

**Compassion Focused Therapy for People with Dementia: A
Feasibility Study**

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Thesis declaration form

I confirm that the work presented in this thesis is my own. Where information has been derived from other sources, I confirm that this has been indicated in the thesis.

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Overview

This three-part thesis reviews the effectiveness of Compassion Focused Therapy (CFT), and details the development and a trial of a CFT intervention for people with dementia and psychological distress.

Part 1: Literature Review. A systematic literature review of 15 studies that evaluated the effectiveness CFT across clinical populations. Significant improvements in symptomatology and increased self-compassion were found following CFT, and the benefits were at least as effective as other psychological interventions, including CBT, mindfulness and treatment at usual. Further high-quality, adequately powered studies are required to assess its place as an evidence-based treatment.

Part 2: Empirical Paper. A feasibility study evaluating the acceptability and impact of a CFT intervention developed for people with dementia and associated psychological distress. An adapted CFT intervention was developed to be delivered to people with dementia based on the relevant literature. A case-series of seven people with dementia was used to assess the intervention's feasibility, and effectiveness on outcomes of self-compassion, mood, anxiety and quality of life. Improvements in self-compassion, mood and anxiety were seen. Six participants with dementia were able to engage in soothing rhythm breathing, and five were able to engage in discussion of self-criticism and developing self-compassion. Overall the intervention was experienced as helpful, and several participants and their carers described increased self-compassion in response to cognitive decline.

Part 3: Critical Appraisal. A reflection and appraisal of the study, including the challenges encountered and lessons learnt.

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Part One: Literature Review

Effectiveness and Acceptability of Compassion Focused Therapy in Clinical

Populations: A Systematic Review

Abstract

Aims

This review examines the effectiveness and acceptability of compassion-focused therapy (CFT) as a psychological intervention in clinical populations and aims to update a previous review (Leaviss & Uttley, 2015) of the psychotherapeutic benefits of CFT.

Method

A comprehensive systematic review of the literature was conducted in November 2016 to identify literature relating to the effectiveness of CFT as a psychological therapy in clinical populations.

Results

Fifteen studies were identified including four randomised controlled trials. Significant improvements in symptomatology and increased self-compassion were found following CFT, and the benefits were at least as effective as other psychological interventions, including Cognitive Behavioural Therapy (CBT), mindfulness and treatment at usual. CFT appears to be well-accepted and is feasible to deliver in clinical settings. However there is a variation in study quality and robustness.

Conclusions

CFT shows promise as a psychological intervention for a range of mental health problems, especially when delivered in a group format over a minimum of 12 hours. There is a lack of trials evaluating individual CFT. Further high-quality, adequately powered studies are required to assess its place as an evidence-based treatment.

Introduction

Purpose

This review examines the effectiveness and acceptability of Compassion-Focused Therapy (CFT) as a psychological intervention and aims to update a previous review (Leaviss & Uttley, 2015) of the psychotherapeutic benefits of CFT. The initial review, which searched the CFT literature up to April 2012, found a lack of rigorously designed trials. Out of the 14 studies identified that evaluated the effectiveness of CFT across clinical and non-clinical populations, only three were randomised control trials (RCTs), with the majority consisting of observational studies as well as an N=1 and a case series. The authors argued that CFT has become more popular in the clinical psychology field and is increasingly used across populations, however there is currently a lack of clear evidence-base for its use. They concluded that the intervention ‘shows promise’ however that more large-scale, high quality trials are needed before it can be considered evidence based practice.

Four years has passed since Leaviss and Uttley (2015) conducted their searches of the CFT literature. The current review seeks to evaluate and integrate subsequent findings of further CFT trials to update our understanding of the therapy’s value among clinical populations.

The Benefits of Compassion

Compassion is defined as a sensitivity to the suffering of the self and others, with a deep commitment to try and relieve it (Dalai Lama, 2001). Those with high levels of self-criticism tend to judge themselves harshly for their perceived weaknesses and inadequacies, with a lack of sensitivity to their own suffering and a well-developed ability to worsen their mental suffering. Developing compassion can help such individuals create a kinder, more compassionate inner voice, which can

counteract negative and critical inner-talk, resulting in improved mood (Gilbert, 2010a).

A growing body of research suggests that having greater levels of self and other compassion has positive effects on mental health and wellbeing. Compassion has found to be positively correlated with wellbeing (Neff, Kirkpatrick, & Rude, 2007) and quality of life (Van Dam et al., 2011). A meta-analysis has found that greater self-compassion is associated with fewer mental health difficulties, yet lower self-compassion is associated with increased psychopathology (MacBeth & Gumley, 2012). Building self-compassion can lead to greater motivation to improve oneself in the face of difficulties (Breines & Chen, 2012) and in improved relationships (Neff et al., 2007; Leary, Tate, Adams, Batts Allen, & Hancock, 2007). Interventions aimed to develop compassion show increased mindfulness, compassion for others and life satisfaction, with a reduction in stress and symptoms of anxiety and depression (Neff & Germer, 2013). Neuroscience research has also shown that compassion meditation practices in established and novice meditators increase overall life happiness (Davidson, 2012).

Compassion Focused Therapy

There are three core components of self-compassion. Neff (2003, 2011) describes these as mindfulness (vs. over-identification), common humanity (vs. isolation), and self-kindness (vs. self-judgement). CFT aims to facilitate the development of these skills and attributes of compassion through compassionate mind training (CMT). Attributes include sensitivity, empathy, care for wellbeing, non-judgement and distress-tolerance (Gilbert, 2009). The key task in the therapy and the process of CMT is to down-regulate the threat system (one of the body's motivational systems that ensures survival through looking out for and responding to

danger in the environment) through the practice ‘soothing rhythm breathing’ (a slowing and regulating breathing technique), responding to self-criticism with compassion (compassionate thinking), compassionate imagery, and compassionate behaviour. Throughout the therapy individuals are encouraged to develop compassion for themselves, for others, and to increase openness in receiving compassion from others.

Aims

The review aims to evaluate the effectiveness and acceptability of CFT as a psychological intervention for clinical populations and to make recommendations for further trials. It aims to update the previous systematic review (Leaviss & Uttley, 2015) of the benefits of CFT, yet will address clinical populations only. There has been an increase in published trials evaluating CFT, and although interesting to explore its effects in non-clinical populations, there is a need to explore the therapy’s utility within the National Health Service (NHS) settings in those with mental health difficulties. Such findings will contribute to the knowledge of the credibility of CFT as an evidence-based psychological treatment.

Method

Search Strategy

A systematic review of the literature was conducted in November 2016 using the databases PsycInfo, Web of Science and MedLine. The search terms used variations of two terms: compassion and therapy. The search terms for compassion were ‘compassion’, ‘compassionate’, ‘compassionate mind’ and ‘compassion-focused’. The search terms for therapy were: ‘treatment’, ‘therapy’, ‘training’, ‘therap\$’ and ‘intervention’. These terms were based upon the previous review of CFT (Leaviss & Uttley, 2015), in order to update the review by incorporating more

recent findings. Searches were conducted so that there had to be at least one term from each category for a study to be included in the search results.

Inclusion Criteria

Papers were included in the literature review if they met the following criteria:

1. Published in a peer reviewed journal
2. Clinical samples were used. For example mental health problems such as psychosis, depression, eating disorders, personality disorders etc.
3. Assessed the effectiveness of a CFT intervention ('compassionate mind training' or 'compassion focused therapy')
4. Any or no comparator (including control group/s, any psychotherapeutic intervention, pharmacological treatment, treatment as usual (TAU), and no treatment)
5. Assessed outcomes of the effectiveness of the intervention (including symptoms of psychological conditions, self-compassion and self-criticism and quality of life)
6. RCT and observational designs

Exclusion Criteria

1. Book chapters and opinion articles
2. Studies that solely evaluated 'Mindful Self-Compassion' (Neff & Germer, 2013) interventions
3. Meditation only interventions (for example, mindfulness meditation, loving-kindness meditation and compassion meditation)
4. One-off CFT intervention sessions
5. Correlational designs

6. Case series and N=1 designs

Screening and Selection

All paper titles were screened for relevance, and the abstracts were reviewed for those that appeared relevant. Any studies that referred to a compassion based psychological therapy were included for further detailed screening. The full articles were obtained, read and checked against the above inclusion and exclusion criteria. See Figure 1.

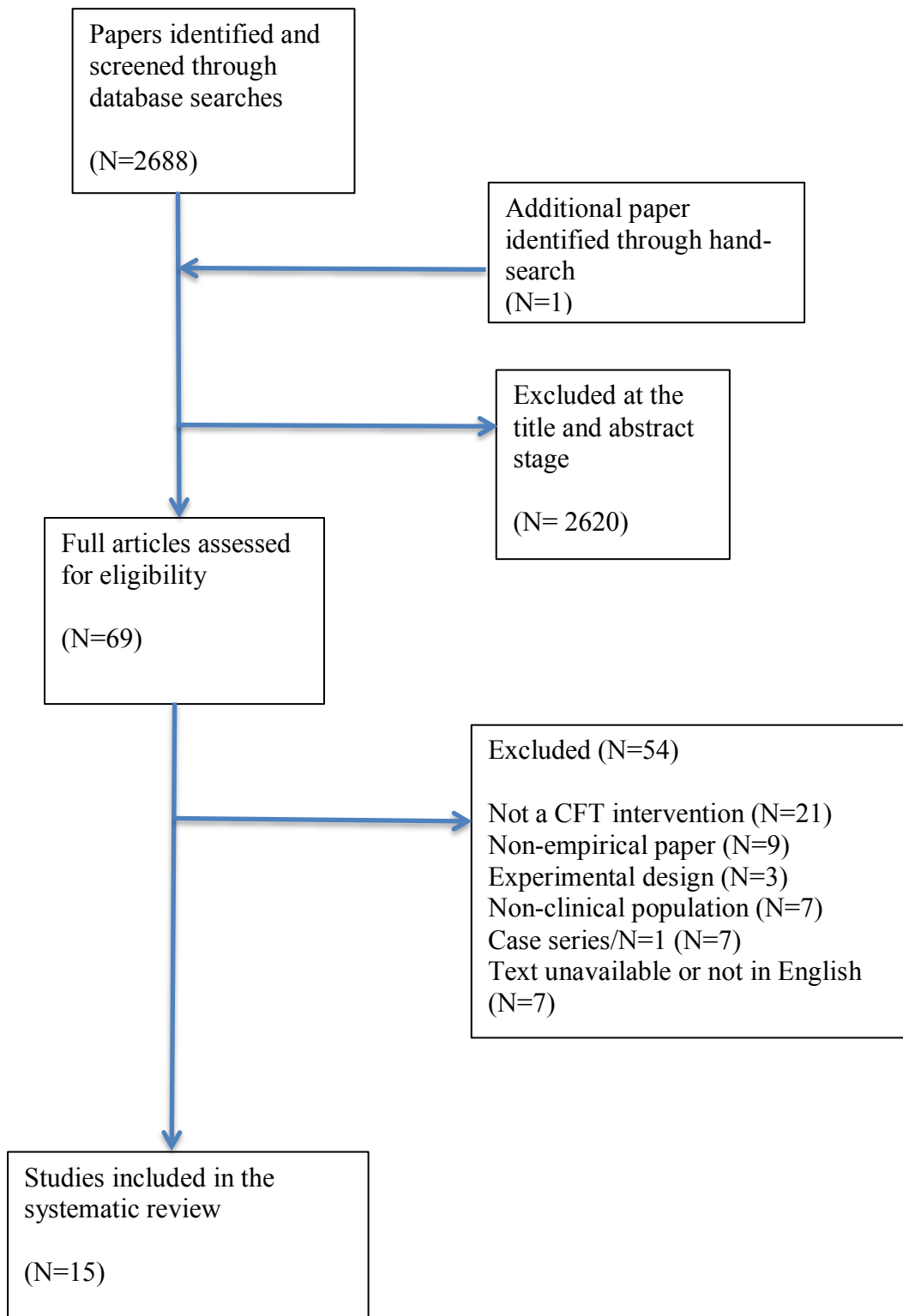
Method of Synthesis

The findings of the papers will be brought together through a narrative synthesis.

Quality Assessment

In order to assess the quality of and risk of bias in the studies a methodological quality checklist was completed for each study (Downs & Black, 1998). The tool contains 27 items, 26 of which are scored either 'yes' or 'no' (and given a score of one or zero, respectively), and item 27 is given a score out of five. The tool covers core domains such as reporting of findings (10 items), external validity (three items), study bias (seven items), confounding and selection bias (six items), and power (one item). Quality checks were conducted separately by two reviewers and inter-rater reliability (percentage agreement) was 83%; any score disagreements were resolved through discussion. For ease of comparison the papers were given an overall percentage score, as well as a percentage score for each subscale outlined above.

Figure 1. Flow diagram of study selection



Results

Table 1 summarises the findings of the electronic database search. Fifteen studies were identified. They varied somewhat in the nature, duration and method of delivery of CFT, for example brief self-help interventions were included, as well as drop-in groups. Of the total studies retrieved four were RCTs, one was a non-RCT, and ten were observational studies. Methodological quality scores ranged from 34 to 72%. The results of the search will be outlined in order of quality of methodological design and outcomes discussed in light of their quality ratings, followed by an outline of how the nature and dose of CFT impacts upon outcome.

Table 1. Summary description of included studies

Study	Design	N	Population	Treatment				Outcome Measures	Main Outcomes	Study Quality
				Intervention	Control	Setting	Sessions			
Feliu-Soler et al. (2016) Spain	Randomized pilot trial	N=32	Borderline Personality Disorder	10 week mindfulness intervention 3 week 'Loving-Kindness and Compassion Meditation intervention (based on CFT, MSC and Mindfulness)	10 week mindfulness intervention 3 week Mindfulness Continuation Training	Group	Once a week over 3 weeks * (excluding mindfulness intervention received by both groups)	DIB-R, BSL-23, SCS, FSCRS, PHLMS	Significant reduction of borderline symptom severity in compassion group Significant increase in self-compassion compared to controls Significant reduction in self-hatred/criticism in both groups Acceptance was significantly greater in compassion group	56%
Kelly & Carter (2015) US	RCT	N=41	Binge eating disorder	Self-compassion self-help	Behavioural self-help Waitlist control	Self-help workbooks	Introductory video PowerPoint * Self-help over 3 weeks	BMI, EDE-Q, Binge eating frequency, SCS, CES-D, FCS, CEQ, HRS	Both interventions reduced mean weekly binge days Self-compassion reduced ED pathology and weight and eating concerns more than the behaviour and control condition	63%
Noorbala et al. (2013) Iran	RCT	N=19	Depression	Group CMT	Waitlist control	Group	12 two hour sessions twice weekly	BDI-II, AS, LSCS	Non-significant reductions in depression, anxiety and self-criticism. Significant reductions in depression and anxiety at follow up	75%

Braehler, Gumley et al. (2013) UK	Feasibility RCT	N=40	Adults with psychosis (community and inpatient)	CFT + TAU Based on CFT for psychosis protocol	TAU: Community Psychiatric treatment (except 1 ppt) included psychotropic medication, contact with psychiatrist and/or CPN, OT, and day centre support	Group	16 sessions (2 hours once a week) over 5 months	Narrative Recovery Style Scale CGI-I, BDI-II, PANAS, FORSE, PBIQ-R	Feasible and safe to deliver in NHS community setting 18% attrition Compared to TAU significant increase in self-compassion Reduced depression Greater observed clinical improvement	78%
Beaumont et al. (2012) UK	Non-RCT	N=32	Trauma	CBT + CMT	CBT	Individual	Up to 12 sessions over 12 weeks *	HADs, IES-R, SCS-SF	Significant reduction in depression, anxiety, avoidance, intrusions and hyper-arousal in both groups. Significant improvements in depression and avoidance in the CBT + CMT group. Significantly increased self-compassion in the CBT + CMT group.	50%
Graser et al. (2016) Germany	Observational	N=11	Chronic depression	Group Mindfulness and CFT	None	Group	12 weekly 100-minute sessions	HRSD, CIPS, PSR-CD, BDI-II, ASQ, RSQ-D, MAAS, SCS, CLS, RSES	Group was acceptable. Significant reduction in depression Reliable change in depression for 5 participants	53%

Bartels-Velthuis et al. (2016)	Observational	N=62	Psychiatric outpatients	CFT Group	None	Group	9 2.5 hour sessions over 9 weeks	BDI-II, GAD-7, FFMQ, SCS	Significant reduction in depression Significant increase in mindfulness and self-compassion	59%
Netherlands										
Ashworth et al. (2015)	Observational	N=12	Acquired brain injury	CFT group (4 days)	None	Individual & group	Up to 22 sessions over 18 weeks *	HADS, FSCRS	Significant reductions in depression and anxiety post intervention and follow-up	44%
UK										
Gale et al. (2014)	Observational	N=139	Eating disorders	Two Step Treatment Programme 1. Psychoeducation on eating disorders 2. Recovery Programme (integrated CBT & CFT)	None	Group	1. 4 2-hour sessions over 4 weeks 2. 20 2.5-hour sessions over 16 weeks total of 20 weeks	EDE-Q, SEDS, CORE	Significant improvements across all measures Bulimia improved most (77% 'recovered' or 'improved') 33% of anorexia 'recovered' or 'improved'	66%
UK										
Heriot-Maitland et al. (2014)	Observational	N=57	Acute inpatient	'Open' CFT group	None	Group	60 minute drop-in session covering a 6 month period	Likert scales: level of distress and calmness at beginning and end of session Understanding and perceived helpfulness	Significant reduction in post-session distress Significant increase in calmness Attrition rate 34% across each session Sessions rated as understandable and very helpful	34%
UK										

Lucre & Corten (2013) UK	Observational	N=8	Personality Disorder	CFT group	None	Group	16 weekly sessions *	SocialCS, SBS, OAS, FSCRS, DASS21, CORE	Significant reduction in depression, shame and self-hatred Significant increase in self-reassurance Significant reduction in risk to self and/or others At one year follow up CORE scores reduced to sub-clinical levels	50%
Judge et al. (2012) UK	Observational	N = 42	Patients open to a community mental health team	CFT Group	None	Group	2 hour weekly sessions for 12-14 weeks	BDI, BAI, FSCRS, ISS, OAS, SocialCS, SBS, Weekly Diary Measuring Self-Attacking and Self Soothing	Significant improvements in depression and anxiety Significant reductions in shame	41%
Laithwaite et al. (2009) UK	Observational	N=19	Forensic, male, psychosis – maximum secure unit	CMT for psychosis	None	Group	20 sessions over 10 weeks *	Social CS, OAS, SCS, BDI-II, RSES, SIP-AD, PANSS	Significant improvements in depression, self-esteem, psychopathology, shame, and social comparison at post-treatment and follow-up	56%
Gilbert & Proctor (2006) UK	Observational	N=9	Severe, chronic, and complex mental health problems	Group CFT	None	Group	12 two-hour sessions over 12 weeks	HADS, FSCS, FSCRS, socialCS, diary measuring self-attacking	Significant reduction in anxiety and depression	53%

								and self-soothing, OAS, SBS		
Gilbert & Irons (2004)	Observational	N=8	Individuals from a self-help depression group who regarded themselves as self-critical	Group CFT	None	Group	4 1-hour sessions over 7 weeks (initial 3 week consecutive sessions and 4 week follow up)	HADs Diary and quantitative ratings of self-criticism and self-soothing	Significant increase in self-soothing and compassion	53%
UK										

Key:

ASQ: Affective Style Questionnaire; AS: Anxiety Scale; BDI: Beck Depression Inventory; BAI: Beck Anxiety Inventory; BSL-23: Borderline Symptom List-23; CES-D: Center for Epidemiological Studies for Depression; CFT: Compassion focused therapy; CMT: Compassionate Mind Training; CORE: The Clinical Outcomes in Routine Evaluation; CGI-I: Clinical Global Impression Improvement Scale; CIPS: Collegium Internationale Psychiatriae Scalarum; CLS: Compassionate Love Scale; DASS21: Depression and Anxiety Stress Scale; DIB-R: Diagnostic Interview for Borderlines Revised; EDE-Q: The Eating Disorder Examination questionnaire; FORSE: Fear of Recurrence Scale; FFMQ: Five Facet Mindfulness Questionnaire; FSCRS: Forms of Self-Criticism/Self-Attacking and Self-Reassuring Scale; GHQ: General Health Questionnaire; HRSD: Hamilton Rating Scale for Depression; HRS: Homework Rating Scale; HADS: Hospital Anxiety and Depression Scale; IES-R: Impact of Events Scale Revised; ISS: Internalized Shame Scale; LSCS: Levels of Self-Criticism Scale; MAAS: Mindful Attention and Awareness Scale; OAS: Other as Shamer Scale; PBIQ-R: Personal Beliefs about illness Questionnaire Revised; PANAS: The Positive and Negative Affect Scale; PANSS: The Positive and Negative Syndrome Scale; PHLMS: Philadelphia Mindfulness Scale; PSR-CD: Psychiatric Status Ratings for Chronic Depression; RSQ-D: Response Styles Questionnaire; RSES: Rosenberg Self-Esteem Scale; SCS: Self-Compassion Scale; SCS-SF: Self-Compassion Scale Short Form; SIP-AD: The Self-Image Profile for Adults; SBS: Submissive Behavior Scale; SocialCS: Social Comparison Scale; SEDS: The Stirling Eating Disorder Scale

* Session length not reported in original paper

Summary of RCTs

Four RCTs were identified in the search, with the populations: borderline personality disorder (BPD), binge eating disorder (BED), depression and psychosis. Three of the RCTs were group-based and the other a brief self-help intervention (for BED). Quality ratings of their methodological rigour ranged from 56 to 78%, which, as expected with the RCT design, were amongst the highest ratings across the studies.

