basic concepts of CBT -i.e. feelings, thoughts and behaviours- are defined and several examples of each category are provided. The second part focuses on teaching individuals how to discriminate between feelings, thoughts and behaviours. Participants are also taught how to use hand gestures that signify respectively feelings, thoughts and behaviours. In the third part, participants are trained in linking activating events to emotions and in the final section in making associations between mediating cognitions and subsequent emotional responses. During the video, participants are presented with scenarios and are asked questions similar to those in the questionnaires. Correct answers are provided in the video and if needed the researcher gives participants further explanations. The video was paused after each part and the researcher responded to the queries of the participants, recapitulated and repeated the core concepts, depending on each individual's needs and comprehension.

Measures

British Picture Vocabulary Scale II (BPVS II; Dunn, Dunn, Whetton & Burley, 1997).

This measure assesses individuals' language comprehension ability. Although it was originally developed for use with children, it has been extensively used among people with LD for clinical and research purposes. According to Glenn & Cunningham (2005), the reliability of the measure is good (Cronbach's alpha: 0.93, median split-half: 0.86), with proven validity. Participants are presented with a series of pages with 4 pictures on each and are asked to select the picture that best illustrates the word they hear each time.

Cognitive mediation task (Dagnan et al., 2009). This questionnaire measures the ability of people with LD to understand cognitive mediation and was initially proposed in 1997 by Dagnan

and Chadwick. Participants are presented with six simple scenarios, such as ‘You want to go on a special trip but there is only one place and your friend is chosen to go instead’ and each scenario is linked to a positive or a negative emotion: ‘You feel happy’ or ‘You feel sad’. Then, individuals are asked ‘What would you be thinking or saying to yourself?’ in this situation. Each scenario was presented twice, each time paired with the opposite feeling and participants could achieve a maximum score of 12. There was auditory and visual presentation of the scenarios to facilitate understanding and aid participants’ memory. Pixton Comics (2014) was used to visualize them and different presentation cards were created for female (Appendix 8a) and for male participants (Appendix 8b). An example of one congruent and one incongruent scenario is shown below in Figure 1.

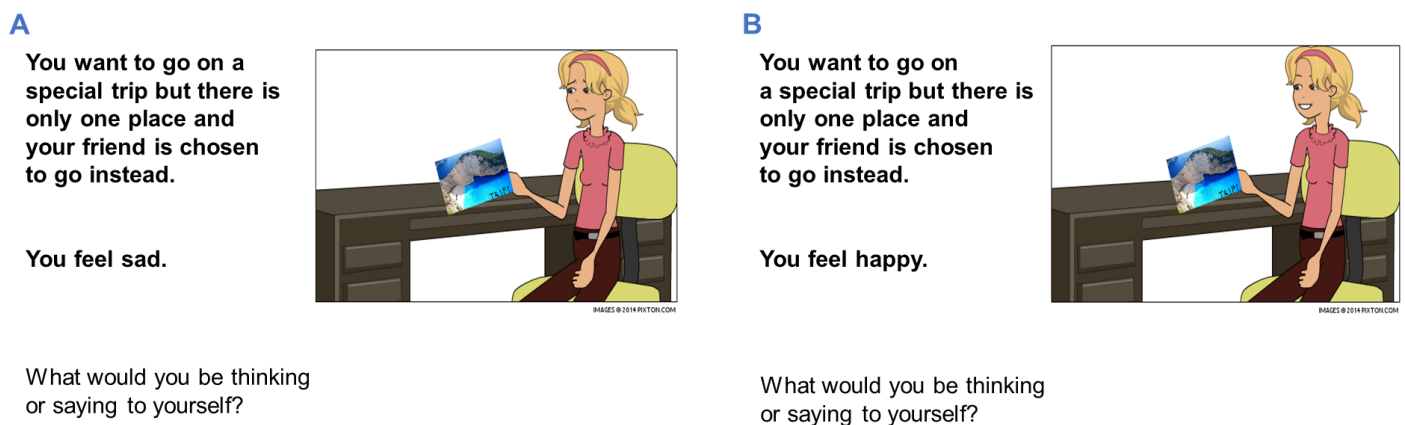


Figure 1. Visual representation of a congruent and an incongruent scenario from the Cognitive mediation task (Dagnan et al., 2009)

This task generates and assesses the inferential (situation-specific) beliefs of the participants. In 2000, Dagnan and colleagues amended the task to assess individuals’ evaluative beliefs, as these are considered to be more indicative of someone’s cognitive mediation skills. However, in 2009 Dagnan and colleagues suggested that although the second task is more rigorous, it has limited

clinical utility. They argued that the performance of individuals on the open-ended cognitive mediation task by Dagnan and Chadwick (1997) is more clinically meaningful and has greater ecological validity. Therefore, this study used the original task and followed the recommendation of Dagnan and colleagues (2009) to present each scenario twice and examine whether incongruity between situation and emotion affects the ability of individuals to identify mediating beliefs. The reliability and the validity of this questionnaire and of its earlier versions has not been assessed, although they have been used extensively among people with LD.

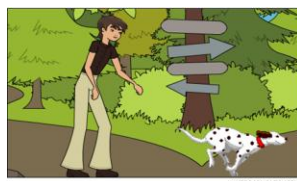
Linking activating events to emotions (Reed & Clements, 1989). This measures the ability of individuals with LD to make associations between activating events and subsequent emotions. The task consists of 4 parts. Its validity and reliability are not known.

- i) Emotion recognition from facial images (happy and sad).
- ii) Emotion recognition from faces modelled by the researcher (happy and sad).
- iii) Participants are shown six different scenarios and are asked whether the protagonist of each scenario feels happy or sad and why. They can respond either verbally or point to the comic face that best represents the emotion of the protagonist. Six was the highest score participants could obtain. Scenarios were visualised using Pixton Comics (2014) and different presentation cards were created for female (Appendix 9a) and for male participants (Appendix 9b). An example of a scenario given to female participants and the respective response options is presented in Figure 2.
- iv) Participants are asked how they would feel if someone verbally offended them (happy or sad).

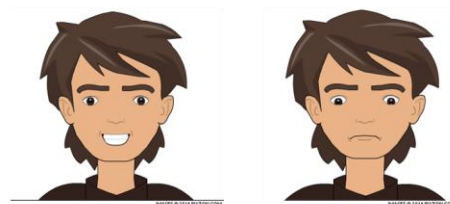
John takes your dog
for a walk.

The dog breaks the
lead.

He has lost his
dog.



Which face is John's
face?



Why?

Figure 2. Visual representation of a scenario from the ‘Linking activating events to emotions’ task and the respective response options (Reed & Clements, 1989)

The Behaviour, Thought, Feeling Questionnaire (Greenberger & Padesky, 1985; Oathamshaw & Haddock, 2006). This questionnaire assesses the ability of individuals with LD to discriminate among feelings, thoughts and behaviours. Participants are presented with a list of words and are asked to identify if each word ‘is something you do, something you think or something you feel’. As Figure 3 shows, emotion icons (emoticons) were used to develop visual aids that assist individuals with differentiating between behaviours, thoughts and feelings.

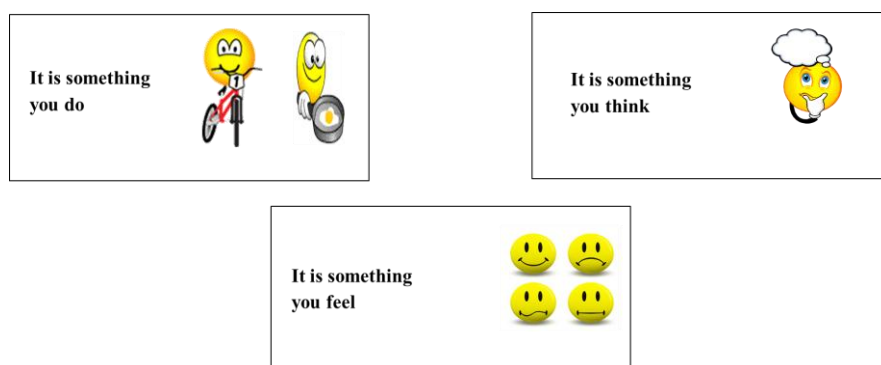


Figure 3. Visual aids for ‘The Behaviour, Thought, Feeling Questionnaire’ (Greenberger & Padesky, 1985; Oathamshaw & Haddock, 2006)

This task was originally developed in 1985 by Greenberger and Padesky and was adapted for people with LD in 2006 by Oathamshaw and Haddock. In that study, four people with LD were consulted and proposed a number of feelings, thoughts and behaviours. The task instructions were written by a Speech and Language Therapist with experience with this population. The measure was piloted with 20 ‘expert’ participants and after one week it was re-administered to 4 of the participants. The test-retest reliability was found to be 0.83, whereas its validity has not been established. The maximum score for this questionnaire is 24.

Questions on video. Following the intervention, participants were asked to provide some qualitative feedback about the video (Appendix 10). Three semi-structured questions were developed asking participants to express their opinion about the content of the video and the knowledge they acquired.

Ethics

Full ethical approval was obtained by the Science, Technology, Engineering and Mathematics Ethical Review Committee of the University of Birmingham (Reference number: ERN_14-0632). The application for ethical review can be found in Appendix 11.

Procedure

All the participants were recruited from a day service for people with LD. The day centre officers and staff were provided with a project information sheet, giving a study outline and describing the inclusion and exclusion criteria. A list with potentially suitable participants was created and the researcher met with those interested in taking part and explained the study to them using the Participant Information Sheet (Appendix 12). Participants were encouraged to ask any questions they might have about the project.

An assessment procedure developed by Arscott, Dagnan and Stenfert Kroese (1998; Appendix 13) was used to assess whether the individuals who wished to participate in the research had the capacity to consent. All the included participants were capable of giving consent and were asked to read and sign the Participant Consent Form (Appendix 14) with the assistance of the researcher.

All the meetings took place in a quiet room in the day centre. Although participants were offered the option of having someone to accompany them if this would make them feel more relaxed, no one asked for a support worker. In the initial pre-intervention meeting, the three outcome measures were administered to the participants and their verbal ability was assessed using BPVS-II. In the second meeting, which took place after one to six days, the intervention was implemented by the researcher and the three questionnaires were re-administered to assess the impact of the intervention. Moreover, the participants were asked to provide qualitative feedback on the video. The follow up assessment took place approximately one week after the intervention and the same measures were administered to the individuals. In every session, the researcher wrote down the answers provided by the participants using specific evaluation forms.

Analysis

The results were analysed separately for each participant. The Reliable Change Index (Jacobson & Truax, 1991) could not be used in this study, because the reliability of the measuring instruments has not been assessed. There was some evidence of test-retest reliability for ‘The Behaviour, Thought, Feeling Questionnaire’ (Greenberger & Padesky, 1985; Oathamshaw & Haddock, 2006), but this was preliminary as it was conducted with only four participants who did not have LD.

To analyse the quantitative data, graphs were plotted and the differences in the pre-, post- and follow up scores of the participants at the three outcome measures were examined. In addition to the differences in their total scores, differences in the subscales of the questionnaires were also investigated (e.g. cognitive mediation in congruent vs incongruent scenarios). Post-intervention and follow-up effects sizes were calculated using the standard mean difference (Busk & Serlin, 1992; Olive & Smith, 2005): the difference between each participant’s pre-intervention and post-intervention and follow up scores was calculated and was then divided by the baseline standard deviation. Regarding the qualitative data, a summary of participants’ qualitative feedback about the training intervention and supporting materials is provided.

Results

The results will be presented separately for each participant. They will include i) a report of individuals’ performance on the quantitative assessments, ii) descriptions and observations of their responses during the video and the sessions, including any difficulties they might have faced and, iii) participants’ feedback about the video and the visual aids the researcher developed. Tables 1, 2 and 3 provide information about individuals’ scores on each of the three outcome measures,

together with the post-intervention and follow up effect sizes. Figures 4, 5 and 6 depict the graphical representations of participants' scores.

Participant one

This 50 year old man achieved the highest BPVS raw score (87) among all participants. He achieved a perfect score in the questionnaire by Reed & Clements (1989) and his ability to associate mediating cognitions to emotional responses improved following the intervention. In contrast, he was less able to distinguish between feelings, thoughts and behaviours at post-intervention and at the one week follow up.

The ability of this participant to correctly identify mediating cognitions (Dagnan et al., 2009) increased following intervention (from five to seven) and this improvement was maintained at the one-week follow up. In particular, he became more capable of identifying mediating beliefs when presented with incongruent scenarios. This is demonstrated by the responses he provided in item five at follow up: 'You have been asked to go and see your manager'. He claimed that in the occasion where the scenario was paired with a sad feeling (congruent pairing), he would be thinking 'I am in trouble with my manager; I will be dismissed'. Conversely, when it was paired with a happy feeling (incongruent), his thought would be 'he will talk about the supervision; I did an excellent job'. Furthermore, in the post-intervention and the follow up assessment the participant expressed incertitude ('don't know; not sure') about some of his answers. He appeared to have an increased awareness of his difficulty in identifying mediating cognitions in incongruent scenarios.

His ability to differentiate between feelings, thoughts and behaviours (Greenberger & Padesky, 1985; Oathamshaw & Haddock, 2006) decreased following the intervention. In the baseline session, he correctly recognised eight feelings, four behaviours and one thought. After the intervention, there was a substantial fall in his ability to distinguish feelings. His score dropped from eight pre-intervention, to four at the post-intervention and five at the follow up assessment. The answers he provided to the post-intervention assessments and the video questions showed that he specifically confounded feelings with behaviours.

This participant provided me with very positive feedback about the video and the visual aids and he enjoyed his participation to the study a lot. He believed that the video was interesting and he particularly liked some of the digital stories (i.e. the ones about the dentist and the chocolate bar). The only thing he did not like and suggested to improve was that ‘there is no story attached to it; it’s not like a film’.

