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Exploring the ability of individuals with an Intellectual Disability to generate and use a compassionate image

Laura Brougham BSc (Hons) MSc

Submitted in partial fulfilment of the requirements for the degree of Doctorate in Clinical Psychology

Institute of Health and Wellbeing
College of Medical, Veterinary and Life Sciences
University of Glasgow

September 2017

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Institute of Health & Wellbeing

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University of Glasgow

Institute of Health & Wellbeing

CHAPTER ONE:

SYSTEMATIC REVIEW

A Systematic Review of the key adaptations in Psychological Therapies for individuals with an Intellectual Disability

Laura Brougham (BSc, MSc)

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Abstract

Background: It has been 10 years since Whitehouse and colleagues (2006) carried out a systematic review examining the key adaptations of psychological therapies for people with Intellectual Disabilities. The past decade has seen developments in this area of research. Following on from their study; this review aimed to examine how these adaptations have changed over time.

Methods: Published studies were systematically reviewed to evaluate the adaptations in individual psychological interventions for people with Intellectual Disability during the period 2007–2017. Seven articles were identified. Articles were evaluated using a quality rating tool. Content analysis was used to examine the key adaptations.

Results: All studies identified the following adaptations: memory aids, augmenting activities, directive methods and involving caregivers in therapy sessions. Six of these studies referred to a treatment manual.

Conclusions: While many of the adaptations remain unchanged, there have been developments which, perhaps in part, reflect recent attempts to incorporate_newly emerging psychological therapies for people with intellectual disability.

Key Words: Intellectual Disability, Cognitive Behavioural Therapy, Solution-Focused Therapy, and Behavioural Activation.

Introduction

There have been growing attempts to adapt individual psychological therapies in particular direct talking therapies, to support people with mild intellectual disabilities. A systematic review was carried out and published by Whitehouse and colleagues in 2006, investigating the therapeutic adaptations for people with intellectual disabilities. The current review will examine any new adaptations to therapies during the 10 year period.

Since the Whitehouse and colleagues (2006) review the evidence base for Cognitive Behavioural Therapy (CBT) has increased within this client group. (Taylor et al, 2005; McCabe, McGillivray, & Newton, 2006; Vereenooghe & Langdon, 2013; Osugo & Cooper, 2016). Vereenooghe and Langdon (2013) completed a systematic review and concluded that adapted CBT was shown to be effective in treating anger and depression in adults who have intellectual disabilities. Furthermore, early results from a study investigating Eye Movement Desensitisation and Reprocessing (EMDR) suggested that the therapy could potentially be effectively adapted for this client group (Barol, & Seubert, 2010).

In addition to the increasing use of CBT approaches, there has also been increased acceptance of third wave therapies for people with intellectual disabilities. For example, there have been several studies exploring an adapted Mindfulness approach for clients with intellectual disabilities (Singh et al, 2013; Hwang, & Kearney, 2013) that showed a reduction in the frequency of aggressive behaviour. Moreover, Sakdalan and Collier (2010) completed a pilot study using Dialectal Behavioural Therapy (DBT) for a group of offenders with mild intellectual disabilities, results identified a reduction in dynamic risk and a global improvement of functioning and wellbeing. Also, Clapton and colleagues' (2017) completed a pilot of Compassion Focused Therapy (CFT) and concluded that it was feasible for this client group.

The development of an evidence base for psychological therapies for people with intellectual disabilities has not been without challenge. A number of obstacles have impacted on the building of a robust evidence base within this population. Bhaumik and colleagues (2011) argued that, although some randomised control trials had been carried out, there were some common limitations such as small sample sizes, inconsistent use of

outcome measures, poor research design and lack of control groups. The Royal College of Psychiatrists (2004) have also suggested that individuals with intellectual disabilities have been routinely screened out of psychological therapy trials which targeted the general population.

A first step towards developing a convincing evidence base is ensuring that the therapies are both accessible and meaningful to the cohort. Lindsay and colleagues (2013) noted that there were key cognitive domains that must be considered when adapting therapy: intellectual functioning, emotional literacy, memory and executive functioning. In studies conducted with the general population, the therapeutic alliance has been shown to be fundamental to effective therapy (Kejisers et al, 2000). Clinicians that nurtured and fostered a supportive and collaborative relationship were found to have better outcomes in therapy. Pert and colleagues (2013) interviewed 15 people with borderline-mild intellectual disabilities about their experiences using CBT found that participants valued characteristics such as, warmth, empathy and validation when they were embodied in the therapeutic relationship. Jahoda and colleagues (2009) studied the therapy transcripts of 15 clients with borderline to mild intellectual disabilities to investigate the nature of collaboration in therapy. Using Interactional Analysis, an equal power balance in the client-therapist relationship, highlighted that effective communication and collaboration in therapy of people with an intellectual disability was possible. Therefore a full range of cognitive deficits and communication abilities should be considered and adapted for accordingly.

Whitehouse and colleagues (2006) were keen to review a set of pre-determined therapeutic adaptations previously researched by Hurley and colleagues (1998), with the intention of increasing the skills and confidence of therapists working with this client group. Hurley and colleagues' (1998) criteria outlined nine overarching areas of adaptations across all psychological therapeutic modalities: simplification, language, activities, developmental level, directive methods, flexible methods, involve caregivers, transference/countertransference, and disability/rehabilitation approaches. Some of these adaptations were described in more detail than others in the original paper. For example, language adaptations suggested: use of shorter sentences, delivering one piece of information at a time and pausing to allow for the individual to assimilate new information. Conversely, the area of flexible methods provided limited information. Using these guidelines as a framework for their analysis, Whitehouse and colleagues (2006) reviewed

25 studies (10 CBT and 15 Psychodynamic), which found that 'flexibility to method' was important within CBT. For example, one study (Clare et al., 1992) took their client to a fire station as part of a fire-setting treatment. Perhaps, unsurprisingly, the most frequently reported adaptation within the Psychodynamic studies was 'transference/countertransference'. Another study (Johnson et al., 2003) discussed therapeutic boundaries to ensure the client understood the role between therapist and client.

Since Whitehouse and colleagues' review (2006), there had been a growing number of studies examining the efficacy of psychological therapies. Furthermore, there has also been an increase in the types of therapies being delivered to people with intellectual disabilities. It was likely that the adaptations found by Whitehouse and colleagues (2006) have been evolved. The present study aimed to systematically review the literature regarding adaptations to individual psychological therapies, for people with intellectual disabilities since Whitehouse and colleagues' (2006) review.

Methods

Review Questions

The questions addressed in this review are:

1. What are the key adaptations described in studies of individual psychological therapy for people with a mild intellectual disability?

2. Have the described adaptations to individual psychological therapies changed since the review by Whitehouse and colleagues' (2006)?

Inclusion and Exclusion Criteria

In keeping with Whitehouse and colleagues' (2006) review, studies were included if they: a) investigated individual psychological therapies that were well established and constructed on evidence based psychological interventions b) applied to people with mild intellectual disability (IQ = 60-70) c) were published in a peer-reviewed journal, d) written in English and e) published in the last ten years. Studies were excluded if they: a) targeted caregivers or children, b) were primarily behavioural and did not focus on talking therapies carried out directly with clients, and c) were case studies d) studies involving group studies. Non-analytical studies such as case series were excluded as there is limited opportunity to generalise results due to the findings being concerned with an individual as opposed to a larger sample. The decision to exclude group interventions, followed the same logic as Whitehouse and colleagues' (2006) review; who used criteria laid out by Hurley and colleagues' (1998). For example, in Hurley and colleagues' (1998) original adaptation criteria, group therapy adaptations were defined separately to individual therapeutic adaptations. Items such as group dynamics and a sense of belongingness were defined under group interventions. Therefore, it was argued that the group adaptations to psychological therapies for individuals with an Intellectual Disability may warrant further study in its own systematic review.

Search Strategy

Electronic search:

The following electronic databases were searched: OVID, Medline, PsychInfo, CINAH, Psychology Behavioural Science Collection, and Applied Social Sciences Index and Abstract between January 2007 and January 2017.

Table 1 contains the search terms that were used. The search term 'therapy' was not included as it was too broad and identified articles that did not match review aims. The search terms used were approved by a librarian for suitability in the context of this review.

Table 1: *Electronic search terms:*

Search Terms
"intellectual disabil*" OR "learning disabil*" OR "developmental diabil*" OR "mental handicap*" OR "mental retard*" AND "CBT" OR "compassion*" OR "counsel*" OR "mindful*" OR "psychodynamic" OR "psychother*" OR "cognitive*" OR "psychological therap*"

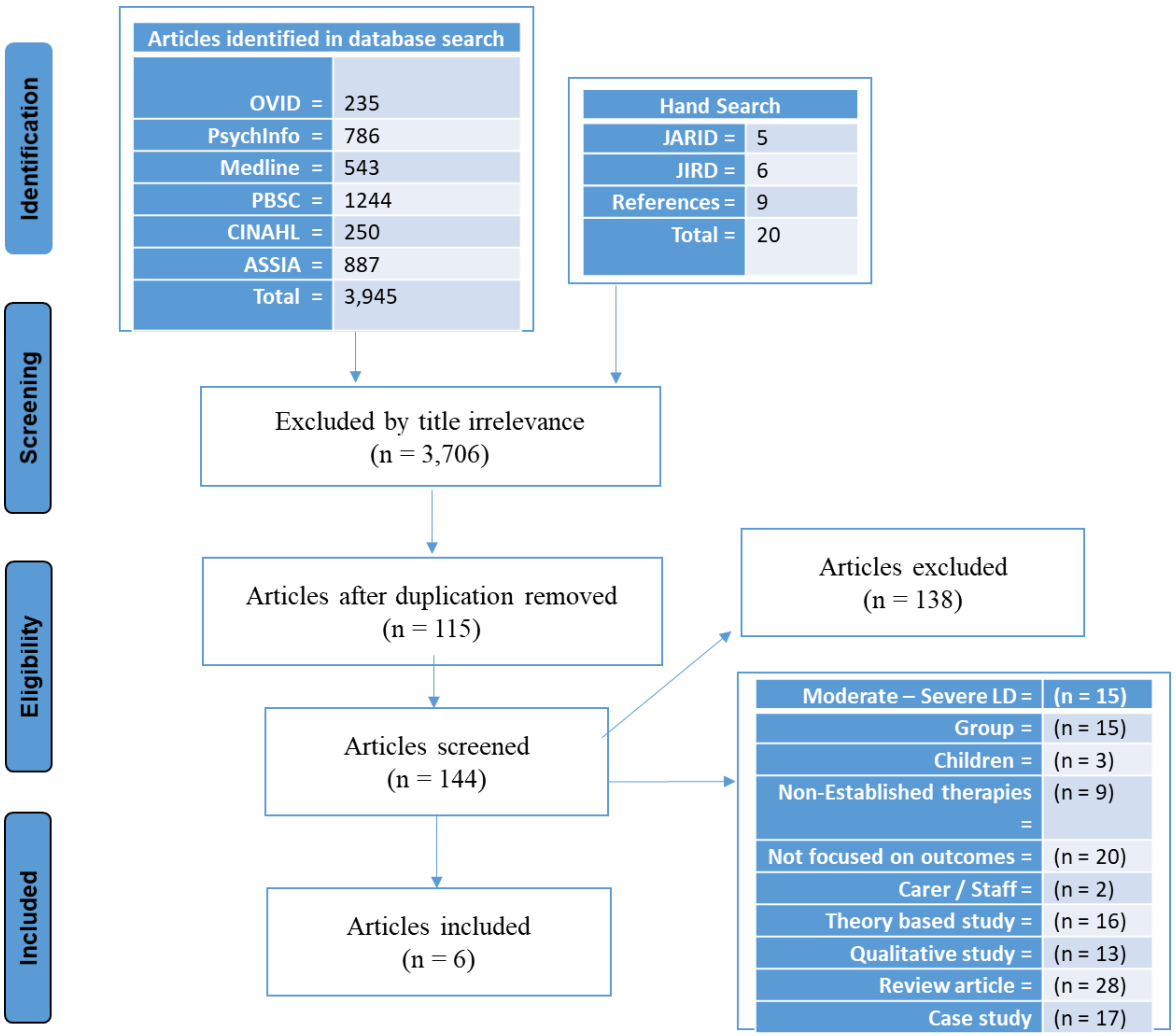
Hand search of key journals:

To ensure all relevant journals were identified, the contents pages of the following journals were hand searched: Journal of Intellectual Disability Research, Journal of Applied Research in Intellectual Disability and American Journal of Mental Retardation / American Journal on Intellectual and Developmental Disabilities. In addition, reference lists from relevant journal articles were also checked.

Article Selection:

Article titles were read for relevance to the review topic (n=3,945) and excluded if not relevant (n=3,706). The abstracts of potentially relevant articles were then read (n=239). After removing duplicates, the full texts of the remaining articles were read (n= 129), of which 123 were discarded. The hand search yielded 20 articles, of which five were duplicates, 14 met exclusion criteria and one was included in the synthesis. Therefore, a total of six studies were selected for inclusion in the current review. A flowchart illustrating the selection process is provided in Figure 1.

Figure 1 - *Flow chart of the process of article selection*



Data Extraction

Article quality and rating criteria:

The Quality Assessment Tool for Quantitative Studies (QATQS) (Thomas, 2003) was selected based on the limited Randomised Controlled Trials (RCT) data available, which meant that the Consolidated Standards of Reporting Trials guidelines (CONSORT; Moher et al, 2001) were not suitable. The QATQS have seven criteria, which are provided in table 2. A description of the criteria is listed in Table 2 below. Each criterion was given a rating of 'weak', 'moderate' or 'strong' based on a guide in the rating tool. Each study was then given an overall rating: 'strong' if no weak rating, 'moderate' if one weak rating, and 'weak' if there were two or more weak ratings as described in the tool. The rating tool allocated equal weight to each criterion. For example, if an RCT trial made no mention of the study 'dropouts' and 'withdrawals' it received a 'moderate' rating, despite performing well in all other areas. Therefore, this tool may not rate an RCT higher by virtue of its study design alone. However, the quality criteria were not used to identify the most robust study in this review, instead aiming to outline key design characteristics and to describe the type of studies found.

The first author reviewed each paper and using the QATQS tool (Thomas, 2003). To ensure reliability, all articles were reviewed by a second independent 'rater', and disagreements with the quality ratings were discussed before an overall consensus was agreed.

Table 2: *Quality Assessment tool for Quantitative studies (Thomas, 2003)*

Item	Criteria
A) Selection Bias	• Participant's representative to target population? • Percentage of selected individuals who agreed to participate?
B) Study Design	• Indicate study Design • Randomised?
C) Confounders	• Were there significant differences between groups? (lists examples of confounders) • (If yes) which percentage of confounders were controlled for?
D) Blinding	• Were outcome assessors aware of the intervention or exposure status of participants? • Were the study participants aware of the research question?
E) Data Collection Method	• Were data collection tools valid? • Were data collection tools reliable?
F) Withdrawals and Dropouts	• Were withdrawals and drop-outs reported with reasons? • Indicate the percentage of participants completing the study?
Global Rating	**Strong = No WEAK ratings** **Moderate = One WEAK rating** **Weak = Two or more WEAK ratings**

Study Adaptations

In their analysis of study adaptations Whitehouse and colleagues' (2006) used a predetermined list outlined by Hurley and colleagues' (1998). In this review, the same process described by Whitehouse and colleagues (2006) was initially carried out. The researcher read all identified papers to become familiar with the content. If a paper referenced an outcome measure or a manual, this was also sourced and included in the analysis. If a study made reference to an adaptation that was carried out to the therapeutic intervention specifically for people with an Intellectual Disability this was included in the results. However, it became apparent that by using a predetermined list a number of other adaptations were missed. Therefore, the researcher complemented this 'top down' process by completing a 'bottom up' analysis of therapy adaptations, using a content analysis (Strauss, 1987).

Three key overarching areas of adaptations were found by using the 'bottom up' analysis: assessment, therapy process and therapy content. Once these three key areas were identified, the researcher then read through the identified adaptations in each study and considered if any further categories could be identified. Following the completion of the final list of categories, each paper was read and coded with the relevant categories. Then an independent second rater (a Trainee Clinical Psychologist) chose three articles of the six studies at random to rate. They read each article, and corresponding referenced materials, and applied the updated categories to each specific adaptation. The rate of inter rater agreement is listed in Table three.