The CFT interventions varied in nature, content, intensity, and clinician involvement, and varied in duration from three weeks (self-help), three once weekly sessions, 12 twice-weekly sessions, to 16 weekly sessions. The briefest and least clinician intensive was Kelly and Carter's (2015) three-week self-help intervention, which involved participants viewing PowerPoint slides outlining the rationale for the intervention, and encouraging participants to respond compassionately towards themselves when they had the urge to binge. Compassionate imagery, self-talk and letter writing were key aspects in the self-help intervention. This was compared against a behavioural self-help intervention and waitlist control. Both active interventions reduced weekly binge days more than the control condition. The compassion intervention also reduced eating disorder symptomatology and increased self-compassion, significantly more so than the other conditions. However, the study's quality was rated at only 63%; it had acceptable reporting of data (80%) and of internal validity (bias: 57%, confounding: 83%), yet it had a low external validity score (0%). Small to medium effect sizes were reported.

Feliu-Soler et al.'s (2016) three-week group intervention was also brief, however it followed a 10-week mindfulness intervention. The group was led by two clinical psychologists and covered psychoeducation on compassion (its evolutionary

roots, differentiating from self-indulgence, the three emotion-regulation systems); and loving kindness meditations (LKM) and compassion meditations (CM) were practiced during the sessions, as were techniques and practices from Gilbert's (2010b) CFT, and Neff and Germer's (Germer, 2009; Neff, 2011) mindful self-compassion programme. In comparison to the participants who continued the mindfulness programme, those who attended the compassion intervention saw a significant reduction in BPD symptomatology and self-criticism, with an increase in self-kindness and acceptance of the present moment. The study's quality rating, however, was the lowest of all the RCTs, with a score of 56%. Its reporting of aims and data were well documented (score of 90%), however it did not meet any of the criteria for external validity (score of 0%), nor did the authors state whether their study had sufficient power to detect the effects they claimed. Internal validity was however similar to Kelly and Carter's (2015) study, with scores of 71% on study bias, and 67% on confounding and selection bias. Its main limitations in these areas were a lack of blinding of participants and those conducting outcomes measures.

Noorbala, Borjali, Ahmadian-Attari and Noorbala's (2013) group was more clinician and time-intensive than the above two studies, with a total of 24 hours over 6 weeks. Their intervention was based upon Gilbert's (2005) 'Manual of Compassionate Mind Training', covering the treatment rationale, psychoeducation on self-criticism, compassion and self-compassion. Techniques covered included soothing rhythm breathing, mindfulness, compassionate imagery, and compassionate letter writing. Compared to their wait-list control they found significant reductions in depression and anxiety at two-month follow-up, but only non-significant reductions were found at post-treatment. Noorbala et al.'s (2013) quality rating of 72% was the second highest among all of the studies. It was the only study that included a full

power calculation to validate their findings, which reported an 81-83% power of their test. The RCT was conducted in a clinical setting, giving the paper a 33% score of external validity. Confounding and selection bias were minimised, which overall gave the study 83% for internal validity. Similarly to the other studies participants and assessor were not blinded to conditions.

Braehler, Gumley et al. (2013) had the greatest intensity of time and clinician involvement, covering a total of 32 hours over a period of 16 weeks and was run by two clinical psychologists. This study trialled the group CFT for psychosis manual (Braehler, Harper & Gilbert, 2013). In comparison to their TAU group CFT saw an overall clinical improvement, with reduced depression and negative beliefs about psychosis, fear of relapse and social marginalisation, with increased self-compassion. The study quality was rated at 78%, the highest score of all the studies. Reporting was comprehensive (with a score of 100%), external validity was the highest among the RCTs (with a score of 67%), and internal validity was also high (with score of study bias at 71% and confounders 83%). Nonetheless, the authors did not adequately power the study as its aim was to determine feasibility, but they did report small to moderate effect sizes.

All studies but one (Noorbala et al., 2013, who used wait-list control) compared the CFT to an active treatment: continuation of mindfulness, behavioural self-help and TAU. All RCTs found significant changes or trends in primary outcomes: importantly, not only did participants' levels of self-compassion increase across the studies, symptoms of psychopathology decreased in all clinical groups, which was not seen in the control groups. An exception to this was Noorbala's depressed sample; only a non-significant reduction in self-criticism and symptoms of

depression and anxiety post-intervention were seen. Significant reductions in depression and anxiety were however found at follow up.

Summary of Non-RCTs

One study utilised a control group but did not randomise the sample. Beaumont, Galpin and Jenkins (2012) recruited individuals who had experienced trauma, and were assigned to receive 12 weekly individual sessions of either Cognitive Behavioural Therapy (CBT) or CBT with CMT. The CBT and CMT group received standard trauma-focused CBT plus compassionate imagery, letter writing and grounding techniques. Both groups saw an improvement in clinical symptoms (anxiety, depression, avoidance behaviour, intrusive thoughts and hyper-arousal) and an increase in self-compassion, however the CBT plus CMT group saw a statistically greater increase in compassion, and a non-significant trend in greater symptom reduction. As the study did not randomise their sample to the interventions and no power calculation was considered the overall study quality was rated at 50%.

Summary of Observational Studies

Ten observational studies with no control arm were identified in the search. A variety of populations were recruited: depression, acquired brain injury, eating disorders, psychiatric inpatient, personality disorder, severe and enduring mental health problems and forensic. All but one study delivered the intervention as part of a group. Ashworth, Clarke, Jones, Jennings and Longworth (2015) delivered a combination of group and individual sessions of CFT. The studies varied in duration of the CFT groups, ranging from one-off sessions on an acute psychiatric ward (Heriot-Maitland, Vidal, Ball & Irons, 2014) to up to 20 twice-weekly sessions (Laithwaite et al., 2009) in a forensic setting. Quality ratings varied from 34 to 66%, typically due to no randomisation processes or comparators, participants being

unrepresentative of the typical clinical population from which the sample was drawn from, and, for some, a lack of clarity over compliance to the intervention and incomplete reporting of data.

Eight of the 10 studies found significant improvements in measures of psychopathology (including depression, anxiety, and bulimia nervosa), and three reported that the gains had been maintained at follow up (Lucre & Corten 2013; Ashworth et al., 2015; Laithwaite et al., 2009). The Lucre and Corten (2013) study delivered the intervention to individuals with a diagnosis of personality disorder. They found that as well as significant reductions in depression scores, they also saw reductions in shame and self-hatred, and of risk to self and others. Participants saw a significant increase in self-reassurance, and at one year follow up scores on the CORE remained at the sub-clinical threshold. The study rating was given 50%, which is an average rating among the observational designs. Its strengths lie in its reporting, follow-up data, and low drop out rate.

Ashworth et al. (2015) reported large effect sizes for reductions in anxiety, depression, and self-criticism in their ABI sample who attended a four-day CFT group with up to 18 individual sessions. A 44% quality rating was given to the study, having strength in its reporting and follow up data and recruitment within one population, but there was a lack of data on percentage recruited and over what time period.

Three studies evaluated CFT groups for those with severe and enduring mental health problems. Bartels-Velthuis et al. (2016) found moderate effect sizes in reduced depression and increased mindfulness, and a large effect size for increased self-compassion in their psychiatric outpatient sample who attended their nine-week CFT group. This study had the second-highest quality review score amongst

observational designs with 59%. Its high score came from their discussion of effect sizes and power of their sample to detect an effect, as well as comprehensive reporting of study information. Judge, Cleghorn, McEwan and Gilbert (2012) evaluated 12-14 week group CFT in a similar population (CMHT), and also found significant reductions in depression and anxiety post-treatment. However this study had the second-lowest quality rating of all papers, predominately due to incomplete reporting of study information. Gilbert and Proctor (2006) delivered a 12-week CFT group to those attending a mental health day centre and found significant reductions in depression, anxiety, shame and self-criticism. The study was rated at 53% in its quality, with acceptable reporting, some external validity (score of 33%), and consideration of confounding variables (score of 50%). As this was designed as a pre-trial no effect sizes were calculated.

Graser, Höfling, Weßlau, Mendes and Stangier's (2016) 12-week compassion group for individuals with chronic depression found a medium effect of reduced depression at post-treatment, and a large effect at a three-month follow up. The study quality score was in the average range for the observational studies at 53%. Its low score is accounted for with low external validity, recruitment of participants from varying populations, and a lack of discussion of possible confounders.

Significant improvements in depression, self-esteem, psychopathology, shame, and social comparison were found in Laithwaite et al.'s (2009) forensic sample who attended 20 sessions over 10 weeks, with gains maintained at six week follow up. Study quality was also 56% and although no power calculation was reported, small effect sizes were found. Gale, Gilbert, Read and Goss (2014) found high recovery rates in those with bulimia nervosa in their two-step treatment programme (which incorporated psychoeducation on eating and combined CBT &

CFT, the latter consisting of 20 sessions over 16 weeks), with 77% rated as ‘recovered’ or ‘much improved’. This is compared to only 33% of those with anorexia nervosa. This study had the highest quality ratings among the observational designs, at 66%. It scored 100% on external validity, however only achieved 33% on confounding and selection bias, due to recruiting participants over varying time periods.

Two of the observational studies did not report measures of mental health difficulties, however both found changes following CFT: Heriot-Maitland et al. (2014) found a reduction in post-session distress ratings in a psychiatric inpatient sample and an increase in calmness (after one session); Gilbert and Irons (2004) found an overall significant increase in self-soothing and compassion in their depression self-help group sample after only four hours of intervention over seven weeks. However, Heriot-Maitland et al. (2014) had the lowest quality rating (34%). This is due to obtaining a low score on reporting (50%) as estimates of variability and descriptions of participants (both those who completed and those who did not) were not fully described. Otherwise, external and internal validity were comparable to the other observational designs. Gilbert and Irons (2004) obtained a 53% quality score, with acceptable external validity and a low drop-out rate.

Nature and Dose of CFT Intervention

All of the published studies identified showed a real variation in intensity and duration of CFT. Importantly, all but three of the studies delivered the CFT solely as part of a group. As all of the studies found positive effects on outcomes it appears that group CFT is likely to have beneficial effects on mood across varying clinical populations. Two of the RCTs (Noorbala et al., 2013; Braehler, Gumley et al., 2013), which had the strongest quality ratings, found favourable results in comparison to

waitlist control and TAU, the findings of which have been confirmed in evaluation of similar groups in clinical settings (i.e. Bartels-Velthuis et al., 2016; Gilbert & Proctor, 2006; Laithwait et al., 2009).

Two studies evaluated individual CFT: Beaumont et al. (2012) compared one-to-one CBT with one-to-one CBT plus CFT, and Ashworth et al. (2015) evaluated a four day group plus up to 18 sessions of individual CFT. The findings show individual integrated CBT and CFT is as effective as stand-alone CBT for trauma, with some indication of greater improvement in self-compassion and symptoms of trauma. There were also large effect sizes in Ashworth et al.'s (2015) ABI sample. This indicates CFT may be feasible to deliver on an individual basis, with some indication that it could be as or more effective than group CFT. However it is difficult to draw firm conclusions based on two studies that had average quality ratings (44 and 50%), one of which also delivered initial group CFT.

Findings from one trial (Kelly & Carter, 2015) suggest that CFT may be feasible and effective to deliver via self-help in binge eating populations, yet further higher-powered research in clinical settings is warranted to evaluate its generalisability.

The dose of CFT ranged from two hours of clinician time (Kelly & Carter, 2015), to up to 50 hours in Gale et al. (2014), however the latter delivered combined CBT and CFT. Four of the studies delivered CFT in less than six hours, and all found positive effects on outcome variables. However, fewer significant findings were found in these studies, indicating a CFT dose of less than six hours may lead to some change but it may be insufficient to result in clinically significant and reliable change that is maintained over time.

Six studies delivered 12-24 hours of CFT and saw significant changes in depression, anxiety, self-compassion, shame and self-criticism. Half saw these changes maintained at follow up. The remaining five studies delivered between 27 and 50 hours of CFT and saw similar significant changes as those delivered in fewer hours. The strongest effect sizes were found among the studies providing between 20 and 50 hours.

Similarly, impressive findings were reported in the observational studies in complex populations, i.e. personality disorder (Lucre & Corten 2013), forensic (Laithwaite et al., 2009), and bulimia nervosa (Gale et al., 2014), with gains often maintained at follow up. These findings are noteworthy in populations that are typically challenging to treat. However, less promising recovery rates were found in anorexia nervosa (Gale et al., 2014).

Acceptability of CFT

Attrition. Drop out rates across the studies ranges from low (5%) to medium (34%). Those with the lowest number of completers were populations with severe and complex mental health problems: Heriot-Maitland et al. (2014) found that only 66% of patients on a psychiatric ward remained for the majority of one session, and Gilbert and Proctor (2006) found only 67% of patients attending a day centre (with long-term and severe mental health problems) completed their 12-week group. However, this differs from Laithwaite and colleagues (2009), and Braehler, Gumley et al. (2013): the former found that 18 out of 19 males on a maximum secure unit completed the 20-session group over 10 weeks and the latter found that 82% of their community psychosis sample completed the 16-session group. Of those who did drop out in the Braehler, Gumley et al. (2013) sample, all did so within the first four sessions.

Judge et al. (2012) regarded ‘completers’ as those who had attended eight or more sessions (out of 12-14), which equated to 86% of their CMHT sample. Only six of 41 of Kelly and Carter’s BED sample dropped out across all self-help interventions, yet four of these were from the self-compassion intervention (compared to one in the behavioural intervention and one in waitlist control).

Acceptability and compliance. Several studies measured levels of acceptability of CFT and compliance with the intervention. Graser et al. (2016) reported that the completers in their chronic depression sample reported ‘overall satisfaction’ with the programme, as measured on a 1-7 likert scale (not at all helpful to very helpful), with a mean score of 5.6. They measured various practices in terms of helpfulness (covering compassionate body scan, breathing compassion in and out, mindful awareness, psychoeducation, discussion of challenges etc.), with an average rating of 3.6 out of 5 (not at all helpful to very helpful). Compliance was measured by self-reported minutes of home practice, which ranged from 55 minutes over the 12-week programme to 2145 minutes (with a suggested home practice of 1980 minutes, equating to 30 minutes practice of six days out of seven).

With regards to acceptability, Heriot-Maitland et al. (2014) noted that the session with greatest attendance was the imagery session, and lowest were the psychoeducation and mindfulness sessions. The majority of those who completed a session rated the material as ‘understandable’ (mean rating of 5.1 of 6), and the sessions as ‘very’ or ‘extremely’ helpful, with a mean score of 5 of 6. Although helpfulness ratings were highest for the compassion and imagery sessions these were not significant.

Kelly and Carter (2015) found no statistical differences in perceived credibility and expectation of effectiveness of the self-compassion and behavioural

self-help interventions. Self-reported compliance ratings between interventions did also not differ, and were rated as ‘high’ overall.

Discussion

The aim of the current study was to evaluate the effectiveness and acceptability of CFT as a psychological intervention for clinical populations. It was hoped that updating the previous review (Leaviss & Uttley, 2015) would provide a greater understanding of CFT’s developing evidence-base as well as providing further recommendations for future trials. Since Leaviss and Uttley’s (2015) search a further three RCTs of CFT in clinical populations had been published and a further four observational trials were identified. This illustrates the growing interest of CFT as a psychological intervention across varying populations.

The RCTs indicate that CFT is more effective than receiving no treatment in chronic depression (Noorbala et al., 2013), and TAU for those with psychosis (Braehler, Gumley et al., 2013). Both Feliu-Soler et al. (2016) and Kelly and Carter (2015) found significantly greater reductions in psychopathology in their brief compassion interventions compared to other active treatments (mindfulness and behavioural self-help). These findings indicate that even brief and self-help compassion interventions show promise in complex clinical populations (personality disorder and BED), which would usually receive support in tertiary care in the NHS.

As CBT is the current treatment of choice for most psychological ailments due to its sizeable evidence-base (Hofman, Asnaani, Vonk, Sawyer & Fang, 2012) it is important that CFT is directly compared with CBT in order to determine if it is as equally, less, or more effective for particular psychological difficulties. Beaumont et al. (2012) found that combined CBT and CFT led to significantly greater self-

compassion and non-significant reduction in trauma symptoms compared to stand alone trauma-focused CBT. However, their sample was not randomised and the study quality rated at 50%. This suggests that CFT may be a useful adjunct to already well-established psychological therapies within the NHS, however this would need to be tested with a randomised design before firm conclusions can be made.

CFT was initially designed for shame-based difficulties (Gilbert, 2014) that are commonly found among those with complex mental health problems, which may explain the intervention's popularity among psychologists as it enables a transdiagnostic approach. Indeed the review found its application across an array of severe and complex mental health difficulties. It is not the remit of this review to determine CFT's effectiveness for particular mental health problems, however the review demonstrates that there were positive effects in ABI, borderline personality disorder, binge eating disorder, chronic depression, trauma, psychosis (acute and chronic), forensic, and eating disorders.

Acceptability

Leaviss and Uttley (2015) stated in their review that CFT was more acceptable among clinical populations than in non-clinical samples; the current review evaluates clinical populations only, and found similar levels of acceptability in this sample. Premature drop out of therapy is a common occurrence: a meta-analysis indicated that therapists report that 40% of clients drop out of therapy prematurely (Swift & Greenberg, 2012), ranging from 30-60% attrition across populations, settings, and modalities (Roseborough, McLeod & Wright, 2015). The studies in the current review found that attrition ranged from 5 to 34%, which appears lower than the average drop-out rates in clinical settings. This may link to the finding of an overall satisfaction with the approach.

Study Quality

Overall the sample sizes lacked power to determine an effect and studies often showed a selection bias due to a lack of a control group and/or no randomisation. There was also a lack of consideration of implementation fidelity; information was lacking with regards to who delivered the therapy, what training they had received, to what extent they were supervised and by whom, and whether there was any measurement of delivering the intervention as intended.

The National Institute of Clinical Evidence (NICE) outline a clear hierarchy with regards to evaluating clinical effectiveness of interventions (NICE, 2004), and RCTs are at the top of this hierarchy. They are considered to have the highest external and internal validity, and minimise bias, allowing a causal inference between the therapy delivered and measured outcomes (McLeod, 2010). Even though four RCTs were identified in the review, only one documented that it had sufficient power to detect an effect (Noorbala et al., 2013); only a further six reported effect sizes. There were also concerns over bias (lack of single and double blinding), and external validity (specifically recruitment bias).

The observational studies were typically conducted in NHS sites with more representative populations not normally seen in RCTs. Although they are limited in their ability to directly infer effectiveness of the intervention, smaller case series and observational studies do allow researchers and clinicians to evaluate the process of therapy, and, for example, identify factors associated with ‘good’ and ‘bad’ outcomes (McLeod, 2010). RCTs are also unable to ascertain how a psychological therapy is effective and why this may be so (Gilroy, 2006), which, with a reasonably novel intervention as CFT, such an understanding is pertinent before larger-scale trials are funded.

Limitations

It is clear from this review that there is a lack of agreement as to what constitutes CFT. The studies utilised a significant range of duration, intensity, content and clinical involvement, resulting in a lack of parity across the comparisons. In addition, a lack of follow up data across the studies leaves unanswered questions with regards to lasting change. It also raises the question as to whether developing self-compassion requires time and practice. For example Noorbala et al. (2013) found non-significant reductions in depression and anxiety post-intervention, however significant reductions at follow up.

All but three of the identified studies evaluated the effectiveness of CFT were delivered as part of a group, which makes it difficult to draw any conclusions on the usefulness and acceptability of individual CFT at this point. However the studies evaluating individual CFT did report promising findings. The ‘common humanity’ (Neff, 2003, 2011) component of developing compassion suggests receiving CFT as part of a group could be more powerful than individual therapy, however this limits the capacity for individual meaning-making (i.e. clinical formulation) between therapist and client, and the tailoring to the individual’s needs. As psychological therapy is typically delivered on a one-to-one basis and recommended for a number of common mental health problems (Hofman et al., 2012) in this format, it is essential that individual CFT is also evaluated in order to determine whether it is comparable to CBT (or any other psychological therapy).

As 11 of the 15 studies identified did not compare CFT to an alternative psychological therapy it is important to consider that the apparent effectiveness may be attributable to a ‘psychological intervention’ rather than CFT per se. These CFT only intervention studies add valuable information to the field, especially with

regards to early feasibility and clinical applicability, yet they provide limited information with regards to the isolated impact of CFT itself. In order for CFT to be considered for any evidence-based national guideline (i.e. NICE) further RCTs need to be funded in order to compare its effectiveness and acceptability against bona fide, evidence-based therapies.

The findings on low attrition, acceptable compliance and participant satisfaction with CFT must be considered in light of the recruitment process whereby participants were self-selected, and often only data of those who completed were included in the studies. It would be valuable to understand reasons why individuals decided not receive a course of CFT, and for those that did start why they did not complete the intervention. This would enable clinicians and researchers alike to tailor CFT to the particular populations with which they are working with.

Implications for Research

Although the current review found a further three RCTs there is a need for high-quality trials with larger sample sizes and robust power evaluating CFT against current evidence-based treatments before it can be confidently recommended or offered as a standard treatment option. The review revealed a considerable lack of effectiveness studies for individual CFT, highlighting a need for further trials evaluating CFT as an individual therapy before there can be any certainty that it is as effective when delivered as part of a group. Further research also needs to focus upon the longer term impact of the therapy in order to ascertain as to whether or not CFT interventions leads to lasting change.

Greater in-depth exploration into the acceptability of CFT is also warranted. The findings illustrate that those who agree to try CFT find it generally acceptable and helpful, but less is known around what might deter individuals from the therapy

and lead to premature drop out for those who do begin. Such information would enable clinicians to tailor the intervention to fit the needs of the particular client group in question in order to facilitate greater psychotherapeutic change.