Table 1. Scores and effect sizes on the ‘Cognitive mediation’ task

	Pre-intervention scores	Post-intervention scores	Follow up Scores	Post-intervention effect sizes	Follow up effect sizes
Participant 1	5 (5 C.S., 0 I.S.)	7 (6 C.S., 1 I.S.)	7 (6 C.S., 1 I.S.)	1,01	1,01
Participant 2	5 (4 C.S., 1 I.S.)	5 (4 C.S., 1 I.S.)	5 (5 C.S., 0 I.S.)	0	0
Participant 3	4 (4 C.S., 0 I.S.)	4 (4 C.S., 0 I.S.)	6 (6 C.S., 0 I.S.)	0	1,01
Participant 4	4 (4 C.S., 0 I.S.)	5 (5 C.S., 0 I.S.)	7 (5 C.S., 2 I.S.)	0,50	1,52
Participant 5	0	2 (2 C.S., 0 I.S.)	1 (1 C.S., 0 I.S.)	1,01	0,50
Participant 6	2 (2 C.S., 0 I.S.)	5 (5 C.S., 0 I.S.)	6 (4 C.S., 2 I.S.)	1,52	2,03

C.S. = Congruent Scenarios; I.S. = Incongruent Scenarios

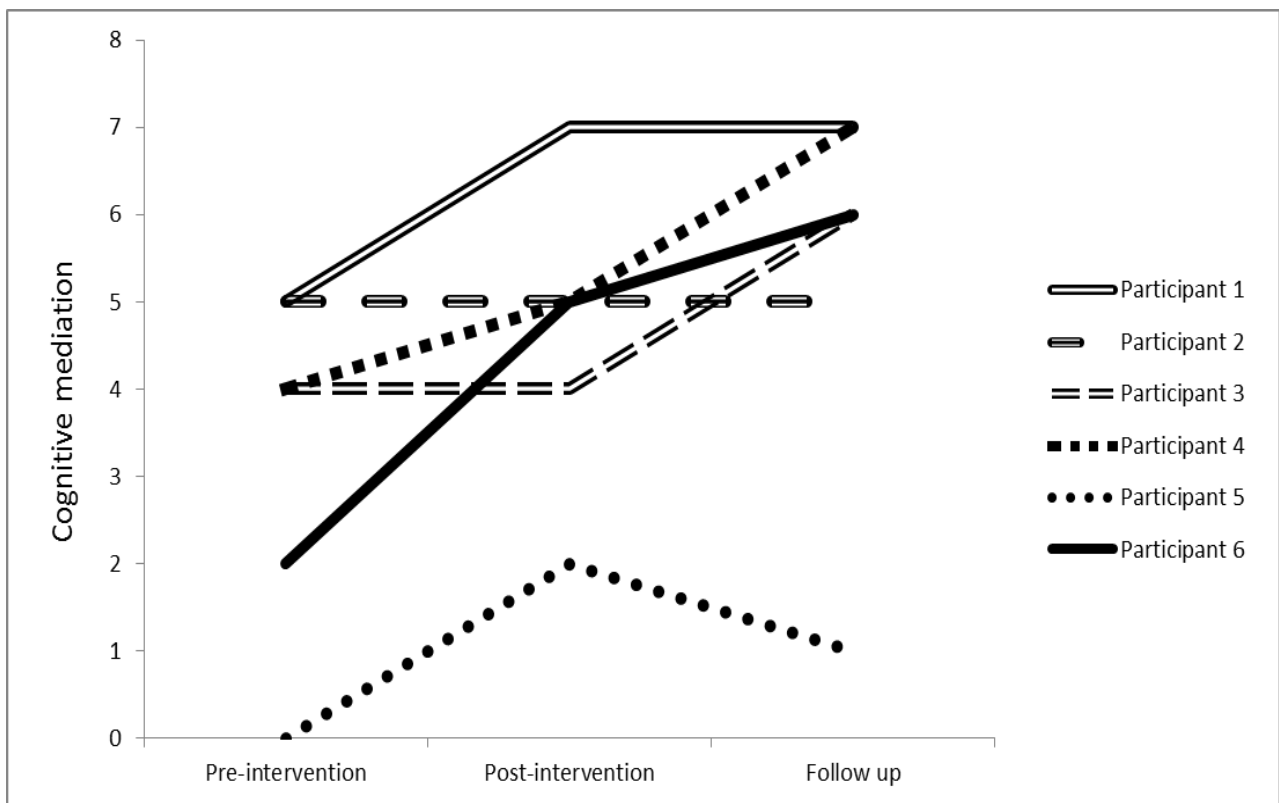


Figure 4. Performance on the ‘Cognitive mediation’ task for each participant

Participant two

This was a 32 year old female, with a relatively low verbal ability (BPVS raw score: 37). Although her performance on the ‘Linking events to emotions’ task was excellent, the intervention had no effect on her cognitive mediation skills and her ability to discriminate between feelings, thoughts and behaviours decreased following the intervention.

The training intervention had no impact on the ability of this participant to identify mediating beliefs and her performance (five) remained steady across all the assessments. Her responses to the video questions demonstrated that she had a particular difficulty in understanding cognitive

mediation when the scenario was incongruent (Dagnan et al., 2009). Although I tried to adapt the intervention to her needs, by repeating the core concepts, using hand gestures more frequently and by constantly checking for comprehension, her ability to identify mediating beliefs did not improve. Another observation is that when she had personal experience of the situation described in a scenario, she was able to identify the correct mediating cognitions more quickly and easily. For example, when she was presented with this congruent situation-emotion pairing, 'You walk into a room where there is a group of your friends. As you walk in they start to laugh. You feel sad', she effortlessly responded that her thought would be 'they make fun of me'. Then she added, 'they always do that to me. Why?' Conversely, she had greater difficulty and more hesitations with scenarios she did not appear to be familiar with, such as the following: 'You are in bed one night and you hear a loud noise downstairs'.

The capacity of this second participant to discriminate between feelings, thoughts and behaviours (Greenberger & Padesky, 1985; Oathamshaw & Haddock, 2006) decreased further after the intervention, although her baseline performance was already very low. Specifically, her baseline score was six and it fell by three points in the post-intervention and the follow up assessment. During the assessment, she appeared to be confused and tended to respond impulsively to the questions.

In her feedback, she said that she liked the video and the pictures a lot. In the question about the most interesting thing in the video, she referred to two specific digital stories, one about the links between events and emotions and one about cognitive mediation. She was even able to recall a story about cognitive mediation, with details about the mediating belief of the protagonist: 'he thought they made fun of him and laughing at him. It was difficult.'

Participant three

The third participant was a 49 year old woman with a raw score of 54 in BPVS. Her ability to relate mediating cognitions with emotional responses increased post-intervention, while her ability to distinguish among feelings, thoughts and behaviours remained stable in all the assessments. In the questionnaire by Reed and Clements (1989), she obtained the highest possible score from the beginning.

The participant could identify the same number of mediating cognitions (four) both before and immediately after the intervention (Dagnan et al., 2009). However, it was found that her cognitive mediation skills were enhanced in the follow up assessment (six). In general, she had greater difficulty in identifying mediating beliefs when she was presented with incongruent pairings of events and emotions. The answer she gave to the following incongruent scenario indicates her difficulty: 'You see a group of your friends, but they do not say hello. You feel happy.' Her spontaneous respond was 'no, I don't feel like that' and was not able to identify a suitable mediating belief. Consequently, her difficulty may be partly associated with her inability to identify herself with this incongruent scenario as it does not fit with her own experience.

The performance of the participant on 'The Behaviour, Thought, Feeling Questionnaire' (Greenberger & Padesky, 1985; Oathamshaw & Haddock, 2006) remained steady between baseline and follow up. Similarly to participants one and two, she was far more able to correctly differentiate feelings compared to behaviours and thoughts in all the assessments (baseline: six feelings vs. three behaviours and one thought; post-intervention: seven feelings vs. three

behaviours and one thought; follow up: seven feelings, three behaviours, zero thoughts). Her responses to the video questions further demonstrated her confusion and her particular inability to recognise thoughts. Finally, she had greater difficulty when she was asked questions that were beyond her experience, such as the following: ‘Is playing darts something you do, something you think, or something you feel?’ Her response was: ‘I don’t know. I don’t do that, I don’t like darts’.

When asked what she has learnt from the video, she answered that she learnt ‘about feelings’, while she could also recall both digital stories that were used to teach people the links between events and emotions. It is notable that her performance in the tasks which examined the concepts presented in these specific digital stories was high. In particular, she was very good at identifying feelings in the discrimination task and she achieved a perfect score in the ‘linking events to emotions’ questionnaire.

Table 2. Scores and effect sizes on the ‘Linking activating events to emotions’ task

	Pre-intervention scores	Post-intervention scores	Follow up Scores	Post-intervention effect sizes	Follow up effect sizes
Participant 1	6	6	6	0	0
Participant 2	6	6	6	0	0
Participant 3	6	6	6	0	0
Participant 4	5	6	6	0,57	0,57
Participant 5	2	4	5	1,14	1,71
Participant 6	3	5	5	1,14	1,14

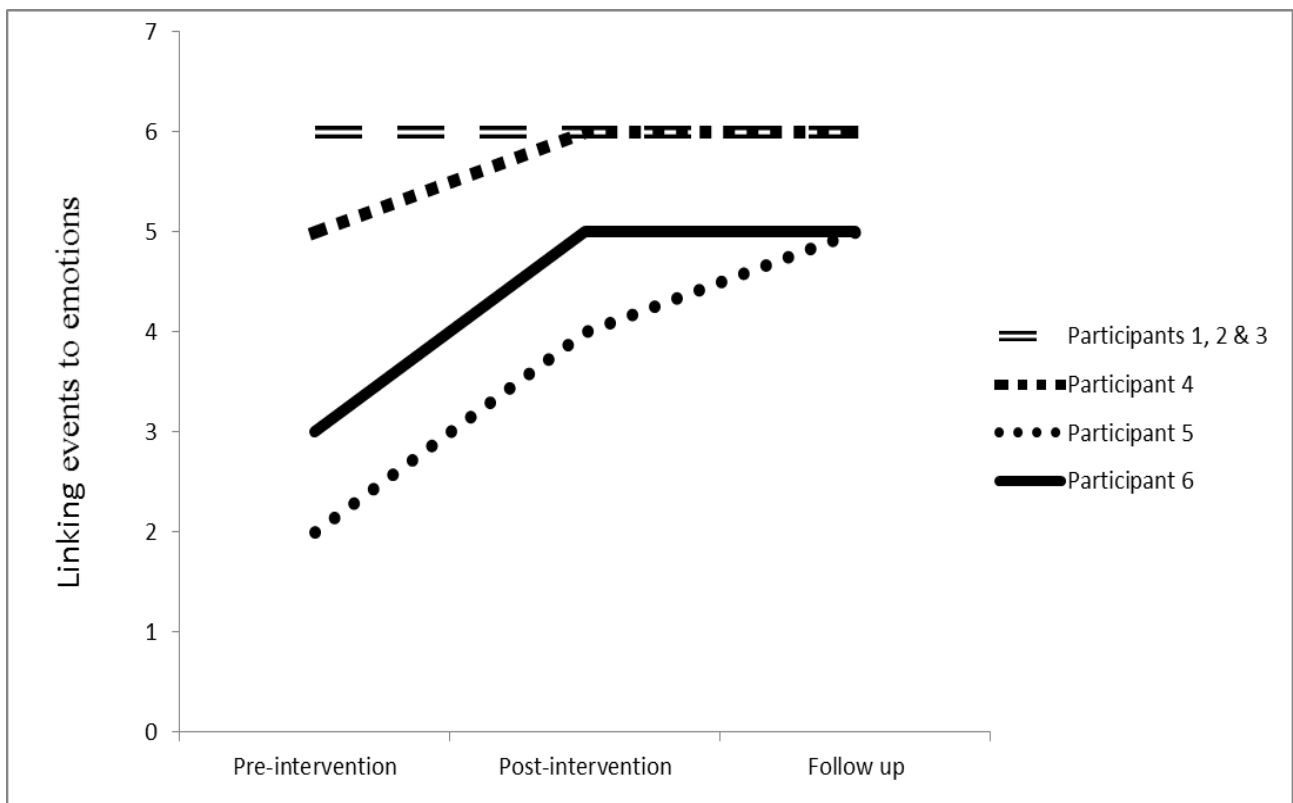


Figure 5. Performance on the ‘Linking activating events to emotions’ task for each participant

Participant four

This was a 44 year old male, who obtained the second highest score in BPVS (66) among all the participants. His performance on both the cognitive mediation and the discrimination task improved after the intervention, while his ability to understand the links between events and emotions was excellent pre- and post-intervention.

The number of mediating beliefs he was able to correctly identify (Dagnan et al., 2009) increased from four in the baseline, to five in the post-intervention and seven in the follow up assessment. His particular ability to recognise cognitive mediation in incongruent scenarios was enhanced only in the follow up, as revealed by his answers to the next story: ‘You walk into a room where there is

a group of your friends. As you walk in they start to laugh'. Post-intervention, he could identify a proper mediating belief only when the scenario was paired with the feeling of sadness (congruent pairing): 'Making fun of me'. In the follow up assessment, he was also able to identify the mediating cognition when the scenario was paired with the feeling of happiness (incongruent pairing): 'I thought nice smiles. That they have nice smiles. They have fun'.

His performance on 'The Behaviour, Thought, Feeling Questionnaire' (Greenberger & Padesky, 1985; Oathamshaw & Haddock, 2006) increased from 10 in the baseline to 12 in the post-intervention assessment, whereas it fell by four points at the one week follow up (eight). Specifically, there was a substantial improvement in his ability to distinguish thoughts after intervention (three thoughts pre-intervention vs. six thoughts post-intervention and four at follow up). During the assessment, the participant used the hand gestures for feelings, thoughts and behaviours that he was taught in the intervention.