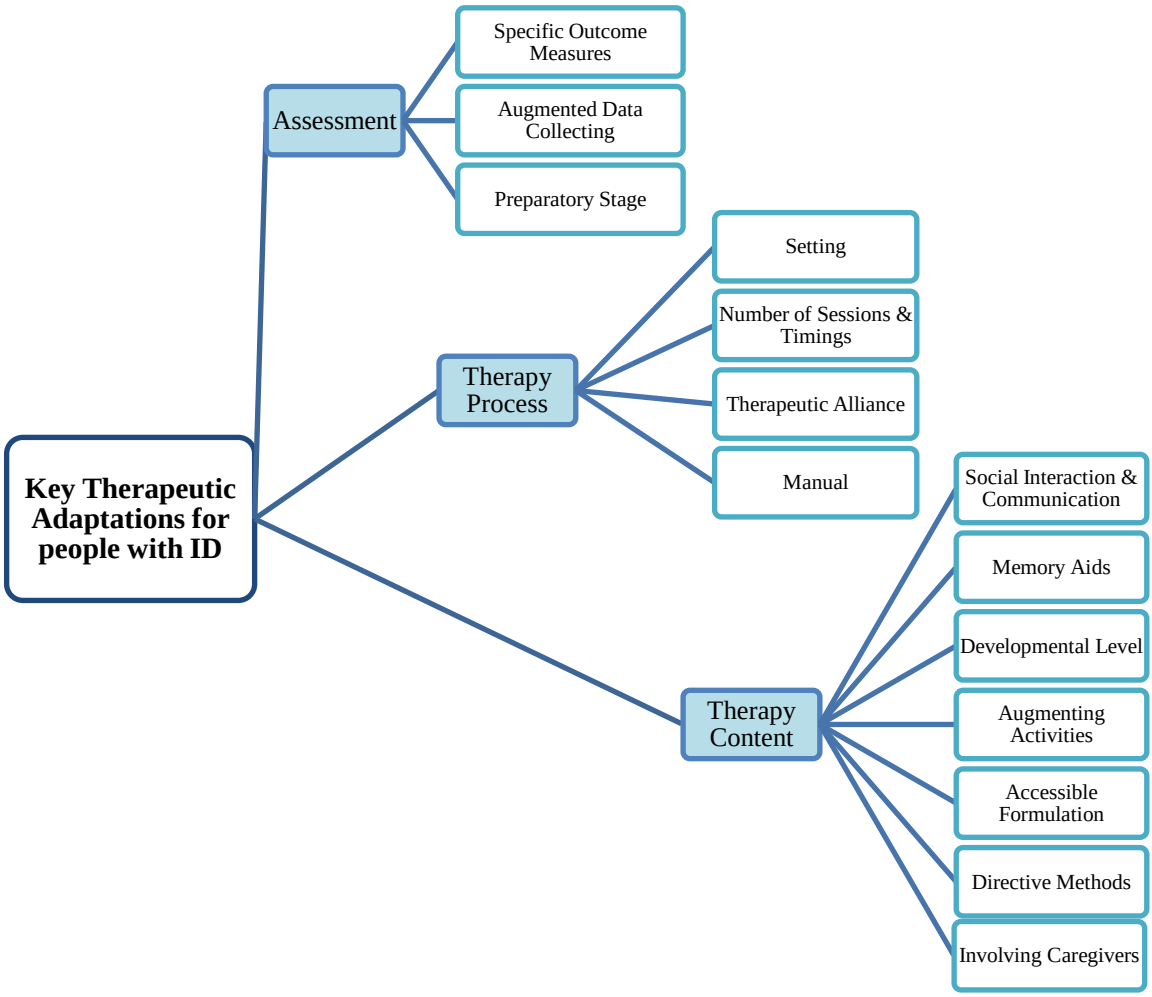
Several adaptations from Whitehouse and colleagues' (2006) study remained in the present review, including: developmental level, augmenting activities, directive methods, and involving caregivers. The adaptation previously called language Whitehouse and colleagues' (2006) paper was expanded to include 'social interaction and communication' in order review the adaptation of non-verbal language. The previous category of language only described adaptations in relation to verbal interactions, such as reduction the amount of language, and checking that the person had understood what had been said.

Results

The current paper reviewed six studies that explored the key adaptations used in individual psychological therapies for people with mild intellectual disabilities (see Table 3). Using the QATQS (Thomas, 2003), one of the studies were assessed as 'weak' (McManus et al., 2014), four 'moderate' (Hassiotis et al., 2013; Lindsay, et al., 2015;, Roeden et al., 2014; Taylor et al., 2016) and one 'strong' (Jahoda et al., 2015). Reviewed studies included a randomised control trial, three cohort designs, and two controlled clinical trials. Studies focused on the following types of therapies: one Solution Focused Brief Therapy (SFBT), one Behavioural Activation (BA) and four CBT (see table 2).

From the content analysis, three main adaptation areas were identified: Assessment, Therapy Process, and Therapy Content. There were a number of adaptations within each of these areas, and the analysis highlighted areas of overlap. The identified adaptations were not mutually exclusive of each other. The findings are summarised in Figure 2 and in Table 4, with adaptations identified by Whitehouse and colleagues' (2006) noted in italics.

Figure 2: *Key Therapeutic Adaptations detailed by area*



As these papers reviewed different psychological therapies, key adaptations will be discussed in relation to each therapeutic modality. Although there were four adapted CBT studies, there was only one identified therapy in other two studies, therefore, there was less information to draw on. The researcher will also outline study quality in these papers.

Table 3:

Study Characteristics

Author, Design	Overall quality rating	Therapy Intervention, Manualised?	Therapist	Presenting Problem	Sample	Adaptations used
Jahoda et al (2015) Cohort Design	STRONG	Behavioural Activation Manual developed for the study from an existing manual Lejuez et al (2001)	A researcher with prior experience of delivering psychological therapy to people with ID under supervision of an experienced Clinical Psychologist working with ID.	Depression	23 adults with ID (16 Mild, 3 Moderate, 5 Severe)	**Rater 1** Assessment: 3 – OM, AD, PS Process: 4 – S, N, P, TA Content:7 – M, SC, MA, DL, AA, SF, IC **Percentage agreed = 93%**
						Rater 2 Assessment: 3 – OM, AD, PS Process: 3 – S, N, TA Content: 7 – M, SC, MA, DL, AA, SF, IC
Hassiotis et al (2013) RCT	MOD.	CBT Manual developed for the study using existing protocol outlined by Clark (2009)	Two BACP accredited CBT therapists were recruited. They did not have a background working with ID therefore, given an induction on engagement and communication with people with ID.	Mood Disorders	32 adults with Mild to Moderate ID	**Rater 1** Assessment: 2 – OM, PS Process: 1 – N, Content: 7 – M, SC, MA, DL, AA, DM, IC
						Rater 2 N/A

Lindsay et al (2015) CCT	MOD.	CBT Manual developed for this study using principles from Farchione et al (2004)	Three primary therapists: a Senior Psychologist who had experience in CBT and two Assistant Psychologists supervised by the Senior Psychologist.	Anxiety, Depression	12 adults with Mild ID	**Rater 1** Assessment: 2 – OM, PS Process: 0 Content: 6 – M, MA, AA, SF, DM, IC
						Rater 2 Assessment: 2 – OM, PS Process: 0 Content: 5 – M, MA, AA, SF, IC **Percentage agreed = 88%**
Roeden et al (2014) CCT	MOD.	Solution Focused Brief Therapy No manual although makes reference to protocol followed principles by DeShazer et al (2007)	Therapist had a Master's Degree in Behavioural Therapy and received training and supervision on how to deliver STBT to people with ID.	Maladaptive behaviour	38 adults with Mild ID	**Rater 1** Assessment: 1 – OM Process: 1 –TA Content: 3 – SC, MA, IC **Percentage agreed = 100%**
						Rater 2 Assessment: 1 – OM Process: 1 –TA Content: 3 – SC, MA, IC
Taylor et al (2016) Cohort design	MOD.	CBT Manual developed by the therapist in previous work (Taylor & Novaco, 2005)	Therapists were Trainee Clinical Psychologists and Higher Assistant Psychologists trained in the approach and	Anger	50 adults with Mild to Borderline ID	**Rater 1** Assessment: 2 – OM, PS Process: 3 – S, N, TA Content: 7 – M, MA, DL, AA, SF, DM, IC

			supervised.			**Rater 2** N/A
McManus et al (2014) Cohort design	WEAK	CBT Manual developed by the authors McManus and McGuire (2010) in consultation with professionals working in the area of chronic pain.	A Trainee Clinical Psychologist with prior experience working with people with ID, supervised by an experienced Clinical Psychologist in both CBT and working with ID.	Chronic Pain	6 adults with Mild ID	**Rater 1** Assessment: 2 – OM, AD Process: 2 – N, P Content: 7 – M, SC, MA, DL, AA, DM, IC
						Rater 2 N/A

Table 4:

Key Adaptations extracted from this review

Area	Adaptation	Description
Assessment	Specific Outcome Measures (OM)	Use outcome measures specifically adapted/developed for people with an intellectual disability, e.g., use of a 3-point Likert scale and supporting visual aids. Measures that have been validated for use with people with intellectual disability
	Augmented data collecting (AD)	Adapting methods of data collecting to account for deficits in language e.g., adapted mood diary with photo symbols and tick boxes, using Dictaphones instead of diaries)
Therapy Process	Preparatory stage (PS)	A pre-therapy stage added to provide psycho-education and socialisation to the therapeutic model, which may be therapeutic modality specific. For example: teaching cognitive skills; labelling emotions; differentiating between thoughts/feelings/behaviour; understanding the link between thoughts/feelings/behaviour.
	Setting (S)	May require observation or intervention in a familiar setting, such as at home or day services rather than clinic setting.
	Number of sessions & timings (N)	May require a greater number of sessions than the general population. Timings of sessions generally shorter (e.g. between 40 – 50 minutes).
	Pacing (P)	May require a slower pace of therapy due to difficulties in attention and concentration. Limiting the amount of information given at one time.
	Therapeutic Alliance (TA)	Therapists to use supervision to discuss boundaries and development of therapeutic alliance. Individuals may acquiesce; therefore, therapists should consider potential power imbalance in therapy. Time spent at the start of the intervention to gauge engagement and motivation to proceed with intervention.
	Manual (M)	Using manuals as a blueprint for therapy whilst remaining flexible to individual needs.
	Social Interaction and Communication	All written information should be given using an 'easy read' format, simple language supported by use of

Therapy Content	*(SC) **expanded from Language*	visual aids (i.e. photo symbols). Spoken language using short sentences, simple words and ideally jargon free. Therapists ensure that verbal content expressed matches their facial expressions, and body language. Sometimes using the non-verbal language of the client. Therapist should be clear and directive in social interaction, explaining to individual what might be expected.
	Memory aids (MA)	Reduction of information given as a way of assisting working memory deficits. Use of visual aids to reduce cognitive load. Repetition of key concepts. Use of caregivers to assist with problems relating to executive functioning, and provide prompts. Providing an individualised booklet at the end of therapy.
	Developmental level (DL)	Assessing the individual's developmental level through Intellectual functioning, adaptive or language functioning assessments. Then adapting therapeutic intervention accordingly. Accounting for individual differences.
	Augmenting activities (AA)	Augmenting traditional therapeutic techniques to support understanding of complex and abstract concepts. Use of role plays to help individuals generalise skills. Give vignettes to contextualise learning.
	Accessible Formulation (SF)	Clinicians present an accessible version of a formulation, i.e., at problem level using visual aids and drawings. Delivering a personalised formulation booklet at the end of treatment with a further aim of relapse prevention.
	Directive methods (DM)	Reduce usual therapeutic techniques in complexity and make techniques simpler and directive. Therapist is more directive in their approach. For example, in Mindfulness, delivering a guided and directive safe place visualisation. Use of structured and guided audio recordings for instructions of techniques.
	Involving caregivers (IC)	Using family members, or support staff to assist in the therapeutic process as co-therapists to help promote motivation. Also in between sessions with prospective memory (prompts), the assimilation/generalisation of new information.

Adapted Cognitive Behavioural Therapy (CBT)

The review identified four CBT studies (Hassiotis et al., 2013; Lindsay et al., 2015; Manus et al., 2014, Taylor et al., 2016), all of which made use of a structured, 'manualised' therapeutic approach (see Table 3 for the adaptations made). For example, the manual in Taylor and colleagues' (2016) study, referenced a book, which detailed an 18-session, staged approach which included handouts, expected timings and exercises. McManus and colleagues (2014) developed a 20-session, manualised approach through consultation with professionals supporting people with an intellectual disabilities who suffered with chronic pain. They suggested that clinicians could decide which modules were most relevant to their client. Topics included activity pacing, positive thinking, use of medication, physical exercise and relaxation skills. Hassiotis and colleagues' (2013) manual described 20 sessions; however, unlike the other manuals, it was less descriptive and was subject to interpretation by the therapist. For example, it did not outline a session-by-session structured guideline as in Taylor and colleagues' (2016) Instead, it suggested general areas that should be covered within the first five sessions, and gave handouts to be used. The researcher was unable to access Lindsay and colleagues' (2015) manual for analysis.

Assessment Adaptations

All studies used 'specific outcome measures' developed for people with an intellectual disability. For example, Lindsay and colleagues (2015) used various measures validated for use with people with intellectual disabilities, including the Brief Symptom Inventory (Derogatis, 1993), The Glasgow Anxiety Scale (Mindham & Epsie, 2003) and the Glasgow Depression Scale (Cuthill et al, 2003). Only McManus and colleagues (2015) referred to 'augmented data collection' which involved augmented pain diaries and made use of a Dictaphone for individuals to record their diaries. Except for McManus and colleagues' (2015); all studies made reference to a 'preparatory stage' of therapy, where similar approaches were noted. For example, psycho-education was delivered during this stage, as well as a process of socialisation to the CBT model. Taylor and colleagues (2016) also described working on the clients' motivation during this preparatory phase, and teaching clients the skills necessary for engaging with CBT such as, labelling emotions, and differentiating between thoughts, feelings and behaviours.

Therapy Processes

Taylor and colleagues (2016) was the only study to discuss the therapy 'setting', which they suggested should flexible. Three studies made reference to the suggested 'number of sessions and timings'; for example, both McManus and colleagues' (2015) and Taylor and colleagues' (2016) studies suggest twice weekly appointments to avoid therapeutic drift. McManus and colleagues (2015) suggested shorter sessions, lasting no longer than 40 minutes, and were the only authors who recommended adopting a slower pace during sessions. Hassiotis and colleagues (2013) and Taylor and colleagues (2016) were the only authors to indicate the benefits 'therapeutic alliance', and highlighted the importance of establishing rapport at the start of therapy.

Therapy Content

There was overlap in content between the CBT studies. Hassiotis and colleagues (2013) and McManus and colleagues (2015) both referred to 'social interaction and communication'. Manuals from both studies gave several suggestions about the ways in which communication can be adapted, for example; delivering one piece of information at a time, and reducing the use of jargon. All four CBT studies referenced the use of 'memory aids'. Hassiotis and colleagues (2015) and Lindsay and colleagues (2015) provided a booklet at the end of therapy to give to individuals. Some studies (Lindsay et al., 2015; Taylor et al., 2015) ensured that therapy sessions followed a similar pattern to provide a memory aid and assist the learning of additional information by the client. McManus and colleagues (2014) also provided a therapy booklet, which detailed coping strategies for the individual.

Three of the CBT studies referred to clients' 'developmental level'. For example, Taylor and colleagues (2016) discussed that although they provided a treatment manual, therapists should personalise their treatment which would support the developmental and individual needs of their client. All four studies mentioned 'augmenting activities'. Hassiotis and colleagues (2015) used a body map to help individuals understand how anxiety affected the body. Lindsay and colleagues (2015) used role-play to rehearse strategies to use in challenging situations. McManus and colleagues (2014) used pre-

recorded demonstrations of relaxation tasks, which were guided and simplified. Several 'augmented activities' were used in McManus and colleagues' (2014) manual, including using road maps to help visualise goals, a calendar to help explain the passage of time and a flipchart to brainstorm ideas. Two studies (Lindsay et al., 2015; Taylor et al., 2016) mentioned an 'accessible formulation'. Taylor and colleagues (2016) provided a pictorial formulation to assist individuals learn how anger develops and is maintained. All four studies discussed 'directive methods'. Hassiotis and colleagues (2015) used photo symbols to help contextualise examples and to help individuals understand the links between thoughts, feelings, and behaviours. All four studies suggested 'involving caregivers', for example, one study employed a support worker to help individuals carry out homework exercises between sessions to help generalise new skills out with therapy sessions (Hasiotis et al., 2015)

Adapted Behavioural Activation

Limited evidence was found with regards to adapted behavioural activation, the identified study was rated as 'strong' (Jahoda et al., 2015). Jahoda and colleagues (2015) developed a 'manual' for use in this study which was adapted from an existing manual (Lejuez et al., 2001). The adaptations within this approach were evident across a number of domains, making it more accessible to people with an intellectual disability. These adaptations were comparable to what was found with adapted CBT studies.