Implications for Practice

Emerging evidence suggests that CFT has positive effects on individuals with a range of mental health problems, and is very likely to be more effective than no psychological treatment, and possibly as or more effective as other psychological therapies. Not only does CFT appear to increase self-compassion, but it also seems to lead to a reduction of mental health symptomatology, even among difficult to treat populations such as forensic and personality disorder. Group CFT currently has significantly more effectiveness evidence than individual and self-help interventions.

With regards to dose of CFT the findings indicate that at least 12 sessions of CFT are required to significantly reduce clinical symptomatology across populations. Briefer interventions may result in some change however at present there is insufficient evidence to suggest that it would be clinically meaningful nor maintained. In more complex and severe populations (such as personality disorder, psychosis, and eating disorders) a higher dose may be warranted, however the current findings indicate there is little evidence to suggest a greater impact when offering over 24 hours of CFT.

Conclusions

CFT is increasing in popularity among psychologists as an alternative therapy for those who do not respond or who decline CBT. This review found evidence that CFT is likely to be more effective than no treatment in clinical populations, and suggests that group CFT might be more effective than other psychological

interventions. CFT shows promise in conditions with underlying shame and self-criticism, with promising results across severe and complex mental health problems.

It is possible that brief CFT may reduce mental health symptoms and increase self-compassion, however there is some evidence that at least 12 hours is required for significant and longer-lasting change.

Currently there is insufficient research evidence to determine whether CFT is feasible and effective to deliver as an individual therapy. Before any conclusions can be made there is a need for both feasibility studies and large-scale trials evaluating individual CFT across populations.

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Part Two: Empirical Paper

Compassion Focused Therapy for People with Dementia: A Feasibility Study

Abstract

Aims: The project firstly aimed to develop a therapeutic intervention based on Compassion Focused Therapy (CFT) for people with dementia who were suffering with depression and/or anxiety. The second aim was to assess the feasibility, acceptability, and utility of the intervention within this population.

Methods: A CFT for dementia intervention was developed from evaluating relevant literature, followed by a consultation process with people with dementia, carers and psychologists. A multiple case-series of seven people with dementia was used to assess the intervention's feasibility, and effectiveness on outcomes of self-compassion, mood, anxiety and quality of life. Data were analysed using reliable change and clinically significant change. Thematic analysis on post-therapy interviews and session rating forms was used to assess acceptability and change as a result of the intervention.

Results: Over the course of the intervention, improvements in self-compassion, mood and anxiety were seen. Six participants with dementia were able to engage in soothing rhythm breathing, and five were able to engage in discussion of self-criticism and developing self-compassion. Overall the intervention was experienced as helpful, and several participants and their carers described increased self-compassion in response to cognitive decline.

Conclusions: CFT can be adapted to be delivered to people with dementia who are suffering from low mood, anxiety or other associated distress. The intervention may improve self-compassion, mood, and anxiety. A larger pilot trial with a comparator group is needed to evaluate the intervention's effectiveness for people with dementia.

Introduction

Background

By 2025 it is predicted that there will be over one million people living with dementia in the UK (Alzheimer's Society, 2014). At present one in 14 people over the age of 65 have dementia in the UK, with 40,000 people having early onset dementia under the age of 65. Dementia has a significant impact on the economy and services, costing the NHS £4.3 billion per year and social care £10.3 billion. The financial impact on the individual and their carers is also high: the cost of paid and unpaid care is considered to amount to £5.8 billion (Alzheimer's Society, 2014).

It is estimated that between six and 87% of people with dementia develop depression (Amore, Tagariello, Laterza & Savoia, 2007; Enache, Winblad, & Aarsland, 2011; Muliya & Varghese, 2010), which has been found to be more commonly experienced in the earlier stages of the disease (Lopez et al., 2003). This may be connected with the awareness of cognitive decline and the meaning of this for the person and their life. Anxiety symptoms are also common, and although difficult to define and conceptualise, prevalence rates have been estimated between 38 and 72% (Badrakalimuthu & Tarbuck, 2012).

The care of people with dementia has focused upon its biomedical conceptualisation as a 'brain disease', which is treated with medication to slow cognitive decline in cases of Alzheimer's Disease. Developments in the psychosocial treatments of dementia have made significant contributions as alternatives and adjuncts to drug therapy, such as Cognitive Stimulation Therapy (Spector et al., 2003), and cognitive rehabilitation (Clare & Woods, 2004). There is a body of literature detailing the emotional impact and the meaning of being diagnosed with dementia (e.g. Aminzadeh, Byszewski, Molnar, & Eisner, 2007; Husband, 1999;

Pearce, Clare, & Pistrang, 2002; Robinson, Clare, & Evans, 2005), yet couples have reported a lack of emotional and psychological support following a diagnosis (e.g. Robinson, Clare, & Evans, 2005).

Psychological Therapy in Dementia

There have been some promising developments in the field of psychological interventions for people with dementia, such as adapted cognitive behaviour therapy (CBT), which has found to be feasible and effective for those with anxiety (Spector et al., 2014). The feasibility and usefulness of third-wave interventions, specifically mindfulness for dementia, are also beginning to be evaluated (Leader et al., 2013; Paller et al., 2015).

The Cochrane Review on the psychological treatments for depression and anxiety in dementia and mild cognitive impairment (Orgeta, Qazi, Spector & Orrell, 2014) reported positive findings (psychological interventions can reduce depression symptoms and have the potential to improve wellbeing), however the review concluded that there were only a small number of studies and considerable variation in the interventions and their delivery. It has been recommended that further well-designed studies, with clearly defined psychological approaches are needed. Hence there is a need to develop and rigorously evaluate interventions in order to establish an evidence-base before we can conclude what is effective for the treatment of depression and anxiety in this population.

Compassion & Ageing

Numerous studies have found links between successful ageing and the ability to be compassionate to oneself. Self-compassion is thought to consist of three components: noticing painful feelings in a non-judgemental way (mindfulness), acknowledging that suffering is part of the wider-human experience (common

humanity), and being kind to oneself rather than self-critical in the face of pain and suffering (self-kindness) (Neff, 2003). Those high in self-compassion in later life have been found to cope better with age-related processes (Allen & Leary, 2014), and to experience positive ageing and greater meaning in life (Phillips & Ferguson, 2013). In older adults who have poor physical health, self-compassion is associated with greater subjective wellbeing (Allen, Goldwasser & Leary, 2012). It appears there may also be a link between self-compassion and mood. Phillips and Ferguson (2013) found positive associations between self-compassion, positive affect, and psychological wellbeing in older adults. Such research indicates the potential benefit of encouraging aging adults to develop self-compassion as they navigate age-related processes.

Compassion Focused Therapy

Origins of CFT. Compassion Focused Therapy (CFT) has its origins in evolutionary and attachment theories and in Eastern traditions, and aims to build self-compassion in the face of self-criticism and shame (Gilbert, 2014). Within CFT compassion is defined as “a basic kindness, with a deep awareness of the suffering of oneself and of other living things, coupled with the wish and effort to relive it” Gilbert (2009, p. xiii).

CFT was developed by Paul Gilbert (2000) after noticing that a number of individuals receiving CBT saw little benefit. He noted that often such individuals rationally understood challenging their own thoughts and beliefs, but were left with little emotional change, for example still *feeling* like a failure, even though logically they knew this not to be true. Gilbert (2010a) observed that these individuals had a tendency to struggle generating kind and soothing internal self-talk, often as a result of early trauma or neglect. CFT therefore initially aimed to facilitate individuals who

did not respond to CBT to generate self-compassion and self-kindness through emotion-based processes rather than cognitive restructuring.

Gilbert (2014) drew upon a vast literature of evolutionary theory and neuroscientific evidence showing that self- and affect-regulation is greatly impacted by affiliative motives, emotions and processes (Cozolino, 2002; Depue & Morrone-Strupinsky, 2005; Panksepp, 2007). The CFT model was built upon these research findings and suggests that humans have three major motivational systems that ensure our survival as a species by avoiding harm and seeking out resources. First the ‘threat system’, which prioritises being on the look-out for, and reacting to danger in the environment (LeDoux, 1998), results in the fight/flight/freeze response (defending against danger, fleeing danger and becoming immobilised) and leads to emotions such as anxiety, anger and fear. Second the ‘drive system’ motivates striving and seeking out resources, and results in feelings of excitement and vitality. Third the ‘soothing system’ is rooted in early attachment experiences (Bell, 2001; Depue & Morrone-Strupinsky, 2005) and is associated with feeling calm, content and peaceful. This latter system is also perceived to play a role in facilitating engagement in close interpersonal relationships and the ability to soothe one another (Porges, 2007).

Gilbert (2000) argues that these three motivational systems contribute to the ‘tricky brain’ – which affords a mind in a constant battle attempting to regulate primitive urges and desires (i.e. for food, safety, procreation, pack mentality) and associated emotions (i.e. fear, lust, anger), with the neocortex (new brain) which can think about thinking, evaluate, plan, and analyse, as well as grapple with the social world of co-operation, social rank, giving and receiving care and nurturing (see Gilbert, 2014 for more detailed account on social mentality theory).

CFT therefore aims to balance the activation and interaction of these three systems, through regulating the threat system via greater activation of the soothing system, as well as engagement of the drive system.

CFT in clinical practice. CFT is a reasonably novel therapy with developing evidence for its effectiveness among clinical populations. Several randomised controlled trials have shown significant symptom reduction and an increase in compassion in people with a diagnosis of personality disorder (Feliu-Soler et al., 2016), depression (Noorbala, Borjali, Ahmadian-Attari & Noorbala, 2013), and psychosis (Braehler, Harper & Gilbert, 2013). Further observational studies without comparison groups provide further support for CFT's potential for reducing symptoms of psychological distress, for example in eating disorders (Gale, Gilbert, Read & Goss, 2014), trauma (Beaumont, Galpin & Jenkins, 2012), and severe and enduring mental health problems (Gilbert & Proctor, 2006; Judge, Cleghorn, McEwan & Gilbert, 2012).

Adaptations to CFT have been trialled for those with cognitive impairment following an acquired brain injury (ABI) (Ashworth, Clarke, Jones, Jennings & Longworth, 2015), and for those with an intellectual disability (ID) (Clapton, Williams, Griffith & Jones, 2017). Both studies found that adapted CFT was feasible to deliver in these populations. Those with ABI experienced reductions in self-criticism, anxiety and depression, with an increased ability to reassure the self. In individuals with ID no significant improvements were found in psychological distress, wellbeing, or self-compassion, however significant reductions were found in self-criticism and reported feelings of inferiority.

Compassion Focused Therapy in Dementia

Receiving a diagnosis of dementia can be described as an ‘existential threat’ (Poz, 2014b, p87): “it is a threat to life, a threat to function, a threat to finances, a threat to self-identity, and a threat to social inclusion”. It is a feared condition by older adults (Bond & Corner, 2001), and receiving a diagnosis has been compared with the experience of a grief reaction, with a loss of autonomy, competency, self-esteem, social roles and relationships, and a sense of identity (Aminzadeh et al., 2007). There is also significant stigma attached to the label, often leading to feelings of shame and embarrassment, self-criticism, and a fear of social exclusion (e.g. Cheston, 2005). It appears, therefore, that there could be a place for offering CFT to individuals with dementia, especially if they experience depression or anxiety, or are struggling to come to terms with their diagnosis.

At present one case study has been published documenting using CFT for an individual with early onset dementia (Poz, 2014b), suggesting that the therapy may be adapted and have some utility in this population. The same author has also presented an audit of group CFT for individuals with dementia and their carers at the Alzheimer’s Europe Conference (Poz, 2014a), which found CFT was feasible to deliver and was an acceptable form of treatment for these couples, with positive benefits found on mood and self-compassion skills were acquired. It is clear from these findings that further exploration of CFT in dementia is warranted in order to assess its feasibility and potential utility in this population.

Aim & Research Questions

Aim

To develop a therapeutic intervention based on CFT for people with dementia who are suffering with depression and/or anxiety, and to assess its feasibility, acceptability, and utility within this population. Although CFT has previously been adapted for people with dementia (Poz, 2014a, 2014b) no therapy manual has been developed to guide the delivery of individual CFT in this population. A manual development will allow for systematic evaluation of this approach, and if deemed feasible it would provide an accessible guide for clinical practice.

Research Questions

1. Is CFT feasible and acceptable to people with dementia in NHS memory clinics or similar settings?
2. Does mood and wellbeing improve in individuals with dementia following CFT?

Method

Overview

The project followed the Medical Research Council's 'developing and evaluating complex interventions framework' (Campbell et al., 2000) and guidance on reporting how the framework was followed (Möhler, Bartoszek, Köpke & Meyer, 2012). The framework consists of 4 stages: development of an intervention, feasibility and piloting, evaluation, and implementation. This project focused on the first two stages: development, and feasibility and acceptability, and is split into two parts:

- 1) Development of a CFT intervention for dementia, and

2) Feasibility study of the intervention.

Part 1 covered the following three phases: a) literature review, b) intervention development, and c) consultation. Part 2 of the project consisted of recruitment of individuals with dementia, delivering CFT, measuring acceptability and impact upon outcome measures.

Part 1 – Development of a CFT Intervention for Dementia

a) Literature review. The literature was informally searched to identify core theoretical and practical components of CFT. A further search was conducted on CFT delivered and researched in similar populations (any form of cognitive impairment, including dementia and brain injury). The literature on psychological therapies offered to individuals following a diagnosis of dementia, and what adjustments are typically made to promote optimal engagement and benefit to the person, were also reviewed. See Table 1 for a summary of the literature and its implications for the intervention development.

Table 1. Literature search summary and key findings

Literature Area	Resource	Finding/Implications
Compassion Focused Therapy	<p>Gilbert (2010b; 2009) An Introduction to the Theory and Practice of Compassion Focused Therapy and Compassionate Mind Training for Shame Based Difficulties Workshop packs Accessed from www.compassionatemind.co.uk</p>	<p>Key theoretical components and practices of CFT:</p> <ul style="list-style-type: none"> - Psychoeducation on compassion, the brain, attributes of compassion, fears and blocks to compassion - CFT model/formulation of three affect regulation systems - Compassion practices, including mindfulness, soothing rhythm breathing, compassionate imagery (safe place imagery, developing the compassionate self), compassionate letter writing <p>Basic outline and process of CFT: 1) Shared formulation, 2) ‘it’s not your fault’ focus, 3) development of compassion for self</p>
	<p>Parker, Woods and Gilbert (2009) Outline and Session by Session Record of Compassion Focused Group Therapy Module in the Context of a Local DBT Program Accessed from www.compassionatemind.co.uk</p>	<p>Example of group session outline:</p> <ul style="list-style-type: none"> - Old brain, new brain, social brain - It’s not our fault, but our responsibility to make changes - Affect regulation systems/three circles model - Compassion as flow - Key targets of therapy (i.e. attention, thinking and reasoning, behaviour, emotions, motivation, imagery and fantasy) - Attributes of compassion - Developing mindfulness and acceptance - Compassionate imagery - Compassionate letter writing
	<p>Gilbert (2009) The Compassionate Mind. Constable and Robinson Ltd: London</p>	<p>Further theoretical components of CFT and compassion exercises</p>

Mindful self-compassion	Neff (2015) Mindful Self-Compassion Course handbook Neff: http://self-compassion.org/ Website	<ul style="list-style-type: none"> - Definition of compassion - Concept of common humanity - Building warmth through touch - Mindful self-compassion practices - Concept of starting session with a practice - Self-compassion exercises
Adaptations to psychotherapeutic interventions for people with dementia	<p>James (2010) chapter: Cognitive Changes, Executive Functioning, Working Memory and Scripts: Their Relevance to Therapeutic Engagement (in Cognitive Behavioural Therapy with Older People).</p> <p>Charlesworth, Sadek, Schepers and Spector (2014). Cognitive behaviour therapy for anxiety in people with dementia: a clinician guideline for a person-centred approach.</p>	<p>Common cognitive difficulties experienced by people with dementia (including attention, concentration, memory, problem solving, motivation, language and processing of information), and ways to adapt therapy to adjust for these difficulties. For example reducing complexity of material, frequently checking understanding, regular summaries, pacing information, repeating core therapeutic concept frequently, use of supportive other, written summaries of sessions, prompting.</p> <p>CBT protocol for anxiety in people with dementia: phases of therapy approach</p> <ul style="list-style-type: none"> - Person-centred approach - Tailoring to accommodate for cognitive deficits; flexibility with the intervention delivery - ‘Less is more’; time set aside for adequate repetition and summarising - Development of ‘pre-therapy skills’ - Supportive other involvement, if available
CFT in brain injury	Ashworth, Gracey and Gilbert (2011) . Compassion focused therapy after traumatic brain injury: theoretical foundations and a case illustration	<p>Adaptations of CFT for brain injury:</p> <ul style="list-style-type: none"> - Shortened sessions and breaks offered; sessions structured with clear agenda - Visual diagrams and repeated verbal summaries - Process slowed down - Prompts to remember practicing <p>CFT content:</p> <ul style="list-style-type: none"> - Self-soothing by development of the ‘perfect nurturer’ imagery - Compassionate reframing through thought records

Ashworth, Clarke, Jones, Jennings and Longworth (2015). An exploration of compassion focused therapy following acquired brain injury

Outline of CFT group and individual sessions:

- Socialisation to the CFT model (definitions of compassion and the common humanity principle, three systems model of affect regulation, ‘tricky brain’ and ‘trickier brain’)
- CMT (soothing rhythm breathing and safe place imagery)
- Planning for practice (i.e. noticing when your threat system is activated and practicing CMT)
- Barriers to compassion

CFT in dementia

Poz (2014b)

Facing degeneration with compassion on your side: using compassion focused therapy with people with a diagnosis of dementia

Case study outlining individual CFT for an individual with dementia

- Dementia as a ‘threat’
- Presentation of the CFT model and formulation
- Adapting CFT for the person’s neuropsychological profile (i.e. deficits in processing speed – slow delivery of information and pacing; strengths in visual memory – utilise imagery)
- Providing visual record and written summaries of the sessions
- Keeping tasks concrete to improve skill acquisition
- Encouragement of the therapist using CFT principles, i.e. noticing if/when during any of the work you find yourself in the threat system
- Usefulness of bringing in the partner of the person with dementia

Poz (2014a)

Delivering compassion focused therapy to couples experiencing a diagnosis of dementia in a group setting: is it feasible?

Outline of group CFT

- Key themes outlined (evolutionary brain and innate sensitivity to kindness, why the brain is tricky to regulate – it’s not your fault’, three circles model, flows of compassion, fears and blocks to compassion, CMT)
 - Adaptations (dementia as a threat, use of more visual images to discuss emotional responses, more breathing practices, compassionate reminiscence, compassionate postcards)
-

b) Intervention development. The CFT intervention manual was developed from Gilbert's (2009; 2010; 2014) compassionate mind training, and integrated components of Neff and Germer's Mindful Self Compassion programme (MSC, 2013). These interventions differ in that Gilbert's CFT focuses equally upon the 'flows of compassion', encouraging the individual to develop compassion for themselves, for others, and to receive compassion from others. MSC, on the other hand, focuses upon developing compassion for the self. As much of the evidence on compassion and ageing demonstrated the benefits of *self-compassion*, this was the core focus of the current intervention, although attention to the three flows of compassion was also included. The explicit focus however, was on how the person with dementia could generate compassion for themselves, as well as allow themselves to experience this from others more fully. The key theoretical components of both interventions were initially outlined in a list format (see Table 1; CFT section). The literature findings from psychotherapeutic interventions for people with dementia and brain injury were then used to format the overall intervention and its delivery.

Firstly, the three phase-based approach over 10 sessions reported in the CBT trial for anxiety in dementia (Charlesworth, Sadek, Schepers & Spector, 2014) was used for the overall intervention structure, and was informed by the key theoretical components of CFT. Phase one was identified as 'Setting up: Introducing compassion focused therapy and engagement'. Phase two: 'Developing compassion for the self', and phase three: 'Managing difficult feelings, consolidating and ending'. The content followed Gilbert's (2010) outline of CFT, starting with psychoeducation on compassion and the evolved mind, followed by introduction of

the CFT model of the three affect regulation systems, and practices mainly to develop compassion for the self.

James's (2010) guidance on adapting CBT for individuals with dementia informed the structure of each session. To facilitate learning and familiarity each session was given a similar format: opening with a compassion 'practice' (such as soothing rhythm breathing), reviewing home practice, key activity/discussion point, setting up home practice. Furthermore, therapy resources were developed for each session, both to maximise visual learning (Poz, 2014b), and to provide reminders and summaries of the session. Participants were given a folder so they could return to the materials in between sessions.

As utilised in the CBT for anxiety trial (Charlesworth et al., 2014) a 'supportive other' was introduced in order to both provide support for the person with dementia to attend the sessions, as well as to act as an external memory aid for both home practice and returning to concepts covered during the sessions.

The literature on psychotherapeutic interventions for people with dementia and brain injury (see Table 1) informed the intervention's process adaptations, and these were included in the intervention manual as guidelines for the therapist. See Table 2.

Finally, the manual was created with an outline of the phases and suggested session content. It was designed in a way that clinicians had a guide for the content and its delivery, however with the flexibility to adapt it to the individual participant – depending on their cognitive ability and 'openness to compassion'. The manual was designed for clinicians who have experience in providing therapeutic interventions for individuals with dementia, as well as some familiarity with CFT. Therefore as with all interventions clinical judgement is necessary when using the manual (e.g.

Connolly Gibbons, Crits-Christoph, Levinson & Barber, 2003). For example, more time may need to be spent on phase one (engagement, formulation and psychoeducation) if the individual struggled to identify and to express their emotions.