This participant provided me with some very useful feedback about the video. He believed that 'it was a good one. I think it's useful, other people will like it' and he particularly liked the pictures in the digital stories. Nevertheless, he 'didn't like the words, hard to read' and suggested to include only pictures or limit the number of words and increase their font size. Finally, he thought that the voice-over was clear and easy to understand.

Participant five

The fifth participant was a 60 year old woman. Her receptive vocabulary ability was low (BPVS raw score: 31) and she also appeared to have expressive language difficulties. Her ability to understand the links between events and emotions and between mediating cognitions and emotional responses improved post-intervention, whereas her performance on the discrimination task decreased.

Before the intervention, this participant had great difficulty in understanding cognitive mediation (Dagnan et al., 2009) when she was presented with both congruent and incongruent scenarios (zero score). And although the intervention had no effect on her ability to correctly identify mediating beliefs in incongruent scenarios, her capacity to identify mediating cognitions in congruent scenarios increased at post-intervention from zero to two. Additionally, this participant had language and communication difficulties, a short attention span and she often gave incomplete and one word answers. During the video, she was unable to concentrate and she became very easily distracted. It is possible that age and any age-related disorder may have confounded her performance on the tasks.

The ability of the participant to differentiate between feelings, thoughts and behaviours (Greenberger & Padesky, 1985; Oathamshaw & Haddock, 2006) decreased from seven pre-intervention, to six post-intervention and four in the follow up. During the assessment, it became evident that the participant responded randomly to the task, and therefore, the reliability of the results is questioned. The answers she provided were entirely dependent on the position of the words 'feel', 'think' and 'do' in the interrogative sentence: 'Is working something you do, you think or you feel?' She used to select the verb that was put at the end of the sentence, for example:

‘Feel, feel.’ I confirmed this response pattern by altering the wording of the question and observing the answers provided by the participant.

The performance of this participant on the ‘Linking events to emotions’ task (Reed & Clements, 1989) was low pre-intervention (two). She was wrong even in the initial assessment stage where she was asked to identify the sad or the happy facial expression modelled by the researcher. Nevertheless, her performance was enhanced in the post-intervention (four) and the follow-up assessment (five).

Finally, she thought that the video ‘is all right. It was good’ and in the question about what she liked most she answered ‘the pictures. I like it.’

Table 3. Scores and effect sizes on the ‘Behaviour, Thought, Feeling questionnaire’

	Pre-intervention scores	Post-intervention scores	Follow up scores	Post-intervention effect sizes	Follow up effect sizes
Participant 1	13 (8F, 1T, 4B)	8 (4F, 1T, 2B)	7 (5F, 1T, 1B)	-1,894338076	-2,27
Participant 2	6 (4F, 1T, 1B)	3 (2F, 1T, 0B)	3 (1F, 2T, 0B)	-1,136602846	-1,13
Participant 3	11 (6F, 2T, 3B)	11 (7F, 1T, 3B)	10 (7F, 0T, 3B)	0	-0,37
Participant 4	10 (3F, 3T, 4B)	12 (1F, 6T, 5B)	8 (1F, 4T, 3B)	0,75773523	-0,75
Participant 5	7 (4F, 1T, 2B)	6 (5F, 0T, 1B)	4 (2F, 0T, 2B)	-0,378867615	-1,13
Participant 6	8 (6F, 1T, 1B)	3 (0F, 1T, 2B)	2 (1f, 1t, 0b)	-1,894338076	-2,27

F = Feelings; T = Thoughts; B = Behaviours

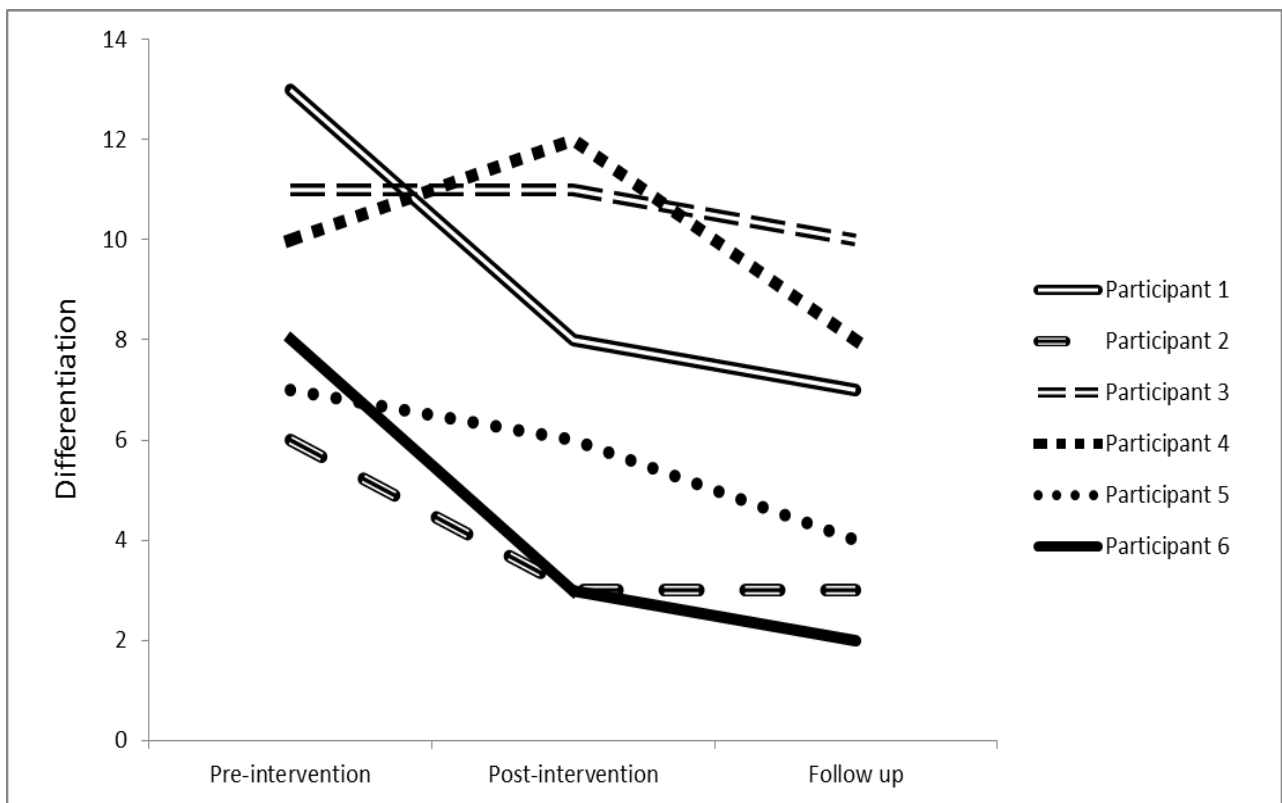


Figure 6. Performance on the ‘Behaviour, Thought, Feeling questionnaire’

Participant six

The last participant was a 31 year old female with a relatively low language comprehension ability (BPVS raw score: 34). Post-intervention, she was more able to understand cognitive mediation and the associations between activating events and emotions. On the contrary, the intervention had no effect on her ability to distinguish among feelings, thoughts and behaviours.

The ability of the participant to correctly identify mediating beliefs (Dagnan et al., 2009) increased from two pre-intervention, to five post-intervention and six in the follow up assessment. Her responses to the following scenario reveal this improvement: ‘It is your first day at a new job that you have not done before’. In the baseline assessment, she was unable to identify a correct

mediating cognition. Post-intervention, she gave a proper response only when the situation was paired with a feeling of happiness (congruent scenario): 'I am happy cause I work; when people working, have job, are happy'. In the follow up evaluation though, she also identified a suitable mediating belief for the incongruent scenario where the situation was paired with a feeling of sadness: 'I do a hard work, job. It gives me a headache'.

The intervention had no impact on the ability of the participant to discriminate between feelings, thoughts and behaviours (Greenberger & Padesky, 1985; Oathamshaw & Haddock, 2006). The participant engaged in random responding, such as participant five, while she also responded impulsively, had poor concentration and talked about things irrelevant to our meetings. Nevertheless, her performance on the 'Linking events to emotions' questionnaire (Reed & Clements, 1989) increased from three before the intervention to five in both the post-intervention and the follow up assessment. This improvement is demonstrated by the answers she provided to the next scenario: 'You get out of bed. You go downstairs. It is your birthday'. Before the intervention takes place, although the participant correctly responded that she would feel happy, the explanation she gave was insufficient: 'cause I am sleeping in bed'. Conversely, the explanation she provided following the intervention was well-founded and demonstrated good understanding of the links between the event and the emotion: 'it's my birthday, have a party'.

The participant provided me with positive feedback on the video, she mentioned that 'it looks nice, I enjoyed it'. Finally, she particularly liked the visual aids that were used.

Discussion

This study aimed to examine whether a newly developed brief CBT preparatory intervention can enhance the cognitive skills of six individuals with mild to moderate LD. Additionally, it explored the acceptability of the intervention among the participants. With respect to the effect of intervention on cognitive mediation skills, the results show that the capacity of participants to correctly identify mediating beliefs (Dagnan et al., 2009) increased after the intervention, as opposed to the study of Vereenoghe and colleagues (2014) which found no significant intervention effect on cognitive mediation. These conflicting results can be possibly explained by the differences between the two interventions, as whilst participants in this study were trained in cognitive mediation, the intervention provided by Vereenoghe and colleagues (2014) had no cognitive mediation element.

It is interesting to note that the cognitive mediation skills of three participants further improved at the one-week follow up and two of them (participants four and six) had an enhanced ability to identify mediating cognitions in incongruent scenarios. This is consistent with the results of Bruce and colleagues (2010) who found that the cognitive skills of people with LD increased one week after the delivery of the intervention, as measured by 'The Thought to Feeling task' (Doherr et al., 2005). It is possible that the improvement which was observed here does not reflect an intervention effect, but practice effects as participants became more familiar with the tasks within sessions. Another possibility is that individuals felt more secure to express their thoughts in the follow up due to the establishment of a better rapport with the researcher. The clinical implications of this post-intervention improvement remain equally important regardless of the reasons behind it. It

suggests that people with LD are able to make connections between mediating cognitions and subsequent emotional responses when they receive some CBT training and acquire some familiarity with CBT concepts.

The intervention had no effect on the ability of people with LD to distinguish among feelings, thoughts and behaviours (Greenberger & Padesky, 1985; Oathamshaw & Haddock, 2006), a finding consistent with the study by Bruce and colleagues (2010). In particular, the ability to discriminate decreased for two participants after the intervention training, increased for one and remained unchanged for another individual. Finally, the fact that the two participants with the lowest verbal ability engaged in random responding indicates that this task might be too complicated for some people with LD and that the present training intervention increased, rather than reduced, their confusion. It appears that individuals need more time to understand and assimilate such complex concepts, something that future studies should take into consideration.

The difficulty of some individuals might be related to the nature of the discrimination task, which asks them to identify whether a number of words and phrases ‘is something’ they ‘do’, ‘think’ or ‘feel’. Participants were particularly confused when they lacked personal experience with some task items, such as ‘gardening’ or ‘I’ve achieved something’ and this demonstrates the need for individually tailored and personally meaningful assessment instruments. Another problem concerns the way that some task items, such as ‘I don’t know what to do for the best’ are worded. In this example, the use of the word ‘do’ may have misled some people, thus ‘forcing’ them to respond that this is a behaviour and not a thought. In addition, it has been revealed that the wording of instructions and the use of language in this questionnaire is rather confusing. For example, participant one answered that ‘upset’ is something he does, ‘Do. I do get very upset’. However, it is

obvious that he did not use the word 'do' to argue that 'upset' is a behaviour, but in order to provide a positive answer. Finally, some participants used the word 'feel' as synonym for 'think'. This is reflected in the response of participant three when she was asked to differentiate the phrase 'I don't know what to do for the best' and she answered 'Feel, I feel I don't know what to do for the best'. Therefore, there is a need to overcome the limitations of the existing outcome measure and design a new reliable, valid and sensitive to change questionnaire, suitable for people with LD.

The vast majority of individuals were more capable of correctly identifying feelings compared to thoughts and behaviours, while only one participant was good at identifying thoughts in the discrimination task (Greenberger & Padesky, 1985; Oathamshaw & Haddock, 2006). This is corroborated by a study conducted by Hebblethwaite, Jahoda and Dagnan (2011) which found that although people with LD and people with normal cognitive function are equally able to identify and describe their feelings about an emotional real-life experience they have had, individuals with LD are less able to talk about their inferential beliefs, as measured by the Cognitive-emotive interview (Jahoda, Pert, Squire & Trower, 1998; Trower, Casey & Dryden, 1988). Furthermore, observations showed that the visual cues were not particularly helpful for the participants, but on the contrary they were distracting sometimes. Sams and colleagues (2006) also found that visual cues did not affect the ability of individuals with LD to discriminate, although the use of prompts increased the discrimination ability of children in a study by Quakley and colleagues (2004).

Most participants achieved the highest score possible in the 'Linking events to emotions' (Reed & Clements, 1989) task. Although the remaining individuals performed close to ceiling levels and there was little space for improvement, the intervention had a positive impact on their ability to link activating events to subsequent emotional responses. Regarding the acceptability of the

intervention, the qualitative feedback of the participants was very positive for both the video and the visual aids. In addition, individuals underlined some areas for improvement. They mentioned that they would like the video to look more like a film and suggested to limit the number of words or increase the font size as these were hard to read.

It has been argued that the evaluation of individuals' capacity for participation in CBT should not depend solely on their performance on assessments of CBT skills (Beail & Jahoda, 2012; Jahoda et al., 2006; Willner & Goodey, 2006). There is a number of other critical factors that influence the successful implementation of CBT in people with LD. The research evidence points out the importance of therapeutic relationship, motivation to participate in therapy, psychological thinking and self-efficacy (MacMahon et al., 2014; Jones, 2013; Willner, 2006) and indicates that the engagement of carers in treatment might be beneficial for people with LD (Rose, Loftus, Flint & Carey, 2005; Rose, West & Clifford, 2000; Whitehouse et al, 2006; Willner, Jones, Tams & Green, 2002). Finally, Willner and Goodey (2006) have highlighted the importance of episodic memory, of the ability of temporal sequencing and of several other skills.