Assessment Adaptations

Jahoda and colleagues (2015) discussed three adaptations: a specific 'outcome measure' developed for people with an intellectual disability, an 'augmented data collection' where they used a pictorial task to assess current level of activity involvement. They also had a 'preparatory stage' of therapy where an individual's motivation was assessed and potential barriers to positive change were explored.

Therapy Processes

Jahoda and colleagues (2015) described four adaptations. They suggested that the therapeutic 'setting' be the client's home, and that the there be between 10 -12 sessions. 'Pacing' was also encouraged to suit the needs of the client and 'therapeutic alliance' was used to foster a collaborative relationship which encouraged the client to take on an active role.

Therapy Content

Jahoda and colleagues (2015) discussed eight adaptations to therapy content. 'Social communication and interaction' was adapted using pictorial activities. A 'memory aid' was used by giving a personalised booklet given at the end of treatment which outlined an 'accessible formulation', identified therapeutic goals met by the client or clients and provided tips on how to maintain and build on change. The client's developmental level or needs was also considered when addressing the barriers to engaging in meaningful activity. For example, consideration was given to the support clients required to engage in an activity. Finally, Jahoda and colleagues (2015) 'involved a caregiver' in the therapeutic sessions to help problem solve barriers to engaging in activity, as well as supporting the individual to carry out exercises in between sessions.

Adapted Solution Focused Brief Therapy

For Solution-Focused Brief Therapy, only one study was found, which was of 'moderate' quality. Roeden and colleagues (2014) developed a treatment protocol for this therapeutic modality; however, there was no reference to a treatment manual, and the study gave a limited account of adaptations made.

Assessment Adaptations

Only one reference was made to assessment: 'specific outcome measure' validated or developed for use with people who have intellectual disabilities.

Therapy Processes

Roeden and colleagues (2014) described spending time developing a 'therapeutic alliance' at the intake session, where the client's experiences are validated.

Therapy Content

Roeden and colleagues (2014) referred to three adaptations to therapeutic content, including the need to 'involve a caregiver' in a supportive role during therapy. Adaptations were noted in 'social communication and interaction', which involved using a structured set of questions to help the individual describe their difficulty and how they would like this to change. Therapists followed the EARS task: Eliciting, Amplifying, Reinforcing and Starting again. Although the paper outlines other therapeutic tasks, such as the use of scaling questions (clients rates their problems on a scale of zero to ten), it was unclear from the description how this differed from the non-adapted therapy.

Discussion

This systematic review aimed to explore the key adaptations to individual psychological therapies for people who have mild intellectual disabilities in the 10 years since the previous review. Whitehouse and colleagues' (2006) review gave clinicians a good basis through which to build their therapeutic skills and knowledge, and to consider what works well with individuals. However, some of the adaptation descriptions in the previous review were described in general terms, which made them difficult to operationalise or translate into practice. The most commonly reported adaptations in the current review were the use of memory aids, augmenting activities, directive methods and involving caregivers. It appears that 10 years on, adaptations described in the studies have become increasingly explicit.

There would appear to have been some changes with regards to the type of psychological therapies delivered to people with intellectual disabilities, since Whitehouse and colleagues' (2006) review. Firstly, there were no studies in this updated review concerning Psychodynamic Psychotherapy, whereas the previous review reported 15 studies using this therapeutic modality. Secondly, two new types of adapted therapies have been developed since 2006: Solution Focused Brief Therapy (Roeden et al., 2014), and Behavioural Activation (Jahoda et al., 2015). In addition to these new adapted therapies, being studied for use with people who have intellectual disabilities; there were five manuals referenced from the six studies identified. While the existence of these manuals might be regarded as a positive development, this might be considered in contrast to the suggested need for 'flexibility to the model' outlined in the previous review.

Another adaptation that was found in both the current and Whitehouse and colleagues' (2006) reviews related to involving caregivers. It appears that the role of a support workers or caregivers in psychological therapies is more clearly defined in recent studies than it was previously. Caregivers were commonly used to provide support for the individual to complete therapeutic tasks between sessions, including support in generalising new skills and assimilating new knowledge. However, none of the articles reflected upon the potential ethical dilemma of involving caregivers in therapy. For example, assisting individuals with homework could be considered to undermine the autonomy and self-efficacy of the person with an intellectual disability and may perpetuate

their belief that they are unable to achieve tasks independently. Furthermore, there was no discussion about how issues of confidentiality may have been addressed when involving caregivers (Willner & Goodney, 2006). Therefore, caution should be exercised when using this adaptation.

It was surprising that few studies mentioned using an accessible formulation. Several studies did state that they used a formulation (Jahoda et al., 2015: Lindsay et al., 2015 & Taylor et al., 2016); however, they provided limited descriptions regarding how this adaptation was completed. Given that developing a formulation with client is a cornerstone of CBT (Leahy et al, 2012) it would be helpful to have a focus on the specifics of providing an accessible formulation. By contrast it appeared positive that all identified studies made reference to the use of memory aids. Lindsay and colleagues (2013) argued that when adapting psychological therapies, clinicians should consider the impact of cognitive deficits such as memory deficits.

Overall, several studies either gave limited descriptions of the actual intervention delivered to individuals, or it was unclear how these adaptations were carried out. The descriptions contained in some papers could have referred to non-adapted interventions conducted with individuals from the general population. This was similar to Whitehouse and colleagues' (2006) review. They concluded that the descriptions of the interventions in the papers they reviewed would have made replication difficult. Ten years on, the same conclusion can be made. While the stringent word limit for many journals may be one reason for poor descriptions of interventions, it is clear that a change is required in order for clinicians to develop a greater understanding of adaptations which can be used with this client group.

Recommendations for Future Research

Not only is there limited information about the nature of adaptations that can be made but there is also a lack of evidence about which adaptations are effective. There is a need for research to help identify the impact of key adaptations on the treatment outcome. More generally, the identified papers in this review had significant weaknesses that should be addressed in future research concerning psychological interventions for people with an intellectual disability. For example, three papers did not use outcome measures that were

validated for use with individuals with an intellectual disability. Therefore, in future studies there could be specific changes to improve the quality of research within this field.

Conclusions

This review synthesised the key treatment adaptations, described in studies of individual psychological interventions for people who had mild intellectual disabilities, as a ten year follow on from a previous research by Whitehouse and colleagues (2006). Three main areas of adaptation were examined, assessment, therapy process, and therapy content. The adaptations which were identified were mainly to address cognitive deficits related to people's intellectual disability such as memory difficulties (Lindsay et al, 2013). The review adds to current knowledge about key adaptations which could be used by clinicians working with this client group. Whilst there appears to be some overarching adaptations that have remained from Whitehouse and colleagues' (2006) such as, augmenting traditional therapeutic activities, having a directive method, assessing for developmental level and involving caregivers. These adaptation appear to have developed with more specificity. There has also been growth in the types of therapy being investigated for use with this client group which is a positive progression. Future research is required to explore how these adaptations may influence therapeutic outcomes.

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CHAPTER TWO:

MAJOR RESEARCH PROJECT

Exploring the ability of individuals with an Intellectual Disability to generate and use a compassionate image

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Plain English Summary

Exploring the ability of individuals with an Intellectual Disability to generate and use a compassionate coping image.

Introduction

People who have an Intellectual Disability are more likely to have mental health problems than those who do not (Cooper et al., 2007). Moreover, people with an intellectual disability experience more negative life events, for example, bullying and abuse, than their non-disabled peers (Cooney et al, 2006). Despite this, there is limited research into the use of psychological therapy for people with an intellectual disability. As a result, people with an intellectual disability are less likely to be offered a range of therapies as those in the general population.

One therapy that could have potential benefit for people with an intellectual disability is Compassion Focused Therapy. The only study in this area so far is by Clapton and colleagues (2017) which showed promise with this client group. Compassion Focused Therapy aims to encourage participants to find kinder things to say to themselves when they feel upset or are being self-critical.

This study explored the ability of people with intellectual disabilities to generate and use the compassionate image. The responses from people with an intellectual disability were compared to those who did not have an intellectual disability.

Methods

Nineteen people with an Intellectual Disability and twenty people without disabilities were recruited to this study from Scottish colleges, who provided classes for individuals with intellectual disabilities. Participants were included if they were over 16 years old, studied at a college, and had an intellectual disability. Participants without an intellectual disability were included as a comparison group. Strict ethical procedures were approved by the University of Glasgow Ethics board. Participants were given information sheets about the research proposal ("easy-read" where applicable) requesting anyone interested to reply in writing. The researcher then met participants at their college, over two sessions in the space of 1 week, to complete the study measures. They were then asked

to take part in a compassionate image task from Compassion Focused therapy, which involved asking participants to imagine someone who could be kind to them in times of distress. During the second session, they were told a series of stories and asked what their imagined compassionate image would say to make them feel better in distressing situations.

Results

This study found that individuals with an intellectual disability used similar coping strategies to their peers, where problem focused coping was most common in both groups. With prompting intellectually disabled participants were able to generate a compassionate image and to generate compassionate words in distressing situations.

Discussion

These results were interesting and promising. Although intellectually disabled participants required more prompting and support to generate the image than their non-intellectual disabled peers, this result is not unexpected. This is similar to the adaptations required in other Psychological Therapies, such as Cognitive Behavioural Therapy with this client group.

This research shows us that there is potential for people with an intellectual disability to learn the compassionate image to cope with stress. Therefore, it is hoped that further research can be completed to explore this in more detail with a bigger sample size, and with individuals with intellectual disability and mental health problems.

Abstract

Background:

There is a growing interest in adapting 3rd wave therapies such as Mindfulness for use with people who have Intellectual Disabilities. This study will consider the adaptation of Compassion Focused Therapy and aim to explore the ability of individuals with an intellectual disability to generate and use a compassionate image.

Method:

The cohort for this exploratory study consisted of nineteen people with an intellectual disability and twenty people without. Participants were recruited from colleges of further education. A technique from Compassion Focused Therapy was specifically adapted for this study to assess if individuals with intellectual disabilities could generate a compassionate image. A vignette based approach was used to help participants imagine that they were in a distressing situation, then they were encouraged to use their compassionate image to generate compassionate self-talk.

Results:

Participants with intellectual disabilities were able to generate their own compassionate image through the use of prompts. Furthermore, when they were asked to imagine themselves in a distressing situation they could use this image to generate compassionate self-talk as a means of self-soothing.

Conclusions:

This study found that individuals with intellectual disabilities were able to understand the rationale of this task and engaged meaningfully. The result warrants further studies to explore the use of Compassion Focused Therapy with this client group.

Introduction

It has been well documented that people with Intellectual disabilities are at higher risk of developing mental health problems than the general population (Cooper et al., 2007, Wigham et al, 2011). In addition, research has suggested that these individuals are also at greater risk of experiencing negative life events such as: maltreatment, sexual abuse, bullying and discrimination (Cooney et al, 2006; Turk & Brown, 1993; Gravell, 2012). Even if they did not face major trauma, Ali and colleagues (2015) found that they were one of the most stigmatised groups within society, placing them at greater risk of developing low self-esteem (Dagnan & Sandhu, 1999).

As well as experiencing more stressors than the general population, Hartley and colleagues (2008) argued that individuals with intellectual disabilities are likely to cope differently. In their study, they interviewed 114 individuals who had mild intellectual disabilities (defined as those with an IQ range between 55-70; APA, 2013). Hartley & MacLean (2008) used the Lifestress Inventory (Bramston & Bostock, 1994) which used a sentence stem, where individuals stated how they coped when faced with various stressors. Coping mechanisms described by participants were categorised in three styles; active, avoidant and non-coping; active coping was defined as strategies that aim to manage the stressful situation and/or the effects of the stressor. Avoidant coping was defined as strategies that aim to avoid the stressor and the negative effects of it. Finally non-coping was defined as responses which exacerbated the stressor and its effects, for example, hitting someone back when faced with bullying (Hartley & MacLean, 2008). A study completed within the general population, showed that use of avoidant coping instead of active coping was linked to depression and anxiety (Compas et al, 2001). Hartley & MacLean (2008) found no significant difference between support seeking (a type of active coping where individuals sought support and comfort from friends and family) and emotion focused coping. They argue that this reflects that there are many people involved in the lives of those with intellectual disabilities.

The present study employed an active coping technique from Compassion Focused Therapy using a compassionate image to elicit self-soothing (Gilbert, 2014). Compassion Focused Therapy has its roots in evolutionary psychology, and has influences from

attachment theory, social psychology and Buddhism (Gilbert, 2014). Drawing on the wisdom from Buddhist teachings, Gilbert (2013) defines compassion as "in essence a basic kindness, with a deep awareness of the suffering of oneself and of other living things, coupled with a wish and effort to relieve it" (p.13). In this definition, Gilbert (2013) is describing a process of both having the awareness and insight our own suffering and that of others, paired with the desire to lessen that suffering through kindness. Gilbert's definition of the soothing system also incorporates a sense of connectedness with others, which is turn is expected to help activate self-soothing.

Gilbert (2014) argues that human beings have evolved with three key systems to regulate emotions: the threat system which alerts danger, the drive system which motivates goal seeking behaviour and the affiliative system which gives a sense of safety. The main aim of Compassion Focused Therapy is to balance the emotion regulation systems, by encouraging more self-kindness and compassion (Gilbert, 2009a; 2009b; 2014). An early systematic review (including three randomised control trials) suggested that Compassion Focused Therapy showed promise as an effective therapy for mood disorders, particularly for those who experience high levels of guilt and shame in the general population, when compared to 'treatment as usual' (Leaviss & Uttley, 2015).

One of the ways that Compassion Focused Therapy helped people activate their self-soothing system is by using imagery (Gilbert & Irons (2004). The compassionate image exercise is one such technique (Gilbert 2009a). This exercise encourages the individual to imagine comfort, kindness and warmth given by an imaginary person, which increases a sense of connectedness. This technique is used as a form of active coping as it encourages the individual to reduce the distress caused by a stressor through eliciting self-soothing and comforting words.

Rockliff and colleagues (2008) found that a single session of compassionate imagery in a student population sample encouraged participants to self-soothe. Gilbert (2009a; 2009b) explained that, whilst imagery can be useful, some clients found difficulty in this approach. It was felt that some people found it hard to generate a compassionate image if their experiences had not provided them with examples of others being compassionate towards them. Gilbert & Irons (2004) carried out a pilot intervention of six individuals with depression by exploring their ability to generate a compassionate image.

They found that some participants could generate a self-soothing response, others had difficulty holding this image in mind, and some recalled a critical person from their past.

As discussed, there is a growing body of evidence for Compassion Focused Therapy in the general population (Leaviss & Uttley, 2014). However, there is a paucity of research exploring whether this approach can be adapted for those with an intellectual disability. There has only been one publication on this subject to date; Clapton and colleagues (2017), that explored the feasibility of group Compassion Focused Therapy for six individuals with mild intellectual disabilities. They found that participants reported being more open to receiving compassion from others following the Compassion Focused Therapy group, which in turn had a positive impact on reducing feelings of shame (Clapton et al, 2017). Idusohan-Mosizer (2015) investigated the use of Mindfulness-based cognitive therapy with fifteen adults with intellectual disabilities which included an element of developing compassion. They concluded that an increase in levels of compassion led to a decrease in symptoms of depression and anxiety.

The main aim of this study was to explore whether or not individuals with an intellectual disability were able to generate and use a compassionate image compared with their non-disabled peers. A comparison group without intellectual disabilities was recruited, as it would be erroneous to assume that potential difficulties engaging in the compassionate image task are unique to people with intellectual disabilities. An exploration of the types of coping the participants reported using provided a backdrop for exploration of their ability to generate and use a compassionate image.

Methods

Design

An exploratory study comparing the ability of people with and without an intellectual disabilities to generate and use a compassionate image as a coping technique.