Table 2. Intervention adaptations for challenges associated with dementia

Possible challenges or problems for the person with dementia	CFT Process adaptations
Memory Including short-term memory loss, difficulties in new learning, working memory, encoding, and retrieval deficits	<ul style="list-style-type: none"> • Use of supportive other • Slow delivery of concepts • Checking-in if the concepts are making sense • Regularly check understanding (after each novel concept) • Repeat main therapeutic concepts frequently • Provide regular summaries (every 10-15 mins) • Provide written summary of the session • Provide visual hand-outs • Provide CDs/audio recordings of meditations/home practices • Consider whether concepts from the previous session/s need to be returned to and prioritise these over introducing new concepts • Generate flashcards for client’s chosen methods of coping/practices • Meditations/practices shortened, less silence
Concentration	
Attention	
Language	
Problem solving	
Motivation	

c) Consultation. Once the intervention was developed a consultation process took place, which involved consulting people with dementia and their carers, staff in a memory service, and clinical psychologists who were familiar with CFT or working with people with dementia. The feedback was used to further develop and amend the intervention accordingly.

Focus group. People with dementia under the care of a memory service, their carers and staff were invited to attend a focus group to ask their views on this new intervention. The focus group was scheduled before the memory service’s monthly ‘Memory Café’, and regular attenders were sent a poster in the post (see Appendix A). Four people with dementia attended, of whom three came with their carers. Four

staff members were present who also gave their views on the intervention (two student occupational therapists and two specialist dementia nurses).

The therapy manual was provided to all attendees and a summary of the therapy and a basic rationale for CFT were given (for example “CFT teaches us to be kind to ourselves when we are suffering. It involves talking about how the brain works, as well as practicing some breathing exercises”). Attendees were asked what they thought about the concept of developing self-compassion for people with dementia, and whether or not this felt relevant to the particular concerns they might have day-to-day. Both individuals with dementia and carers expressed thinking that compassion may help them cope better when they forget something or struggle with a particular task, for example. Recent work (Lacey, Hiskey & Andrews, in press) has underscored the importance of participants fully understanding abstract phenomena such as compassion prior to an intervention (e.g. expressive letter writing).

The concept of basic mindfulness and soothing rhythm breathing was explained to attendees, and they were asked what they thought of the practices and if they seemed feasible to do. These were well received and individuals with dementia suggested the need for audio CDs of the practices to help them practice at home.

Attendees were also asked for their thoughts on a family member attending as a ‘supportive other’, whether or not they liked the idea, and if they did how they would like them to be involved (for example joining for the whole or part of the session). There was a positive response for the inclusion of a supportive other, both from individuals with dementia and their carers. However, one person with dementia disliked this concept as they did not feel they had such a person in their life. Others were keen for the involvement of the supportive other to be flexible and for this to change as the therapy process evolves.

Lastly, the group were asked about the practical aspects of the intervention, such as offering it over 10 sessions and whether an hour felt appropriate or too long. They were also asked to comment overall on anything they would like to be added or adjusted. Attendees expressed that 10 sessions seemed enough, and that they would like this to be flexible, by offering more or less if needed. A similar response was given for session length, that on some days an hour may be too much, on others it may be manageable, so again flexibility would be key. No one identified any specific aspects of the intervention that they did not like or think should be excluded. See Appendix B for detailed feedback from the service user consultation.

Specialists' consultation. Twelve clinical psychologists experienced in the delivery of care and therapeutic interventions for people with dementia or in CFT consulted on the intervention. Written feedback was provided and the intervention was amended accordingly. Changes included using postcards for the compassionate letter writing, and adding in soothing rhythm breathing before this to ensure the participant had engaged their soothing system. Further emphasis was given on flexibly following the manual, allowing for more time at the beginning to discuss the impact of the dementia diagnosis. Returning to participants' goals at each session was also added. See Appendix C for full comments and suggested changes.

Part 2 - Feasibility Study

In order to explore the feasibility and acceptability of the CFT for dementia intervention it was delivered to seven individuals with dementia across three NHS memory services and one charity setting.

Ethics. Ethical approval for the design and evaluation of this intervention was obtained from the London Dulwich Research Ethics Committee (Ref: 16/LO/0588; Appendix D). Local R&D approval was also obtained in each NHS site.

Recruitment. People with dementia were recruited from three memory clinics and one dementia charity organisation. Those who met the inclusion criteria at the memory clinics were contacted to discuss the study. The dementia charity organisation disseminated a recruitment poster to carers of people with dementia (Appendix E). For those who were interested in participating, the study was discussed over the phone and information sheets were sent to the person with dementia and their carer, if they had one (Appendix F and G). At least 24 hours was given to individuals and dyads to consider taking part in the study prior to contacting them again.

For those who agreed to take part, written consent was obtained from both the person with dementia and a carer at the initial assessment (see Appendix H and I for consent forms). The general practitioner of the participant was informed of their participation in the study (see Appendix J).

Inclusion criteria. Individuals were eligible to take part in the study if they met the following criteria:

1. Met the Diagnostic and Statistical Manual of Mental Disorders, Fourth Edition (DSM-IV, APA, 1994) for dementia of any type, as diagnosed by a memory service.
2. Had mild-moderate cognitive impairment, as rated from the most recent cognitive assessment either on the Montreal Cognitive Assessment (MoCA; Nasreddine et al., 2005) as 10-25, or on the Addenbrooke's Cognitive

Assessment, Third Edition (ACE-III; Hsieh, Schubert, Hoon, Mioshi, & Hodges, 2013) as 88 or below.

3. Experienced symptoms of:
 - depression (scored 10 or above on the Cornell Scale for depression in dementia [CSDD; Alexopoulos, Abrams, Young, & Shamoian, 1988]). and/or
 - anxiety (scored 11 or above on the Rating Anxiety in Dementia [RAID; Shanker, Walker, Frost, & Orrell, 1999])
 - or significant subjective distress at the cognitive impairment (as expressed and determined by the individual)
4. Had capacity to consent to take part in the research
5. Were able to communicate in English
6. Acknowledged the dementia or cognitive difficulties
7. Had some ability to verbally communicate and understand verbal communication
8. Were not participating in another research programme concurrently

Design. A mixed-methods case series design was used to measure change across the intervention. This design uses case study methodology – looking at individual change on outcome measures, but the replication increases the robustness of the design and is considered an important contribution to the evolution of establishing clinical effectiveness or ineffectiveness of interventions (Whitney, 2000). Quantitative measures of change were assessed using outcome measures at three time-points (pre-intervention, mid-point, and post-intervention). Post-therapy change interviews were conducted with six participants in order to gain qualitative feedback on the participants' individual experiences of the intervention and any

positive or negative changes they have noticed since the intervention begun. Session rating forms were completed following each session, which provided both quantitative and qualitative data for usefulness of the sessions.

Measures. All participants were assessed by an assistant psychologist or a trainee clinical psychologist at baseline (within a two-week period prior to the commencement of CFT), at mid-point (which fell within a week following session five), and post-intervention (within two weeks of session 10). Three participants attended the assessments at the clinic and four were seen at their home.

Self-compassion. Self-compassion in people with dementia was measured using the Short-Self-Compassion Scale (SCS-SF; Raes, Pommier, Neff, & Van Gucht, 2011). The SCS-SF is a validated and reliable 12-item scale measuring self-compassion. It measures the following domains of compassion: self-kindness, self-judgement, common humanity, isolation, mindfulness, and over-identification. Items are rated on a likert scale from 1 (almost never) to 5 (almost always). The SCS-SF was delivered in an interview format to the person with dementia and assistance from the carer was sought if any difficulties with items were experienced. Responses are averaged to give an overall score between 1 and 5. A score of 3.5 or over is considered high self-compassion; a score of 2.5 or lower is considered low. The SCS-SF has good internal consistency ($\alpha \geq 0.86$), factorial validity and convergent validity (Castilho, Pinto-Gouveia & Duarte, 2015; Raes et al., 2011). The SCS-SF is validated in clinical and non-clinical populations however it is not specifically validated for use in the dementia population. See Appendix K for SCS-SF.

Mood. Mood in people with dementia was assessed using the Cornell Scale for depression in dementia (CSDD; Alexopoulos et al., 1988). The CSDD is a 19-item scale that measures five areas of depression, delivered in an interview format

with the caregiver and the person with dementia. The interview covers domains of mood-related signs, behavioural disturbance, physical signs, cyclic functions (such as sleep disturbances), and ideational disturbance, occurring during the week prior to the interview. The carer is interviewed first, after which the person with dementia is interviewed. Any discrepancies are discussed and resolved between the interviewer and the carer, and the final rating represents the rater's clinical impression. Items are rated on a four-point scale, where absent =0, mild or intermittent = 1, moderate =2, and severe =3. A score of 10 or more indicates a likely episode of depression, a score of above 18 indicates a definite major depression, and a score below six indicates absence of significant symptoms of depression. The cut off score of 10 was used as the clinical cut off to determine a presence of absence of depression. The scale has been found to have good reliability and validity (Alexopoulos, et al., 1988). See Appendix L for the CSDD.

Anxiety. Symptoms of anxiety in people with dementia were assessed using the Rating Anxiety in Dementia (RAID; Shanker et al., 1999). The RAID is an 18-item scale covering four domains of anxiety: worry, apprehension and vigilance, motor tension, and autonomic hypersensitivity; see Appendix M for scale. It is delivered in the same way as the CSDD (outlined above). Items are scored on a 4-point scale where absent =0, mild or intermittent = 1, moderate =2, and severe =3. A score of 11 or over indicates clinical symptoms of anxiety. Inter-rater reliability and test-retest values on the scales are fair to excellent (Seignoural, Kunik, Snow, Wilson, & Stanley, 2008). The scale also has satisfactory internal consistency ($\alpha=.83$). It is sensitive to change and correlates with quality of life (Qazi, Shankar, & Orrell, 2003, cited in Spector et al., 2012).

Quality of life. Quality of life for people with dementia was measured using the Quality of Life-Alzheimer's Disease (QOL-AD; Logsdon, Gibbons, McCurry, & Teri, 1999). The QOL-AD is a 13-item measure completed separately by the person with dementia and their supportive other. The individuals rate the quality of various aspects of their life. Domains assessed cover: physical health, energy, mood, living situation, memory, family, marriage, friends, self as a whole, fun, ability to do chores around the house, ability to do things for fun, money, and, life as a whole. Each item is rated on a four-point scale, where poor =1, fair =2, good=3, and excellent=4. Scores range from 13 to 52, with the higher the score indicating a higher quality of life. See Appendix N for QOL-AD. Inter-rater reliability and internal consistency has been found to be excellent (0.84-0.88), and content validity, construct validity, and criterion validity are good (Logsdon, Gibbons, McCurry, & Teri, 2002).

Helpfulness of sessions. Perceived helpfulness of the sessions was measured at the end of each session via a participant rating form designed for the study. First, the person with dementia is asked how helpful they found the session, using a likert scale from 1 to 5, whereby 1=extremely unhelpful, 2=somewhat unhelpful, 3=neither helpful nor unhelpful, 4=somewhat helpful, and 5=extremely helpful. Second, the person with dementia is asked what they liked about the session, if anything. Third, they are asked what they did not like about the session. The participant rating form can be found in Appendix O.

Experience of therapy. The person with dementia and their supportive other's experience of the intervention was explored through a semi-structured interview conducted by an assistant psychologist or a trainee clinical psychologist. To limit bias the interviews were conducted by a different practitioner than the one who had delivered the therapy.

The interview schedule was designed for the study (see Appendix P), and was based upon Elliot, Slatick and Urman's (2012) change interview. Questions cover areas such as what brought the person to therapy, and what changes they have noticed since starting the intervention, what they are doing differently in their day-to-day life, and how they are responding to themselves and others differently when they feel distressed. The interview also asks whether there are any specific ideas and strategies that they have taken from the sessions, as well as what was helpful. Lastly it asks about what was less helpful, and areas of their life that have not changed or got worse since starting therapy. A carer version was also created for dyads where the person with dementia is more impaired and may struggle to reflect on the therapy experience and any changes (see Appendix Q).

Intervention. The intervention was designed to be delivered to people with dementia and their carers on an individual basis, over a course of up to 10 one-hour sessions. The intervention manual was designed for clinicians as a guide for the content of each session (see Appendix R for full manual). It was written in a way that it can be adapted to the individual person with dementia, depending on cognitive ability, presenting difficulties and 'openness' to compassion. The intervention was separated into three phases, an approach which has been found to be useful in adapting CBT for dementia (Spector et al., 2012). Session content could therefore be guided by the phase the participant was perceived to be in. For example, phase one could require the whole 10 sessions for those who were more cognitively impaired or less open to compassion. See Table 3.

Visual materials were designed for the intervention in order to create a therapy folder for each participant, in line with the adaptations outlined in part one. Audio practices were recorded and CDs were provided so that participants could

practice at home. A partner, carer, or a friend was encouraged to attend with the person with dementia as a ‘supportive other’, in order to act as a memory aid and support to facilitate home practice.

The manual encouraged a consistent structure to each session, regardless of specific content: each session starts with a practice (for example soothing rhythm breathing), review of home practice, main discussion/activity (for example psychoeducation on compassion), setting up home practice.

The intervention was delivered by four clinical psychologists (including one trainee clinical psychologist*), all of whom have attended training in CFT.

* As the author of the thesis I delivered the intervention to four participants (totalling 40+ hours of therapy), and three clinical psychologists in other NHS research sites saw one participant each. I additionally conducted five outcome measures interviews for participants seen in other sites, and a further post-therapy interview (totalling a further 12 hours).

Table 3. Phases of the CFT Intervention.

Phase	Topic	Content
Phase 1 (Sessions 1-3)	Setting up: Introducing compassion focused therapy and engagement	<ul style="list-style-type: none"> - Psychoeducation - Experiencing/Developing mindful awareness - Collaborative formulation and goal setting - Developing physical self-soothing (soothing rhythm breathing) - Starting to experience compassion (flow)
Phase 2 (Sessions 4-7)	Developing compassion for the self	<ul style="list-style-type: none"> - Loving-kindness for the self - Fears and blocks to compassion - Imagery: safe-place, compassionate self - Compassion in everyday life - Compassionate letter/postcard
Phase 3 (sessions 8-10)	Managing difficult feelings	<ul style="list-style-type: none"> - Threat-based emotions - Soften, soothe, allow - Returning to key concepts/reflection on practices
	Consolidating & ending	<ul style="list-style-type: none"> - Reviewing the therapy and compassionate future

Analysis

Quantitative analysis. Attendance and participant rating form data are presented to evaluate feasibility and acceptability of the intervention.

Reliable change (RC) (Jacobson & Truax, 1991) allows clinicians to determine whether change on an outcome measure exceeds that of the measurement error. RC was calculated for each participant on each measure that reported reliability coefficients (i.e. Cornell, RAID, QOL-AD, SCS-SF). Morley and Dowzer's (2014) reliable change indicator was used to calculate whether participants improved, did not change, or deteriorated over the intervention. The reliable change index (RCI) was calculated for each measure, and this score represents the number of points a participant is required to change by in order for the improvement or

deterioration to be considered reliable. Clinically significant change was also calculated to determine whether or not participants' post-intervention scores reduced to the sub-clinical range. Measures that identified clinical cut off points or clinical sample means allowed this calculation (i.e. Cornell, RAID, SCS-SF).

Change was also observed graphically across the three time points of the intervention. This method is used for case studies to assess change over time on outcome measures following an intervention (Barlow, Nock & Hersen, 2008).

Qualitative analysis. Qualitative data were used to understand the participants' and their supportive others' experience of CFT, as well as to capture behavioural and emotional change that may not have been depicted through the outcome measures. It was also hoped that any adverse events or dislikes of the therapy components would be identified through this method. Data were captured through two questions on the participant rating form and through post-therapy change interviews with five of the participants and one supportive other.

Interviews were transcribed verbatim and all personal information was removed to preserve confidentiality. The transcripts were evaluated using thematic analysis (Braun & Clarke, 2006), through familiarisation with the data, coding of meaningful and relevant aspects of the dialogue, and synthesising the codes into emerging themes. The proposed themes were re-examined in relation to the initial dialogue before being refined and named.

Results

Participants

All people with dementia who met the inclusion criteria were invited to take part in the study, along with a carer, family member or friend as a 'supportive other'.

Individuals were not excluded if they did not have a supportive other. Within the memory services all individuals that the study was discussed with agreed to participate. From the charitable organisation four carers requested further information about the study, however only one person with dementia met the inclusion criteria, and they subsequently commenced with the therapy.

Out of the seven people with dementia six were female and one was male. Ages ranged from 53 to 88. Five were white British, one was white European and one was black African. Alzheimer’s Disease was the most common form of dementia. Table 4 outlines basic demographic data of the participants who consented.

Table 4. Participant demographics

Participant	Dementia	Age	Gender	Cognitive Impairment	Ethnicity	Supportive Other
1	Mixed AD & Vascular	76	Female	Mild-Moderate	White, British	None
2	Alzheimer’s Disease	83	Female	Moderate	White, British	Husband
3	Alzheimer’s Disease	80	Female	Mild-moderate	White, British	Friend
4	Alzheimer’s Disease	83	Female	Moderate	Black, African	Daughter
5	Alzheimer’s Disease	88	Female	Moderate	White, British	Husband
6	Vascular	53	Male	Mild	White, British	Partner
7	Alzheimer’s Disease	73	Female	Mild-Moderate	White, European	Husband

Feasibility and Acceptability

Attendance. Five of the seven participants (71%) completed the full ten sessions of the intervention. Two participants completed eight sessions: one participant sadly died of natural causes. This participant’s partner provided consent to use their data as they had completed baselines and mid-point measures. Another completed eight sessions due to time constraints of the project.

Participant rating forms. Participant rating forms were completed for 48 out of 66 (73%) sessions. They indicated that participants found the sessions useful. No participants rated any of their sessions as unhelpful. One supportive other rated session 1 (assessment session) as ‘neither helpful nor unhelpful’. See Table 5.

Table 5. Session helpfulness ratings

Extremely unhelpful 0%	Somewhat unhelpful 0%	Neither helpful nor unhelpful 1.9%	Somewhat helpful 28.8%	Extremely helpful 69.2%
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Overall the feedback for the sessions were positive, with very few comments on what was experienced as unhelpful. Comments from participants with dementia are denoted as P1, P2 etc. (i.e. participant 1, 2). The supportive others’ comments are denoted as SO1, SO2 etc. (i.e. supportive other of participant 1, 2).

Key themes.

1. Feeling heard and helped

Several participants commented that they felt listened to and that the therapist wanted to help them.

P1: *‘I like that you are trying to help me’*

P6: *‘<Therapist> was very helpful and listened to what I had to say’*

2. Enjoyment of the breathing practices

Four participants expressed that they enjoyed the soothing rhythm breathing and mindfulness practices.

P1: *'I like the breathing'*

P3: *'The breathing helped me to relax'*

P6: *'I really enjoyed the mindfulness and relaxation exercises'*

3. Valued space for conversation

Two of the carers/supportive others and one person with dementia expressed that it was helpful to have the time to talk through concerns.

SO2: *'I always enjoy the conversation, interesting conversations'*

P1: *'Talking about the frustration'*

SO4: *'I found it helpful to talk – to release everything and getting things off my chest'*

4. Sessions as personal to me

Two of the participants with dementia commented how they felt the sessions were tailored to them.

P6: *'<Therapist> listening to me and my girlfriend and fitting the sessions around our experiences'*

P3: *'Personalised practice'*

5. Developing self-compassion

A number of comments reflected that participants found it valuable to develop self-kindness.

SO4: *'Thinking of ways of being kind to myself and different ways of helping ma';
'Being reminded of needing to take care of myself in order to look after mum'*

P1: *'You telling me about compassion and the brain'; 'I liked the hand on heart practice'*

P6: *'Being told it's ok to be kind to myself'*

P3: *'It was helpful to find out that it is not the end of the world if I make a mistake'; 'Not criticizing myself'*

6. Nothing unhelpful.

In response to the question: *'what did you not like about the session (if anything)? For example was there anything you found unhelpful or not enjoyable?*

Participants repeatedly responded that there was nothing unhelpful or not enjoyable in the session. However one participant (carer) expressed disliking the compassion psychoeducation: *'I'm not a theory person, it was a bit much, like a biology lesson'*. Nevertheless another carer verbally fed back that they found the psychoeducation interesting.

Intervention coverage. The intervention was not fully completed by any participant. Informal feedback from clinicians delivering the intervention indicated that most people with dementia managed phase one and two (setting up CFT and engagement, and developing compassion for the self). Six out of the seven participants with dementia were able to engage in soothing rhythm breathing, and five of the seven were able to engage in a discussion of self-criticism and developing kindness and self-compassion. The latter part of the therapy – phase three (managing difficult emotions), was often not reached, due to the need to spend more time on the earlier phases and time to discuss the impact of dementia on the person and their lives. This indicates that as it stands the manual would either need to be reduced for a 10-session course of CFT for people with dementia, or further sessions would need to be offered.

One carer described the mindfulness and breathing practices as ‘mind games’, and referred to his previous loathed experiences of a retreat run by the church. This was discussed with the carer and as a result no further mindfulness and compassion exercises were practiced during their sessions. In addition, this dyad did not identify any particular concerns or difficulties, stating they wanted to help with the research, but they expressed still wanting to attend all sessions. As a result the intervention was considerably adapted with this couple.

One participant with dementia appeared to struggle with much of the intervention. She was only able to understand and manage the basic breathing practice (soothing rhythm breathing). It is unclear if this was due to deteriorating cognition or hearing difficulties, or a combination. She chose not to wear her hearing aids, and was unable to engage in even basic back-and-forth conversation. As a result, the intervention was delivered primarily to her supportive other – her daughter – with the view to help her mother develop self-compassion, as well as addressing the daughter’s self-criticism in her role as carer for her mother.

Mood and Wellbeing

Table 6 outlines changes across the intervention time points on measures of mood, anxiety, quality of life and self-compassion. Statistical significance of pre to post changes was calculated using reliable change based on the co-efficient of each measure (see Appendices S-V for graphical representation of RCI and all measures). Clinically significant change was calculated using either the measure’s clinical cut-off (Cornell, RAID) or the clinical and non-clinical sample means and standard deviations (SCS-SF). In order for clinically significant change to be reached scores had to be above the clinical cut off at baseline, reach reliable change, and the post-treatment score had to fall below the clinical cut off (or fall closer to the mean of the

comparison group than the clinical group when using sample means). Scores in brackets indicate that the participant scored below the clinical cut off at baseline, and so were not able to further improve.