Limitations and recommendations for future research

The use of a case series research design permitted the in depth examination of the CBT skills of people with LD. However, the internal validity of the present study is low and the outcomes preliminary, hence more robust research is required to substantiate and extend them. In addition, all participants were recruited from a non-clinical population and had mild to moderate LD. Therefore, the outcomes cannot be generalised to individuals with more severe LD or clinical populations. There is also a limitation with qualitative data. Although the qualitative feedback acquired from

participants provided us with useful information about the acceptability of the intervention, it did not permit formal qualitative analysis. Finally, although the researcher tried to be objective and systematic in the presentation of the results, her feelings, thoughts and preconceptions may have influenced the narrative presentation (McLeod, 2008) and led to some reporting bias.

An important caveat to the study results presented here is the unknown reliability, validity and sensitivity to change of the outcome measures that were used. This is a new area of research and although the questionnaires appear to have face validity, there has been no assessment of their predictive validity. Future research should investigate whether a relationship exists between assessments of prerequisite skills for CBT and positive therapeutic outcomes (Bruce et al., 2010; Dagnan et al., 2009). There is a need to assess the psychometric properties of the existing questionnaires and develop individualised measures meaningful to participants, which will allow them to achieve their full potential.

Future research should also examine the possibility that CBT training is not very useful for specific groups of people with LD. For example, participants with low verbal comprehension and poor concentration skills did not appear to benefit a lot from the intervention training in this study and there is a body of evidence which demonstrates strong associations between verbal ability and ability to understand CBT concepts (Dagnan et al., 2000; Dagnan & Chadwick, 1997; Joyce et al., 2006; Reed & Clements, 1989; Sams et al., 2006). Moreover, the results of participant five suggest that preparatory training may not be very effective for older people. It is likely that the CBT skills of individuals are negatively affected by age-related diseases such as dementia, which is common among this population (BPS, 2009; Cooper, 1997; Kalsy-Lillico, Adams & Oliver, 2012; Zigman et al., 2004). Finally, although research has not addressed if there is an IQ or verbal ability cutoff for

participation in CBT, it is generally accepted that those with severe LD would probably not possess the skills required for CBT.

Researchers and clinicians need to collaborate and synthesise existing evidence and materials from different interventions to develop an effective preparatory training programme for CBT. Some of this programme's constituent elements can be the video and visual aids used in this study, the computerised training tasks developed by Vereenoghe and colleagues (2014) and the manualised intervention by Bruce and colleagues (2010). It is hypothesised that the use of various supporting materials and training aids will increase the intervention's effectiveness. Furthermore, more time should be dedicated to teaching individuals how to discriminate between feelings, thoughts and behaviours and identify cognitive mediation when presented with incongruent scenarios, as the present and previous studies have demonstrated that people find it difficult to understand these concepts. Finally, another idea would be to provide participants with more than one training sessions and use training items that are personally meaningful to them.

Recently, it has been emphasised that there is a need to shift from intervention to prevention services in the provision of healthcare in the UK (DOH, 2010; Gone, Hatton & Caine, 2012). Taking into consideration the increased rates of mental disorders among people with LD (Borthwick-Duffy, 1994; Cooper et al., 2007; Tsiouris et al., 2011), Unwin and colleagues (2014) have suggested that a preventative staff-delivered mental health promotion programme could possibly make psychological therapies, including CBT, accessible to more individuals. Since the ultimate aim of this study was also to increase access to CBT, the training intervention developed here could possibly constitute a component of such a preventative mental health promotion programme.

References

- Arcsott, K., Dagnan, D., & Kroese, B. S. (1998). Consent to psychological research by people with an intellectual disability. *Journal of Applied Research in Intellectual Disabilities*, 11(1), 77-83.
- Beail, N., & Jahoda, A. (2012). Working with people: direct interventions. In E. Emerson, C. Hatton, K. Dickson, R. Gone, A. Caine & J. Bromley (Eds.), *Clinical Psychology and people with Intellectual Disabilities* (pp. 121-139). Chichester: Wiley-Blackwell.
- Borthwick-Duffy, S. A. (1994). Epidemiology and prevalence of psychopathology in people with mental retardation. *Journal of Consulting and Clinical Psychology*, 62(1), 17-27.
- British Psychological Society (2009). *Dementia and People with Learning Disabilities: Guidance on the assessment, diagnosis, treatment and support*. Retrieved from <http://www.rcpsych.ac.uk/usefulresources/publications/collegereports/cr/cr155.aspx>
- Bruce, M., Collins, S., Langdon, P., Powlitch, S., & Reynolds, S. (2010). Does training improve understanding of core concepts in cognitive behaviour therapy by people with intellectual disabilities? A randomized experiment. *British Journal of Clinical Psychology*, 49(1), 1-13.
- Busk, P. L., & Serlin, R. C. (1992). Meta-analysis for single-case research. In T. R. Kratochwill & J. R. Levin (Eds.), *Single-case research designs and analysis: New directions for psychology and education* (pp. 187-212). Hillsdale, NJ: Lawrence Erlbaum Associates.
- Clarke, D. (2003). Diagnostic criteria for psychiatric disorders for use with adults with learning disabilities/mental retardation (DC-LD) and psychiatric phenotypes. *Journal of Intellectual Disability Research*, 47(1), 43-49.
- Cooper, S. A. (1997). High prevalence of dementia among people with learning disabilities not attributable to Down's syndrome. *Psychological medicine*, 27(03), 609-616.

- Cooper, S. A., Smiley, E., Morrison, J., Williamson, A., & Allan, L. (2007). Mental ill-health in adults with intellectual disabilities: prevalence and associated factors. *The British Journal of Psychiatry*, 190(1), 27-35.
- Dagnan, D., & Lindsay, W. R. (2012). People with Intellectual Disabilities and mental ill-health. In E. Emerson, C. Hatton, K. Dickson, R. Gone, A. Caine & J. Bromley (Eds.), *Clinical Psychology and people with Intellectual Disabilities* (pp. 313-338). Chichester: Wiley-Blackwell
- Dagnan, D., Chadwick, P., & Proudlove, J. (2000). Toward an assessment of suitability of people with mental retardation for cognitive therapy. *Cognitive Therapy and Research*, 24(6), 627–636.
- Dagnan, D., Mellor, K., & Jefferson, C. (2009). Assessment of cognitive therapy skills for people with learning disabilities. *Advances in Mental Health & Learning Disabilities*, 3(4), 25–30.
- Deb, S., Thomas, M., & Bright, C. (2001). Mental disorder in adults with intellectual disability. 1: Prevalence of functional psychiatric illness among a community-based population aged between 16 and 64 years. *Journal of Intellectual Disability Research*, 45(6), 495–505.
- Department of Health (2010). *Healthy lives, Healthy People: Our strategy for public health in England*. Retrieved from <https://www.gov.uk/government/publications/healthy-lives-healthy-people-our-strategy-for-public-health-in-england>
- Doherr, L., Reynolds, S., Wetherly, J., & Evans, E. (2005). Young children's ability to engage in cognitive therapy tasks: Associations with age and educational experience. *Behavioural and Cognitive Psychotherapy*, 33(2), 201–215.
- Dunn, L.M., Dunn, L.M., Whetton, C., & Burley, J. (1997). *British Picture Vocabulary Scale-II* (2nd edition). Windsor: NFER-Nelson.
- Ellis, A. (1957). Rational Psychotherapy and Individual Psychology. *Journal of Individual Psychology*, 13, 38-44.

- Ellis, A. (1962). *Reason and Emotion in Psychotherapy*. New York: Stuart.
- Emerson E. (2003). Prevalence of psychiatric disorders in children and adolescents with and without intellectual disability. *Journal of Intellectual Disability Research*, 47(1), 51–58.
- Emerson, E. (2007). Poverty and people with intellectual disabilities. *Mental Retardation and Developmental Disabilities Research Reviews*, 13(2), 107-113.
- Emerson, E., & Gone, R. (2012). Social Context. In E. Emerson, C. Hatton, K. Dickson, R. Gone, A. Caine & J. Bromley (Eds.), *Clinical Psychology and people with Intellectual Disabilities* (pp. 51-61). Chichester: Wiley-Blackwell.
- Emerson, E., & Hatton, C. (2007). Mental health of children and adolescents with intellectual disabilities in Britain. *The British Journal of Psychiatry*, 191(6), 493-499.
- Glenn, E., Bihm, E. M., & Lammer, W. J. (2003). Depression, anxiety and relevant cognitions in persons with mental retardation. *Journal of Autism and Developmental Disorders*, 33(1), 69–76.
- Glenn, S., & Cunningham, C. (2005). Performance of young people with downs syndrome on the Leiter–R and the British picture vocabulary scales. *Journal of Intellectual Disability Research*, 49(4), 239–244.
- Gone, R., Hatton, C., & Caine, A. (2012). Service Provision. In E. Emerson, C. Hatton, K. Dickson, R. Gone, A. Caine & J. Bromley (Eds.), *Clinical Psychology and people with Intellectual Disabilities* (pp. 23-49). Chichester: Wiley-Blackwell.
- Greenberger, D., & Padesky, C. A. (1985). *Mind Over Mood*. Guildford Press, New York.
- Hamelin, J., Travis, R., & Sturmey, P. (2013). Anger management and intellectual disabilities: A systematic review. *Journal of Mental Health Research in Intellectual Disabilities*, 6(1), 60–70.
- Hatton, C. (2002). Psychosocial interventions for adults with intellectual disabilities and mental health problems: A review. *Journal of Mental Health*, 11(4), 357-374.

- Hebblethwaite, A., Jahoda, A., & Dagnan, D. (2011). Talking About Real-life Events: An Investigation Into the Ability of People with Intellectual Disabilities to Make Links Between Their Beliefs and Emotions Within Dialogue. *Journal of Applied Research in Intellectual Disabilities*, 24(6), 543-553.
- Hulbert-Williams, L., & Hastings, R. P. (2008). Life events as a risk factor for psychological problems in individuals with intellectual disabilities: A critical review. *Journal of Intellectual Disability Research*, 52(11), 883-895.
- Jacobson, N. S., & Truax, P. (1991). Clinical significance: a statistical approach to defining meaningful change in psychotherapy research. *Journal of consulting and clinical psychology*, 59(1), 12.
- Jahoda, A., Dagnan, D., Jarvie, P., & Kerr, W. (2006). Depression, social context and cognitive behavioural therapy for people who have intellectual disabilities. *Journal of Applied Research in Intellectual Disabilities*, 19(1), 81-89.
- Jahoda, A., Pert, C., Squire, J., & Trower, P. (1998). Facing stress and conflict: a comparison of the predicted responses and self-concepts of aggressive and non-aggressive people with intellectual disability. *Journal of Intellectual Disability Research* 42(5), 360-369.
- Jones, R. A. (2013). Therapeutic relationships with individuals with learning disabilities: a qualitative study of the counselling psychologists' experience. *British Journal of Learning Disabilities*, 42(3), 193-203.
- Joyce, T., Globe, A., & Moody, C. (2006). Assessment of the component skills for cognitive therapy in adults with intellectual disability. *Journal of Applied Research in Intellectual Disabilities*, 19(1), 17-23.

Kalsy-Lillico, S., Adams, D., & Oliver, C. (2012). Older adults with Intellectual Disabilities: issues in ageing and dementia. In E. Emerson, C. Hatton, K. Dickson, R. Gone, A. Caine & J. Bromley (Eds.), *Clinical Psychology and people with Intellectual Disabilities* (pp. 359-392). Chichester: Wiley-Blackwell.

Lindsay, W. R., Steele, L., Smith, A. H., Quinn, K., & Allan, R. (2006). A community forensic intellectual disability service: Twelve year follow up of referrals, analysis of referral patterns and assessment of harm reduction. *Legal and Criminological Psychology*, 11(1), 113-130.

MacMahon, P., Stenfert Kroese, B., Jahoda, A., Stimpson, A., Rose, N., Rose, J., ... & Willner, P. (2014). 'It's made all of us bond since that course...'—a qualitative study of service users' experiences of a CBT anger management group intervention. *Journal of Intellectual Disability Research*.

McGillivray, J. A., & Kershaw, M. (2014). Do we need both cognitive and behavioural components in interventions for depressed mood in people with mild intellectual disability? *Journal of Intellectual Disability Research*.

McLeod, S. A. (2008). *Case Study Method in Psychology - Simply Psychology*. Retrieved from <http://www.simplypsychology.org/case-study.html>.

Nezu, C. M., Nezu, A. M., Rothenberg, J. L., & DelliCarpini, L. (1995). Depression in adults with mental retardation: Are cognitive variables involved? *Cognitive Therapy and Research*, 19(2), 227–239.

NICE (2009). *Depression: the Treatment and Management of Depression in Adults (Update)*. NICE clinical guideline 90. Available at www.nice.org.uk/CG90 [NICE guideline].

NICE (2011). *Generalised Anxiety Disorder and Panic Disorder (With Or Without Agoraphobia) in Adults: Management in Primary, Secondary and Community Care*. NICE clinical guideline 113. Available at www.nice.org.uk/CG113 [NICE guideline].