Participants

Thirty nine people were recruited from further education colleges across Scotland to participate in this study; nineteen were identified as having an intellectual disability and twenty did not have an intellectual disability. All participants were aged between16 and 65 years of age. Participants were included in the study if they met the following criteria: (i) were able to give informed consent, and (ii) had sufficient expressive and receptive language ability to describe everyday activities. Exclusions occurred if participants (i) had significant mental health difficulties, such as psychosis, or dementia or had (ii) significant sensory impairments, which would make it difficult for them to engage with the study materials, (iii) had a diagnosis of Autism Spectrum Disorder (ASD). Having a diagnosis of ASD can lead to difficulties processing some social signals (Baron-Cohen, 2012) which may be important in the development of a compassionate image. Therefore, exploring the ability of people with a diagnosis of ASD to generate a compassionate image may require a separate investigation.

Recruitment Procedure

Through liaison with senior members of staff at further education colleagues; who offered courses to individuals with an intellectual disability, students were identified if they possessed sufficient expressive and receptive language skills to complete the research assessments and tasks. Staff were supported to use the Adaptive Behaviour Scale (ABS-RC: 2) (Nihira, Leland & Lambert, 1993) to identify the necessary communicative abilities necessary to participate. Participants were successful if they could: (i) talks to others about sports, family, group activities, (ii) sometimes uses complex sentences containing ‘because’ and ‘but’, and (iii) answers simple questions such as ‘What is your name?’ or ‘What are you doing?’.

The researcher met with identified students in a group setting and they were provided an information sheet (see Appendix 2.4) an easy read version was also provided

for clarity (see Appendix 2.3). The aim of the meeting was to give potential participants a chance to question the researcher. Those interested in participating were requested to complete a reply sheet (see Appendix 2.5). Participants were reminded that they were under no pressure to participate and that withdrawal at any time would in no way impact any college related activity. Students who expressed an interest were then contacted to arrange an individual face to face meeting in a private room within their college; where written consent was obtained (See appendix 2.6 & 2.7).

The individual meetings took two formats. For participants with an intellectual disability measures were administered over 2 sessions, for a period of 30 minutes and 60 minutes respectively. For those without disabilities, all measures were administered in one sitting for approximately 90 minutes. During both meetings time was spent building rapport with participants and they were reminded that they could withdraw, and that there were no 'right' or 'wrong' answers.

Measures and experimental task

The following measures were administered to both groups of participants in the order presented below:

1. **Background information sheet**: was used to obtain background socio-demographic data on the participants. To ensure that both groups were closely matched on the following information was recorded: (i) gender, (ii) age, (iii) post code, and (iv) living situation (see appendix 2.8). The postcode of each participant was used to generate the Scottish Index of Multiple Deprivation (SIMD) quintile in order to gain an idea of their level of deprivation (Scottish Government, 2016). The SIMD index is comprised of seven factors, which contribute to overall deprivation: Income, Employment, Education, Health, Access to services, Crime, and Housing. It provides a range from 1 (most deprived) to 5 (least deprived).

2. **Glasgow Anxiety Scale for people with an Intellectual Disability (GAS-ID)**; (Mindham & Espie, 2003). The GAS-ID is a 27-item self-rating questionnaire (Appendix 2.9) used to measure anxiety in individuals with an intellectual disability. This was used to ensure that there were no significant differences in anxiety levels between groups. The GAS-ID has good test-retest reliability (r=0.95) and internal consistency ($\alpha = 0.96$).

3. **Reported coping strategies**: using an adapted version of the Lifestress Inventory (Hartley & MacLean, 2008) originally designed by Bramston & Bostock (1994). Participants were presented with a variety of incomplete sentences which depicted a series of stressful situations, for example '*When I hear people I know arguing…*' Participants were asked to finish the sentence and to describe which coping strategy they would use in that given situation.

Pilot

The adapted Lifestress Inventory was piloted with two participants (one with an intellectual disability and one without) prior to the main study. The original Lifestress Inventory required participants to say whether or not a stressful situation affected them, then to rate the severity of its impact. In this study the severity or impact of stressful situations was not the main interest, and as such this part of the measure was removed for the purposes of this study. Therefore, it was not essential to retain the psychometric properties of this part of the measure as its purpose was to provide a context for the subsequent measures, and to provide a descriptive account of the participants' reported coping strategies. The foci of interest were stressful situations in keeping with the themes relevant to Compassion Focused Therapy, such as failure, rejection and interpersonal difficulties. Thus the Lifestress Inventory was shortened from 30 items to 17 items. The pilot also helped to ensure that the items were salient to both participant groups. For example, some items that focused on disability issues such as *'When I do not feel confident handling money and counting change…'* would only have been relevant to one group of participants. The final adapted Inventory had 17 sentence stem questions which participants were asked to complete; stating their coping strategies for each scenario presented (see Appendix 2.10). Reducing the number of sentence stems also allowed the measure to be delivered within a reasonable timescale.

4. **Generating a compassionate image using an adapted 'Compassionate Image' coping technique:** This exercise was adapted specifically for this study (Appendix 2.11). The Compassionate Image technique is a task used in Compassion Focused Therapy (Gilbert, 2014) which encouraged people to imagine a person or animal who embodied the characteristics of warmth, non-judgement, wisdom, and empathy. The individual focused on this 'image' and uses this image in times of

distress to engage their soothing system. Previous research suggested that Compassion Focused Therapy exercises could be taught in one session with some success (Rockliff et al., 2008).

Development and Pilot of the 'Compassionate Image' task

The original task was not developed for individuals with an intellectual disability and as such was likely to be too cognitively demanding for use with this client group. Therefore, careful adaptation and piloting were required. The researcher initially began by talking about a maladaptive coping technique of rumination which was supported by a storyboard with three coloured photos, showing someone ruminating over a mistake they made in class. This provided a context to discuss how individuals coped with stress and the importance of developing coping techniques to self soothe at such times, particularly when being self-critical. Drawing from Gilbert's three systems model, particularly were encouraged to imagine receiving kindness from others to ease distress, therefore activating the soothing system / affiliative system. For example, participants were encouraged to remember times when someone was kind to them, and were encouraged to imagine the associated feelings and bodily sensations related to this memory. This was an anchor to the compassionate image task, as participants were then required to focus on an imaginary person of their choosing being kind to them.

The language of the compassionate image exercise (developed by Gilbert 2009a) was considered too complicated, and was simplified. The information was broken down into shorter chunks to allow for potential processing delay and more direct prompts were given to scaffold the task. For example, in the original exercise individuals were asked, "*What do you think this person looks like*?" It was felt that this question was too vague and broad. To make it more suitable, a series of forced choice questions were used such as; "*Is this image a person, an animal or a fictional character?"* and open-ended questions were used to develop this image. Follow up questions were used as prompts when required.

Following the pilot an example of how bodily sensations may change when distressed was included in the rumination storyboard, as some participants found this concept difficult to comprehend. Throughout the exercise participants were reassured that there were no right or wrong answers. If individuals were not able to generate a

compassionate image in the exercise, then they were not required to continue with the self-soothing task. At the end of this task individuals who were able to engage, had developed a verbal description of their own image with a name, and were able to describe some compassionate words that this image would say to them in times of distress. The researcher recorded the responses and verbally fed back to the participant.

5. **Using a compassionate image to self-sooth when facing stressful situations:** this task was developed specifically for use in this study using vignettes (appendix 2.12). Previous research found that using vignettes proved to be successful for people with an intellectual disability to elicit cognitive and emotional responses to hypothetical situations (Pert, & Jahoda 2008; Ackland, 2011). Study vignettes also used storyboards, where 3 colour photographs taken by the researcher were used to reduce cognitive load and scaffold understanding. The vignettes consisted of six inter-personal scenarios: academic failure, feeling foolish at a party, social rejection by friends, college course rejection, a helpful friend and having a fight with a friend. One of the vignettes was positive in order to prevent the participants being caught in a repetitive response set and was not analysed. Participants were presented with each storyboard depicting a hypothetical situation that elicited distress, and were then asked to imagine that they were involved in these distressing scenarios. A narrative was read out in conjunction with the storyboard and participants were given corresponding cognitions, affect and bodily sensations. An example of the narrative for a vignette is listed below. This was read aloud whilst the participant looked at the storyboard of a tutor calling them into his office.

   You have been working hard at your college course
   You hand in a piece of work for marking
   Your tutor asks you to come in to his office
   You go into his office and he looks at you
   You feel nervous
   They tell you that you have failed, and that they are disappointed in you
   You feel ashamed
   You notice your heart beating faster
   You are thinking "I never do well"

   Following the presentation of the storyboard vignette, participants were then encouraged to imagine that their own compassionate image was beside them

supporting them during this imagined stressful situation. They were then asked to report what their compassionate image would say to them to help reduce their distress. The participants were also asked if they experienced any changes in bodily sensation after they imagined their image being kind to them.

Development and pilot of the self-soothing task

During the pilot the researcher was able to explore whether the stories depicted within the vignettes resonated with both groups of participants. The pilot was used to finalise the self-soothing task by changing the order of the vignettes to ensure they flowed when presented. For example, there were subtle changes made to the narrative to aid with this. In addition, it felt important to change focus to further emphasise and draw the participant's attention to the associated bodily sensations in relation to each scenario.

6. **Wechsler Abbreviated Scale of Intelligence Second Edition (WASI)** (Pearson Corporation, 1999). The WASI is a standardised assessment used to measure intellectual ability and has a high level of internal reliability (0.96-0.98) and good concurrent validity (0.87) (Pearson Corporation, 1999). The two subset forms of the WASI were administered, to provide an estimate of the participant's general intellectual ability and were completed at the end of the session. As this test has a set of predetermined 'right' and 'wrong' answers which set a tone contrary to the expectation of the rest of the measures where there were no 'right' and 'wrong' answers.

Ethical Approval

Ethical approval was sought, and approved on 22/11/2016, through the College of Medicine, Veterinary & Life Sciences Ethics Committee (see Appendix 2.2). There are several challenges when conducting research with individuals with an intellectual disability which were considered and addressed in detail. In particular it was important to ensure that participants fully understood what the study involved, while maintaining their rights and dignity (Iacono, 2006; Arscott et al, 1998).

Sample size

As this was an exploratory study it was therefore inappropriate to calculate a sample size. Moreover, as there were no similar past studies, it was not possible to establish a sample size based on past findings. However, a study by Ackland (2011), which explored individuals with intellectual disabilities' responses to praise and criticism, used a total of 42 participants (21 in each group). Ackland's research provided meaningful and noteworthy results, and therefore this study also aimed to recruit 42 participants.

Data coding and data analysis

Interviews were audio-recorded and transcribed by the main researcher. The data from the Lifestress Inventory task was analysed using a method by (Hartley and MacLean, 2008). This method categorised responses into 6 types of coping strategy; 3 types of Active coping (Problem Focused, Emotion Focused and Social support), 2 types of Avoidant coping (Behavioural and Cognitive Avoidance) and a category of Non-coping (see Appendix 2.13). If the participant gave more than one response, only the first response given was coded. The coding guide provided by Hartley and MacLean's (2008) was followed. An independent rater (a Trainee Clinical Psychologist) was asked to repeat the coding process as described above. There were discrepancies in scoring, due to different interpretations of the coding guidelines. It was possible to code some coping strategies in different ways, depending on the context. For example, if someone 'walked away' as a coping strategy, this could have been viewed as Avoidant behavioural coping, however, if they described that they did this in order to diffuse an argument and allow their emotions to settle, then this could have been viewed as Emotion focused coping. Therefore, the raters met and reviewed the items where there were different interpretations. Following this, further guidance was written on the coding system was outlined and agreed between the raters.

Transcribed data from the compassionate image task and self-soothing task were subject to content analysis (Strauss, 1987). This process involved identifying the types of compassionate images, compassionate words and bodily sensations that emerged from the participants' responses on each task. Then a set of categories were produced for each set of responses; for example for type of image this was categorised as: a person, animal or fictional character. Furthermore, it was noted whether individuals were capable or incapable of generating compassionate words and able to identify bodily sensations

Results

Results of the study will be structured in the following order: Participant socio-demographic data will be outlined first. This will be followed by a description of the coping responses the participants reported on the Lifestress Inventory. Finally, the results concerning the participants' ability to generate a compassionate image and to generate self-soothing statements when faced with imagined distress will be presented.

Participants

The researcher met 19 participants with an Intellectual Disability and 20 participants without an intellectual disability. The two individuals in the pilot, were not included in the main study. Four participants with intellectual disabilities were excluded (two individuals who did not speak English as a first language, one person who was actively engaged with mental health services and one whose IQ score was within the borderline range of intellectual functioning).

Three individuals without intellectual disabilities were excluded because their WASI scores placed them in the borderline range of intellectual functioning. One individual, who was initially recruited to the nondisabled group, was reallocated to the group with intellectual disabilities, as their WASI score was within the intellectual disability range. Fifteen individuals with an intellectual disability were included in the analysis and 15 without.

Table 1 provides an overview of the participant characteristics on the measures. The two groups of participants were similar on a range of socio-demographic characteristics. They were mainly young, with those with an intellectual disability having a mean age of 19.6 years and those without had an average age of 21.3 years. Most participants lived at home with their families, and most lived in fairly deprived areas of Scotland. As expected, the non-ID group had significantly higher WASI-IQ scores.

Table 1:

Participant characteristics

Socio-demographic data		***ID group***	***Non-ID group***
Gender	Male	9	9
	Female	6	6
Age	Mean (SD)	19.6 (2.02)	21.27 (4.62)
	Range	17-24	17-35
Deprivation Score SIMD Quintiles	Mean (SD)	2.73 (1.34)	2.53 (1.26)
	Range	1-5	1-5
Living Situation	Lives Alone	0	1
	With family	13	11
	Partner	0	1
	Flatmate	0	2
	Supported Accommodation	2	0
Measures completed by participants			
WASI	Mean (SD)	57.3 (4.65)	97.2 (8.53)
	Range	55-69	82-113
GAS-ID	Mean (SD)	15.8 (4.65)	16.47 (7.88)
	Range	7-21	8-36

A) Coping Strategies

Using the same criteria used by Hartley and MacLean (2008), there were six identifiable coping strategies used in the coding. Active Problem Focused was defined as cognitive and behavioural efforts to manage the stressor. Active Emotion Focused coping was defined as an effort to manage the emotional distress caused by a stressor. As per the coding example in Hartley & MacLean (2008) if individuals with an intellectual disability had made use of other people as a vehicle for solving their problem this was coded as Active Problem Focused, whereas if the participant used other people for advice or solutions this was coded as Social Support. Avoidant Behavioural coping was defined as

efforts to avoid the problem by staying away from it or leaving the situation. Avoidant Cognitive coping was defined as cognitive efforts to wish the problem away or to avoid thinking about it. Non-coping was defined as responses which involve verbal or physical actions to hurt others, or reactions which make the stressor or problem worse.

Table 2 outlines the frequencies of the coping strategies reported by each group of participants. The most common type of coping reported by both groups was Active Problem Focused coping (ID group mean = 8.67, and non-ID group mean = 8.2). Individuals with an intellectual disability used Active social support (mean = 0.53) and Avoid cognitive (mean = 0.53) less compared to other types of coping.

Table 2:

Coping strategies: Frequencies for each group

Coping strategy	**Mean (SD)**		**P Value**	**Effect size**
	ID group	**Non-ID group**		
Active Problem Focused	8.67 (3.02)	8.2 (2.11)	0.627	0.18
Active Emotion Focused	1.60 (1.55)	2 (1.93)	0.536	0.23
Active Social Support	0.53 (1.06)	0.93 (0.96)	0.288	0.40
Avoidant Behavioural	3.47 (2.88)	3.07 (1.83)	0.653	0.16
Avoidant Cognitive	0.53 (0.915)	1.07 (1.03)	0.146	0.55
Non-coping	1.33 (2.09)	1.6 (1.45)	0.688	0.15

Table 3 outlines examples of coping reported by both groups of participants. Whilst the quantitative data showed few differences between groups on the types of coping strategies employed, the qualitative data showed subtle differences. For example, with regard to the category of emotion focused coping; participants with an intellectual disability spoke of using activities to reduce distress, whereas those without described using emotional reasoning. Participants in the intellectual disability group gave similar answers to avoidant behaviour coping, such as leaving the situation. However, when asked further, they were unable to describe how they might carry out that plan. Furthermore, when describing active problem focused coping individuals with an intellectual disability mainly described using a caregiver or staff member as a vehicle for helping them to cope. Whereas, those without an intellectual disability described how they would solve the problem on their own.