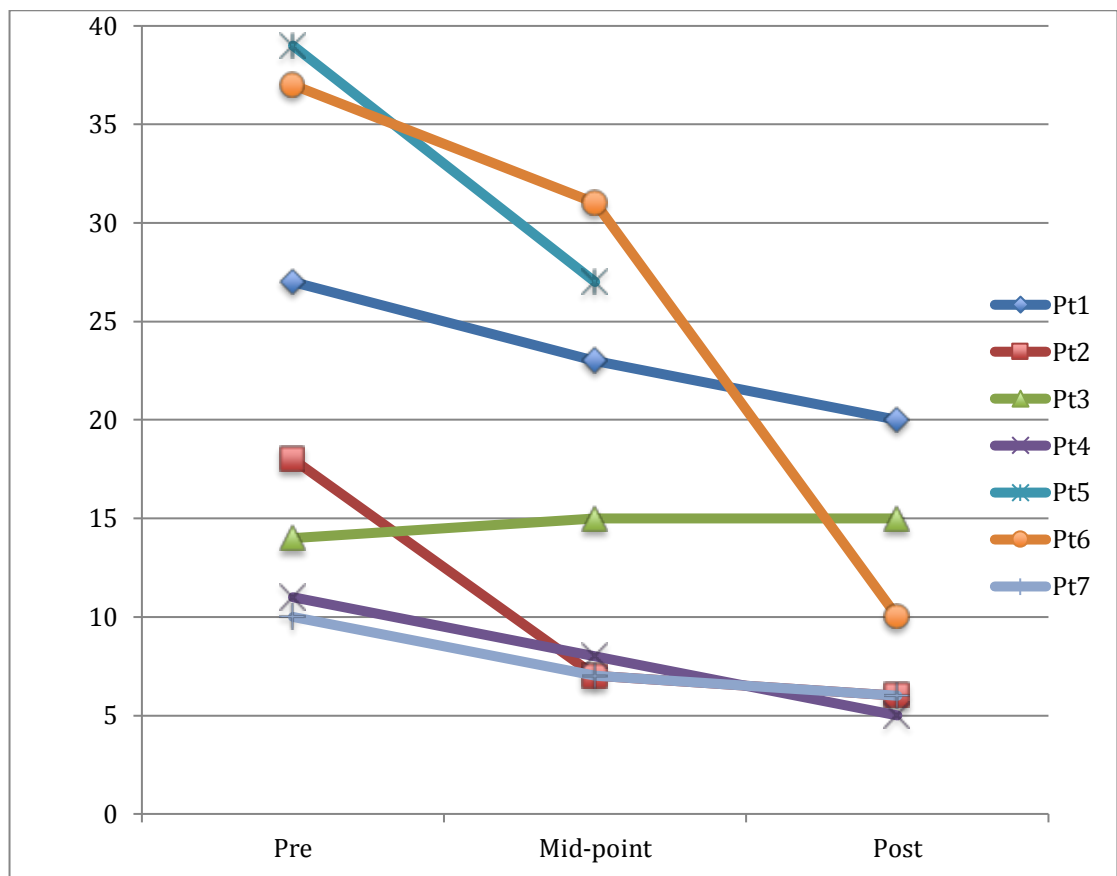
Table 6. Pre-post raw scores, reliable change and clinically significant change

Participant	1	2	3	4	5	6	7	
Mood (Cornell)								
Score	Pre	27	18	14	11	39	37	10
	Mid	23	7	15	-	27	31	7
	Post	20	6	15	5	-	10	6
Range	Pre	Definite dep.	Definite dep.	Probable dep.	Probable dep.	Definite dep.	Definite dep.	No dep.
	Mid	Definite dep.	No dep.	Probable dep.	-	Definite dep.	Definite dep.	No dep.
	Post	Definite dep.	No dep.	Probable dep.	No dep.	-	No dep.	No dep.
Reliable change (RCI 4.43)		Improve	Improve	No change	Improve	Improve	Improve	(No change)
CSC (≤ 10)		NO	YES	NO	YES	NO	YES	(NO)
Anxiety (RAID)								
Score	Pre	32	19	13	23	25	31	11
	Mid	36	5	10	-	14	21	9
	Post	27	12	7	15	-	17	9
Range	Pre	Clinical anx.	Clinical anx.	Clinical anx.	Clinical anx.	Clinical anx.	Clinical anx.	Clinical anx.
	Mid	Clinical anx.	No anx.	No anx.	-	Clinical anx.	Clinical anx.	No anx.
	Post	Clinical anx.	Clinical anx.	No anx.	Clinical anx.	-	Clinical anx.	No anx.
Reliable change (RCI 10.17)		No change	No change	No change	No change	Improve	Improve	(No change)
CSC (≤ 11)		NO	NO	NO	NO	NO	NO	(NO)
QoL (QoL-AD)								
Pre	29	31	39	37	24	25	31	
Mid	26	37	37	-	25	21	36	
Post	27	37	39	38	-	27	36	
Reliable change (RCI 6.33)		No change	No change	No change	No change	No change	No change	No change
Self-Compassion (SCS-SF)								
Score	Pre	2.08	3.2	3.58	-	2.08	3.00	2.25
	Mid	2.25	3.92	4.6	-	2.33	3.08	3.08
	Post	2.58	4.5	4.5	-	-	4.6	-
Range	Pre	Low SC	Moderate SC	High SC		Low SC	Moderate SC	Low SC
	Mid	Low SC	High SC	High SC		Low SC	Moderate SC	Moderate SC
	Post	Moderate SC	High SC	High SC			High SC	-
Reliable change (RCI 0.64)		No change	Improve	Improve	-	No change	Improve	Improve
CSC		NO	YES	YES	-	NO	YES	YES

Pre – baseline assessment; Mid – mid-point assessment; Post – post-intervention assessment; dep. – depression; anx. – anxiety; CSC – clinically significant improvement; QoL – quality of life; SC – self-compassion; ‘-’ denotes missing data

Mood. Six out of the seven participants scored in the clinical range for depression symptoms prior to the intervention. All but one of the participants saw a decrease in their depression scores across the intervention, with three moving from the clinical range to the sub-clinical range. See Table 6 for clinical categories and Figure 1 for graphical change for mood across time.

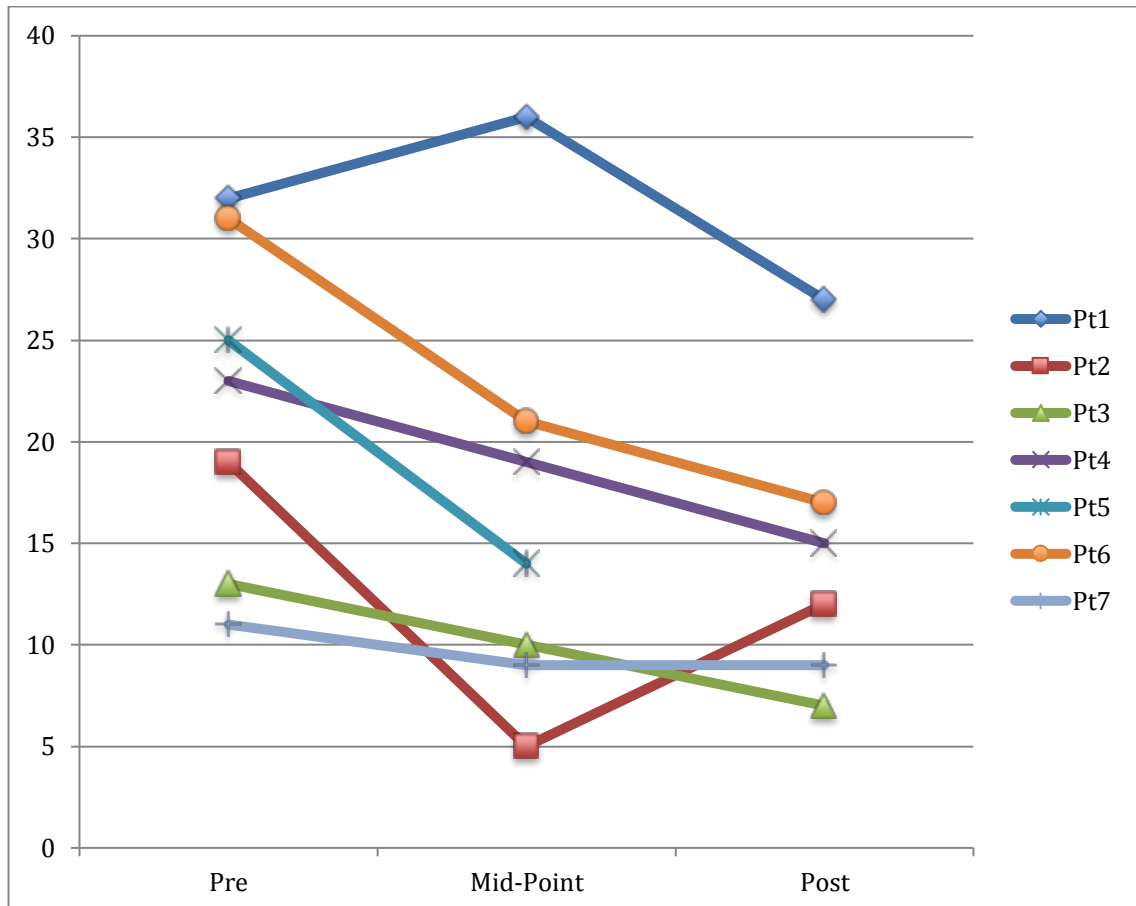
Figure 1. Mood: scores on the CSDD for all participants across time points



Anxiety. All participants scored in the ‘clinical anxiety’ range prior to the CFT intervention. All saw a reduction of anxiety symptoms following the intervention, however only two moved to the sub-clinical anxiety range. No participant met a reduction of clinical significance. Due to the measurement error and standard deviation of the clinical sample that was used to validate the measure, a

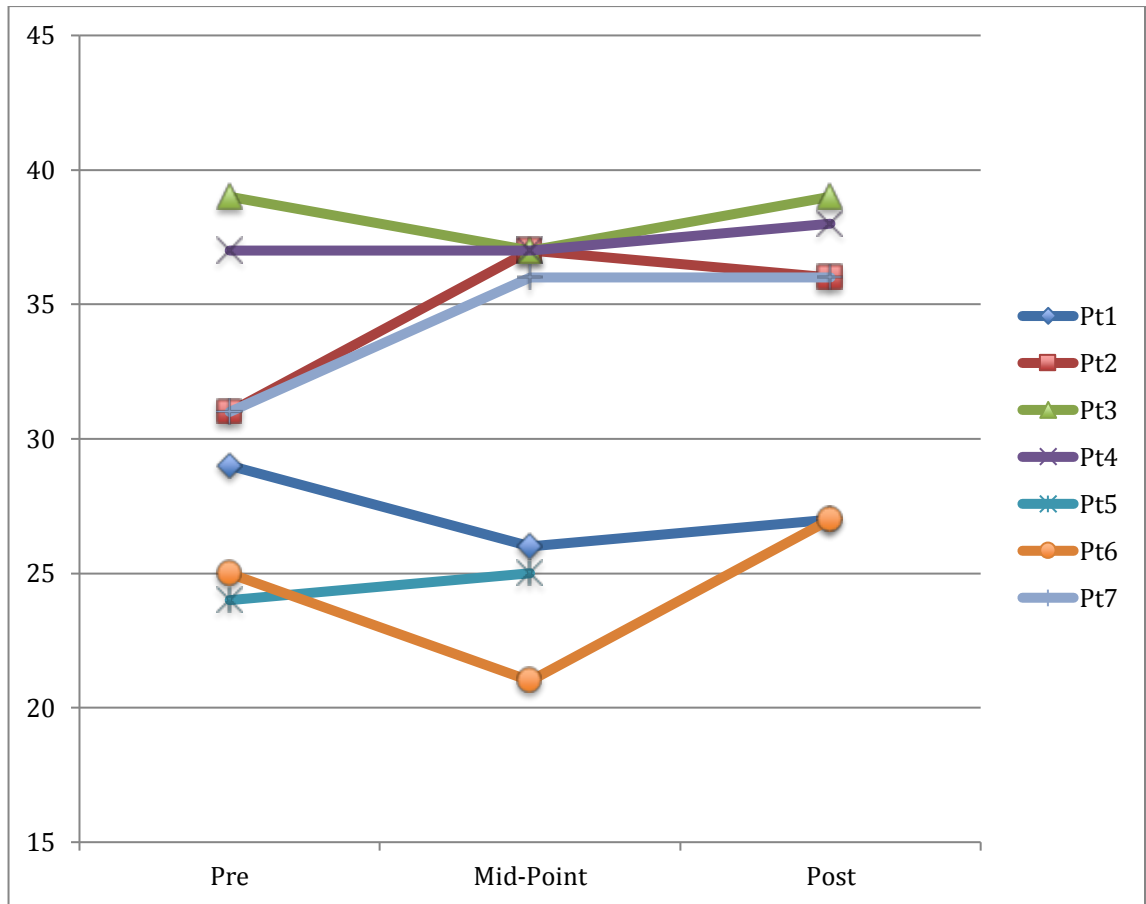
change of 10.17 points on the RAID was required to reach reliable change, which was met by only two participants.

Figure 2. Anxiety: scores on the RAID for all participants across time points



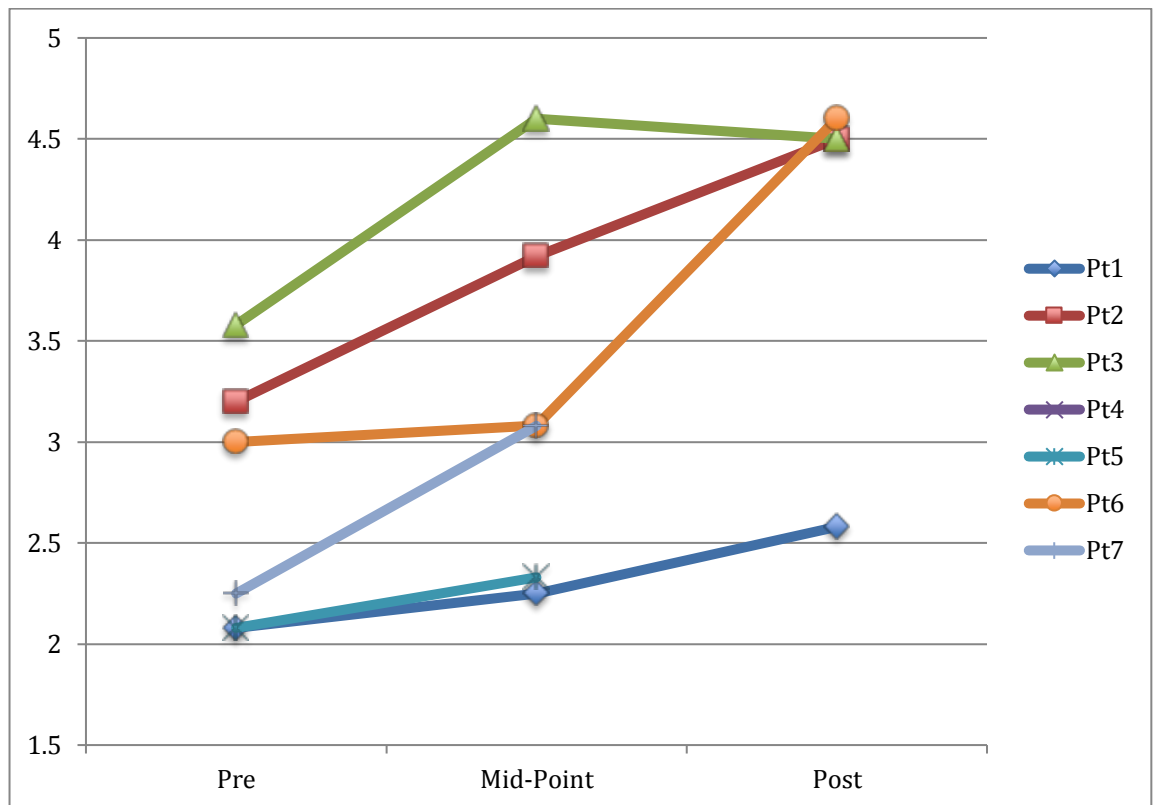
Quality of life. Participants' QOL-AD scores ranged from 24-39 prior to the CFT. There was very little change seen on this measure, with the largest changes seen in participants two and seven, who saw increases of six and five points, respectively (see Figure 3). The RCI was calculated as 6.33, and as no one participant exceeded this change no one saw a reliable improvement. As this measure does not intend to measure clinical cut-off scores for quality of life clinically significant change was not calculated.

Figure 3. Quality of Life: self-reported scores on the QOL-AD for all participants across time points.



Self-compassion. At baseline six out of the seven participants scored in the low or moderate self-compassion range (see Table 6). All participants' scores improved on the SCS-SF across the intervention (see Figure 4), and with the exception of participant five, all completed the intervention in the moderate or high self-compassion range.

Figure 4. Self-Compassion: scores on the SCS-SF for all participants across time points



Post-Therapy Interviews

The thematic analysis generated five superordinate themes: ‘starting the journey’; ‘support when I needed it’; ‘changes in self and other relating’; ‘barriers to developing compassion’; and ‘something more needed’. Each theme contained a number of sub-themes. See Table 7 for a summary of the analysis. Participants are referred to by numbers to demonstrate that findings are grounded in a variety of perspectives, for example P1, P2 etc. (participant 1, 2), and SO1, SO2 etc. (supportive other of participant 1, 2).

Table 7. Post-therapy interview themes

Superordinate Themes	Sub-Themes
1. Starting the Journey	<ul style="list-style-type: none"> - Being diagnosed with dementia: shock, and adjustment - Did not know what to expect
2. Support When I Needed it	<ul style="list-style-type: none"> - Someone to talk to - Dementia knowledge and skills - A positive experience - Compassionate therapist
3. Changes in self and other relating	<ul style="list-style-type: none"> - I am calmer - I am kinder to myself - Awareness and acceptance
4. Barriers to Developing Compassion	<ul style="list-style-type: none"> - Memory and cognition - Fears and blocks - No problems
5. Something More Needed	<ul style="list-style-type: none"> - I do not feel different - More support

Theme 1. Starting the journey. Both participants with dementia and their supportive others spoke of the shock of receiving the dementia diagnosis, its impact upon their lives, and the process of adjusting to living with the condition. Many also wanted some support but did not quite know what to expect from the CFT.

Being diagnosed with dementia: shock and adjustment. A common narrative that arose from participants was the disbelief of the dementia diagnosis.

P6: *I've done more than most people. Full time teacher, part-time fireman, part-time DJ or whatever, I did a lot more than most people. The next minute, nothing really. It's a big void.*

I: *A big shock, yeah.*

P6: *...so a big shock to a lot of things and I think for a lot of other people for a lot to have happened and it also happened to me when I was quite young. And I might be 53 but I acted like I were 33 to a lot of people.*

SO4: *...so I went with her and we saw a doctor from the memory clinic and he said we've got the results in, and yeah your mum has Alzheimer's. And I just burst in to tears.*

P7: *...I was angry with myself because I didn't want this thing, and I fought it every way I could.*

Participants' partners spoke of the subsequent adjustment process.

SO2: *And of course we are adjusting in any case...you know you look back and you can see change over three years perhaps, four years, maybe...and you recognise that you're going to have to give more help...*

SO6: *the (name) that's there now I think 'I miss the old (name)'. Which is quite sad really; I know he's in there, but because of him not being well and everything's that's gone on this other (name's) coming out.*

Did not know what to expect. A common experience across participants was a sense of going in to the unknown with starting CFT.

P3: *Well, I didn't really know what it was going to be all about*

I: *Ok*

P3: *So I had to come*

I: *Just to give it a try sort of thing*

P3: *Yeah*

P7: *I had no knowledge of what was going to happen*

I: *Ok, so, these...*

P7: *I'd never even heard of dementia before, so to me the whole thing was totally new*

Theme 2. Support when I needed it. Even though participants did not know what to expect from the therapy, many expressed finding it very helpful. In particular, participants valued having the space to talk to someone who was supportive and compassionate, and also knowledgeable about dementia.

Someone to talk to. What emerged from the analysis was that some participants valued having the therapist to talk to, over any specific aspects of the CFT:

I: *Was there anything else about your sessions with (therapist) that you enjoyed?*

P1: *Just being able to talk to her*

P6: *...I did get lots of support from (therapist), lots of support from him, and the first part of the sessions he did uh, give me, um like open questions where he'd ask me how I was last week and how I was this week...he basically opened me up, and um gave me time to talk about my week, and problems and things...*

Dementia knowledge and skills. It was clear from the interviews that both participants and their supportive others valued the therapy being relevant to dementia, and having a therapist who could answer specific questions they had about the condition.

P7: *I was very pleased to meet.... It's nice to talk to people who know what they're talking about*

I: *Oh that's good*

P7: *I'd ask a question and you'd get an answer, I appreciate that*

P6: *But also...being able...having (therapist) there...who was knowledgeable about the condition...where I could ask him questions...where if we had just a facilitator...you know that didn't know the condition...it might be...*

I: *So it was important to you that it was specific to dementia.*

P6: *Yeah.*

A positive experience. Most of the participants described attending the therapy as useful and worthwhile.

P1: *I think it has helped me quite a bit yeah. Yes.*

Two supportive others, who expressed that they had not seen any changes in their loved ones with dementia, still described the experience as a helpful one.

SO2: *No all in all it's been a good experience, I'm very happy with it.*

I: *What else have you found helpful?*

SO4: *Having the sessions with ma – that was quite sweet because we've never done something like that together before, so that was quite special. And in a way, it was like having quality time with my mum!*

Compassionate therapist. Several of the participants commented on the kindness of the therapist and how they were made to feel comfortable.