- Nicoll, M., Beail, N., & Saxon, D. (2013). Cognitive behavioural treatment for anger in adults with intellectual disabilities: A systematic review and meta-analysis. *Journal of Applied Research in Intellectual Disabilities*, 26(1), 47-62.
- Oathamshaw, S. C., & Haddock, G. (2006). Do People with Intellectual Disabilities and Psychosis have the Cognitive Skills Required to Undertake Cognitive Behavioural Therapy? *Journal of Applied Research in Intellectual Disabilities*, 19(1), 35–46.
- Olive, M. L., & Smith, B. W. (2005). Effect size calculations and single subject designs. *Educational Psychology*, 25(2-3), 313-324.
- Quakley, S., Reynolds, S., & Coker, S. (2004). The effect of cues on young children' abilities to discriminate among thoughts, feelings and behaviours. *Behaviour Research and Therapy*, 42(3), 343–356.
- Reed, J., & Clements, J. (1989). Assessing the understanding of emotional states in a population of adolescents and young adults with mental handicaps. *Journal of mental deficiency research*, 33(3), 229–233.
- Reid, K. A., Smiley, E., & Cooper, S. A. (2011). Prevalence and associations of anxiety disorders in adults with intellectual disabilities. *Journal of intellectual disability research*, 55(2), 172-181.
- Reiss, S., & Benson, B. A. (1984) Awareness of negative social conditions among mentally retarded, emotionally disturbed outpatients. *American Journal of Psychiatry*, 141(1), 88-90.
- Richards, M., Maughan, B., Hardy, R., Hall, I., Strydom, A., & Wadsworth, M. (2001). Long-term affective disorder in people with mild learning disability. *The British Journal of Psychiatry*, 179(6), 523-527.

- Rose, J., Loftus, M., Flint, B., & Carey, L. (2005). Factors associated with the efficacy of a group intervention for anger in people with intellectual disabilities. *British Journal of Clinical Psychology, 44*(3), 305-317.
- Rose, J., West, C., & Clifford, D. (2000). Group interventions for anger in people with intellectual disabilities. *Research in Developmental Disabilities, 21*(3), 171-181.
- Safran, J. D., Segal, Z. V., Vallis, T. M., Shaw, B. F., & Samstag, L. W. (1993). Assessing patient suitability for short-term cognitive therapy with an interpersonal focus. *Cognitive Therapy and Research, 17*(1), 23-38.
- Sams, K., Collins, S., & Reynolds, S. (2006). Cognitive therapy abilities in people with learning disabilities. *Journal of Applied Research in Intellectual Disabilities, 19*(1), 25-33.
- Sequeira, H., & Hollins, S. (2003). Clinical effects of sexual abuse on people with learning disability: Critical literature review. *The British Journal of Psychiatry, 182*(1), 13-19
- Smiley, E. (2005). Epidemiology of mental health problems in adults with learning disability: an update. *Advances in Psychiatric Treatment, 11*(3), 214-222.
- Stenfert Kroese, B. (1997). Cognitive-behaviour therapy for people with learning disabilities: Conceptual and contextual issues. In B. Stenfert Kroese, D. Dagnan, & K. Loumidis (Eds.), *Cognitive-behaviour therapy for people with learning disabilities* (pp. 1-15). London: Routledge.
- Stenfert Kroese, B., Dagnan, D., & Loumidis, K. (1997). *Cognitive-behaviour therapy for people with intellectual disabilities*. London: Routledge.
- Trower, P., Casey, A., & Dryden, W. (1988). *Cognitive-Behavioural Counselling in Action*. SAGE Publications, London.

- Tsiouris, J. A., Kim, S. Y., Brown, W. T., & Cohen, I. L. (2011). Association of aggressive behaviours with psychiatric disorders, age, sex and degree of intellectual disability: a large-scale survey. *Journal of Intellectual Disability Research*, 55(7), 636-649.
- Unwin, G. L., Tsimopoulou, I., Azmi, S., & Stenfert Kroese, B. (2014). *Effectiveness of Cognitive Behavioural Therapy (CBT) programmes for anxiety or depression in adults with intellectual disabilities: A review of the literature*. Unpublished manuscript.
- Vereenoghe, L., & Langdon, P. E. (2013). Psychological therapies for people with intellectual disabilities: A systematic review and meta-analysis. *Research in developmental disabilities*, 34(11), 4085-4102.
- Vereenoghe, L., Reynolds, S., Gega, L., & Langdon, P. E. (2014). *Can a computerised training paradigm assist people with intellectual disabilities to learn cognitive mediation skills? A randomised experiment*. Unpublished manuscript.
- Vygotsky, L. S. (1978). *Mind in society*. Cambridge, MA: Harvard University Press.
- Wechsler, D. (1999). *Wechsler abbreviated scale of intelligence*. Psychological Corporation.
- Wechsler, D., & Hsiao-pin, C. (2011). *WASI-II: Wechsler Abbreviated Scale of Intelligence*. Pearson.
- Whitehouse, R. M., Tudway, J. A., Look, R., & Stenfert Kroese, B. (2006). Adapting individual psychotherapy for adults with intellectual disabilities: A comparative review of the cognitive-behavioural and psychodynamic literature. *Journal of Applied Research in Intellectual Disabilities*, 19(1), 55-65.
- Willner, P. (2005). The effectiveness of psychotherapeutic interventions for people with learning disabilities: a critical overview. *Journal of Intellectual Disability Research*, 49(1), 73-85.

- Willner, P. (2006). Readiness for cognitive therapy in people with intellectual disabilities. *Journal of Applied Research in Intellectual Disabilities*, 19(1), 5-16.
- Willner, P., & Goodey, R. (2006). Interaction of cognitive distortions and cognitive deficits in the formulation and treatment of obsessive–compulsive behaviours in a woman with an intellectual disability. *Journal of Applied Research in Intellectual Disabilities*, 19(1), 67-73.
- Willner, P., Jones, J., Tams, R., & Green, G. (2002). A randomized controlled trial of the efficacy of a cognitive-behavioural anger management group for clients with learning disabilities. *Journal of Applied Research in Intellectual Disabilities*, 15(3), 224-235.
- Willner, P., Rose, J., Jahoda, A., Stenfort Kroese, B., Felce, D., MacMahon, P., ... & Hood, K. (2013). A cluster randomised controlled trial of a manualised cognitive behavioural anger management intervention delivered by supervised lay therapists to people with intellectual disabilities. *Health Technology Assessment*, 17(21), 1-173.
- Zigman, W. B., Schupf, N., Devenny, D. A., Mizejeski, C., Ryan, R., Urv, T. K., ... & Silverman, W. (2004). Incidence and prevalence of dementia in elderly adults with mental retardation without Down syndrome. *American Journal of Mental Retardation*, 109(2), 126-41.

Appendices

Appendix 1. Search terms

- 1. Terms related to Learning Disabilities:** learning disabilit*.mp. OR exp intellectual impairment/ OR *mental deficiency OR intellectual disabilit*.mp. OR mental* retard*.mp.
- 2. Terms related to mental health problems:** anxiety.mp. OR anxiety/ OR exp anxiety disorder/ OR depression.mp. OR exp depression/
- 3. Terms related to CBT:** cognitive behav* therap*.mp. OR CBT.mp. OR cognitive behav* treatment
- 4. 1 AND 2 AND 3**

Appendix 2. Data extraction form

Authors (year)	
Aim of study	
Study design	
Engagement of carers/staff	-Yes
	-No
	-As “therapists” -As “co-participants”
Number of participants	-Intervention group
	-Control group
Characteristics of Participants	-Gender
	-Age
	-Level of ID
Intervention	
Outcome measures	
Analysis	
Outcomes	
Limitations	
Other information	

Appendix 3. Search terms

Ovid MEDLINE(R) 1946 to February Week 2 2014 & Embase 1974 to 2014 Week 08

Date of research: from 18-02-2014 to 22-02-2014

5. **Terms related to cancer and general surgery:** cancer surgery OR major surgery OR sarcoma surgery OR exp General Surgery/ OR exp Surgical Procedures, operative/ OR exp Surgical Procedures, Elective/ OR exp Surgical Procedures, Minimally Invasive/ OR exp Surgical Procedures, Minor/
6. **Terms related to the psychological intervention:** psychological intervention OR psychosocial intervention OR psychological therapy OR (needs assessment*) OR (holistic assessment*) OR (psych* assessment*) OR (holistic adj3 need* adj3 assessment*) OR (psycholog* adj3 need* adj3 assessment*) OR Cognitive Therapy OR Gestalt Therapy OR Behavior Therapy OR Psychoanalytic Therapy OR Marital Therapy OR Relaxation Therapy OR Couples Therapy OR Mind-Body Therapies
7. **Terms related to post-operative outcomes:** (post-operative adj3 outcome*) OR (post-surgical adj3 outcome*) OR (outcome* adj3 after surger*) OR (exp postoperative complications/) OR (surg* outcome*) OR (exp morbidity/) OR (exp mortality/) OR (exp length of stay/)
8. 1 AND 2 AND 3

PsycINFO 1967 to February Week 3 2014

Date of research: 22-02-2014

1. **Terms related to cancer and general surgery:** cancer surgery OR major surgery OR sarcoma surgery OR exp surgery/
2. **Terms related to the psychological intervention:** psychological intervention OR psychosocial intervention OR psychological therapy OR (needs assessment*) OR (holistic assessment*) OR (psych* assessment*) OR (holistic adj3 need* adj3 assessment*) OR (psycholog* adj3 need* adj3 assessment*) OR Cognitive Therapy OR Gestalt Therapy OR Behavior Therapy OR Psychoanalytic Therapy OR Marital Therapy OR Relaxation Therapy OR Couples Therapy OR Mind-Body Therapies
3. **Terms related to post-operative outcomes:** (post-operative adj3 outcome*) OR (post-surgical adj3 outcome*) OR (outcome* adj3 after surger*) OR (exp postsurgical complications/) OR (surg* outcome*) OR (exp morbidity/) OR (exp mortality/) OR (exp length of stay/)
4. 1 AND 2 AND 3

Appendix 4. Quality assessment of the included studies (Kmet, Lee and Cook, 2004)

	Garssen et al. (2013)	Cohen et al. (2011)	Parker et al. (2009)	Haase et al. (2005)	Larson et al. (2000)	Burton et al. (1995)	Williams et al. (1988)
1. Question / objective sufficiently described?	2	2	2	2	2	1	2
2. Study design evident and appropriate?	2	2	2	2	2	1	2
3. Method of subject/comparison group selection or source of information /input variables described and appropriate?	2	2	2	2	1	0	1
4. Subject (and comparison group, if applicable) characteristics sufficiently described?	2	2	2	1	1	1	1
5. If interventional and random allocation was possible, was it described?	2	2	2	2	1	1	0
6. If interventional and blinding of investigators was possible, was it reported?	0	2	2	2	0	0	0
7. If interventional and blinding of subjects was possible, was it reported?	N/A	N/A	N/A	N/A	N/A	N/A	N/A
8. Outcome and (if applicable) exposure measure(s) well defined and robust to measurement / misclassification bias? means of assessment reported?	1	2	2	2	1	0	1
9. Sample size appropriate?	2	1	1	2	0	1	0
10. Analytic methods described/justified and appropriate?	2	2	2	2	2	1	1
11. Some estimate of variance is reported for the main results?	1	1	1	1	0	0	0
12. Controlled for confounding?	1	2	2	2	1	0	1
13. Results reported in sufficient detail?	2	2	2	2	2	1	2
14. Conclusions supported by the results?	2	2	2	2	1	2	2
Total Score	21	24	24	24	14	9	13

Appendix 5. Characteristics of the studies included in the review

Authors, year	Study aims	Cancer type	Surgery	Participants
Garssen et al, 2013	To assess the effect of a pre-surgical stress management training intervention on the psychological outcomes of breast cancer patients that undergo surgery.	Breast cancer	Breast cancer surgery (mastectomy or lumpectomy)	70 participants <ul style="list-style-type: none"> One Intervention Group: 34 women (mean age: 52) Control Group: 36 women (mean age: 54)
Cohen et al., 2011	To investigate the effectiveness of a pre-operative stress management intervention in improving the immune function of patients with prostate cancer that go through Radical Prostatectomy.	Early-stage prostate cancer	Radical prostatectomy	159 participants <ul style="list-style-type: none"> Two Intervention Groups: 107 men (mean age: 60) Control Group: 52 men (mean age: 60.9)
Parker et al., 2009	To investigate the effectiveness of a pre-operative stress management intervention in enhancing QoL and decreasing stress in patients with prostate cancer that go through Radical Prostatectomy.	Early-stage prostate cancer	Radical prostatectomy	159 participants <ul style="list-style-type: none"> Two Intervention Groups: 107 men (mean age: 60) Control Group: 52 men (mean age: 60.9)
Haase et al., 2005	To assess whether brief psychological interventions can improve the post-operative outcomes of elderly cancer patients that undergo conventional colorectal surgery.	Colorectal carcinoma	Conventional resection of colorectal carcinoma	60 participants (45 with rectal cancer and 15 with colon cancer) <ul style="list-style-type: none"> Two Intervention Groups: 42 men (mean age: 64.8) Control Group: 18 men (mean age: 65.8)

Larson et al., 2000	To evaluate the feasibility of a pre-operative psychological intervention for breast cancer patients and investigate whether it can increase their postoperative immune function.	Breast cancer	Breast cancer surgery	41 participants <ul style="list-style-type: none"> One Intervention Group: 23 women (mean age: 56) Control Group: 18 women (mean age: 56)
Burton et al., 1995	To assess the effect of a pre-surgical brief psychotherapeutic intervention on the post-operative psychological outcomes of breast cancer patients that undergo mastectomy.	Breast cancer	Breast cancer surgery (mastectomy or sector mastectomy)	215 participants <ul style="list-style-type: none"> Three Intervention Groups: 162 women (mean age: 62) Control Group: 53 women (mean age: 57)
Williams et al., 1988	To examine the effect that pre-operative teaching for mastectomy and hysterectomy has on the post-operative self-care behaviours of women that went through these types of surgery.	Breast or gynaecological cancer	Breast cancer surgery (mastectomy) or hysterectomy	60 participants (age: 18-64 years old) <ul style="list-style-type: none"> One Intervention Group: 30 women (15 with breast and 15 with gynaecological cancer) Control Group: 30 women (15 with breast and 15 with gynaecological cancer)