Table 3:

Examples of coping strategies provided by participants

Coping strategy	**Examples**
Active Problem Focused	*Tell the teacher or something* (Female ID group) *I would try to diffuse it and try to resolve it* (Male non-ID group)
Active Emotion Focused	*I draw and listen to music* (Male ID group) *I would try and think positive, like nothing is going to happen to you* (Female non-ID group)
Active Social Support	*I talk to my caregivers…they would understand and give me advice* (Female ID group) *I would surround myself with friends and family* (Male non-ID group)
Avoidant Behavioural	*I would just leave* (Male ID group) *I would probably isolate myself. So I would be myself. I wouldn't like to be around a lot of people* (Female non-ID group)
Avoidant Cognitive	*Just ignore them* (Female ID group) *Just keep it to myself, I just wouldn't tell anyone about it* (Male non-ID group)
Non-coping	*I would hit back* (Male ID group) *I would tease them or call them names back* (Female non-ID group)

B) Compassionate Image coping task

Individuals in both groups were asked to generate an image of a person, animal or fictional character with the characteristics of warmth, empathy, wisdom and non-judgement. They were also asked to state what words of compassion and warmth their image might say to them when they felt distressed.

Findings of Group Differences on Compassionate coping image task

Table 4 shows the frequencies of the types of images: person, animal, or fictional character generated by both groups. Since 50% of the cells had an expected frequency of less than 5, Fisher's Exact Probability test was carried out on all data. There were no significant differences between the groups, which suggests that they both generated similar images. Table 4 also shows that there were few differences between groups in terms of their ability to generate compassionate images, where they were both able to do this (with the exception of two participants from the ID group). The only statistically significant difference found using Fisher's Exact Probability was for the use of prompting. This gave $p = 0.017$ for a two tailed hypothesis and the value of Cramer's V was 0.5. This showed that individuals with an intellectual disability required more prompting than those without to engage in this technique.

Table 4:

Frequencies in Compassionate Image coping task

Variable	Categorisation	ID group	Non-ID group	P-Value
Type of Image generated	Person	5	8	0.796
	Animal	7	5	
	Fictional Character	3	2	
Able to generate Compassionate words	Yes	13	15	0.483
	No	2	0	
Required prompting	Yes	6	0	0.017
	No	9	15	

The following quotes are described below in italics, although a rationale was not sought during the task, as they were deemed too difficult for individuals with an intellectual disability, some participants gave a spontaneous rationale for choosing their particular image as outlined below.

Views of the process

Drawing on life: A closer inspection of how the participants described their compassionate images provided insight into the sense they made of the task. One woman with an intellectual disability drew on their real-life preferences to choose their compassionate image.

A woman because I get on better with females. (Female: ID group)

For one woman without an intellectual disability the use of a compassionate image made intuitive sense and was a strategy that they already used and found helpful.

It's weird because I already do that, I already imagine people saying nice things to me, it makes me feel better. (Female: Non-ID group)

Building an image: Even when the participants with an intellectual disability chose particularly striking or vivid image, such as *"A wolf"* (female: ID group) scaffolding was required to help build a more detailed image, such as its colour and other characteristics. In contrast, the nondisabled participants provided a more vivid description of their compassionate images, such as one participant's description of *"a small, black pug who is really cheeky and friendly*'. (Male: non-ID group)

A meaningful image: Despite requiring scaffolding, the participants with an intellectual disability did appear to grasp the meaning of the task. The participant with an intellectual disability who chose a wolf, clearly given the matter thought. They highlighted characteristics of the wolf that would make them feel safe, looked after and part of a family.

I have always wanted to live with them, a pack of wolves…I would like to be part of that neat tight pack, they always look out for each other. (Female: ID group)

When describing a rational for choosing the Pug, the nondisabled participant drew on characteristics they valued in a dog and compared these to human frailties.

Dogs are so much more caring than humans are, it's more natural for them to be caring, which helps because you know he does care. (Male: non-ID group)

A fictional character: Both people with and without an intellectual disability chose someone famous who they looked up to and admired.

Randy Orton Wrestler (Male: ID group)
Marlon Brando (Male: Non-ID group)

The participant with an intellectual disability felt that the wrestler would give him unconditional support.

"(Wrestler) He is a true friend and kind person, the kindest that I have ever met. If someone was in trouble then he would go to help them" (Male: ID group)

In a similar way, the nondisabled participant thought that Marlon Brando (film star) would be unconditionally understanding.

In that film he is so gentle and nice, in a beautiful way…but he is a tortured soul and you can see that so he would understand you. (Male: non-ID group)

Overall, individuals with an intellectual disability were able to generate their own image, and develop words of compassionate to self soothe with the aid of prompting. Although, they gave less elaboration in the development of their image, individuals with an intellectual disability showed that they grasped and understood the rationale behind the exercise.

C) Self-soothing task

Individuals were asked to use their image following an imagined distressing situations, to generate compassionate words as a means of self-soothing. They were also asked if they were able to identify any corresponding bodily sensation that they experienced.

Three key questions are reported in table 5 below in response to each of the five vignette situations: i) participants' ability to generate compassionate words, ii) whether prompting was required, and iii) whether participants identified bodily sensations associated with self-soothing? Since 50% of the cells had an expected frequency of less than 5, Fisher's Exact Probability test was carried out on all data. There were no significant differences between the groups, on all three questions across all five vignettes. As shown in table 4 all individuals with an intellectual disability were able to generate compassionate words across each vignette with the exception of one participant who was not able to generate compassionate words in the first vignette (tutor tells you that you have failed). There were no statistical differences found with reference to individuals with an intellectual disability requiring a prompt. It is noteworthy to mention that the nature of the compassionate words for those with an intellectual disability was often about practical support as opposed to words of empathy and warmth. For example on Vignette C (social rejection) often participants with an intellectual disability would say that their image had offered to be their friend when their other friends had rejected them. Both groups had mixed success at being able to identify bodily sensations.

Table 5:

Frequencies on the self-soothing task per vignette task

Vignette task	Variable	ID group	Non-ID group	P-Value
Vignette A (Tutor fails you)	Compassionate words generated	Yes = 13 No = 1	Yes = 15 No = 0	0.483
	Required prompting	Yes = 2 No =12	Yes = 1 No =14	0.598
	Bodily Sensation Identified	Yes = 9 No =5	Yes = 13 No =2	0.215
Vignette B (mixed up words)	Compassionate words generated	Yes = 14 No =0	Yes = 15 No =0	No difference to report
	Required prompting	Yes = 2 No =12	Yes = 2 No =13	1.00
	Bodily Sensation Identified	Yes = 9 No =5	Yes = 9 No =6	1.00
Vignette C (Social rejection)	Compassionate words generated	Yes = 14 No =0	Yes = 15 No =0	No difference to report
	Required prompting	Yes = 6 No =8	Yes = 1 No =14	0.080
	Bodily Sensation Identified	Yes = 5 No =9	Yes = 9 No =6	0.272
Vignette D (college rejection)	Compassionate words generated	Yes = 14 No =0	Yes = 15 No =0	0.483
	Required prompting	Yes = 5 No =9	Yes = 2 No =13	0.215
	Bodily Sensation Identified	Yes = 6 No =8	Yes = 9 No =6	0.466
Vignette F (Fight with friend)	Compassionate words generated	Yes = 13 No =0	Yes = 15 No =0	No difference to report
	Required prompting	Yes = 1 No =12	Yes = 3 No =12	0.600
	Bodily Sensation Identified	Yes = 10 No =3	Yes = 11 No =4	1.00

One vignette was chosen (vignette A - your tutor tells you that you have failed) to give descriptive accounts of the words generated by participants and the bodily sensations identified which is shown in table 6. In the examples below the individuals with an intellectual disability is able to both generate a compassionate phrase and identity a bodily sensations, where they described the feeling of butterflies leaving their stomach.

Table 6:

Examples of responses to Vignette A (Your tutor tells you that you have failed)

Question	**Examples**
Compassionate words?	*You can try again* (Female: ID group) *No one is successful all of the time* (Male: Non-ID group)
Bodily sensations?	*When the tutor told me I had failed I was angry but when I thought of (name of kind helper) being kind to me I was like (large exhale) I was like calm and all the butterflies went away at the same time. Phew it's gone!* (Male: ID group) *Less tense when she spoke to me and more relaxed* (Female: Non-ID group)

Discussion

This study explored the ability of individuals with an intellectual disability to generate and use a compassionate image. The main finding of this study was that individuals with an intellectual disability were able to generate a compassionate image, and self-soothing statements when presented with distressing hypothetical situations. The types of images generated by the participants with intellectual disabilities were very similar to those produced by the nondisabled participants, even if they required more scaffolding to generate their compassionate images and put them into use. Results suggested that individuals have the potential to learn and use this technique with appropriate support.

The compassionate image task used in this study was carefully adapted from the version used within Compassion Focused Therapy for the general population (Gilbert, 2014). The researcher initially had concerns that the abstract nature of the task could potentially be a barrier for those with an intellectual disability. Scaffolding was used with success in order help contextualise what was being discussed with prompts to help intellectual disability participants build their own images. It was clear that participants with intellectual disability understood the rationale behind the approach and were able to use their imagination beneficially. For example, all participants understood that their image was someone, for whom they could use to generate compassionate and kind words during distressing situations. Similar results were found by Clapton and colleagues (2017) who investigated the feasibility of group Compassion Focused Therapy and found that participants with intellectual disability were able to generate compassion for themselves and others.

There was also an investigation of the coping strategies as reported by intellectual disability participants. The most common coping strategy reported by participants in both groups was actively findings ways to manage a stressor. Although, there were no statistical differences found between groups, there were qualitative differences in their use of these coping strategies. For example, most people with an intellectual disability described how they would use the support of someone, to help them actively solve a problem. Whilst this was coded as an active form of coping, their descriptions of coping were more passive and dependent on others to help them than those without an intellectual disability, who were able to describe a more independent approach. The use of the compassionate image was an

example of an active coping technique that individuals could use independently as a means for managing their own stress. Research has suggested that individuals with an intellectual disability were more likely to be dependent on others to cope. (Hartley & MacLean, 2008). Developing forms of active coping that individuals can utilise independently is therefore important. However, paradoxically they would still rely on others to scaffold this for use.

Prior to building their compassionate image in this study, both groups showed high levels of anxiety as measured by the Glasgow Anxiety scale (GAS). The mean scores for both groups were over 15, which suggests elevated levels of anxiety. It should be noted that at the time of data collection, students in both groups were going through various assessments, deadlines and exams. However these participants were unlikely to be a clinical population, as their stress and anxiety could be viewed as temporary.

Limitations

This study had a number of limitations. Due to difficulties recruiting from colleges, there were a smaller number of participants than anticipated. Therefore, this study is underpowered and the findings should be interpreted with caution. One of the reasons that there were recruitment difficulties in this study was that college lecturers lacked understanding about intellectual disability, confusing it with specific learning difficulties such as dyslexia. Other organisational issues made recruitment within the necessary timeframe extremely challenging; such as timetabling issues, holidays, exams and college strikes.

This study used a non-clinical sample therefore it is difficult to make generalisations about its use with individuals who have an intellectual disability and mental health problems. However, the findings from this exploratory study suggests that the compassionate image exercise may have potential clinical utility and warrants further investigation.

The researcher, on reflection, would reduce the number of vignettes for a few reasons, firstly, there were too many and some participants began to disengage. Secondly, the order and flow could have been developed further in order to avoid repetition of slightly similar vignettes. Another element that would have been changed, was the use of the pre-determined coding system in the Lifestress Inventory. In order to analyse the data

only the first response was coded, which is a limitation as other responses had to be excluded. Furthermore, there was some confusion with the defined categories, where some responses could have been considered under a several different coping styles.

Future Work

The use of the compassionate image within Compassion Focused Therapy would be developed over several of sessions whereas in this study it was developed and implemented in one session. In this study during the 3rd vignette task one participant reported that his image had become critical and rejected him. Gilbert & Irons (2004) found a similar result when developing a compassionate image with individuals presenting with depression. They found that a participant's image became tainted by thoughts of an abusive ex-partner. In clinical practice, this type of difficulty could be explored and examined with the client whereas in this project there was no ability for such interaction. Future research should focus on developing a compassionate image of a clinical population. Using a clinical population would provide opportunity to explore the potential mechanisms that cause a compassionate image to become contaminated.

Gilbert (2014) mentions that one of the most challenging aspects of developing the compassionate abilities, stems from the individual's fear of compassion, which prompted him to develop a measurement scale to measure the fear of compassion received from others, given to others and given to the self. Future work could focus on this and explore whether this is a barrier to engaging with the compassionate image for individuals who have an intellectual disability. To date the author is not aware of any work on this. Clapton and colleagues (2013) also suggested that there were limitations to further research with intellectual disability and Compassion Focused Therapy, as none of the measures used for the general population have as yet been validated for those with this client group.

The researcher did not do a relaxation exercise prior to the compassionate image, which Gilbert & Irons (2004) describes an important element in order to engage the soothing system before the start of the technique. There was not enough time for this during this study, however, in future work exploration of relaxation tasks would be key. Gilbert (2014) also outlined that some individuals appear to choose a non-person for their image if there is a background of difficulty and abuse. However, there does not appear to

be any papers on this hypothesis, therefore, it would be interesting to explore this more within a clinical population of people with an intellectual disability.

Conclusions

The lack of differences between the individuals with and without an intellectual disability during the compassionate image task and the vignettes, is an interesting finding. Both groups engaged well with the task, however those with an intellectual disability required additional prompts. This shows real encouragement in terms of clinical implications and suggests that Compassion Focused Therapy could be further explored with this population. The researcher believes that intellectual disability individuals have a right to be offered the same treatment options as those in the general population. Historically, there has been a lack of therapeutic interventions offered to individuals with an intellectual disability. However, this study along with others (Clapton et al, 2017), showed initial promising results for Compassion Focused Therapy for clients with intellectual disability. It is suggested that the compassionate image is a potentially viable technique that can be taught to individuals to empower them to manage their own distress.

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Appendix 1.1 – Requirements for submission to *Journal of Applied Research in Intellectual Disabilities*

Full Guidelines can be found at:

http://onlinelibrary.wiley.com/journal/10.1111/(ISSN)1468-3148/homepage/ForAuthors.html

Appendix 2.1 – MRP Proposal

Name:

Matriculation Number: XXXXXXXX

Name of Assessment:
Please select 7- MRP proposal
(If Other, please specify): *[ ]*

Title of Assessment: Exploring the use of Compassion Focused Therapy approaches with people who have Intellectual Disabilities: Can these techniques be successfully adapted for this population?

University Supervisor: Professor Andrew Jahoda

Field Supervisor: Dr Carol Pert

Clinical Supervisor: N/A
(If Applicable)

Submission Date: 30.05.16

Version Number: 10

Word Count: 3323

Maximum Word Count: 3,000

For Office Use Only
Date Received:

Major Research Project - Proposal

Exploring the use of Compassion Focused Therapy approaches with people who have Intellectual Disabilities: Can these techniques be successfully adapted for this population?

Matriculation Number: XXXXXXXX

Version 9

Word Count: 3323

Abstract

Background

Individuals with an Intellectual Disability (ID) are more likely to experience mental health problems and negative life events such as bullying and abuse than the general population. Compassion Focused Therapy (CFT) has been developed in order to help individuals with high levels of guilt and shame learn to self soothe through creating inner warmth and compassion. However, there is currently no published research on this therapeutic model for individuals with an ID.

Aims

The aim of this study is to explore whether individuals with an ID can meaningfully engage in core CFT techniques, specifically the 'Compassionate Image'. A further aim is to establish whether individuals can use the Compassionate Image to self soothe in response to perceived social threat, evoked using a vignette.

Methods

The aim is to recruit a sample of 42 participants; 21 individuals with an Intellectual Disability and 21 individuals without. This study will explore the ability of the participants

to generate a compassionate image. Participants will be asked to use a compassionate image to self-soothe after being asked to imagine themselves being in socially threatening situations. Participants will be recruited from colleges in the Central Belt of Scotland. The data will be analysed using content analysis, and a between groups analysis.

Applications

The research will help in adapting Compassionate Focused Therapy for individuals with an Intellectual Disability.

Introduction

It has been noted that there are higher levels of mental health problems with people who have intellectual disabilities (ID) than within the general population (Cooper et al., 2007). In addition, research has suggested that individuals with an ID are at greater risk of experiencing negative life events such as: maltreatment, sexual abuse, bullying and discrimination (Cooney et al, 2006; Turk & Brown, 1993; Horner-Johnstone & Drum, 2006). Esbensen & Benson (2006) found that life events perceived as negative by individuals with an ID had a role in the development of depressive symptoms. Webb and colleagues (2007) found that guilt was positively correlated with depression, and that psychological maltreatment was positively correlated with shame. We can hypothesise that individuals with an ID are therefore more likely to experience guilt and shame as a result of both negative life events, and higher rates of mental health problems.