SO6: *But with (therapist), with (name) he was very compassionate I suppose. It was really good*

I: *He embodied it*

SO6: *Yeah*

SO4: *Umm...and also the therapist, because you don't always get on with the person – you know I've had some therapists and I was like 'oh god', but no she was good.*

I: *And what was it about (therapist) that...*

SO4: *I think she had empathy, and she had a very gentle voice, she wasn't judgemental, well obviously you're not supposed to be are you, umm but yeah. A good listener.*

Theme 3. Changes in self and other relating. This theme reflects that many of the individuals with dementia were able to engage in specific compassion practices, which led to considerable emotional changes. The sub-themes describe changes in self-relating, including finding ways to regulate threat-based feelings, and increasing the activation of the soothing system. Some participants also spoke of increased awareness of their own patterns of self and other relating, and of finding a way to accept whatever happens.

I am calmer. Several participants spoke of feeling more relaxed and able to manage feelings of anger and anxiety.

I: *I know you said earlier that you used to be so, if something annoyed you used to get really really angry, has that changed now since the therapy?*

P1: *Yes, and no. Because I still get like it but I try and control it a bit*

I: *Ok*

P1: *I go like this sometimes (breathes in deeply) like you know as if I'm hugging somebody*

I: *So since your sessions with (therapist) do you find you're doing anything differently in your day-to-day life?*

P3: *Yes I'm trying to relax more, and to take one day at a time. Like if you ask me what I'm doing tomorrow I can't remember – it doesn't matter – I'll look it up in the morning when I get up and see what I'm doing tomorrow*

I: *Ok*

P3: *So I'm more relaxed I think*

P7: *<pause> I'm calmer than I was...*

I: *Ok, um..*

P7: *I don't rant and rave and get angry so much*

One of the supportive others mentioned that they also feel more able to manage angry feelings in relation to caring for her mother.

SO4: *It still angers me a lot. But maybe the difference is I don't let it last. So, if I was pissed off with (sister) because when I went there there was no food, the bins hadn't been emptied, the place was a...not you know, as clean as I would like it, I probably wouldn't speak to her for about a week, well I'd be angry with her for about a week. But now I just let it slide, so the next day I'm fine. And that's a big step for me.*

I am kinder to myself. Many of the participants with dementia described that they have more self-compassion and have changed how they respond to themselves in relation to their memory problems.

I: *Are you responding to yourself differently? So for example if you make a mistake or...*

P3: *Yes, yes I am...*

I: *Yeah in what ways would you say?*

P3: *Well I'm more um...<pause> 'it doesn't matter', more forgiving. 'Well what of it! You've forgotten something'*

I: *Ok so you just tend to let it go easier*

P3: *Yeah*

I: *Hmm. So you're nicer to yourself now?*

P7: *Well I don't shout at me anymore*

One participant expressed that he had become more assertive.

P6: *But by doing this therapy, and talking to (therapist), I realised, wait a minute I'm not being selfish, I need this time for me, and basically doing this therapy gave me permission to say, uhm, sorry I can't do it.*

A supportive other expressed that she was criticising herself less.

SO4: *I think I remind myself now...that I'm actually doing a good job. Looking after my mum and everything else I'm dealing with.....and sometimes I forget and I take a step back and I think 'damn, you've been through a lot'. So cut yourself some slack, because what you've been through...I don't know if everyone else would still be standing...*

Awareness and acceptance. Some of the participants spoke of noticing themselves and their needs more, as well as accepting themselves and the effects of the dementia.

P7: *I have accepted the fact that I have a 'memory problem' and I am happy being me. I also do not blame myself anymore for something that is not my fault.*

P1: *I thought no I'm not having it no more. I just carry on from day to day, whatever happens, happens.*

A supportive other expressed how she became more aware of how her mum sometimes felt smothered receiving her care, and the role she plays in this.

SO4: *...there was one day where she did open up and she talked about how much I care about her and um...but maybe sometimes it can be quite suffocating for her – so that was quite interesting to listen to. I mean I know I am anyway, I'm very overprotective when it comes to mum. And sometimes she will say to me – just back off. But I don't listen because I think, well somebody needs to protect you, so that's my job.*

Another supportive other powerfully described his wife's journey from anger and denial of the dementia, to some acceptance.

SO7: *Well the main thing is you've gone from total denial, anger, self-blame, um, to uh some acceptance – not complete acceptance*

P7: *No way – put up with it*

SO7: *But self-blame – there's still some of that, but uh, in general the change is total*

P7: *Mmm*

SO7: *It wouldn't have happened without the therapy*

P7: *No, oh no.*

Theme 4. Barriers to developing compassion. Even with the significant changes that participants had made a number of challenges in developing compassion were identified in the participants' responses.

Memory and cognition. Aspects of dementia may have made it difficult for participants to engage with and process the material, as well as to hold on to the information and experience.

I: *So, other than that are there any other specific ideas you've gotten from therapy that have helped you learn different things about yourself, or certain strategies that have helped you in any way?*

P3: *There was something, but guess what? I can't remember what it was!*

SO3: *<laughs>*

P3: *I gotta think about it*

I: *That's alright*

P3: *Um <pause> no it won't come like that, no.*

SO4: *...the breathing exercises, I think maybe for her was an activity – I don't know whether she understood it fully, you have to sit up straight, keep your feet apart, you know, so she*

would listen when they were giving her the instructions and <laughs> whether she followed it right to the end I don't know, because I would close my eyes when I was doing the mindfulness breathing...umm...so I wasn't watching her, but yeah she did do it sometimes <laughs>

Fears and blocks. Some participants spoke of the difficulty in being kind to themselves.

I: *And how are you feeling in yourself that you've developed this more assertive (name)*

P6: *Still feel guilty! <Laughs> Needs must.*

SO4: *Yeah because she talked a lot about compassion, which was not really in my vocabulary. I was like, why would I want to put myself...why would I want to think about myself, why would I want to do self-compassion? That for me was a waste of time because 'I've got stuff to do!' so I put myself last.*

One supportive other described experiencing the compassion exercises as 'mind-games', which led to the removal of these practices from their therapy.

SO2: *...there was one session, session 2, (therapist) said she had a CD that she was going to give us to take away, but she thought better of that afterwards, I think. We never took it away. Because we did the thing I've done on retreats, which is 'close your eyes and go on a journey', and that's not me.*

I: *Yeah was that mindfulness sort of thing*

SO2: *Yeah, I'm always in the same room at the end. You know and they draw you gently back. And I referred to that as 'mind games' – that's how I see it. The classic was I was on training where we were, split into pair and given a piece of paper and told to draw death, but um, that's like I said again not me.*

No problems. The same couple spoke of starting the therapy to help dementia research rather than having a particular problem that they wanted help with. This may have also gotten in the way of openness to compassion.

SO2: *Mainly because as I said earlier we didn't come with specific difficulties to which we were seeking resolution*

I: *Yeah you just thought 'oh this might be helpful for..'*

SO2: *Yeah I mean there was always a thought that it might be helpful, but uh, more helpful for the study and therefore to the greater good.*

Themes 5: Something more needed. There was a general sense from participants' responses that even though they had experienced the CFT as useful, there was a wish for more support.

I do not feel different. Two participants described not feeling any different since the therapy.

I: *So you've not taken up anything differently that you weren't doing before or you're not reacting to things differently or?*

SO2: *No*

I: *No nothing like that. Are you responding to yourself differently in any way?*

P2: *No*

I: *What about to other people? Or do you feel the same?*

SO2: *I would say so.*

I: *Have you noticed other changes in your mum? Have there been...I know it's difficult but it sounds like she became a bit more confused coming back from Ghana. Have there been any other changes?*

SO4: *Mmmmmm not really no.*

Another participant expressed that even though she had found this and previous therapies useful, the effects do not tend to last.

I: *Do you think that the therapy helped at all with your mood?*

P1: *Yes yes it did help me*

I: *Ok*

P1: *As I said, but it doesn't last long*

I: *Oh right ok.*

P1: *It's like the injections in my back and that. I've had injections down my back that side is like a pincushion and my hips right, and as the doctor said about the injections, I said I did have 'em and they did hurt, but I said they don't last long, same sort of thing.*

More support. Some of the participants had suggestions of what could be added to the therapy. In particular, one expressed wanting more help with memory loss.

P6: *...But it's just basically, um, this has been brilliant, this has been brilliant, but I would like to know a bit more about memory training...*

I: *Yep, so those practical strategies*

P6: *To keep it. Yeah practical strategies that's right.*

The same participant also voiced that they wanted more sessions.

P6: *Yeah personally I would have liked more. Yeah I found...I found it a big void afterwards.*

The participant's partner spoke of worrying about their future as a couple, and expressed wanting some support for her, too.

SO6: *...But that does worry me and that's where I think having the support for both of us would be good*

I: *Yeah. And is there any support for you?*

SO6: *I'm...I don't know.*

Discussion

This project aimed to develop a CFT intervention for people with dementia who were suffering with low mood or anxiety, or were distressed by their diagnosis. It also aimed to assess the intervention's feasibility and acceptability within this population, and to evaluate whether there were changes in self-compassion, mood, anxiety, and quality of life. A manual was developed and trialled using a case series of seven participants, in order to assess both its feasibility and acceptability, and change over time using pre and post outcome measures. Acceptability was also evaluated through post-therapy interviews conducted with six of the participants.

Summary of Results

Acceptability and feasibility. Attendance, participant rating forms, intervention coverage and post-therapy interviews were used to determine the feasibility and acceptability of the CFT intervention. Overall, the findings show that the intervention was both feasible to deliver - and acceptable - to people with dementia. No adverse events were identified.

The sessions were well attended, with five out of the seven participants having completed the 10 sessions. Participants fed back that overall they found the sessions very helpful. Much of the session feedback was related to core components of any psychological therapy, for example having felt heard and valued a space to talk about the dementia and its impact upon the individuals' lives and upon those within their system. However participants also expressed having appreciated the compassion-specific aspects, such as soothing rhythm breathing and developing self-kindness.

Six of the seven participants with dementia were able to engage in basic compassion practices, including soothing rhythm breathing, and flows of

compassion. Most were also able to discuss concepts related to compassion, such as ‘threat’ and ‘self-soothing’. These findings are consistent with Poz’s (2014a; 2014b) initial reports of using CFT in this client group, that the CFT model can be shared in a way that is understandable and relevant, and can be adopted by people with dementia and their carers. This also adds to the wider findings on the success of adapting CFT for populations with cognitive impairments, including ABI (Ashworth et al., 2015) and ID (Clapton et al., 2017).

During the interviews all of the participants expressed appreciation for the opportunity to talk with someone who knows about dementia, suggesting that this may be an important feature, and found the therapy a supportive and positive experience. Four of the five individuals with dementia who were interviewed spoke of having made changes with regards to how they relate to themselves, for example no longer criticising themselves for their memory problems, and developing both acceptance of their experience and kindness for themselves. One supportive other also spoke of significant changes she had noticed in herself, including greater self-care and a reduction of chronic self-criticism.

Nevertheless, participants did speak of challenges that may have inhibited engaging with - and making use of - the therapy. Several spoke of not being able to remember what was helpful, and that they did not feel any differently when directly asked, and one expressed that the benefit she did derive was not long-lasting. It is difficult to ascertain how much the cognitive deficits inherent in dementia impacted upon engagement with the therapy, and how much the demands of asking participants to freely recall information in the interview influenced participants’ answers.

Mood and wellbeing. All participants saw an increase in self-compassion, some considerably so, with four out of six seeing both reliable and clinically significant improvements. Furthermore, three participants completed the intervention with 'high' self-compassion, with scores of 4.5-4.6 out of a possible 5. These scores are of note, as they are considerably higher than the mean of an adult community sample ($M=3$, $SD=.76$), and of a sample of meditators ($M=3.66$, $SD=.61$) (Neff, Whittaker & Karl, 2017). The study participants had baseline scores between 2.08-3.58, so unusually high self-compassion scores prior to the intervention cannot account for this.

Six out of seven participants saw improvements in mood, four reliably so. All participants also saw a reduction in anxiety symptoms, however only two were considered a reliable improvement. A further two individuals completed the intervention with sub-clinical anxiety scores, however they were not deemed as clinically significant due to their pre-post score change not exceeding the RCI. All participants saw very little change in their quality of life, with no reliable change found on this measure. The overall pattern of the results indicates that the CFT intervention had a positive effect on self-compassion, mood, and anxiety.

Implications for Practice

Given that self-compassion appears to have a protective effect for older adults through the ageing process these findings are noteworthy. Higher levels of self-compassion have found to be associated with positive ageing (Phillips & Ferguson, 2013), greater subjective wellbeing and positive affect (Allen, Goldwasser & Leary, 2012; Phillips & Ferguson, 2013). This study suggests that self-compassion can be increased in individuals with dementia, and that a compassion intervention can also improve mood and anxiety. This may be particularly relevant in this client group, as

a diagnosis of dementia and its associated neurological impairments can leave individuals vulnerable to feelings of shame (Cheston, 2005), and a sense of ‘existential threat’ (Poz, 2014b). CFT is well placed to address these difficulties. The intervention addresses the ‘tricky brain’ and the ‘even trickier brain’ in dementia, and de-shames the experience of cognitive impairment through the message of ‘it’s not your fault you have dementia’ and ‘you are doing the best you can given where you have found yourself’. This can reduce the sense of threat, and the development of self-soothing abilities can help moderate this further.

Several carers expressed difficulties of their own during the CFT. It may be that the experience of supporting a person with dementia through the intervention will highlight carer needs. Feast et al. (2016) have highlighted the importance of the carer’s unmet needs within psychological treatments for people with dementia and so this might be planned for during assessment. Services employing interventions such as the one outlined above will therefore need to remain mindful of the possibility that carer needs might surface in light of another’s therapy and require a dedicated intervention.

Given that the project was a feasibility study it was not the intention to generalise findings to the wider clinical context at this point. However, in the absence of definitive evidence of what *kind* of psychological therapy works in this client group (Orgeta et al., 2014), the current study suggests that CFT could be a feasible choice for psychologists in NHS memory services.

Implications for Research

As the study used a case series approach to assess feasibility of a novel intervention it is difficult to draw firm conclusions regarding its effectiveness upon the wider population. Further work is needed on the content of the CFT manual. The

flexibility of the manual allowed for adapting the CFT to the person's cognitive ability and 'openness' to compassion, however the study found it could not be sufficiently covered in 10 sessions, and therefore it is not feasible in its current form. The literature review in part one of the thesis - which evaluated the effectiveness of CFT across populations - indicates that at least 12 hours is required for an effect. Therefore further research could trial offering up to 12-15 sessions (depending on the need and wishes of the person), to determine if this would be more clinically useful for people with dementia.

Once the manual is deemed feasible the next step could be a trial with a larger sample, in order that effectiveness could be evaluated using inferential statistics, as well as the effect size and the power of any effect. It would also be useful to compare CFT to a wait-list control group, as well as another psychological intervention for people with dementia, for example CBT. Such an investigation would help determine whether CFT is more or less effective than no intervention and another psychotherapeutic intervention with some early evidence of effectiveness in this population. This would allow greater certainty as to whether CFT is a robust intervention for people with dementia and associated psychological difficulties.

One supportive other was unable to tolerate the breathing and compassion practices, which were core components of the intervention. He later acknowledged that his 'attitude' might have gotten in the way of the couple benefitting from the therapy. It is reasonably common to encounter difficulties in peoples' abilities and motivations to develop compassion, for example avoidance and fear, especially in those who have experienced early low affection environments or abuse (Gilbert, McEwan, Matos & Ravis, 2011; Gilbert, 2007). It is important, therefore, that CFT interventions actively address these fears and blocks to compassion (Gilbert,

McEwan, Catarino & Baião, 2014). The study's CFT intervention did include a section on fears and blocks, aimed for the person with dementia. However in this case it was the supportive other who expressed a dislike of the compassion practices, and the intervention was not equipped for this. Further thought is needed on how the supportive other can both assist the person with dementia, but also be worked with if difficulties arise for them that may become a barrier to the therapy.

Most research into CFT evaluates the effectiveness of group interventions. This study in comparison assessed its impact through an individual intervention. Not only are group interventions more cost-effective, but also for CFT they can harness a core experiential component of 'common humanity' (Neff & Germer, 2013). The experience of sharing affiliative experiences can be powerfully de-shaming, (Judge et al, 2012; Clapton et al., 2017; Gilbert, 2010a). It would be useful to determine, therefore, how feasible and effective group CFT is in this population.

Limitations

The SCS-SF - which measured self-compassion - is not validated for use in the dementia population. At least one participant was unable to understand the measure, which led to it being excluded for this individual. All other participants completed it, however it cannot be certain that it was fully understood and therefore confidently measured the construct of self-compassion as it was intended. Similarly, one participant did not have a supportive other, which meant the CSDD, the RAID, and the QOL-AD were completed by the person with dementia only. These measures are validated when completed by a carer, which brings in to question the validity of one of the participant's scores.

Even though the manual was designed to be adapted to each participant, the intervention was changed considerably for two of the participants. For example

delivering the therapy to the supportive other due to a lack of understanding from the person with dementia, and removing the compassion practices for another couple. Arguably the change scores for these participants may not reflect the CFT intervention as it was designed. These participants were not excluded from the study primarily as it provides useful information on the feasibility of the intervention, as well as likely challenges that may be encountered when it is delivered in clinical settings. This does suggest, however, that the intervention may be less suitable or helpful for individuals who are more cognitively impaired.

Four different therapists delivered the intervention, and due to the feasibility nature of the study no adherence ratings were completed. Even though all had attended training in CFT it is difficult to ascertain whether the manual was delivered as intended and consistently across practitioners. As the author of the intervention and one of the delivering clinicians of the intervention, it is also possible that the study was affected by researcher allegiance (Leykin & DeRubeis, 2009). It is difficult to ascertain whether this bias influenced the outcome of participants' scores, however steps were taken to reduce bias elsewhere, including all assessments and interviews being conducted by a different practitioner than who delivered the intervention.

The study did not measure extra-therapeutic factors that may have hindered or enabled the therapy, which have been estimated to contribute to 40% of change (Miller, Duncan & Hubble, 1997). Extra-therapeutic factors include clients' individual strengths and resources, aspects in their environment, their support system, and change events (Hubble, Duncan & Miller, 1999). Therefore, the changes that were observed cannot be confidently explained by the intervention alone.

The analytic approach taken to analyse the interview data (thematic analysis), although provides an overall summary of themes and integration of participants' experiences of CFT (and may provide greater protection of privacy for those who took part), does not allow for individual meaning-making for each particular case. For example, the use of Yin's (2014) mixed method approach to case series could have allowed the interview data to be presented alongside participants' outcome measure data, creating greater depth of understanding as to why participants may or may not have changed on the individual outcome measures.

Conclusions

This study suggests that CFT can be adapted in such a way that it can be delivered to people with dementia who are suffering from low mood or anxiety or other associated distress. The intervention was mostly well liked by participants, and improvements were seen on measures of self-compassion, mood, and anxiety. This indicates that people with dementia can develop self-compassion skills, which may be protective as they continue to navigate progressive cognitive decline. A larger pilot trial with a comparator group is now needed before firm conclusions can be made on the intervention's effectiveness for people with dementia.

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Part Three: Critical Appraisal

Introduction

I will begin this appraisal by introducing my professional and personal contexts that informed my particular choice of research into dementia and Compassion Focused Therapy (Cronen & Pearce, 1980). I will then discuss the benefits of using case study research, and reflect upon the methodological and practical challenges of attempting to design an intervention and pilot it within the constraints of a doctoral research project. Lastly, I will reflect upon the professional and personal learning outcomes.

Locating Myself in the Research

Early on in my psychology career I worked in a care home for people with dementia as a support worker. I observed that family members and friends rarely visited many of the residents, and there was a sense that they merely existed day by day. I also noticed the power of positive emotional experiences in the presence of memory loss; it was not the content that was remembered, but the felt-sense of the moment. This appeared to have a considerable impact on the person's mood and their ability to engage in meaningful contact with others. It also appeared to me that when the person was not defined by the dementia and its associated deficits, the person with a history, with interests and hobbies and relationships shone through.

I felt saddened by the experience that individuals with such a wealth of life experience and contribution to society had been seemingly forgotten. I further experienced this disinterest in older adults and people with dementia whilst on training, as other trainees' enthusiasm appeared to lie within working with children and early intervention in the prevention of mental health difficulties, or with adults who have the rest of their lives ahead of them. I soon realised that I wanted to focus

my research in the realm of wellbeing in older adults and in those with dementia, and to use this opportunity so that these people were not forgotten.

Directly prior to training I worked for several years in an Increasing Access to Psychological Therapies (IAPT) team, delivering cognitive behavioural interventions en-mass to those suffering with anxiety and depression. Although for some this approach worked and relieved symptoms, for me it lacked emotional depth and I became frustrated at a sense that something deeper was missing. I discovered Compassion Focused Therapy (CFT), a third wave CBT approach, which appeared to have an emotional focus, leaving behind the rational thought challenging which sat so uncomfortably with me. CFT encouraged the development of kindness and courage in the face of emotional pain, through activating the innate human motivation for connection and care. Self-soothing exercises such as soothing rhythm breathing and compassionate imagery were encouraged as a way to down-regulate feelings such as fear, anxiety and shame.

In my exploration of what is typically offered to individuals following a diagnosis of dementia I was struck that NHS resources are predominantly channelled into the early identification and diagnosis, and that some services do not offer post-diagnostic psychological support. An increasing amount of resources have been put into the development and delivery of support for partners and family members of those with dementia, due to the associated ‘burden’ and ‘stress’ of living with someone with dementia (Lyman, 2000). Prevalence rates of significant emotional distress in individuals with dementia are well documented (e.g. depression: Amore, Tagariello, Laterza & Savoia, 2007; Enache, Winblad, & Aarsland, 2011; Muliya & Varghese, 2010; and anxiety: Badrakalimuthu & Tarbuck, 2012), yet there has

been a lack of research effort to develop and evaluate effective psychological treatments for those living with dementia (Orgeta, Qazi, Spector & Orrell, 2014).