Appendix 6. Description of the psychological interventions

Garssen et al. (2013)	Cohen et al. (2011) & Parker et al. (2009)	Haase et al. (2005)	Larson et al. (2000)	Burton et al. (1995)	Williams et al. (1988)
<p>Stress management training: <u>Pre-surgery</u> Meditation exercise Relaxation Audio CD for home Instructions for active coping Guided imagery (to prepare for the operation) Audio CD with the instructions – suggested to practice</p> <p><u>Post-surgery</u> Meditation and visualisation exercises Promote an active coping style Reflect on learning</p>	<p>Stress management (Cognitive-Behavioural orientation): Relaxation skills (diaphragmatic breathing, guided imagery) Audiotapes of the relaxation techniques Imaginal exposure to surgery Concerns and fears Problem-focused coping strategies (activity pacing, seeking out social support, having realistic expectations about recovery) Stress management guide</p> <p>Booster sessions: Reinforcement of the relaxation and the problem-focused coping strategies.</p> <p>Supportive attention: Detailed psychosocial and medical history Empathy and reflective listening by the psychologist Extra attention and environment that facilitates the discussion of worries</p> <p>Booster sessions: discussion for their pre and post-operative experiences</p>	<p>Guided Imagery: Imagine being at a place where they feel safe Process their anxiety feelings Relaxing music</p> <p>Progressive Muscle Relaxation: Imagine that they tense and relax specific muscles Breathing Relaxing music</p>	<p>Psychosocial intervention: Psychoeducation about anxiety Individualised problem-solving strategies Progressive muscle relaxation Audio tape Psychosocial support through discussion Identifying participants' concerns and thoughts</p>	<p>Preoperative interview: Discussion around: The diagnosis Illness beliefs Worries regarding body image Social support Stressful events Anxiety & depression Reflection on the patient's worries and coping strategies.</p> <p>Psychotherapeutic intervention: Positioning cancer in patient's life Exploring his/her feelings about cancer</p> <p>'Chat' a general discussion about patients' life (e.g. hobbies)</p>	<p>One set for mastectomy and one for hysterectomy patients</p> <p>Preoperative teaching programme: Checklist of patient's knowledge about surgery Simple explanation of breast's/uterus's anatomy and physiology Simple explanation of surgery including: diagnostic procedures, terminologies, physical preparation, incision and dressing, intervening sequences, ambulation exercises, answer questions</p> <p>Discharge planning: Clinic visits Exercises Home activities Marital relations Adjunct therapy and toxic effects Answer questions</p>

Appendix 7. Thorough list of post-operative outcomes

Authors, year	Garssen et al., 2013	Cohen et al., 2011	Parker et al., 2009	Haase et al., 2005	Larson et al., 2000	Burton et al., 1995	Williams et al., 1988
Outcomes	Anxiety Depression QoL Well-being Perception of control Fatigue Sleep problems Pain Breast cancer surgery- related symptoms Satisfaction with the intervention	Mood disturbance and anxiety Natural Killer Cell Cytotoxicity (NKCC) Proinflammatory cytokines (IL-1 β , IL-12p70, interferon [IFN] γ , IL-6, IL-8, IL-10 and TNF- α) Lymphocyte populations	Mood disturbance and anxiety Intrusive thinking and avoidance behaviours General QoL related to health (physical and mental health functioning) QoL related to prostate cancer Post-operative complications and hospitalisations	Analgesic consumption Subjective pain intensity (at rest and coughing) Pulmonary function Fatigue Acceptance of the intervention Duration of ileus	Interferon- γ (IFN- γ) production Natural Killer Cell Activity (NKCA) Depression Emotions Intrusive thoughts Optimism	Anxiety & depression Staff's ability to recognise individuals' mental health problems Coping Stressful life events Social support Distress about body image Physiological measures (temperature, pulse, blood pressure) Recovery measures: length of hospital stay, pain, medical complications Mortality	Ambulation and rehabilitation tasks Self-care activities at home Preventable complications

Appendix 8a. Female presentation cards for the ‘Cognitive mediation’ task (Dagnan et al., 2009)

1.

A

You are in bed one night and you hear a loud noise downstairs.

You feel happy.



What would you be thinking or saying to yourself?

B

You are in bed one night and you hear a loud noise downstairs.

You feel sad.



What would you be thinking or saying to yourself?

2.

A

You walk into a room where there are a group of your friends.

As you walk in they start to laugh.

You feel happy.



What would you be thinking or saying to yourself?

B

You walk into a room where there are a group of your friends.

As you walk in they start to laugh.

You feel sad.



What would you be thinking or saying to yourself?

3.

A

You want to go on a special trip but there is only one place and your friend is chosen to go instead.

You feel sad.



What would you be thinking or saying to yourself?

B

You want to go on a special trip but there is only one place and your friend is chosen to go instead.

You feel happy.



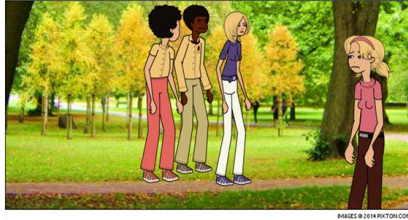
What would you be thinking or saying to yourself?

4.

A

You see a group of your friends but they do not say hello.

You feel sad.

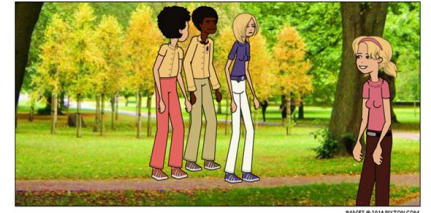


What would you be thinking or saying to yourself?

B

You see a group of your friends but they do not say hello.

You feel happy.



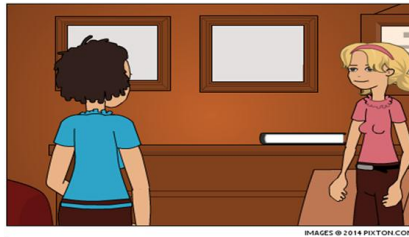
What would you be thinking or saying to yourself?

5.

A

You have been asked to go and see your manager.

You feel happy.

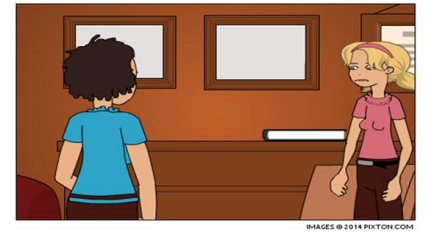


What would you be thinking or saying to yourself?

B

You have been asked to go and see your manager.

You feel sad.



What would you be thinking or saying to yourself?

6.

A

It is your first day at a new job that you have not done before.

You feel sad.



What would you be thinking or saying to yourself?

B

It is your first day at a new job that you have not done before.

You feel happy.



What would you be thinking or saying to yourself?

Appendix 8b. Male presentation cards for the ‘Cognitive mediation’ task (Dagnan et al., 2009)

1.

A

You are in bed one night and you hear a loud noise downstairs.

You feel happy.



What would you be thinking or saying to yourself?

B

You are in bed one night and you hear a loud noise downstairs.

You feel sad.



What would you be thinking or saying to yourself?

2.

A

You walk into a room where there are a group of your friends.

As you walk in they start to laugh.

You feel happy.



What would you be thinking or saying to yourself?

B

You walk into a room where there are a group of your friends.

As you walk in they start to laugh.

You feel sad.



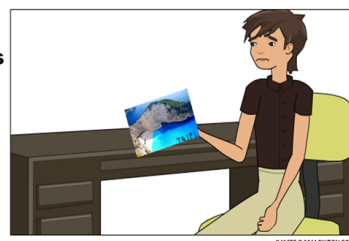
What would you be thinking or saying to yourself?

3.

A

You want to go on a special trip but there is only one place and your friend is chosen to go instead.

You feel sad.

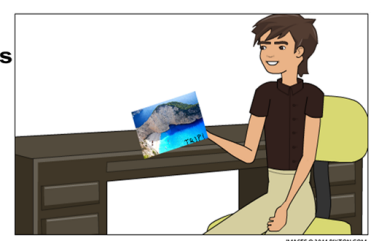


What would you be thinking or saying to yourself?

B

You want to go on a special trip but there is only one place and your friend is chosen to go instead.

You feel happy.



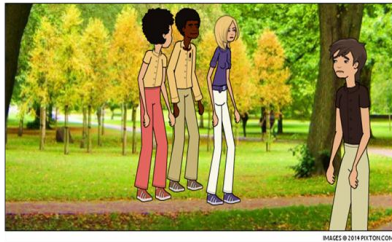
What would you be thinking or saying to yourself?

4.

A

You see a group of your friends but they do not say hello.

You feel sad.

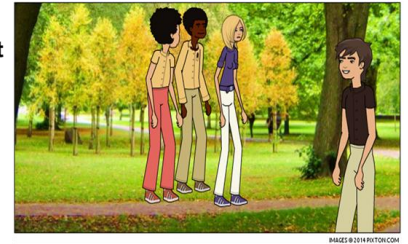


What would you be thinking or saying to yourself?

B

You see a group of your friends but they do not say hello.

You feel happy.



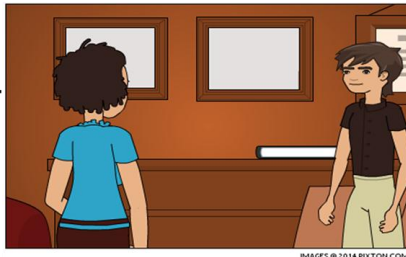
What would you be thinking or saying to yourself?

5.

A

You have been asked to go and see your manager.

You feel happy.

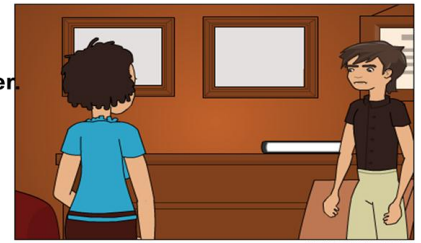


What would you be thinking or saying to yourself?

B

You have been asked to go and see your manager.

You feel sad.



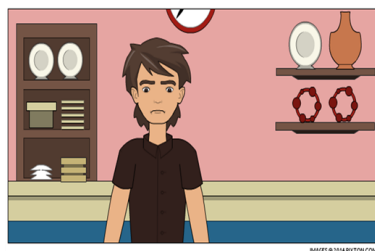
What would you be thinking or saying to yourself?

6.

A

It is your first day at a new job that you have not done before.

You feel sad.



What would you be thinking or saying to yourself?

B

It is your first day at a new job that you have not done before.

You feel happy.



What would you be thinking or saying to yourself?

Appendix 9a. Female presentation cards for the ‘Linking activating events to emotions’ task (Reed & Clements, 1989)

Which face is Julia’s face?



Why?

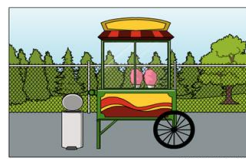
1.

It’s a very hot day.

Julia wants an ice cream.



The ice cream shop is closed.



2.

Julia and her friend have a fight.



Her friend walks away.



3.

Julia goes to work.

She works very hard.



Her supervisor says, “that’s good work”.



4.

Julia gets out of bed.

She goes downstairs.



It is her birthday.



5.

**Julia takes her dog
for a walk.**

**The dog breaks the
lead.**



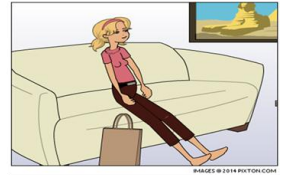
**She has lost her
dog.**



6.

**Julia comes home
from work.**

She is very tired.



**Someone makes
her a cup of tea.**



Appendix 9b. Male presentation cards for the ‘Linking activating events to emotions’ task (Reed & Clements, 1989)

Which face is John's face?



Why?

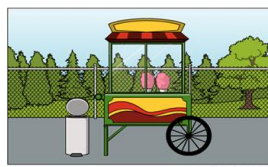
1.

It's a very hot day.

John wants an ice cream.

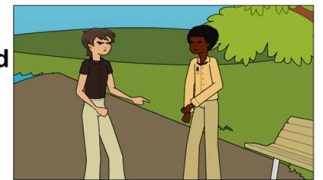


The ice cream shop is closed.

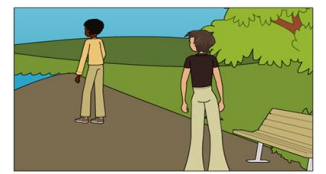


2.

John and his friend have a fight.



His friend walks away.



3.

John goes to work.

He works very hard.



His supervisor says, "that's good work".



4.

John gets out of bed.

He goes downstairs.



It is his birthday.



5.

John takes his dog
for a walk.

The dog breaks the
lead.



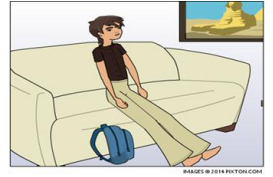
He has lost his
dog.



6.

John comes home
from work.

He is very tired.



Someone makes
him a cup of tea.



Appendix 10. Qualitative feedback about the video

Did you like the video you watched?

- Why / Why not?
- Tell me something you didn't like.
- What did you like most?

Do you think that the video you watched was interesting?

- Why?
- Which was the most interesting thing?

Did you learn anything from the video?

- Do you want to give me some details?

<p style="text-align: center;">UNIVERSITY OF BIRMINGHAM APPLICATION FOR ETHICAL REVIEW</p>
--

Who should use this form:

This form is to be completed by PIs or supervisors (for PGR student research) who have completed the University of Birmingham's Ethical Review of Research Self Assessment Form (SAF) and have decided that further ethical review and approval is required before the commencement of a given Research Project.

Please be aware that all new research projects undertaken by postgraduate research (PGR) students first registered as from 1st September 2008 will be subject to the University's Ethical Review Process. PGR students first registered before 1st September 2008 should refer to their Department/School/College for further advice.