Compassion Focused Therapy (CFT) has been developed from evolutionary psychology, which blends Cognitive Behavioural Therapy and Mindfulness approaches (Gilbert, 2014). CFT helps to make sense of the emotions we experience and in particular our drive to interact with those around us in a social world. Gilbert (2009a) proposes that each individual's emotional life operates within three systems; the threat system, the drive system, and the soothing system. Gilbert (2014) explains that we usually experience compassion and warmth through our personal relationships. A key technique of this therapy aimed at building warmth and compassion, is the 'Compassionate Image' exercise, whereby a person creates an ideal compassionate other which embodies warmth, wisdom, non-judgement, and strength. When an individual feels threatened they can actively use

this Compassionate Image to elicit feelings of safety, warmth and comfort, and therefore activate their soothing system.

An early systematic review suggested that CFT was an effective therapy for mood disorders, particularly for those who experience high levels of guilt and shame in the general population (Leaviss & Uttley, 2015). However, there is a paucity of evidence about the effectiveness of 3rd wave therapies such as CFT and Mindfulness for people with an ID. There has been some development of adapted Mindfulness for people with ID (Singh 2013, Chapman et al 2013, and Hastings & Manikam, 2013), which suggests that mindfulness can be effective. However, there are no current studies exploring a CFT approach, or specific elements of it, such as the Compassionate Image exercise.

Within the adult mental health literature, there are a few studies that investigate an individual's ability to generate a Compassionate Image. Rockliff & et al (2008) found that a single session of compassion focused therapy imagery in a student population sample had the ability to help students to self-soothe. Another study completed by Gilbert & Irons (2004) explored a pilot intervention with individuals with depression and their ability to generate a compassionate image which embodied calming, soothing and caring characteristics. The researchers found that if individuals were able to hold their compassionate image in mind, this led to an increase in their self-soothing, which was measured through a 0-10 point rating scale monitored in a diary (Gilbert & Irons, 2004). However, this research had a very small sample size (n=6), and therefore it is difficult to draw conclusions from it. One individual in the study noted that they found the exercise challenging because they found it difficult to recall the image, hold it in mind and practice it. One possible reason why it might be difficult for individuals to use a Compassionate Image may be because they have not experienced warm, and accepting social interactions in the past (Gilbert and Irons, 2004).

There are some potential challenges to adapting Compassion Focused Therapy for individuals with an intellectual disability. Firstly, as noted, individuals with an ID are more likely to experience negative life events (Cooney et al, 2006), which perhaps impacts on the individual's ability to experience self-compassion. Moreover, holding an image in mind and practicing it requires some skills using working memory, in order to generate an

image, and then imagine receiving kindness from a hypothetical character (Gilbert & Irons, 2004).

As a way of mitigating some of these difficulties, previous research has successfully made use of vignettes (Pert, &Jahoda 2008; Ackland, 2011). By using vignettes, the cognitive load placed on individuals by asking them to recall events where they felt threatened is reduced. Furthermore, by giving a situation which elicits imagined distress ensures that the participants do not have to recall personal memories, which could potentially lead to distress.

Despite, some of the potential challenges to adapting these techniques, there are potential benefits that warrant investigation such as the emphasis on empathy. A study by Pert et al., (2013), which explored clients' experience of Cognitive Behavioural Therapy, found that individuals valued the therapeutic relationship above all else, in particular the characteristics of warmth, empathy, and understanding. Given this finding, Pert et al., (2013) highlight the potential value of CFT for individuals who have an ID, as CFT can help to foster a client's feeling of validation and being cared for.

Aim

The aim of this study is to explore whether individuals with Intellectual Disabilities can meaningfully engage in core CFT techniques; more specifically whether or not they can generate a 'Compassionate Image'. A further aim is to establish whether the individuals can use this 'Compassionate Image' to self-soothe in response to feelings of social threat, evoked using a vignette. In order to evaluate if there are any differences in ability to generate a Compassionate Image, there will be a comparison group of individuals without an Intellectual Disability.

Research question

The aim of this project is to explore whether individuals with mild to moderate ID can successfully generate and use a compassionate image?

This will be separated into two focus areas.

1. Can individuals with and without intellectual disabilities generate a compassionate image?

   <u>If they can generate image</u>

a) What kind of images do the participants generate (for example, fictional characters, animals etc)?
b) What is the rationale given for the images generated?
c) What characteristics are important to incorporate into the image (for example kindness, wisdom, understanding etc)?
d) Do participants with and without intellectual disabilities generate different compassionate images?
e) Are there key characteristics of the image that vary between groups?

<u>If they cannot generate an image</u>

a) What were some of the barriers to developing an image?
2. Following the use of vignettes to evoke perceived threat, can participants use the compassionate image they have generated as a way of self-soothing?

Design

This will be an exploratory study, adopting an experimental group comparison design using vignettes, in order to explore participants' ability to generate and use a Compassionate Image.

Plan of Investigation

Participants

The study aims to recruit participants with ID from colleges and a control group of individuals who do not have an ID will also be recruited.

Inclusion criteria

- Participants will be aged 18 – 65
- Participants must be able to give informed consent
- Participants must have sufficient expressive and receptive language in order to be able to describe the desired characteristics in a 'compassionate image'.

Exclusion criteria

- Individuals who have significant mental health difficulties, such as psychosis, or dementia, which would interfere with their ability to engage meaningfully with the experimental tasks.
- Individuals with significant sensory impairments that would interfere with their ability to take part in the tasks and engage with the materials.

Measures and experimental task

The following measures will be used:

1. **Glasgow Anxiety Scale for people with an Intellectual Disability (GAS-I**D; Mindham&Espie, 2003). The GAS-ID is a 27 item self-rating questionnaires, used to measures levels of anxiety for individuals with an ID. The GAS-ID has good test-retest reliability (r=0.95) and internal consistency ($\alpha = 0.96$).
2. **Glasgow Depression Scale for people with an Intellectual Disability (GDS-ID)** (Cuthill et al, 2003) The GDS-ID is a 20 item self-rating questionnaire based on the DSM IV criteria of depression. It has good test-retest reliability (r=0.97), and internal consistency (Cronbach's $\alpha = 0.90$).
3. **Vignette task to elicit social threat.** This task will be designed for use within this study. Similar methods have been used successfully in previous studies (Pert &Jahoda, 2008; Ackland, 2011). The vignette task will consist of a series of scenarios designed to elicit feelings of perceived social threat. They will be provided with photos accompanied by a story, and asked to imagine themselves within this situation.
4. **Semi structured interview.** Individuals will be asked a series of questions regarding their emotions, before and after the experimental task, in order to explore the effects of the Compassionate Image exercise.
5. **Compassionate Image Exercise (Gilbert, 2007).** This technique will be adapted for use with both groups of participants. The purpose of this task is for the individual to create an image, which embodies qualities such as warmth, wisdom, non-judgement, and strength. The participant will be encouraged to notice any bodily sensations when they imagine their Compassionate Image, such as feelings of warmth.
6. **Wechsler Abbreviated Scale of Intelligence Second Edition (WASI-II)** (Person Corporation, 2011). The WASI-II is a four subtest measure that includes Verbal comprehension IQ, Performance IQ and a Full-Scale IQ, it has good validity (0.87) and reliability (0.88-0.92). The researcher will complete 2 subtests from this measure which will be used in order to confirm that the participants meet the inclusion criteria.

A pilot study will be conducted with a small number of individuals (n=4, 2 in each group) before recruiting participants for the main study. The pilot stage will help to establish the following:

- Ensure that the adapted 'Compassionate Image' exercise is salient, accessible and meaningful to both groups
- Ensure that the open-ended questions and prompts woven throughout the vignette and experimental task are accessible to both groups of participants. A starting point for questions about the compassionate image could be: What do they look like? Is it a person or something else? Are they a man or woman? What is their hair like? What are they wearing? Is there a colour you can see? How do they sound? Do they have a smell? Do you feel anything in your body when you imagine them talking to you?
- Ensure that the vignette task is engaging and meaningful to both groups. As a way of gauging if the vignette elicits a threat response, the researcher will ask the participant to state how they are feeling within the imagined situation.
- Establishing how long it takes to administer the task. For example, it is currently estimated that all the study measures and experimental tasks will be carried out over one session with a break in the middle.

Procedure

Recruitment

The groups will be matched as closely as possible on the characteristics, such as socio-economic status. Participants for both groups will be recruited from colleges and local service providers within the central belt of Scotland. The researcher will design a poster to advertise the study which will be provided in an easy to read format. The researcher will liaise with key staff members from the local service providers and colleges, who will identify suitable classes of students or groups of individuals. In order to ensure that the individuals have sufficient expressive and receptive language skills to engage with the research tasks, the following items will be used from the Adaptive Behaviour Scale (ABS-RC: 2) (Nihira, Leland & Lambert, 1993) when discussing potential classes of participants with teachers and support staff.

- Talks to others about sports, family, group activities.
- Sometimes uses complex sentences containing 'because' and 'but'

- Answers simple questions such as ‘What is your name?’ or ‘What are you doing?’

The researcher will go into colleges to provide information, answer questions and hand out information sheets to potential participants. They will then be given at least 24 hours with the information sheets. If an individual is interested in taking part in the study they will be asked to complete a contact details sheet, which they will pass on to their teacher, who will send these back to the researcher. Only participants who have given verbal consent and registered their interest to take part in the study will be contacted by the researcher to agree on a suitable time to meet.

The researcher will meet with participants on an individual basis in rooms, which will be free from noise and distraction, provided by the college or service provider to carry out the experimental task. The researcher will meet with each participant on their own on one occasion to obtain written informed consent, complete the study measures and experimental task. It is estimated that this will be take place over 2 hours with a break, however, timings will be confirmed during the pilot stage.

The first part of the study will involve the adapted Compassionate Image exercise during which participants will be reassured that there are no right or wrong answers during this task as it is a personal and unique experience. The second part of the study will use the vignettes, which will be designed to elicit the imagined distress response. The anticipated cognitive response to the scenario will be given to the participant, and they will be asked how they might feel in that situation (see Appendix B). The participant will then be asked to use the Compassionate Image in order to soothe themselves. Finally the WASI (Pearson, 2011) will be completed at the end of the experimental task, because it has ‘right’ and ‘wrong’ questions, and therefore sets a tone contrary to that of the research process. In total it is estimated that these exercises will last no longer than 2 hours with a break.

Settings and Equipment

The experimental tasks will take place in a room provided by the college or service provider. The sessions will require recording equipment which will be borrowed from the University of Glasgow. Access to the WASI will be required through the university, and responses will be recorded straight onto the response booklets.

Justification of sample size

The current study is an exploratory one as there are currently no other studies which have looked at the feasibility of CFT within the ID population, meaning it is not possible to establish a sample size based on past findings. However, another doctorate project by Ackland (2011), who investigated individual's responses to praise and criticism, used a total of 42 participants (21 in each group). This project provided meaningful and significant results, and therefore we can justify using 42 participants in the current study. There will be an additional 4 participants recruited for the pilot stage (2 in each group).

Data Analysis

Data will be transcribed from the experimental tasks and will be analysed using Content Analysis. This process allows the researcher to systematically extract and identify specific characteristics of the data into a manageable representation (Stemler, 2001). Content analysis will therefore be utilised in order to explore the individual's ability to generate an image, and the differences between groups. In order to establish whether there are statistically significant differences between the two groups of participants a between groups analysis (the data of analysis will be dependent on the type of data gathered) will be conducted.

Health and Safety Issues

Participant safety issues

All individuals who will be recruited to this study are required to have sufficient receptive and expressive verbal ability in order to describe characteristics of a Compassionate Image. Due to their level of receptive and expressive verbal ability, the researcher will explain the study, and the participant is likely to be able to consent. The researcher will ensure that the participants have fully consented (written consent required) prior to taking part in the study.

The vignette task has been used successful in other studies (Ackland, 2011) without causing the participant too much distress. Individuals have also noted that they found this process engaging and meaningful. However, if individuals do find the vignette task too distressing, then it will be stopped. The researcher in the first instance will obtain the participant's consent to contact someone who can support them such as a lecturer, their GP or support worker. Participants will be given a full debrief. If they remain distressed, the

researcher will help to contain their anxiety, and provide numbers for Breathing Space/Samaritans/other relevant charities should the individual require additional support. During the pilot stage, participants will be asked to rate their distress when completing the vignette task. If it is rated too high, the researcher, will review this prior to the main study.

Researcher safety issues

The researcher will collect the data within a safe room at a college, which they will become familiar with. The study will take place during staff working hours to ensure that someone will be located nearby to the researcher, and who will be aware of when the researcher is meeting with participants. Although the researcher may not know individuals participating in the study well, they will liaise with college tutors who will be familiar with the individuals taking part (see Appendix D).

Ethical Issues

The researcher agrees to abide by the ethical principles underlying the Declaration of Helsinki and good practice guidelines on proper conduct of research (World Medication Association, 2013). The researcher will apply for ethical approval through the University of Glasgow Ethics Committee.

The researcher will follow all good practice guidelines relating to data protection and confidentiality. The sessions will be recorded and stored on encrypted equipment borrowed from the University of Glasgow. Only the consent forms will hold patient identifiable information and these will be stored securely within the university building.

Financial Costs

The estimated cost of this study is £191.20 (see appendix C). WASI manual, and recording, transcribing equipment will be borrowed from the University department. The Glasgow Scales are freely available online, therefore will only incur photocopying costs.

Time Scale

September 2015	Draft Outline to Mental Health & Wellbeing, University of Glasgow
December 2015	Outline to Mental Health & Wellbeing,

	University of Glasgow
May 2016	Final Proposal to Mental Health & Wellbeing, University of Glasgow
August 2016	Submission to Ethics committee
August 2016 – April 2017	Data Collection
March 2017 – May 2017	Analysis & Write Up
May 2017	Draft to Supervisors
July 2017	Thesis Submission

Practical Applications

As discussed earlier, there is a vital importance in ensuring that adaptations made to therapies for individuals with Intellectual Disabilities are done so with careful thought, planning and consideration. If therapies are not adapted properly then it can have a damaging effect on the outcomes of therapy (Taylor et al, 2013). Therefore, this research will have clinical utility and help to adapt Compassion Focused Therapy for individuals with an ID. Furthermore, there is a paucity of research in 3rd wave approaches with this client group, and this research aims to encourage discussion on the feasibility of CFT techniques.

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Appendix A (MRP Proposal)

Compassionate focused exercise <u>to be adapted</u>

Building a Compassionate Image
This exercise is to help you *build* up a compassionate image for you to work with and develop (you can have more than one if your wish, and they can change over time).Whatever image comes to mind, or you choose to work with note that it *is your* creation and therefore your own personal ideal what you would really like from feeling cared for and cared about. However, in this practice it is important that you try to give your image certain qualities. These will include:
Wisdom, Strength, Warmth and Nonjudgement

So in each box below think of these qualities (wisdom, strength, warmth and non judgement)
and imagine what they would look, sound or feel like.

If possible we begin by focusing on our breathing, finding our calming rhythm and making a half smile. Then we can let images emerge in the mind –as best you can –do not too try to hard if nothing comes to the mind, or the minds wanders, just *gently* bring it back to the breathing and practice compassionately accepting.

Here are some questions that might help you build an image: would you want your caring/nurturing image to feel/look/seem old or young; Male or female (or non human looking e.g., an animal, sea or light). Would your 'image' have gone through similar experiences to you? Would they be like a friend or even part of a team that welcomes you to belong? What colours and sounds are associated with the qualities of wisdom, strength, warmth and non judgement. Remember your image brings full compassion to you and for you.

How would you like your ideal caring compassionate image to look – visual qualities?
How would you like your ideal caring compassionate image to sound (e.g., voice tone)?
What other sensory qualities can you give to it?
How would you like your ideal caring compassionate image to relate to you?
How would like to relate to your ideal caring compassionate image?

©P Gilbert 2007
Exercise taken from the Compassion mind website (accessed on the 01.03.16)

Appendix B (MRP proposal)

Vignette Exercise DRAFT

Situation A:

- You are at your college / work place (insert as appropriate) in the lunch room
- You go over to sit with people you know
- But your friends turn around say to you " you are NOT welcome here with us"
- You are thinking "I'm not good enough to be their friend"

If you were in this situation, how might you be feeling?
Corresponding photos to be taken by the researcher and added in.

Situation B:

- You are at a party
- You go up to speak to someone new
- They stare at you, and you can't think of anything to say to them
- They stare at you and walk away
- You are thinking – "There is something wrong with me"

If you were in this situation, how might you be feeling?
Corresponding photos to be taken by the researcher and added in.