Given my findings on the lack of emotional support offered to individuals with dementia, Gilbert's (2009) description of compassion aptly described how I felt: "a basic kindness, with a deep awareness of the suffering of oneself and of other living things, coupled with the wish and effort to relieve it" (p. xiii). Given my journey that I outlined above, I wondered whether CFT might be a useful approach for people living with dementia and experiencing emotional distress. I wondered whether those who were suffering the effects of cognitive impairment and decline on a daily basis might criticise or blame themselves for their perceived deficits, and whether fostering self-compassion could facilitate a greater sense of 'living positively with dementia' (Bryden, 2005), and help counteract the narrative of loss of the self and abilities that surrounds it (Beard, Knauss & Moyer, 2009). I was fortunate that my supervisor, a lead researcher in the field and a fellow advocate for increasing wellbeing in older adults and those with dementia, supported my idea to trial it.

Case Study Research with People with Dementia

Case studies have given the field of psychology and psychotherapy a wealth of knowledge and understanding of the theory of emotional distress and have provided the foundations of clinical interventions (McLeod, 2015). Any novel approach or treatment is typically tried first with individuals before ethical approval can be granted for research in larger trials (McLeod, 2010). The advantage of case study research at the early stage of the development of a therapeutic approach is that it can explore the 'how' and 'why' it works (or does not, as the case may be). This approach can also take into account the complexity of the individual, and provide

indications of how an approach should be adapted to meet the needs across populations. For me, case study research fitted with my identity, firstly as a clinician, and secondly as a researcher, who wanted to evaluate a clinical intervention on an individual basis with people with dementia, rather than evaluate an amalgamation of numbers and effect sizes, where individual variability can be lost.

It also appeared that case study research would provide people with dementia the opportunity and the space to reflect upon and process their emotional experiences of being diagnosed with a neurodegenerative condition, and to potentially find ways to navigate cognitive decline with compassion. The dominant historical discourse around people with dementia is that they have a lack of insight, defective memories, and their thoughts are of little importance in their care planning (Beard et al., 2009). Kitwood (1997) described this loss of considering the person as ‘malignant social psychology’, which has helped start to shift this narrative and encourage a person-centred approach where the person with dementia is seen and heard. To me it was very important that individuals with dementia were first consulted during the intervention development, and that the participants engaging in the therapy were interviewed and asked their opinions on their experience of the intervention. I wanted to ensure that changes on outcome measures was not the only way the therapy was evaluated, and that the participants were given a voice to express what they thought had (or had not) changed for them as a result of the therapy.

Case series, however, do receive criticism for having a lack of internal validity, as any observed change is not compared to a comparator or a control group. In addition, unless extra-therapeutic factors are considered in detail, it is difficult to be sure what causes the improvements on outcome measures. Nevertheless, employing a mixed methods approach is suggested as one way to increase the

validity of the findings, through integration and triangulation of the data (e.g. Hanson, Creswell, Clark & Petska, 2005; Wood, Mollasiotis & Payne, 2011). Given that this was a feasibility project, it was considered that the case study approach would be most suitable in adequately addressing this research question. The validated measures in this study provided concrete and tangible data on emotional changes over the course of the intervention, with information on statistically significant and reliable change for each individual. Additionally, the interview data provided rich, detailed accounts of the persons' journey into the dementia diagnosis, their responses and reactions to the content and process of the therapy, and how they might be responding to themselves differently as a result. For example, one participant was considered to have sub-clinical symptoms of depression and anxiety prior to the intervention, and she saw only minor improvements in her symptoms over the course of treatment. However, her interview data communicated that she was distraught with the dementia diagnosis, and that through receiving CFT, she was able to mostly accept and live more comfortably with the condition, which others around her also noticed.

Methodological and Practical Challenges

The Issue of Compassion

The decision to focus mainly upon self-compassion throughout the intervention was based on several considerations. Gilbert's (2014) CFT places equal importance upon the 'flows of compassion', that is developing compassion for the self, compassion for others, and receiving compassion from others. It is thought that by focusing upon these flows of compassion, a 'compassionate self' can be developed, whereby one has a grounded position associated with organising ways of attending, thinking, feeling and behaving (Gilbert, 2014, p30). Much of the research

on positive ageing and wellbeing in older adults identifies the protective benefit of *self-compassion* (e.g. Allen, Goldwasser & Leary, 2012; Allen & Leary, 2014; Phillips & Ferguson, 2013), and the hypothesis driving the intervention was that reducing self-criticism in relation to perceived impairments and increasing self-compassion in people with dementia, would increase overall mood and quality of life for the individual. During discussions with my external supervisor (who delivers CFT to people with dementia), we wondered whether placing equal focus upon the different flows of compassion might in fact be conceptually too challenging for those with dementia, and ultimately, the goal was to increase self-compassion. Consequently, components of Neff and Germer's (2013) Mindful Self-Compassion programme were considered and integrated into the current intervention, with exercises on flow included, but after self-soothing was grasped. It was hoped then, that by focusing upon this one concept, people with dementia had more time to make sense of the notion of self-compassion, and through repeatedly returning to it, learning and change was more likely (James, 2010).

It is possible, however, that greater benefit could be derived from including the development of other components of compassion, for example being able to receive care from loved ones as the dementia progresses may reduce distress experienced during the transition. Additionally, increasing the person's ability to relate to loved ones with care and concern may facilitate the person's identity as not being purely defined by the dementia (by themselves and others). Integrating these components of compassion in the CFT for dementia intervention calls for further research and evaluation.

NHS Ethics and Recruitment

As in all research, I encountered a number of unforeseen practical difficulties throughout the journey. The process of gaining NHS ethical approval for the study was lengthy and arduous, as trialling a new intervention was put under the upmost scrutiny. I had to argue the likely benefit of ‘Compassion Focused Therapy’ to the NHS ethics panel, and to disprove that it may be harmful to people with dementia. And although I understood the need for scrutiny for offering a new intervention, the process left me wondering whether future DClinPsy trainees and/or researchers might be put off by the intensity of the scrutiny they experience from NHS ethics committees, and by what I experienced as a lack of collegial feeling and support during the ethics meeting.

The sense of achievement of finally being granted ethical approval quickly dissipated once the recruitment process began. I had a large London memory service on board as the research site, but as a non-staff member I was prohibited to contact patients under their care. After months of liaison with the team and the intervention being discussed in regular team meetings I still had no participants. My initial aim to recruit 12-15 participants became unlikely, although with hindsight this was an ambitious number to recruit within a project of this size. Eventually, an assistant psychologist within the memory clinic was given some time to assist me with recruitment, and they identified several people with dementia who met the inclusion criteria. As an employee she contacted these individuals, and seven months after gaining ethical approval, I finally recruited my first participant. Having realised that I would be unable to recruit enough participants on my own in this one research site, I liaised with another memory service, which agreed to see two-three participants for the project, and by this point had recruited two people with dementia. In the end,

only three participants were recruited from the main research site, whom I saw and delivered the CFT intervention to. I managed to recruit one further participant from advertising across London dementia charities, and a further participant from an additional NHS site, totalling seven participants.

Compassionate Participants and Clinicians

Another unforeseen dilemma arose during the recruitment process, whereby a participant and her supportive other met the inclusion criteria (i.e. the participant had dementia and scored in the clinical range for low mood), however the couple chose to participate to help with dementia research, rather than wanting to engage in a psychological therapy for their own benefit. This made it very challenging to deliver the intervention in the way it was intended, because the person with dementia did not have any goals or wish to make any changes, nor did her supportive other. It is understandable then, that this couple refused to engage in any of the breathing and compassion practices, which I formulated as a ‘block’ or ‘fear’ of compassion, an occurrence well documented in the literature (e.g. Gilbert, McEwan, Matos & Ravis, 2011; Gilbert, 2007). It is possible, however, that neither understood the rationale nor considered the practices relevant to their situation. Even though the relevance of the intervention was discussed with the couple at every session, they expressed a wish to continue in order to assist with the research. This was potentially a compassionate thing for the couple to do, however it is questionable as to how much this participant’s change scores actually reflect the impact of the CFT intervention, as it was impossible to follow the manual in this case. With hindsight, this highlighted the possible need for an additional explicit inclusion criterion of ‘has a wish to engage in psychological therapy’, and this could have been further explored during the initial assessment.

In my aim to reduce bias in the project I was fortunate that a number of clinicians kindly assisted me in conducting the outcome measures and post-therapy interviews. However, this also led to a loss for the project – the interviewers varied in their knowledge of CFT, interviewing skills, familiarity with change interviews and experience in working with people with dementia. The post-therapy interviews varied significantly in their length and depth, and having delivered the intervention to a number of the participants, often their comments did not seem to reflect the changes they had made or how they appeared to experience the intervention. This could be in part attributable to participants having difficulty recalling details of the therapy, and reflecting upon any changes over time. During the planning stage it was suggested to me that I conduct the interviews, as knowing the intervention and the therapy that was delivered to each individual meant that I could ask sensitive and more detailed questions, which could lead to more idiosyncratic responses and descriptions. Nevertheless, this was discussed with my supervisor and we agreed that reducing bias was more important for the project. However in retrospect, I would have invested some time to train the interviewers on the content and process of the intervention, as well as explored their confidence and ability to conduct semi-structured interviews with this client group.

Professional and Personal Learning

Looking back, I appreciate that I was ambitious taking on this project. However, it has taught me several important lessons as a researcher. Firstly, I learned the importance of believing in the research and maintaining motivation in the face of practical barriers, such as difficulties recruiting and a considerable amount of travel. I was fortunate to be in the position of creating and developing my own research project based on my journey into training, and this gave me a sense of ownership and

autonomy. I am confident that this is what kept me going during times of physical and emotional fatigue.

Secondly, this process has taught me the need for open and on-going communication with staff at research sites, especially during the recruitment phase, as research will rarely remain at the forefront of clinicians' minds – it is the role of the researcher to sensitively remind, prompt, and encourage busy clinicians who have other pressing priorities. Similarly, if I had not made contact with psychologists who had an interest in CFT in dementia, the project would have not come together as it did. Making this contact enabled me to be invited to observe a CFT for dementia group run by Dr Rebecca Poz (clinical psychologist and neuropsychologist), who, to my knowledge, is the first person to have written about CFT in dementia. Seeking out contact also led to the setting up of specialist supervision for me as a relative novice in the field, from Dr Syd Hiskey (clinical psychologist), who shared with me his knowledge of CFT and delivering it to people with dementia in an NHS memory service. Their valuable contributions and support enormously shaped both the development and the delivery of the project.

Thirdly, this research journey taught me to stay anchored during those times where it was easy to feel lost at sea amongst the competing demands, not only from the research, but also from clinical placements, other academic work, and maintaining a personal life on weekends and evenings. I found it incredibly useful to employ the self-compassion practices that I was delivering to participants. The 'common humanity' principle described by Neff (2003) helped remind me that I was not alone in my (research) suffering; at least another 50 of my peers were on their research journey and were facing their own challenges, which gave me strength and motivation to continue. Soothing rhythm breathing regularly kept me grounded

throughout this process, especially on long car journeys to research sites and the minutes before starting a session. Developing compassion gave me the courage to create an adapted version of an established therapy and test it in a new client group, and to take the role of the main delivering therapist. I paid attention to self-critical thoughts related to my abilities, and decided whether I could benefit from further supervision and/or a return to the CFT literature, or whether it was my threat-system that needed down-regulating. When I felt pulled in different directions or encountered difficulties with delivering the intervention, simply taking a moment (or many moments) to breathe and to remind myself that I was doing the best I could given the situation, helped me regulate my own threat system (Gilbert, 2014).

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Appendices

Appendix A – Focus Group poster



Compassion-Focused Therapy for People with Memory Problems: FOCUS GROUP

Do you experience problems with your memory?

Are you a partner or a ~~carer~~ of someone who has problems with their memory?

Would you like to take part in a focus group to help develop a new psychological therapy for people with memory problems?

By participating in our focus group you can help us design a new psychological intervention that will aim to help people cope with their memory problems by developing self-compassion

Wednesday 4th May 2016
12:30pm-2pm
Before the Memory Café at the Broad street Health Centre

Refreshments and snacks will be provided

Appendix B: Intervention development: Consultation with People with Dementia and their carers

Individual	Comments	Suggested Changes
Carer/partner	<p>Wish for more support for carers – lots to cope with with all of the changes in their relative, struggles with day to day activities etc. Desire for some time alone with therapist, partly for own support and wish to be heard but actually so able to feed back on how they are without the person there (not wanting to upset them etc)</p> <p>Thought 50 minutes is a good amount of time, if feeling well would go quickly, but suggested flexibility so that if one week the person was tired/unwell the session would be shorter</p> <p>10 sessions ok</p>	<p>Consideration of time alone for carer (although confidentiality issues?)</p> <p>Keen for relative/carer to be present and involved</p> <p>50 minute sessions but flexibility to cut shorter if necessary</p>
Carer	<p>Liked the idea of supportive other. Expressed that mum would need help with discussion in the sessions.</p> <p>10 sessions ok. Flexibility of 50 minutes, depending on how doing that day.</p> <p>Asked if intervention could be done during home visits as mum is not mobile so could not attend the clinic</p> <p>Wanted handouts/written resources to help with concepts</p>	<p>Include supportive other</p> <p>Flexibility of 50 minute sessions</p> <p>Home visits or transport</p> <p>Handouts</p>
Carer	<p>Liked the idea of supportive other Relative was keen to be involved in the process as a support. Also thought it was not too much to ask to help with home practice activities etc</p> <p>10 sessions ok 50 minutes a good time</p>	<p>Supportive other Help with remembering appointments and home practice</p>
PwD	<p>Liked the idea of supportive other Wanted their family member (mum) fully involved with whole process. Thought this would be useful for reminding about appointments, helping her to get there, to help her remember what was discussed, as well as reminding and doing the home</p>	<p>Supportive other Help with remembering appointments and home practice</p>

	<p>practices together</p> <p>10 sessions ok 50 minutes a good time</p> <p>Liked that would receive an audio copy of the practices so that can practice at home.</p> <p>Liked the idea of developing the compassionate self</p> <p>Wanted handouts/self-help guide</p>	<p>Audio CDs. Option of MP3?/online access?</p> <p>Handouts</p>
PwD	<p>Liked the idea of supportive other</p> <p>10 sessions ok</p>	
PwD	<p>Did not like the idea of a supportive other (person stated did not have any family or friends)</p> <p>Liked the idea of starting each session with breathing exercises (has found them relaxing in the past)</p> <p>Suggested transport</p>	<p>Ensure start with breathing</p> <p>Transport to sessions</p>
PwD	<p>Liked the idea of supportive other, but wanted it to be flexible so that maybe they could be involved more or less initially, and depending on what they wanted to discuss the supportive other's involvement could change.</p> <p>Liked the idea of compassion (expressed she had low self-esteem), as the mindfulness aspect (in the being mode vs the doing mode)</p> <p>Keen for practices to be audio recorded and given as a CD to listen to at home</p>	<p>Flexibility for supportive other throughout intervention</p> <p>Audio CDs</p>

Appendix C: Intervention development: Consultation with Professionals

Professional	Comments	Suggested Changes
1. Psychologist	<p>- Is dementia always a threat? Does it always trigger threat-based emotions? Might clients have other perspectives on this? Do you need to specify with your clients when doing the formulation what specifically is generating threat-based emotions?</p> <p>- Something about drawing out clients strengths and existing self-soothing strategies and building on this (you may do this in your formulation session)</p> <p>- I was trying to think what sort of goals people would come up with and I was wondering if for some people the diagnoses may mean a loss/change in roles and so including something about values might help with the rationale for compassion work in this case? I appreciate you have limited sessions and may want to stick to CFT more than mixing with ACT..</p> <p>- I like your adaptations!</p> <p>- Don't know about the diversity of your client group but do you need to consider individuals religious or cultural beliefs and giving time as part of the formulation/psychoeducation to discuss this</p> <p>- I can see this would be the maximum that you would include, my initial impression was that this may be quite ambitious for some clients. Do you have flexibility for more psychoeducation at the start e.g. if you have a client who struggles with identifying/expressing emotions?</p> <p>- I may have missed it but does self-critical thinking come in anywhere?</p>	<p>-Exploring meaning of the dementia dx for the person: what aspects are linked to threat-based emotions?</p> <p>-Identify client's strengths and existing self-soothing strategies in formulation session</p> <p>- Linking goals to values</p> <p>- In process section add consideration of religious and cultural beliefs and discussion of this in formulation and psychoeducation section</p> <p>- If needed take additional time for psychoeducation initially, especially if struggles with identifying/expressing emotions</p> <p>- Include section on self-critical thinking</p>
2. Psychologist	<p>The initial sessions- I wondered how much in the engagement phase considers how CFT is relevant specifically for carers and whether they will feel that some of their common concerns have been heard. Something about the evidence base for common difficulties for carers and how SC helps with these things as part of the psychoeducation. Perhaps the three systems could make ref to this with a carer appropriate example? It looks like this is probably something you are doing? I guess I wondered whether linking back to caring role may help make it feel less MH stigmatising?</p>	<p>Including carers regarding their experiences of being a carer. (could use an example but the intervention is for the pwd so not really the focus here)</p> <p>- Returning to fears and blocks of</p>

	<p>Its great to see fears and blocks are in here, in my own group we didn't have chance to spend enough time on this which I feel could have been really helpful. I think it helps to tap in to the humanness of our difficulties to SC. I would imagine going back to this throughout sessions would be helpful.</p> <p>I can see there are lots of breathing exercises in here which I think is great- but I guess just always going back to the theory behind why this is important and delivering it in a humorous way to begin with (ha I saw it as just breathing and then I read all this stuff/ saw how it helped others). Obviously this is just one way and may not be group appropriate or feel right</p>	<p>compassion</p> <ul style="list-style-type: none"> - Linking breathing practices to the theory - deliver in a 'humourous' way
3. Psychologist	<p>Really like the fact that keep repeating things to help consolidate. The other thing I was thinking is maybe some more concrete and reminiscing things so maybe the list of things to be grateful for</p>	<ul style="list-style-type: none"> - Included reminiscence – list of things to be grateful for (use in tool box for options)
4. Consultant Psychologist	<p>- Those delivering it stick to your guidance (in bold) that the content needs <i>adapting</i> depending on the client's availability to the work. This is vital, of course. In many ways the content (as is) can be viewed as a guide and therefore can probably stay as is. Formatting each session is generally a helpful thing to do and is a good idea for consistency, and a common framework for the therapy.</p> <p>I especially like the practice at the start to set-up each session. Keep this in as it's very behavioural/grounding and exactly what we want (i.e. the experience of soothing rather than all of the intellectualising about it - which is what many PWD might struggle with).</p> <p>I agree, don't worry about compassionate reasoning too much in terms of thoughts diaries. This skill can be addressed in conversation and if it needs formalising can take the form of one or two key self-critical thoughts that can be routinely challenged (on paper if needed). It's these we want to target (key thoughts/reasoning) and we're not aiming to help develop cognitive flexibility a la CBT (akin to that which ACT is interested in).</p> <p>I think you'll need Therapy Folders, to contain handouts etc. We found these really useful in</p>	<ul style="list-style-type: none"> - Keep outline as a guide and adapt according to client - Keep opening practice - Address self-critical thoughts through conversation, and if needed write down one or two key thoughts on paper and consider compassionate alternative.