Researchers in the following categories are to use this form:

1. The project is to be conducted by:
 - staff of the University of Birmingham; or
 - a research postgraduate student enrolled at the University of Birmingham (to be completed by the student's supervisor);
2. The project is to be conducted at the University of Birmingham by visiting researchers.

Students undertaking undergraduate projects and taught postgraduates should refer to their Department/School for advice.

NOTES:

- Answers to questions must be entered in the space provided.
- An electronic version of the completed form should be submitted to the Research Ethics Officer, at the following email address: aer-ethics@contacts.bham.ac.uk. Please **do not** submit paper copies.
- If, in any section, you find that you have insufficient space, or you wish to supply additional material not specifically requested by the form, please it in a separate file, clearly marked and attached to the submission email.
- If you have any queries about the form, please address them to the [Research Ethics Team](#).

✓ ☐ Before submitting, please tick this box to confirm that you have consulted and understood the following information and guidance and that you have taken it into account when completing your application:

- The information and guidance provided on the University's ethics webpages
(<https://intranet.birmingham.ac.uk/finance/accounting/Research-Support-Group/Research-Ethics/Ethical-Review-of-Research.aspx>)
- The University's Code of Practice for Research
(http://www.as.bham.ac.uk/legislation/docs/COP_Research.pdf)

**UNIVERSITY OF BIRMINGHAM
APPLICATION FOR ETHICAL REVIEW**

OFFICE USE ONLY:

Application No:

Date Received:

1. TITLE OF PROJECT

Can adults with learning disabilities understand the link between mediating cognitions and subsequent emotional responses?

2. THIS PROJECT IS:

University of Birmingham Staff Research project ☐

University of Birmingham Postgraduate Research (PGR) Student project ☒

Other ☐ (Please specify):

3. INVESTIGATORS

a) PLEASE GIVE DETAILS OF THE PRINCIPAL INVESTIGATORS OR SUPERVISORS (FOR PGR STUDENT PROJECTS)

Name: Title / first name / family name	Dr. Biza Stenfert Kroese
Highest qualification & position held:	PhD, Senior Lecturer and Consultant Clinical Psychologist
School/Department	Clinical Psychology
Telephone:	
Email address:	

Name: Title / first name / family name	Dr Gemma L. Unwin
Highest qualification & position	PhD, Research Fellow
School/Department	Psychology
Telephone:	
Email address:	

b) PLEASE GIVE DETAILS OF ANY CO-INVESTIGATORS OR

CO-SUPERVISORS (FOR PGR STUDENT PROJECTS)

Name: Title / first name / family name	Dr Sabiha Azmi
Highest qualification & position	Lead Clinical Psychologist
School/Department	Psychology Department, Learning Disabilities Services, Birmingham Community Healthcare
Telephone:	
Email address:	

c) In the case of PGR student projects, please give details of the student

Name of Course of Principal	Ioanna Tsimopoulou	Student No:	
	Clinical Psychology	Email	

Name of student: Course of study: Principal		Student No:	
		Email address:	

4. ESTIMATED START OF Date: June 2014 **PROJECT**

ESTIMATED END OF Date: September 2014 **PROJECT**

5. FUNDING

List the funding sources (including internal sources) and give the status of each source.

<i>Funding Body</i>	<i>Approved/Pending /To be submitted</i>
There is no funding body.	

If applicable, please identify date within which the funding body requires acceptance of award:

Date:

If the funding body requires ethical review of the research proposal at application for funding please provide date of deadline for funding application:

Date:

6. SUMMARY OF PROJECT

Describe the purpose, background rationale for the proposed project, as well as the hypotheses/research questions to be examined and expected outcomes. This description should be in everyday language that is free from jargon. Please explain any technical terms or discipline-specific phrases.

People with learning disabilities (LD) suffer from mental health problems more often than the general population (Cooper et al., 2007), with depression and anxiety being the most common disorders (Reid et al., 2011; Richards et al., 2001; Smiley, 2005). The development of psychosocial interventions has been slow (Hatton, 2002), while pharmacological and behavioural interventions have been the treatment of choice (Stenfert Kroese, 1997).

Research has shown that Cognitive Behavioural Therapy (CBT) is the most effective treatment for anxiety and depression in the general population (NICE, 2007; NICE, 2009). The theory underpinning CBT is that the emotional and behavioural responses of the individuals (e.g. their anxiety or depression symptoms) are determined by their thoughts. As a result, CBT aims to challenge mediating cognitions which are deemed dysfunctional. Although CBT is used for individuals with LD, evidence on how effective these interventions are remains modest (Vereenoghe & Langdon, 2013; Willner, 2005).

A number of studies have assessed whether people with LD have the capacity to understand the CBT model (Dagnan & Chadwick, 1997; Dagnan, Chadwick & Proudlove, 2000; Joyce, Globe, & Moody, 2006; Oathamshaw & Haddock, 2006; Sams, Collins, & Reynolds, 2006). They found that the majority of adults with LD were able to link specific events with emotions, but had difficulties understanding cognitive mediation and linking thoughts, emotions and events. It has been suggested that structured interventions that aim to teach individuals the basic elements of CBT can enhance their understanding about the cognitive elements of the model and their appropriateness to receive CBT (Dagnan et al., 2000; Sams et al., 2006).

This research will aim to explore what young adults with a LD understand about cognitive mediation, what can be taught with the use of digital stories, and how much and what information is retained at follow-up. The primary research question is: Can young adults with LD understand the link between mediating cognitions and subsequent emotional responses? The secondary research question is: What can be taught to young adults with a LD about the link between mediating cognitions

and subsequent emotional responses. At each stage of the research participants will be asked to complete three questionnaires which measure their ability to 1) identify cognitive mediation 2) link activating events and emotions and 3) differentiate between behaviours, thoughts and feelings.

7. CONDUCT OF PROJECT

Please give a description of the research methodology that will be used

The proposed study will use a series of case studies. Participants will be informed about the research by their manager and asked whether they would like to take part. The participant information sheet (Appendix 1) will be used to facilitate this process. Those wishing to take part in the research will complete a capacity to consent assessment (Arscott, Dagnan and Stenfort Kroese, 1998) which asks potential participants questions about the research, what it will entail and their right to withdraw.

The research will involve 4 phases: pre-intervention, intervention, post-intervention and follow-up. At the pre-assessment phase participants will be asked to complete the British Picture Vocabulary Scale (BPVS; Dunn et al., 1997) which assesses receptive language, the Cognitive Mediation Questionnaire (Dagnan and Chadwick, 1997; Appendix 4), the Reed & Clements (1989) questionnaire which measures ability to link activating events and emotions (Appendix 5), and finally “The Behaviour, Thought, Feeling Questionnaire” (Greenberger & Padesky, 1985; Appendix 6) which assesses the ability to differentiate between behaviours, thoughts and feelings. During the intervention phase participants will be shown digital stories lasting no more than 10 minutes. Comic Software was used to create the stories with a voice over commentary. They use simple language to teach the difference between feelings and thoughts and the link between mediating cognitions and emotional responses. The post-intervention phase will require participants to complete the same questionnaires (apart from the BPVS) and provide qualitative feedback (Appendix 7) regarding their experience of viewing the digital stories (do they think they were interesting and have they learnt something?). Participants will

be asked to attend a follow up appointment (approximately) 1 week later when they will be asked to complete the same three questionnaires as before.

The sessions will take place in a private and quiet room in a mutually convenient venue -e.g. participants' own home, a day service or university. Participants will be offered the option of having someone to accompany them to the session, as this might make them feel more relaxed.

In order to assess the accessibility of the content of the digital stories and the questionnaires, a pilot study will be carried out. The pilot will also obtain feedback from participants about what it was like to take part in the research and whether they thought it was useful. The pilot will involve exactly the same procedure as the full scale study described earlier but will include 2-3 people only.

8. DOES THE PROJECT INVOLVE PARTICIPATION OF PEOPLE OTHER THAN THE RESEARCHERS AND SUPERVISORS?

Yes ☒ No ☐

Note: "Participation" includes both active participation (such as when participants take part in an interview) and cases where participants take part in the study without their knowledge and consent at the time (for example, in crowd behaviour research).

If you have answered NO please go to Section 18 . If you have answered YES to this question please complete all the following sections.

9. PARTICIPANTS AS THE SUBJECTS OF THE RESEARCH

Describe the number of participants and important characteristics (such as age, gender, location, affiliation, level of fitness, intellectual ability etc.). Specify any inclusion/exclusion criteria to be used.

According to consultation with the research tutor, five participants with a LD are required for a series of case studies research design.

The sample will include males and females, aged over 18, who have a significant LD (IQ= 55-70) and English is their first language. Participants from different racial, ethnic, cultural, religious and sexual orientation groups will be welcome to take part in the research. Participants will be selected using opportunity sampling.

Those who do not have a significant LD or do not have capacity to give consent will not be able to take part in the research. People who have a severe and enduring mental health problem (e.g. psychosis) and people who have visual and/or auditory impairments will be excluded from the research on the grounds that their difficulties may introduce factors to the research that are not being examined in this study. Finally, individuals who are currently receiving CBT will be excluded to decrease confounding due to learning being attributable to the therapy.

10. RECRUITMENT

Please state clearly how the participants will be identified, approached and recruited. Include any relationship between the investigator(s) and participant(s) (e.g. instructor-student).

Note: Attach a copy of any poster(s), advertisement(s) or letter(s) to be used for recruitment.

A day centre officer from each day centre will be responsible for identifying potential participants. He/she will be sent an information sheet which includes an outline of the research project, the inclusion and exclusion criteria and the contact details of the academic supervisors (Dr Biza Kroese, Dr Gemma Unwin), clinical supervisor (Dr Sabiha Azmi) and student (Ioanna Tsimopoulou). The recruitment information sheet can be found in Appendix 2.

Participants will be asked whether they would like to take part in the research. The participant information sheet (Appendix 1) will be used to facilitate this process. Participants will be given a minimum of 24 hours and a maximum of 14 days to decide whether they would like to take part in the research.

11. CONSENT

a) Describe the process that the investigator(s) will be using to obtain valid consent. If consent is not to be obtained explain why. If the participants are minors or for other reasons are not competent to consent, describe the proposed alternate source of consent, including any permission / information letter to be provided to the person(s) providing the consent.

Informed consent will be obtained from each potential participant. This will be achieved by an informal meeting between each potential participant and the researcher, who will explain the research using the participant information sheet. This will provide an outline of the research and describe what will be expected of the participant should he/she consent to take part.

In addition to obtaining informed consent participants will be assessed for capacity to consent to test their understanding of the research. This will be achieved by a one to one meeting with the researcher, where the potential participant will be asked to answer some questions. This is a standard procedure that was adapted from Arscott, Dagnan and Stenfort Kroese, 1998 (Appendix 8). The researcher has experience interviewing people with LD and will receive supervision by the academic and clinical supervisor.

Participants who give consent to take part in the research and have capacity to do so will be asked to sign a participant consent form. This can be found in Appendix 3. As the research is comprised of three different stages it cannot be assumed that consent given at the beginning of the research applies to the other stages. Therefore informed consent will be obtained prior to each stage of the research.

Note: Attach a copy of the Participant Information Sheet (if applicable), the Consent Form (if applicable), the content of any telephone script (if applicable) and any other material that will be used in the consent process.

b) Will the participants be deceived in any way about the purpose of the study? **Yes**
☐ **No** ☒

If yes, please describe the nature and extent of the deception involved. Include how and when the deception will be revealed, and who will administer this feedback.

12. PARTICIPANT FEEDBACK

Explain what feedback/ information will be provided to the participants after participation in the research. (For example, a more complete description of the purpose of the research, or access to the results of the research).

At the end of the follow-up session, participants will be offered the opportunity to meet as a group to receive a summary of the overall findings of the research. All data will be kept anonymous and the summary will report on the group as a whole rather than individuals. A copy of the report will be made available to each residential and day service that agreed to take part in the research.

13. PARTICIPANT WITHDRAWAL

a) Describe how the participants will be informed of their right to withdraw from the project.

All participants will have the right not to take part in the research. At each stage of the research participants will be asked whether they would like to take part in the study and reassured that there are no consequences to the study. It will be made clear to all participants that their decision to or not to take part in the research will not affect any services they are currently in receipt of or may require in the future. This is detailed on the participant information sheet which can be found in Appendix 1.

Due to the design of the research, it may be that participants who initially gave informed consent to take part in the research later change their mind and decide to withdraw from the study. To allow participants the right to withdraw at any point during the research, informed consent will be sought from each participant at the beginning of each stage of the research. Those who wish to withdraw from the research but would still like to view the digital stories will be able to do so.

b) Explain any consequences for the participant of withdrawing from the study and indicate what will be done with the participant's data if they withdraw.

Participants wishing to withdraw from the research can ask for their data to be removed from the database. Participants will be able to have their data successfully removed from the database up until the point when the data have been analysed, following this it will not be possible for individuals to withdraw their data. The data will be analysed in September 2014. Participants wishing to withdraw from the research will still be able to view the digital stories should they wish to.

14. COMPENSATION

Will participants receive compensation for participation?

i) Financial

Yes ☐ No

☐✓

ii) Non-financial

Yes ☐ No

☐✓

If **Yes** to **either** i) or ii) above, please provide details.

--

If participants choose to withdraw, how will you deal with compensation?

Not applicable

15. CONFIDENTIALITY

a) Will all participants be anonymous?

Yes ☐

No ☒

b) Will all data be treated as confidential?

Yes ☒ No ☐

Note: Participants' identity/data will be confidential if an assigned ID code or number is used, but it will not be anonymous. Anonymous data cannot be traced back to an individual participant.

Describe the procedures to be used to ensure anonymity of participants and/or confidentiality of data both during the conduct of the research and in the release of its findings.

The proposed study will ensure confidentiality is maintained throughout by assigning a number to each participant at the beginning of the study. This number will serve to replace the participant's name and will be kept separately to any other identifying information about the participants, ensuring anonymity. Therefore other professionals/persons who are not part of the research will not be able to identify individual participant's data. Paper records will be kept locked away in a cabinet and electronic information on a password protected University computer. Only the chief investigator, academic supervisor and clinical supervisor will have access to the data.