Situation C:

- You are meeting with your college tutor
- They want to talk to you about recent work that you did
- They tell you that you have failed
- You are thinking – " I have let them down, I can't do anything right"

If you were in this situation, how might you be feeling?
Corresponding photos to be taken by the researcher and added in.

Situation D:

- It's your friend's birthday
- You light the candles on the cake
- You carry the cake to them as a surprise
- When you start to walk you drop the cake on the ground
- You are thinking – " I have ruined their birthday"

If you were in this situation, how might you be feeling?
Corresponding photos to be taken by the researcher and added in.

Appendix C (MRP Proposal)

Research Equipment cost form

RESEARCH EQUIPMENT, CONSUMABLES AND EXPENSES

Trainee: XXXXXXX

Year of Course: **2nd Year** **Intake Year**: **2014**

Please refer to latest stationary costs list (available from student support team)

Item	**Details and Amount Required**	**Cost or Specify if to Request to Borrow from Department**
Stationary	N/A	Subtotal: N/A
Postage	N/A	Subtotal: N/A
Photocopying and Laser Printing (**includes cost of white paper**)	Black and white print 1 sheet = 5 pence 560 prints in total at 5p each (including: background information sheets, consent forms, measures, and experiments, excluding the WASI)	Subtotal: £28.00
Equipment and Software	Digital Voice Recorder Transcription Software.	Both to be borrowed from the Doctorate in Clinical Psychology programme Subtotal: N/A
Measures	WASI forms available from the Pearson website. 46 copies required Manual and materials available to borrow from the department.	Pack of 25 = £81.60 (including VAT) Pack of 25 X 2 from Pearson website = 50. Subtotal: £163.20
Miscellaneous	N/A	

		Subtotal: N/A
Total		**£191.20**

For any request over £200 please provide further justification for all items that contribute to a high total cost estimate. Please also provide justification if costing for an honorarium:

Trainee Signature…….x…… … Date……30.05.16..…

Supervisor's Signature …….. Date ……

Appendix D (MRP Proposal)

Health and Safety Form

WEST OF SCOTLAND/ UNIVERSITY OF GLASGOW

DOCTORATE IN CLINICAL PSYCHOLOGY

HEALTH AND SAFETY FOR RESEARCHERS

1. Title of Project	Exploring the use of Compassion Focused Therapy approaches with people who have Intellectual Disabilities: Can these techniques be successfully adapted for this population?
2. Trainee	XXXXXXX
3. University Supervisor	Professor Andrew Jahoda
4. Other Supervisor(s)	Dr Carol Pert
5. Local Lead Clinician	N/A
6. Participants: (age, group or sub-group, pre- or post-treatment, etc)	Experimental group – Individuals with an Intellectual Disability aged 18-65 Control group – Individuals without an Intellectual Disability aged 18-65
7. Procedures to be applied (eg, questionnaire, interview, etc)	All participants will complete the following: • Background information sheet (including demographic information) • Adaptive Behaviour Scale (ABS-RC II) – abbreviated • Glasgow anxiety scale • Glasgow Depression scale • Compassionate image exercise (to be adapted for this study) • Vignette task to elicit feelings of social threat (to be adapted for this study) • Structured questions throughout the experimental task • Wechsler Abbreviated Scale of intelligence 2nd edition (WASI-II)

8. Setting (where will procedures be carried out?) i) Details of all settings	Procedures will be carried in an approved room in one of the colleges of recruitment, where there will be access to local staff.
ii) Are home visits involved	No

WEST OF SCOTLAND/ UNIVERSITY OF GLASGOW
DOCTORATE IN CLINICAL PSYCHOLOGY
HEALTH AND SAFETY FOR RESEARCHERS

9. Potential Risk Factors Considered (for researcher and participant safety): i) Participants ii) Procedures iii) Settings	**Participants' Safety Issues:** The participant will be asked to imagine that they are experiencing the feelings provoked within the vignette, in order to elicit feelings of social threat. **Researcher Safety Issues:** The researcher will be working with individuals that they have not met prior to the study commencing. **Setting:** Sessions will take place within a location familiar to the participant.
10. . Actions to minimise risk (refer to 9) i) Participants ii) Procedures iii) Settings	**Participants' Safety Issues:** Individuals will be asked to imagine a situation of social threat, and therefore not placing them in any real threat. These vignettes will be based on a hypothetical situation, and therefore not directly about a negative event that the participant may have experienced, which removes some potential distress. Previous studies have used this method without individuals becoming too distressed. However, the researcher will monitor mood of the participant at all times, and stop the task if they become too anxious or upset. A full debrief will be provided. **Researcher Safety Issues:** The researcher will develop links with college tutors who will be familiar with participants, and therefore will be able to provide background information to the researcher about them. **Setting:** The researcher will access the room for the study prior to the study commencing, in order

	to become familiar with the setting. Furthermore, the researcher will also familiarise herself with local safety policies and procedures.

Trainee signature: X.....Date: 30.05.16.....

University supervisor signature: ..... Date: .....

Appendix E (MRP Proposal)

Plain English Summary

Exploring the use of Compassion Focused Therapy approaches with people who have Intellectual Disabilities: Can these techniques be successfully adapted for this population?

Introduction

Research tells us that people who have a Learning Disability (LD) are more likely to have mental health problems than those who do not (Cooper et al., 2007). It also says that people with an LD experience more negative life events, for example, bullying, and abuse than those who do not (Cooney et al, 2006). These experiences can lead to people feeling guilt and shame.

Compassion Focused Therapy (CFT) is used to help people understand their feelings, and experiences. CFT proposes that we have 3 systems that our mind operates; the drive system, soothing system, and the threat system (Gilbert, 2009). People who experience high levels of guilt and shame are more often in the threat system, which can lead to depression. This therapy designed to help address these feelings of guilt and shame, and has had some success (Leaviss & Uttley, 2015).

Aim

There are currently no studies to tell us if this type of therapy can be useful for people who have a LD. It is hoped that this study will explore this, and find ways that CFT might be adapted for people with a LD.

Procedure

This research will achieve this by adapting an exercise from CFT called the 'Compassionate Image'. Participants will be recruited from local colleges in the Central belt of Scotland. There will be two groups of participants to compare; a group of adults with a LD and a group of adults without a LD. Participants will meet with the researcher to complete the Compassionate Image exercise, which builds an ideal image of someone or something that brings comfort to the person. After this image is built, the participant will be asked to imagine they are in a situation that makes them feel shame, guilt and rejection. The participant will then be asked to use the compassionate image to make them feel safe,

warm, and secure. They will be asked various questions about their experience, to find out what they thought of it. The data will then be analysed to explore whether this is a useful exercise or not.

Ethics

The project has considered the effects on its participants thoroughly. Participants will be given the opportunity to opt into the study, at which time they will be given full information on the details of the study. They will be told that they have the right to withdraw at any time and that their details will be made anonymous. Ethics will be sought through Glasgow University Ethics Committee, and the study will not proceed until this is completed.

Practical Implications

It is hoped that this research will build on an evidence base, which is lacking in this area, to explore adapting CFT for this group of people.

References

- Cooney, G., Jahoda, A., Gumley, A., & Knott, F. (2006). Young people with learning disabilities attending mainstream and segregated schooling: Perceived stigma,
  social comparisons and future aspirations. *Journal of Intellectual Disability Research, 50,* 432 – 445.
- Cooper SA, Smiley E, Morrison J, Williamson A, Allan L. Mental ill-health in adults with intellectual disabilities: prevalence and associated factors (2007). *British Journal of Psychiatry, 190,* 27–35.
- Gillbert, P. (2009). *The compassionate mind: A new approach to the challenges of life.* London, UK: Constable & Robinson.
- Leaviss, J. &Uttley, L. (2015). Psychotherapeutic benefits of compassion-focused therapy: an early systematic review, *Psychological Medicine,45,* 927–945.

Appendix 2.2: Ethical Approval

University of Glasgow

22/11/2016

MVLS College Ethics Committee

Project Title: Coping responses and the use of a Compassion Focused Therapy exercise to self soothe: An exploratory study with individuals who have Intellectual Disabilities
Project No: 200160012

Dear Professor Jahoda,

The College Ethics Committee has reviewed your application and has agreed that there is no objection on ethical grounds to the proposed study. It is happy therefore to approve the project.

- Project end date: End September 2017
- The data should be held securely for a period of ten years after the completion of the research project, or for longer if specified by the research funder or sponsor, in accordance with the University's Code of Good Practice in Research: (http://www.gla.ac.uk/media/media_227599_en.pdf)
- The research should be carried out only on the sites, and/or with the groups defined in the application.
- Any proposed changes in the protocol should be submitted for reassessment, except when it is necessary to change the protocol to eliminate hazard to the subjects or where the change involves only the administrative aspects of the project. The Ethics Committee should be informed of any such changes.
- You should submit a short end of study report to the Ethics Committee within 3 months of completion.

Yours sincerely,

Jesse Dawson
MD, FRCP, BSc (hons), MBChB (hons)
Clinical Reader / Honorary Consultant

Chair MVLS Ethics Committee
College of Medicine, Veterinary & Life Sciences
Institute of Cardiovascular and Medical Sciences
Western Infirmary
Glasgow
G11 6NT
jesse.dawson@glasgow.gla.ac.uk
Tel – 0141 2116395 or page 4824

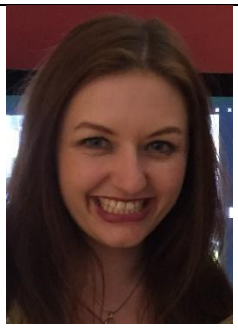
Appendix 2.3: Background information sheet – easy read

Study Information Sheet

Study: Coping styles and exploring a new way of coping called 'The Kind Helper in my mind'.

Name of Researchers: Laura Brougham (Trainee Clinical Psychologist), Professor Andrew Jahoda (Consultant Clinical Psychologist) and Dr Carol Pert (Clinical Psychologist)

	Please read this information sheet
	You can ask someone to read it with you
	You can talk to someone you trust about it
	Take time to think about it

	My name is Laura Brougham I am doing research at the University of Glasgow
	This study is looking at ways of coping
	You are part of a group of people I would like to speak to: • You have a Learning Disability • You go to college I will be looking to speak to 42 people
	It takes place from November 2016 – July 2017
	If you start the study and want to stop – this is OK You do not have to give a reason to stop

	If you want to take part, this is what will happen
	You would meet with the researcher in a room at your college
	There would be 1-2 meetings. These may last for an hour each
	The researcher would talk to you about: • Stressful things in your life • How you cope • A new way to cope • Imagined situations and your thoughts on these
	I would record what you said This would help me remember

	Nothing bad would happen to you
	Things you say will be kept private Unless the researcher is worried about your safety
	You can say stop at any time if you want to
	Once the research is finished it will be written up in a report Other people will read this report

Contact details	
	Laura Brougham Trainee Clinical Psychologist. Mental Health and Wellbeing 1st floor, Administration Building Gartnavel Royal Hospital 1055 Great Western Road Glasgow G12 0XH
	l.brougham.1@research.gla.ac.uk
	0141 211 3920

	You can also ask my supervisor questions **Professor Andrew Jahoda** Consultant ClinicalPsychologist Mental Health & Wellbeing, Gartnavel Royal Hospital 1055 Great Western Road, Glasgow, G12 0XH Tel: 0141 211 0607 Email: Andrew.Jahoda@glasgow.ac.uk

	If you are interested Fill in the reply sheet and pass over to the researcher or to your tutor

Appendix 2.4: Background information sheet

Study Information Sheet

Title

The use of a Compassion Focused Therapy exercise to self soothe: An exploratory study with individuals who have Intellectual Disabilities

You are being invited to take part in a research study. The research study is voluntary so you do not have to take part. Before you decide if you want to take part, it is important for you to know why the research is being done and what it will involve. Please take time to read the following information carefully and discuss it with others if you wish. Ask me if anything is not clear or if you would like more information. Take time to decide whether or not you wish to take part.

Who I am

My name is Laura Brougham and I am a Trainee Clinical Psychologist. I am carrying out this study with help from my supervisor Professor Andrew Jahoda who is a University Professor and a Consultant Clinical Psychologist. I also have help from Dr Carol Pert, who is a Clinical Psychologist.

What is the purpose of the study?

This study aims to explore coping styles and a type of therapy called Compassion Focused Therapy, to find out if it is useful to people who have a Learning Disability. The study starts in September 2016 and ends in July 2017.

Why have I been chosen?

You have been asked because you go to a college in Scotland, and are between 18-65 years old. I am trying to meet with about 42 people to make two groups, one for people with a Learning Disability and one for people without a Learning Disability. If you have a diagnosis of Psychosis, Severe Sensory Impairment, Dementia, or Autism Spectrum Disorder, you will not be able to take part in the study.

Do I have to take part?

It is up to you to decide whether or not to take part in this study. It is okay if you decide that you don't want to take part. You don't have to tell anyone why you don't want to take part. If you do decide to take part, you will be given this information sheet to keep and be will asked to sign a consent form.

It's also okay to start taking part in the project and then change your mind. You still won't have to give a reason for changing your mind and you will still keep the information sheet and consent form. You will be free to withdraw at any time, should you decide not to take part.

Taking part in this research or not taking part in this research will not affect your grades in any way.

What will happen to me if I take part?

I would ask to meet with you for an hour (with a break) between 1-2 meetings, which would occur in a room at your college. During our meeting I would ask you to do the following things:

- Fill in a short form about yourself (for example, your age, gender etc)
- Fill in a couple of short questionnaires about your mood
- Complete some questions about your style of coping to stressful events
- An exercise called the 'Kind Helper', where you would be encouraged to think about a kind person in your mind who could help you when you felt upset
- A task where you will be asked to imagine different situations that might make you feel upset, and then you will be asked to use your 'Kind Helper' to see if this helps you to feel better.
- You will be asked also to give your opinion on the 'Kind Helper' which is a chance for you to have your say
- A couple of short tasks from an Intelligence test

I would record what we say on a voice recorder to help me remember the things that you have told me.

What do I have to do?

You would have to attend the meetings with me in order to go through the tasks of the study. You will not be asked to do anything before and after these meeting.

What are the possible disadvantages and risks of taking part?

You will be taking part for about an hour, with a break, on two occasions at an agreed time. Other than that, there shouldn't be anything bad that happens if you decide to take part.

What are the possible benefits of taking part?

You will receive no direct benefit from taking part in this study. However, the information that is collected during this study will give us a better understanding coping styles and this type of therapy. This might be able to help other people in the future.

Will my taking part in this study be kept confidential?

All information which is collected about you, or responses that you provide, during the course of the research will be kept strictly confidential. You will be identified by a fake name or ID number, and any information about you will have your name and address removed so that you cannot be recognised from it. All of the information that you give me in our meeting will be kept safe in a locked drawer and on a password protected computer. This means that no one apart from me and my supervisor will be able to see the information that you shared with me.

Please note that confidentiality will be followed carefully unless there is evidence of serious, or risk of serious harm, is uncovered. In such cases the university may have to contact other agencies. The researcher will contact, with your knowledge, a college tutor and your GP if they are worried about your safety.

What will happen to the results of the study?

Once I have spoken to all the people who want to be involved in the study, I will write about what I have found out in a paper that may be read by other people. None of the participants will be named in this paper so that no one else knows that I spoke to you. I might use direct quotes of what you have told me, but these won't include your name or any details about your life that might help people to identify you.

I can also give you a copy of the results of the study if you would like them.

Who is organising and funding the research?

The research is part of the researcher's Doctorate training, and as such is funded as part of her training.

Who have reviewed the study?

The project has been reviewed by the College Ethics Committee.

Contact for further information

If you have any more questions about the study then you can get in touch with me.

You can write to me at:

Laura Brougham

Trainee Clinical Psychologist.

Mental Health and Wellbeing

1st floor, Administration Building

Gartnavel Royal Hospital

1055 Great Western Road

Glasgow

G12 0XH

Or you can email me at:

l.brougham.1@research.gla.ac.uk

Or you can call me on:

0141 211 3920

If you are interested in taking part…

If you would like to take part in this study then please complete the attached slip and give it to your class tutor. I will collect these slips and make contact with anyone who has handed one in.

Thank you for taking the time to think about this study.

Appendix 2.5 – Participant reply sheet

CONTACT DETAILS

Title of Study: Coping responses and the use of a Compassion Focused Therapy exercise to self soothe: An exploratory study with individuals who have Intellectual Disabilities.
Researcher: Laura Brougham**,** Trainee Clinical Psychologist

I am interested in finding out more about this study and consent for my details to be passed to the researcher who will then contact me.

My preferred means of contact is (*tick appropriate response)***:**

Post ☐

Email ☐

Telephone ☐

Please provide details of your preferred means of contact in the space below.

Address: _____
_____

Telephone Number: _____

Email Address: _____

If you wish to be contacted by telephone, are you happy for a message to be left on an answering machine (*tick appropriate response)*?

Yes ☐

No ☐

Participant Name: _____

Signature: _____

Date: _____

Appendix 2.6 – Consent form – easy read

Study Consent Form

Study: Coping styles and exploring a new way of coping called 'The Kind Helper in my mind'.
Name of Researchers: Laura Brougham (Trainee Clinical Psychologist), Professor Andrew
Jahoda (Consultant Clinical Psychologist) and Dr Carol Pert (Clinical Psychologist)

Please circle the answer you agree with:		**YES**	**NO**
	Have you read the information sheet?		
	Have you had the chance to ask questions?		
	I would like to participate in the research?		

	I know that I can change my mind or stop at any time		
	I agree that the meeting will be tape recorded		
	I agree to the things I have said being written about without my name being on them		
	I agree to the researcher phoning my Doctor if they are worried about me		

Signed by the participant:
Date:
Signed by the appropriate adult (if necessary):
Date:
Signed by the researcher:
Date:

(1 copy for participant; 1 copy for researcher; 1 copy for appropriate adult if signature given)

Appendix 2.7 – Consent form

University of Glasgow | College of Medical, Veterinary & Life Sciences

Centre Number:

Project Number:

Subject Identification Number for this trial:

CONSENT FORM

Title of Project:

Title of Project: Coping responses and the use of a Compassion Focused Therapy exercise to self soothe: An exploratory study with individuals who have Intellectual Disabilities

Name of Researcher: Laura Brougham

Please sign your initials in the boxes if you agree

I confirm that I have read and understood the Plain Language Statement/Participant Information Sheet for the above study and have had the opportunity to ask questions. ☐

I understand that my participation is voluntary and that I am free to withdraw at any time, without giving any reason. ☐

I consent to the researcher contacting my GP should they feel concerned about my safety or wellbeing. (I acknowledge that they will tell me if this should happen). ☐

I consent / do not consent (delete as applicable) to interviews being audio-recorded. ☐

I acknowledge that participants will be referred to by pseudonym. ☐

I confirm that I give consent for my anonymised data to be used in this research, and in any publications. ☐

I agree that the data collected in the course of this research will be shared with other genuine researchers as set out in the Plain Language Statement. ☐

I agree to waive my copyright to any data collected as part of this project ☐

I agree to take part in this research study ☐

I do not agree to take part in this research study ☐

Name of Researcher(s):

Please initial box

I confirm that I have read and understand the information sheet dated _____ (version _____) for the above study and have had the opportunity to ask questions. ☐

I understand that my participation is voluntary and that I am free to withdraw at any time, without giving any reason, without my legal rights being affected. ☐

I agree to take part in the above study. ☐

_____	_____	_____
Name of participant	Date	Signature

_____	_____	_____
Researcher	Date	Signature

(1 copy for subject; 1 copy for researcher)

Appendix 2.8 – Background Information Sheet

University of Glasgow | College of Medical, Veterinary & Life Sciences

Background information sheet

Name	
Gender	**Male** ☐ **Female** ☐
DOB	
Address (including post code)	
GP details	
Scottish Index of Multiple Deprivation (SIMD)	
Living situation	**Living alone** ☐ ☐ **Living with family** **Living with partner** ☐ **Living with a housemate** ☐ **Living in a group home** ☐
College course	
Regular activities/ hobbies	
Employment?	
Accessing services from a Mental Health Team?	

Diagnosis of Mental Health problem or Neurodevelopment Disorder?	
Copy of results?	**Yes** ☐ **No** ☐
Group	**Case** ☐ **Control** ☐
Initial meeting	**Date:** **Location:**
Consent given	**Date:**
Participation in study	**Date:** **Location:**
Results sent	**Yes** ☐ **No** ☐ **Not applicable** ☐ **Date:**

Appendix 2.9 – Glasgow Anxiety Scale

Glasgow Anxiety Scale for People with Intellectual Disabilities by Mindham & Espie (2003)

Each item scored as: (0) 'never'; (1) 'sometimes'; and (2) 'always'.
Question Score

Worries
1 Do you worry a lot? (…feel worked up/wound up/uptight/up to high doh)
2 Do you have lots of thoughts that go round in your head? (…thoughts that you can't stop/come from nowhere)
3 Do you worry about your parents/family?
4 Do you worry about what will happen in the future? (tailored to the individual; e.g. What will happen if you can't live with your mum anymore?)
5 Do you worry that something awful might happen?
6 Do you worry if you do not feel well? (…if you feel sick)
7 Do you worry when you are doing something new? (…like for the first time)
8 Do you worry about what you are doing tomorrow?
9 Can you stop worrying? (reverse score)
10 Do you worry about death/dying?

Specific fears
11 Do you get scared in the dark? (…think of being in bed with the lights out: Would you be scared?)
12 Do you feel scared if you are high up? (…think of being up a high building…)
13 Do you feel scared in lifts or escalators? (Would you go in?)
14 Are you scared of dogs? (Would you stroke/clap?)
15 Are you scared of spiders? (Would you go near?)
16 Do you feel scared going to see the doctor or dentist?
17 Do you feel scared meeting new people?
18 Do you feel scared in busy places? (…like crowds, shopping centre)
19 Do you feel scared in wide open spaces? (…nothing round about you)

Physiological symptoms
20 Do you ever feel very hot or sweaty? (…all hot and bothered)
21 Does your heart beat faster?
22 Do your hands and legs shake?
23 Does your stomach ever feel funny, like butterflies?
24 Do you ever feel breathless? (…hard to breathe/out of breath)
25 Do you feel like you need to go to the toilet more than usual? (…for a 'pee')
26 Is it difficult to sit still? (…feel you can't sit at peace)
27 Do you feel panicky? (…get into a panic/a 'state')

Appendix 2.10 – Adapted Lifestress Inventory

Adapted from the Lifestress Inventory by Bramston& Bostock (1994)

Record form
Participant Number: _____
Date:_____
Instructions: Read the participant the statement and encourage them to note what they would do in the given situation

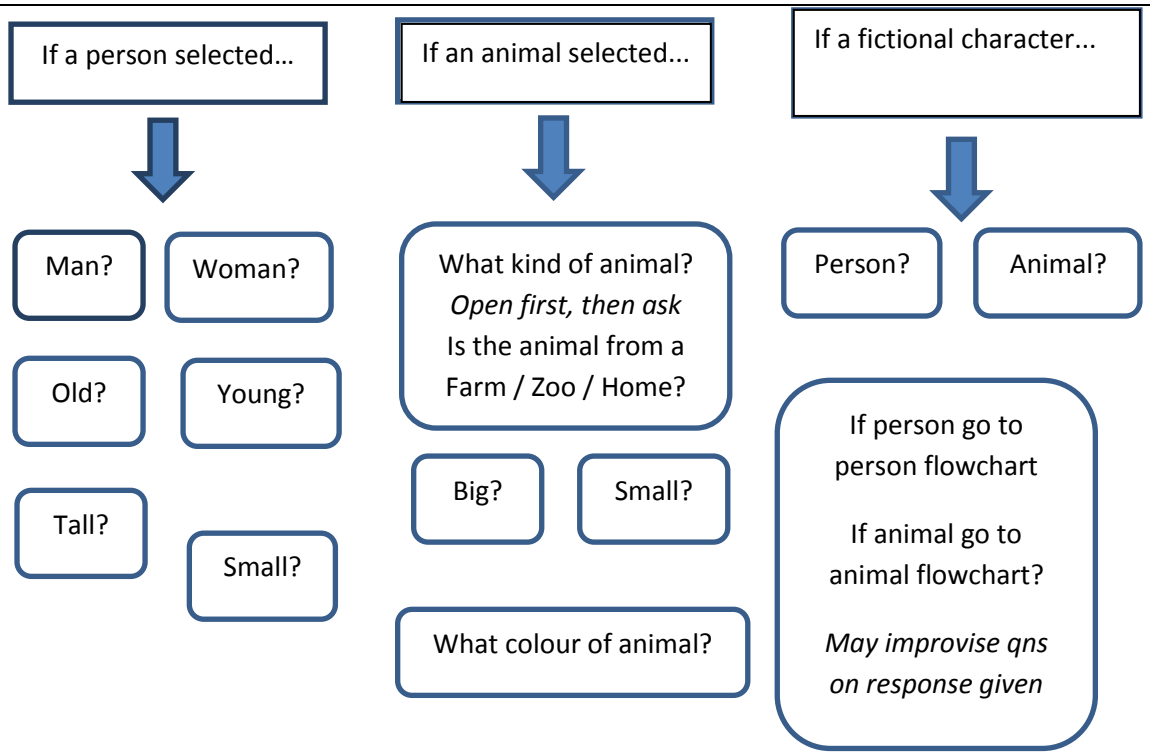
Question Number	Item	Sentence stem response
1.	When I hear people I know arguing… (Argue)	
2.	When people treat me as though as I'm different…(Treatdf)	
3.	When someone I know is seriously ill or has died… (Death)	
4.	When I have not been getting on with my partner/girlfriend/boyfriend… (Partner)	
5.	When I do not get on well with my family… (Family)	
6.	When someone bullies or hits me…(Bully)	
7.	When people tease me or call me names… (Tease)	
8.	When people make me do things I don't really want to do… (Coerce)	
9.	When I have had an argument or fight with someone… (Fights)	

10.	When I am in really crowded places… (Crowds)	
11.	When I have been in a difficult situation where I didn't know what to do… (Helpless)	
12.	When people around me don't let me know what's going on… (Informed)	
13.	When I can't always find a job… (Findjob)	
14.	When I don't like living where I live… (Home)	
15.	When I have been in trouble… (Intrub)	
16.	When I don't have enough friends… (Friends)	
17.	When people don't like talking to me…(Likeyou)	

Appendix 2.11 – Adapted Compassionate Image task

The Kind Helper record sheet

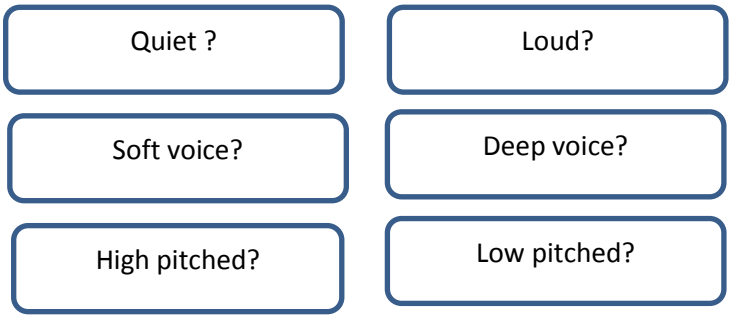
1. Would you imagine this to be a person (man or woman), an animal or a cartoon/film character?



2. Is there anything else that you can tell me about how it looks?

3. Give it a name? (once it is named X, refer to this throughout the rest of the exercise)

4. Can you imagine what X's voice is like?



5. Can you imagine what X would say to you? (open ended)

6. I'll going to say some other phrases and I want you to tell me if you can imagine X saying these to you?

I care about you	
I'll be here for you no matter what	
You can depend on me	
I understand how you feel	
I'm here to help you	

7. Is there anything else that you want to add about X?

Appendix 2.12 – Vignette task

Vignette script

I am going to show you some photos about a story and I would like you to imagine how you would feel if you were in that same situation. I want you to use your imagination to really imagine that these situations are happening to you. If anything I say is not clear just let me know.

Vignette A: Failure

Images the same the both male and female participants

- You have been working hard at your college course
- You hand in a piece of work for marking
- Your tutor asks you to come in to his office
- You go into his office and he looks at you
- You feel nervous
- They tell you that you have failed, and that they are disappointed in you
- You feel ashamed
- You notice your heart beating faster
- You are thinking "I never do well"

Vignette B: Mixed up words

Gender specific images (i.e. male and female versions)

- You go to a party and you see two people who you want to talk to
- You try to say hello to them, but you get your words mixed up
- You feel very silly
- They start to laugh and turn away from you
- You are thinking “I’m really stupid” and “I’ll never make new friends”.
- You have butterflies in your tummy
- You feel upset

Vignette C: Social rejection

Gender specific images

- You are at your college in the lunch room.
- You see an empty seat and think, I’ll sit there
- You go over to sit with them
- But they all turn around and stare at you
- “you are NOT welcome here with us”
- You are thinking “I’m not good enough to be their friend”
- You notice your legs feeling like jelly
- You are feeling very hurt and rejected

Vignette D: College rejection

Gender specific images

- You recently applied to do a new college course
- You were looking forward to starting this course

- Your letter tells you that you have not been accepted
- You are thinking "I will never pass my course"
- You notice that you are starting to sweat
- You are feeling useless

Vignette E: Problem – solving

Gender specific images

- You have a problem that you are worried about
- You need to set up a bank account but you don't know how to do it
- You speak to your friend
- They tell you "don't worry it will be alright" "I'll help you"
- They agree to go with you to the bank
- You are thinking " they are a good help to me"
- You have a warm feeling in your body
- You are feeling happy now

Vignette F: Fell out with friend

Gender specific images

- You at home after visiting a friend
- You are thinking about an argument that you had
- During the fight you said something nasty to your friend
- You knew you should not have said that
- You are thinking – "I'm a bad friend" "They won't talk to me now"
- You notice that your hands are shaking
- You feel very upset because you did something wrong

Vignette record form (same questions following each vignette)

Participant Number: _____
Date: _____

Vignette A: Failure

So, imagine X is there with you. Remember X is on your side, understands how you feel; and is someone you can always trust and depend on. Imagine X's voice as they say kind words like "I care about you; I'll be here for you; you can depend on me; I understand, I'll help you." (*add other words chosen earlier by the participant*). Imagine how it feels to hear those words.

1. Were you able to imagine X saying kind / comforting words to you? *(Show symbols / Visual prompts)*

Yes ☐

No ☐

2. What you X say to you when you have X (wording relevant to each vignette)?

3. Are you feeling better, worse or the same? (Show the visual prompt)

Better	
The same	
Worse	

4. How did it feel when you thought about X being kind to you? *(Start with open ended question followed by offer choices*).

Happy	
Loved	
Comforted	
Warm	
Felt the same	

5. Did you notice any feelings in your body?

Appendix 2.13: Criteria for coding the lifestress inventory

Lifestress Inventory	
Item	**Coding key**

Scoring criteria followed from Hartley and MacLean paper (2010) Example from p16 of their paper copied below:

Coping	***Definition***	***Examples***
Active Problem-focused	*Cognitive and behavioural efforts to manage the stressful situation itself*	1. *"Talked to (roommate) and worked it out"* 2. *"I told (staff) that he wasn't doing dishes so th make him do dishes"*
Active Emotion – focused	*Efforts to manage the emotional response to a stressor by focusing directly on it in an active and constructive fashion*	1. *"Think about my best friend who likes me. Is n friend"* 2. *"Tell myself that I'm living by myself soon so have to see her"*
Active Support seeking	*Use of other people as a resource to identify solutions for a stressor or provide understanding of feelings*	1. *"Talked to (staff) about it and they told me to my boss"* 2. *"Told my Doctor about it and they made me fe better"*
Avoidant Behaviou ral	*Efforts to avoid the problem by staying away from it or leaving it*	1. *"Yelled back and then go to my room so don't her"* 2. *"I was so mad at my boss so I left work and di go back"*
Avoidant Cognitive	*Cognitive efforts to repress or not think about the problem or wish it away*	1. *"Try to forget about it. Pretend they don't exis* 2. *" Dream about being pretty"*

Note. Criteria are modified from Ayers, Sandler, Bernzweig, Harrison, Wampler, and Lustig (1989) and Program for Prevention Research (1999). If coping effort involved managing the stressful situation itself through using staff or family (e.g., staff enforced rule or changed practice/policy), it was coded as Problem-Focused coping. If coping effort involved soliciting advice or solutions from staff or family that latter resulted in altering the stressful situation, it was coded as Support Seeking coping.

*****Ayers et al. (1989) also has a code for non-coping, which is defined as *"responses that involved verbal or physical actions to implicitly or explicitly hurt or threaten others or vent feelings with no intention of altering these feelings were coded as Non-Coping efforts.*