Confidentiality will be broken only in case that a participant reveals information which indicates i) that s/he is dangerous to himself/herself or others, ii) a suspected case of child abuse.

If participant anonymity or confidentiality is not appropriate to this research project, explain, providing details of how all participants will be advised of the fact that data will not be anonymous or confidential.

Not applicable

16. STORAGE, ACCESS AND DISPOSAL OF DATA

Describe what research data will be stored, where, for what period of time, the measures that will be put in place to ensure security of the data, who will have access to the data, and the method and timing of disposal of the data.

All data will be anonymised and stored securely; paper records will be stored in a locked cabinet, electronic data on a password protected university computer. Personal data will be kept on a password protected university computer and encrypted memory stick.

Biza Kroese (academic supervisor), Gemma Unwin (academic co-supervisor), Sabiha Azmi (clinical supervisor) and Ioanna Tsimopoulou (student) will have access to all participant data throughout the duration of the research. Raw data will be kept until the degree has been awarded. Electronic files containing anonymised data will be kept for 10 years from publication, as per University's Code of Practice for Research. Upon completion of the research, the information will be kept by Biza Kroese (academic supervisor). Paper records will be destroyed one year after completion of the research.

17. OTHER APPROVALS REQUIRED? e.g. Criminal Records Bureau (CRB) checks

YES ☐ NO ☐ NOT APPLICABLE ☐

If yes, please specify.

18. SIGNIFICANCE/BENEFITS

Outline the potential significance and/or benefits of the research

Benefits/significance of the research includes

- Providing teaching materials to professionals to enable them to better support young people with a LD. The materials could be used as part of the education curriculum as well as by health professionals, such as Nurses and Clinical Psychologists who work with young people with a LD.
- The digital stories could be used as part of an individual care package for someone with a LD who may receive CBT.

RISKS

a) Outline any potential risks to **INDIVIDUALS**, including research staff, research participants, other individuals not involved in the research and the measures that will be taken to minimise any risks and the procedures to be adopted in the event of mishap

A potential risk to the participant may be the overall time they each commit to the research which may detract from their everyday activities. The study will be comprised of several different parts which will involve participants having to complete part of the research over a period of several weeks. This burden will be minimised by keeping the duration and frequency of research sessions to a minimum.

Although it is not anticipated that the procedure will cause any psychological distress, all participants will be given a debriefing sheet which will advise them of organisations that can contact if this occurs. Participants will be also offered access to a Clinical Psychologist (Dr Sabiha Azmi) who will be able to offer emotional support.

The main potential risk to the researcher is lone working. Usual lone worker policies will apply, i.e. the researcher will identify any potential risks associated with the participants before meeting via community homes or day services. When going to meet the researcher will ensure someone knows her whereabouts and expected

b) Outline any potential risks to **THE ENVIRONMENT and/or SOCIETY** and the measures that will be taken to minimise any risks and the procedures to be adopted in the event of mishap.

There are no anticipated risks to the environment and/or society as a result of the proposed research.

19. ARE THERE ANY OTHER ETHICAL ISSUES RAISED BY THE RESEARCH?

Yes ☐ No ☒

If yes, please specify

The main ethical and design issues are detailed below:

- Participants will be informed about the research and given a choice as to whether they would like to take part.
- Participants will include people with a significant LD who may find it difficult to access and understand complex information. In order to facilitate participant understanding of the research, all the material used in the study will be presented using clear language that can be easily understood by people with a significant LD. To ensure this is achieved as well as it can be Speech and Language Therapists working with people with a LD will be consulted on the material used for the research where possible.
- The proposed project will use a longitudinal research design as data will be collected at several points throughout the research. As a result it may be that participants who initially gave consent to take part in the study subsequently change their minds and decide they want to withdraw from the research. To allow participants the opportunity to withdraw at any time during the research informed consent will be sought at each stage.
- In addition, each participant will be assessed for their capacity to give informed consent. This will be achieved by a meeting between the researcher and the potential participant, who will be asked questions about the research, what will be expected of them if they give consent to take part and their right to withdraw (Arscott et al., 1998).
- Participants who decide they would like to withdraw from the research will still be entitled to view the digital stories and ask any questions they may have. It will be made clear to participants that their decision to withdraw from the research will not affect any services they are currently in receipt of or may require in the future.

CHECKLIST

Please mark if the study involves any of the following:

- Vulnerable groups, such as children and young people aged under 18 years, those with learning disability, or cognitive impairments ☒

- Research that induces or results in or causes anxiety, stress, pain or physical discomfort, or poses a risk of harm to participants (which is more than is expected from everyday life) ☐
- Risk to the personal safety of the researcher ☐
- Deception or research that is conducted without full and informed consent of the participants at time study is carried out ☐
- Administration of a chemical agent or vaccines or other substances (including vitamins or food substances) to human participants. ☐
- Production and/or use of genetically modified plants or microbes ☐
- Results that may have an adverse impact on the environment or food safety ☐
- Results that may be used to develop chemical or biological weapons ☐

Please check that the following documents are attached to your application.

	ATTACHED	NOT APPLICABLE
Recruitment advertisement	<input type="checkbox"/> ✓	<input type="checkbox"/>
Participant information sheet	<input type="checkbox"/> ✓	<input type="checkbox"/>
Consent form	<input type="checkbox"/> ✓	<input type="checkbox"/>
Questionnaire	<input type="checkbox"/> ✓	<input type="checkbox"/>
Interview Schedule	<input type="checkbox"/> ✓	<input type="checkbox"/>

20. DECLARATION BY APPLICANTS

I submit this application on the basis that the information it contains is confidential and will be used by the University of Birmingham for the purposes of ethical review and monitoring of the research project described herein, and to satisfy reporting requirements to regulatory bodies. The information will not be used for any other purpose without my prior consent.

I declare that:

- The information in this form together with any accompanying information is complete and correct to the best of my knowledge and belief and I take full responsibility for it.
- I undertake to abide by University Code of Practice for Research (http://www.as.bham.ac.uk/legislation/docs/COP_Research.pdf) alongside any other relevant professional bodies' codes of conduct and/or ethical guidelines.
- I will report any changes affecting the ethical aspects of the project to the University of Birmingham Research Ethics Officer.
- I will report any adverse or unforeseen events which occur to the relevant Ethics Committee via the University of Birmingham Research Ethics Officer.

Name of Principal investigator/project

Biza Stenfert Kroese

Date:

Please now save your completed form, print a copy for your records, and then email a copy to the Research Ethics Officer, at aer-ethics@contacts.bham.ac.uk. As noted above, please do not submit a paper copy.

UNIVERSITY OF BIRMINGHAM

Information about the research

My name is **Ioanna Tsimopoulou**.

I am doing research.

Research is when we want to find out about something new so we can give people a better service.



I want to tell you about this research.

I will go through this leaflet with you.

Then you can decide if you want to join in.



To help you understand this letter, you can also:

Ask someone you trust to read it with you



Talk about it with them.

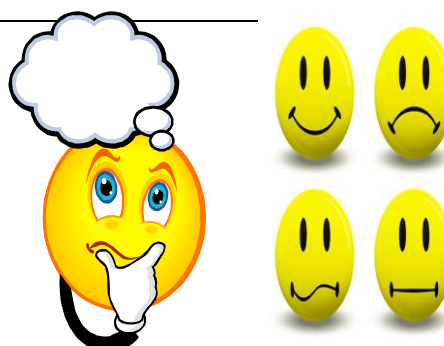


What are we trying to find out?



We want to find out what people understand about thoughts and feelings.

We want to find out what people can learn about thoughts and feelings.



**Why have I been asked to
take part?**



You have been asked to
take part because

- you have a learning
disability
- you are aged over
18



Do I have to take part?



You can tell me yes.



You can tell me no.

You can stop taking part at any time without giving a reason. Just tell me you would like to stop.



If you say no, it will not change the care you get.



What will happen if I take part?



I will meet you 3 times.

3 times



You can choose to see me with a member of your family, a friend or a carer/support worker.



We can talk at a place you choose.

For example

- at your home
- day service
- church
- our office.



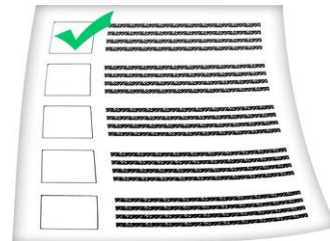
At a day and time to suit you.



Meeting 1

You will fill in some questionnaires. I will help you with this.

Our meeting will last about 1 hour.

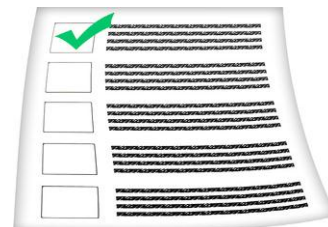


Meeting 2

You will watch a short video with stories about the thoughts and the feelings of people.



You will fill in the same questionnaires that you filled in during the first meeting.



I will ask you if you found

the video interesting and if you learnt something.

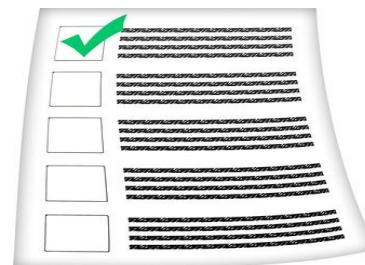
Our meeting will last about 1 hour and 30 minutes.



One week after meeting 2

Meeting 3

You will fill in the same questionnaires.



Our meeting will last about 45 minutes.

I will not talk to anyone else about you. Our meetings are **confidential**.

There are times where we might have to tell someone about what you have said. We will only tell someone what you have said when we think you or someone else is in danger or might get hurt. If this happens, we will only tell people who need to know to make sure everyone is safe.



What if I get upset?



The research should not upset you in anyway.

If you feel upset during the video or while you fill in the

questionnaires, you can tell me. You can move onto a different question or you can decide not to answer a question.

You can make a complaint if you are not happy about the research. You can make a complaint to Uta Noppeney at the University of Birmingham. Uta is not involved with the research.

Her contact details are:

Dr. Uta Noppeney,
University of
Birmingham,
Edgbaston,
Birmingham,
B15 2TT.



What happens after this?



I will then look at the questionnaires and the answers you gave to the questions:

- To see how helpful the video was for you.
- To see if we need to do it differently next time.



If you decide you do not want us to use what you have said, tell the researcher. You will need to do this by the end of September.

I will store the information on a safe computer for 10 years. No one else will be able to see it. Then I will destroy the file.



I will write this down in a report and share it with you and with others if they are interested. Your name will not be used in the report and I will make sure that no-one can tell who has said what in the report.



Want to know more before deciding?



If you have questions or you would like to talk to me more about this:

My number is
07463968894



If you would like to talk
to someone else-
someone who knows
about the research:

Phone Biza Kroese on
0121 414 4919



Thank you for
reading this.

Please ask any
questions if you need
to.



This research has been looked at by a Research Ethics Committee, who
are there to make sure that you are treated well.

Appendix 13. Capacity to consent assessment (Arscott, Dagnan and Stenfert Kroese, 1998)

If people can't answer at least 3 of the questions correctly, they are not considered to have capacity to consent.

(The following information will be read twice before questions below are asked)

-I want to ask you some questions that will help me with a project I am doing. The questions are about feelings and thoughts.

1. What will I be asking you about today?

(Acceptable responses include: talking about feelings and thoughts, about a project you are doing etc. If the respondent does not know repeat the information above.)

2. Are there any good things about talking to me?

3. Are there any bad things about talking to me?

(If an individual indicates that they no longer want to take part, thank them for their time and reassure them that it is okay for them to say this, i.e. that there will be no negative consequences)

4. What can you do if you decide you do not want to talk to me anymore?

(Sometimes it can be helpful to ask the same question but with reference to someone who is known to the person i.e. 'If (name of key worker/tutor) was here what could you say if you did not want to talk to them anymore?' Then repeat the original question again.)

(Acceptable responses include; tell you, say stop, halt, refuse to do it. If participant cannot give a response that indicates understanding, repeat the information above). If the participant is still unable to provide a response ask them if they would like to take part, but their answers will not be included. Check with the individual that they would actually do what they say if they no longer wished to talk to you.

5. Are you happy to answer my questions?

If an individual indicates that they no longer wish to take part thank them for their time and reassure them that it is okay for them to say this i.e. that there will be no negative consequences.

UNIVERSITY OF BIRMINGHAM

Consent form to join in the research

Research project: CBT for people with Learning Disabilities

The names of people who will be doing this study are:

Ioanna Tsimopoulou

Biza Stenfert Kroese

Gemma Unwin

Sabiha Azmi

I have read the information sheet or had it read to me.



I have had time to think and talk about it with friends, family or carers/support workers.



I have been given the chance to ask questions about the research with the Researcher Ioanna Tsimopoulou.

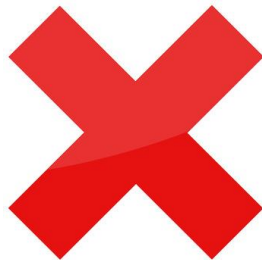


I agree to joining in
the research:

- To filling in questionnaires
- To watching a video
- To being asked some questions about the video



I know that I can say
no to the research
until my answers to
the questionnaires
have been analysed.



I know that no one will
be able to identify me
in any information that
is presented.



I know that I do not
have to take part in
this study.

I know that I can stop
taking part in this
study whenever I
want to.



If I leave this study, I
know that my care
will not be affected.

I would like to take part in this research.

Name: _____ Signature: _____

Date: _____

If the person is unable to sign, use this space to record details of a witness to confirm consent.

I have witnessed _____ giving consent to take part in the study.

Name: _____ Signature: _____

Date: _____

The Researcher promises to hide my personal identity and keep the information safe.

Ioanna Tsimopoulou: _____

(Researcher)

Date: _____