	<p>Aimee's CBT for PWD pilot.</p> <p>You ask whether SRB should be repeated in session (i.e. x2). Rebecca may have done this but I don't think we'll have time. We really do need to allow time and space for conversation and questions, not to mention uncertainty (which can be explored and helped with compassion). Overall less = more in this instance. My sense is that x1 SRB etc. in session with provide an anchor for people to remember when doing daily practice. Repeated exposures in session may not be needed. Of course, ultimately, this is an empirical question.</p> <p>Make sure and mention specific <i>goals</i> in the therapy protocol from Session 2 onwards. Currently what you have is great but might be rather generic to dementia. Our stated aim is to see if CFT can be acceptable to PWD and the more we can anchor this to a <i>specific</i> aim (i.e. my anxiety, my depression, how I cope with the news of my dementia or the changes I experience) then that's what we should seek to return to in session. The task for the therapist will be to weave the goal into every session as they can.</p> <p>Are we intending to have Carers/Supporters present during therapy? I'd say we should make this an explicit aim. I don't know what Aimee thinks and so have copied her into this email for her thoughts. Asking someone to do all of this with just the therapist is OK but the presence of a Carer/Supporter can make this so much more powerful. Obviously there are pros and cons but a potential boon is that the Carer themselves might be encouraged to use the practices too. I know this could spin off into all sorts of research tangents but I'd be interested to hear what you both think about the presence of others, throughout the whole treatment. If they are included a carer's measure might be needed. Also, if you do include carers this gives you more to explore in your focus groups in terms of acceptability of their presences to both parties. As you can tell I'm keen on Carers being present. The CBT pilot featured this and it really seemed to help.</p>	<ul style="list-style-type: none"> - Use therapy folders for handouts - 1 SRB in each session. - Allow for time for discussion, uncertainty etc. - Return to goals from session 2 onwards - Anchor tx to specific aim -Involve carer/supporter
5. Psychologist	Involvement of carers. I agree with Syd that they should be involved, but that this should be	- Invite carer to be 'supportive other' if

	<p>determined a) on whether people have one and b) whether they want one involved. The degree to which they are involved (ranging from attending every session to just being informed and helping a bit with work outside sessions) should be dictated by the person with dementia I think, in a similar manner to the CBT trial. I would be keen not to exclude people without a named carer, as they will be at early stages of dementia, it will increase our chances of recruiting and will also be interesting, as part of the feasibility work, to examine the possible range of carer roles.</p> <p>'Tool kit'. In the CBT trial, we had a kind of 'you choose' list of possible techniques that you might employ in the intervention phase (e.g. behavioural experiments, cue card, etc). Is this something that might work here?</p>	<p>pwd wants this. If they do can agree on how much they want their supportive other to be involved</p> <ul style="list-style-type: none"> - Do not exclude people without a carer. - Tool kit of 'you chooses' techniques/resources (i.e. soothing rhythm breathing, LKM, imagery, letter writing, list of things to be grateful for etc)
6. Occupational Therapist	Thought it is important that a carer/relative is involved, but that this is discussed and agreed on a case basis, including how much the supportive other is involved as the therapy evolves	Involvement on supportive other and involvement as flexible
7. Psychologist	<p>I can't really think of much feedback, as I think you have it all covered. The only things I can think might be an idea:</p> <p>The compassionate letter - would you maybe have to adapt this so that it does not confuse the person if they have forgotten they wrote it. Obviously depends how impaired they are but could be a bit confusing to suddenly get a letter from yourself? Maybe you could include a bit at the top reminding them that it is part of the compassion course. Or maybe not leaving such a big gap between writing and receiving it?</p> <p>When I asked for feedback about the CFT group in the CMHT for my SRRP, a lot of the feedback was about how difficult the three systems model is to understand, so maybe keeping that bit as slow and simple as possible. Using real life examples of compassion/examples of what it might be like if you are very drive/threat focused etc and sharing these with the group was seen as being very helpful.</p>	<ul style="list-style-type: none"> - In compassionate letter include initial section on reminding why they are receiving the letter - Consider length of time between writing the letter and sending it - Keeping 3 systems model simple as possible - Using real-life examples of what it might be like when in the drive/threat/soothing

	<p>We used examples like you mentioned a bit like the hot-cross bun. So we would say, you get lost on the way to the shop. What happens if your threat system is really big/on overdrive. What would you think, feel, do etc. And then it was more about what sorts of things could you do to get your soothing system bigger? Could you use a compassion exercise? If you had a large soothing system - what things would you be doing etc. So I guess it fit with the compassionate thoughts/behaviours bit</p>	<p>- Hypothesising through the model – unpicking what the person would think, do, feel etc. And ask what could they do in that situation to increase their soothing system? If you have a large soothing system what would you be doing etc.</p>
10. Nurse	<p>Ensure the person’s culture and religion is taken into account</p>	<p>Ensure the person’s culture and religion is taken into account</p>
11. Psychologist and Carer	<p>As a side note, given this is me speaking as a carer who is profoundly biased- I think a lot of resources goes into people who are in early stages of dementia, with those in the later stages-e.g. moderate to severe- don't get the same attention from services/MH research. It's a shame really, considering the more severe the more help we need. But anyhow- I'll give it a think from how my experience was a few years ago (mild-mod) and shall get back to you ASAP. Look super feasible to me.</p> <p>I read your proposal and went through it with family members for feedback; I think it looks great and can't really add much beyond the cultural-non- English language and severity part, but as this is not aim there's not much I can see that might need addressing.</p>	<p>- support for individuals with more severe dementia - provide for people who do not speak English</p>
12. Psychologist	<p>How long are the sessions? Too long and they might not be able to manage the whole session. Worth reminding/refreshing 3 components at second meeting? 3 circles model: This is quite complex and a lot to retain. Unless this is done very simply they might not be able to hold all this, process it and remember it. Keep it really really simple.</p>	<p>Be mindful of length of session; agree with ppt how long they want to meet Remind of 3 components of compassion at second session – link to psychoed Depending on client’s cognitive ability break down model into separate parts</p>
13. Psychologist	<p>Overall, I think you've done a great job on planning the intervention. Seems to cover</p>	

	<p>everything, yet not overwhelmingly so.</p> <p>I notice that there will be review of the home practice but, given the clientele, I was wondering if there would be a review of the material covered in the previous session before each session? Also, will you be providing clients with an appointment card with all the sessions or calling them up a day before to remind them/their supportive other of it? Based on my experience with a CST group I'm running, that can make a big difference with individuals who have dementia.</p> <p>3 systems model: I'm wondering if the formulation will need to be simplified for them? Definitely use the three systems but I would think it had to be broken down a lot.</p> <p>Safe place imagery: Wondering if it would be useful to first determine whether or not they are able to hold the image in their minds for 5-10 minutes? I understand that you'll be using autobiographical memory, but I think some of them may encounter some problems.</p>	<p>Review material covered at last session?</p> <p>Practical aspects of appointment reminders; i.e. apt card, call them/supportive other, text reminders?</p> <p>- break down model into components; judge based on cognitive ability</p> <p>- When considering imagery determine if person can hold an image in mind for 5-10 mins</p>
<p>14. Consultant Psychologist and neuro-psychologist</p>	<p>Thanks again for inviting me to look at your adaptation of CFT for PwD. It has been really good to see it actually written out session by session, and I think it will be a fabulous contribution to the third wave therapies for PwD.</p> <p>However, as well as the positives, I guess you want to hear some thoughts about possible changes/ improvements?! So a couple of thoughts...</p> <p>I wasn't sure if this is individual or group, so it would be helpful to be explicit about the format of delivery. It may just be that I run a CFT group for PwD, so most people would assume that it is individual.</p> <p>Again just in terms of being overt about your aims, I was interested in whether this intervention is aimed at people who have just received a diagnosis of dementia to improve their adjustment, or whether it is aimed at people who have depression/anxiety as a primary problem, but who additionally have dementia. If it is the latter I would be interested in hearing more about targeting the CFT towards the MH problem.</p>	<p>Specify in the intervention that it is individual therapy</p> <p>Targeting the mental health problem – link to goals?</p>

	<p>From my experience of delivering CFT with PwD, they want to spend a significant amount of time on (psychoeducation) understanding the diagnosis of dementia, the different forms of dementia and the prognosis. Included in this the patients often want pragmatic advice, such as whether they can continue driving. Initially I trialled delivering post-diagnostic CFT with these elements either excluded, or towards the end of the programme, but the feedback has been that they definitely want it included and they want it at the beginning of the programme. However this can be a nice way to monitor people's natural responses to the diagnosis/restrictions during the conversation and then dovetail in to the CFT theory.</p> <p>The use of postcards has been very well received, and even for people who no longer retain the cognitive ability to write a postcard, I have either captured their thoughts about the postcard and written it for them, or we have discussed which ones we 'like'. I have delivered this exercise immediately after an SRB exercise so that as much as possible the person is making their choice from their 'soothing' system.</p> <p>The only other point that I would make is to anticipate covering less in each session than you think you will be able to!</p>	<p>More time to discuss and understand diagnosis, different forms, prognosis, practical advice Ensure time is given at the beginning for this, and link in with the CFT theory</p> <p>- If the person does not have the cognitive ability to write a postcard therapist captures their thoughts - Deliver immediately after SRB so person in soothing system</p>
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Appendix D – Ethics Approval Letter


Health Research Authority
London – Dulwich Research Ethics Committee
Health Research Authority
Skipton House
80 London Road
London SE1 6LH
Tel: 020 7104 8113
Email: nrescommittee.london-dulwich@nhs.net

18 May 2016

Dr Aimee Spector
Department of Clinical, Educational and Health Psychology
UCL, Gower Street
London
WC1E 6BT

Dear Dr Spector

Study title:	Compassion Focused Therapy for people with Dementia: a feasibility and pilot study
REC reference:	16/LO/0588
Protocol number:	N/A
IRAS project ID:	196908

Thank you for your letter of 12 May 2016, responding to the Committee's request for further information on the above research and submitting revised documentation.

The further information has been considered on behalf of the Committee by the Chair.

We plan to publish your research summary wording for the above study on the HRA website, together with your contact details. Publication will be no earlier than three months from the date of this opinion letter. Should you wish to provide a substitute contact point, require further information, or wish to make a request to postpone publication, please contact the REC Manager, Mr Michael Higgs, nrescommittee.london-dulwich@nhs.net.

Confirmation of ethical opinion

On behalf of the Committee, I am pleased to confirm a favourable ethical opinion for the above research on the basis described in the application form, protocol and supporting documentation as revised, subject to the conditions specified below.

Conditions of the favourable opinion

The REC favourable opinion is subject to the following conditions being met prior to the start of the study.

Management permission must be obtained from each host organisation prior to the start of the

study at the site concerned.

Management permission should be sought from all NHS organisations involved in the study in accordance with NHS research governance arrangements. Each NHS organisation must confirm through the signing of agreements and/or other documents that it has given permission for the research to proceed (except where explicitly specified otherwise).

Guidance on applying for NHS permission for research is available in the Integrated Research Application System, www.hra.nhs.uk or at <http://www.rdforum.nhs.uk>

Where a NHS organisation's role in the study is limited to identifying and referring potential participants to research sites ("participant identification centre"), guidance should be sought from the R&D office on the information it requires to give permission for this activity.

For non-NHS sites, site management permission should be obtained in accordance with the procedures of the relevant host organisation.

Sponsors are not required to notify the Committee of management permissions from host organisations

Registration of Clinical Trials

All clinical trials (defined as the first four categories on the IRAS filter page) must be registered on a publically accessible database within 6 weeks of recruitment of the first participant (for medical device studies, within the timeline determined by the current registration and publication trees).

There is no requirement to separately notify the REC but you should do so at the earliest opportunity e.g. when submitting an amendment. We will audit the registration details as part of the annual progress reporting process.

To ensure transparency in research, we strongly recommend that all research is registered but for non-clinical trials this is not currently mandatory.

If a sponsor wishes to contest the need for registration they should contact Catherine Blewett (catherineblewett@nhs.net), the HRA does not, however, expect exceptions to be made. Guidance on where to register is provided within IRAS.

It is the responsibility of the sponsor to ensure that all the conditions are complied with before the start of the study or its initiation at a particular site (as applicable).

Ethical review of research sites

NHS sites

The favourable opinion applies to all NHS sites taking part in the study, subject to management permission being obtained from the NHS/HSC R&D office prior to the start of the study (see "Conditions of the favourable opinion" below).

Non-NHS sites

The Committee has not yet completed any site-specific assessment (SSA) for the non-NHS research site(s) taking part in this study. The favourable opinion does not therefore apply to any non-NHS site at present. We will write to you again as soon as an SSA application(s) has been reviewed. In the meantime no study procedures should be initiated at non-NHS sites.

Approved documents

The final list of documents reviewed and approved by the Committee is as follows:

<i>Document</i>	<i>Version</i>	<i>Date</i>
Covering letter on headed paper [Cover Letter]	V1.0	29 January 2016
Evidence of Sponsor insurance or indemnity (non NHS Sponsors only) [UCL Insurance Certificate]		13 July 2015
GP/consultant information sheets or letters [GP Information Sheet]	V1.2	27 April 2016
Letter from funder [Funding Confirmation email]		17 February 2016
Letter from sponsor [UCL Insurance Confirmation Letter]		14 March 2016
Other [Cover Letter in Response to REC Meeting Review]	V1.0	12 May 2016
Other [Carer Information Sheet]	V1.2	27 April 2016
Other [Carer Consent Form]	V1.1	27 April 2016
Other [Intervention Manual]	V.2	02 May 2016
Participant consent form [Participant Consent Form]	V1.2	27 April 2016
Participant information sheet (PIS) [Participant Information Sheet]	V1.2	27 April 2016
REC Application Form [REC_Form_18032016]		18 March 2016
Referee's report or other scientific critique report [Peer Review]		
Referee's report or other scientific critique report [Research Committee Study Review]	V1	20 October 2015
Research protocol or project proposal [Study Protocol]	V6	31 January 2016
Summary CV for Chief Investigator (CI) [Aimee Spector CV]		04 February 2015
Summary CV for student [Catrina Craig CV]		
Summary, synopsis or diagram (flowchart) of protocol in non technical language [Study Flow Chart]	V1	

Statement of compliance

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

After ethical review

Reporting requirements

The attached document "*After ethical review – guidance for researchers*" gives detailed guidance on reporting requirements for studies with a favourable opinion, including:

- Notifying substantial amendments

- Adding new sites and investigators
- Notification of serious breaches of the protocol
- Progress and safety reports
- Notifying the end of the study

The HRA website also provides guidance on these topics, which is updated in the light of changes in reporting requirements or procedures.

User Feedback

The Health Research Authority is continually striving to provide a high quality service to all applicants and sponsors. You are invited to give your view of the service you have received and the application procedure. If you wish to make your views known please use the feedback form available on the HRA website:

<http://www.hra.nhs.uk/about-the-hra/governance/quality-assurance/>

HRA Training

We are pleased to welcome researchers and R&D staff at our training days – see details at

<http://www.hra.nhs.uk/hra-training/>

16/LO/0588	Please quote this number on all correspondence
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With the Committee's best wishes for the success of this project.

Yours sincerely



Dr Michael Philpot
Chair

Email: nrescommittee.london-dulwich@nhs.net

Enclosures: "After ethical review – guidance for researchers"

Copy to: *Ms Suzanne Emerton*
Ms Fiona Horton
Miss Catrina Craig

Appendix E – Charity Recruitment Poster



Compassion-Focused Therapy for People with Dementia

Do you struggle at times with the challenges of living with dementia?

Would you like to receive 10 free sessions of psychological therapy?

Compassion-focused therapy has been found to help people develop kindness and compassion towards themselves, and increase their mood and wellbeing

This pilot study aims to explore if compassion-focused therapy can help people *with dementia* achieve improved mood and wellbeing

If you would like more information or might be interested in taking part then please contact Catrina Craig [REDACTED]

This study is being conducted in conjunction with University College London and NHS NELFT and has been approved by London ~~Quipb~~ NHS Research Ethics Committee

Appendix F – Participant Information Sheet

RESEARCH DEPARTMENT OF CLINICAL, EDUCATIONAL AND HEALTH
PSYCHOLOGY



PARTICIPANT INFORMATION SHEET

Study Title: Compassion Focused Therapy for people with Dementia: a pilot and feasibility study (Student Study)

Invitation to participate in a research study

You are being invited to take part in a research study. Before you decide, it is important for you to understand 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. Thank you for reading this information sheet.

What is the purpose of the study?

This study aims to find out whether compassion focused therapy can help improve mood, anxiety and quality of life of people experiencing memory problems and low mood or anxiety.

What is Compassion Focused Therapy?

Compassion focused therapy helps us to develop kindness to ourselves when we are in distress. When we are unhappy we may become self-critical about how we are coping, or mentally ‘attack’ ourselves about things we have done wrong in life. Developing compassion towards ourselves and others may reduce stress and low mood and increase our wellbeing.

Research has shown compassion focused therapy to be helpful for many different kinds of people experiencing a range of difficulties, especially those who experience shame and self-criticism. Research has also shown that those who have higher levels of self-compassion in older age are happier. Memory problems can make us feel low and at times criticize ourselves. Therefore, this study is designed to find out if people with memory problems attending compassion-focused therapy experience improvements in their mood, anxiety, quality of life and self-compassion.

This study is a ‘pilot’. This means it is a small-scale study that will be used to prepare for a larger study. This pilot will help test out and improve the way future studies in this area are conducted.

What happens in Compassion Focused Therapy?

You will be invited to attend up to 10 once-a-week sessions of compassion focused therapy. The sessions last up to an hour and will involve meeting with a therapist to talk about your mood, memory problems, and how you cope. During the sessions you will also do activities such as gentle breathing and self-compassion exercises.

We will also ask you whether you would like to invite a family member or carer to attend the sessions with you as a 'supportive other'. This is because some people with memory difficulties find it helpful to attend psychological therapy sessions with a family member or carer.

Why have I been invited to take part?

You have been invited to take part because you recognise you are experiencing difficulties with your memory and mood.

Do I have to take part?

It is up to you to decide whether or not to take part. If you do decide to take part, you will be given this information sheet to keep and be asked to sign a consent form.

If you decide to take part, you are still free to withdraw at any time without giving a reason. A decision to withdraw at any time, or a decision not to take part, will not affect the standard of care you receive.

You can still take part in the study if you do not have a family member or carer who can attend, or if you decide that you would prefer to attend alone.

What will happen to me if I take part?

Following discussion of any questions you may have with a researcher, and signing the consent form, all participants will be asked to:

- Meet with a researcher for around one hour to answer questions about your mood, anxiety, quality of life and thinking. In order to complete the assessment, we will also invite a family member/carer.
- Attend up to 10-weekly compassion-focused therapy sessions.
- The compassion focused therapy sessions will be audio recorded for research purposes with consent from both parties and will be kept password protected.
- Meet with a researcher again after five sessions, and following the intervention to answer the same questions as before. The researcher will invite a family member/carer to complete some questionnaires.
- You and a family member/carer will be invited to attend an interview to discuss your experience of attending the compassion focused therapy sessions. You can choose if you would like to attend the interview together or separately.

What do I have to do?

You can carry on your everyday activities as normal while participating in the study. All we ask is that you try to attend all 10 sessions. We understand there may be times when you are unwell and therefore unable to attend a session.

What are the possible disadvantages and risks of taking part?

We appreciate that when you are experiencing memory problems, it may be hard to talk about things like your mood and quality of life. The researchers carrying out the assessment, intervention, and interview work in clinical psychology and is working under supervision.

You will be encouraged but never forced to take part in a particular activity during the sessions.

Overall the risks of taking part in this study are minimal. However, some people find that certain types of therapy do not help them or make them feel worse. If you find participating in the study distressing, you are free to withdraw at any point. We can also discuss options of alternative support.

What are the possible benefits of taking part?

If you do decide to take part in the study, we hope that attending the sessions is a helpful experience for both you and your family member/carer, although we cannot promise this. Previous research into compassion suggests that people can experience greater awareness, acceptance, control, improved coping and wellbeing. We hope also that you may find having the opportunity to talk about the therapy an interesting experience. For all participants, the information we get from this study may help us to support people with memory problems and their carers better in the future.

Will my taking part in the study be kept confidential?

We will ask for your permission to send your GP a letter explaining that you will be taking part in the study. All information collected about you over the course of the study will be kept private unless we became aware of something that made us worry about you or someone around you, in which case we will discuss the issue with you. All documents that leave the memory service will have your name removed with the exception of the consent form. Any quotes from interviews that are used for publication will be anonymised. Once the study has finished, University College London will keep the study data in a secure location for 7 years.

What will happen if I don't want to carry on with the study?

You will be free to withdraw from the study at any time, without giving a reason. Withdrawing from the study will not affect the standard of care you receive. We will need to use all data collected in the study, up to the point of withdrawal.

What if something goes wrong?

Every care will be taken in the course of this study. However, in the unlikely event that you are injured by taking part, compensation may be available.

If you suspect that the injury is the result of the Sponsor's (University College London) or the memory service's negligence then you may be able to claim compensation. After discussing with the researcher, please make the claim in writing to Dr. Aimee Spector who is the Chief Investigator for the research and is based at University College London. Her details are provided at the end of this form. The Chief Investigator will then pass the claim to the Sponsor's Insurers, via the Sponsor's office. You may have to bear the costs of the legal action initially, and you should consult a lawyer about this.

Regardless of this, if you wish to make a complaint about any aspect of the way you have been approached or treated during the course of this study or if you are unhappy with

anything about your participation, you can contact Dr Aimee Spector.

If you have private medical insurance, you should inform your insurance company that you are intending to take part in this study.

Who is organising and funding the research?

The research is being organised and funded by University College London. The study will be conducted by Catrina Craig and Dr Syd Hiskey. Catrina works as a Trainee Clinical Psychologist, and the study will form part of an educational qualification (Doctorate in Clinical Psychology) at University College London (UCL). She is being supervised by Dr. Aimee Spector, who is a Clinical Psychologist at UCL, and Dr Lindsay Royan, who is a Consultant Clinical Psychologist at the North East London Foundation Trust. Dr Syd Hiskey is a Consultant Clinical Psychologist working in the NHS.

What will happen to the results of the research?

The results will be published in health journals. No participants will be identified in any publication. Once the study has ended, you can meet with a researcher to find out about the results, you can also request a written summary of the findings.

Who has reviewed the study?

All NHS research is looked at by a group of people, called a Research Ethics Committee to protect your safety, rights, and dignity. This study has been cleared by London - Dulwich Research Ethics Committee.

Who can I contact for further information?

For more information about this research, please contact:

Catrina Craig
Department of Clinical,
Educational and Health Psychology
UCL Gower Street
WC1E 6BT



If you would like seek advice from an independent person who is not associated with the project, please contact:

Dr Will Mandy
Department of Clinical,
Educational and Health Psychology
UCL
Gower Street
WC1E 6BT



Or if you have any complaints about this study please contact:

Dr Aimee Spector
Department of Clinical,
Educational and Health Psychology

UCL
Gower Street
WC1E 6BT



Thank you for thinking about taking part in this research study.

RESEARCH DEPARTMENT OF CLINICAL, EDUCATIONAL AND HEALTH
PSYCHOLOGY



INFORMATION SHEET FOR CARER, FAMILY MEMBER OR FRIEND

Study Title: Compassion Focused Therapy for people with Dementia: a pilot and feasibility study (Student Study)

Invitation to participate in a research study

You and your family member/friend are being invited to take part in a research study. Before you decide, it is important for you to understand 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/your family member/friend if you wish. Thank you for reading this information sheet.

What is the purpose of the study?

This study aims to find out whether compassion focused therapy can help improve mood, anxiety and quality of life of people experiencing memory problems and low mood or anxiety.

What is Compassion Focused Therapy?

Compassion focused therapy helps us to develop kindness to ourselves when we are in distress. When we are unhappy we may become self-critical about how we are coping, or mentally ‘attack’ ourselves about things we have done wrong in life. Developing compassion towards ourselves and others may reduce stress and low mood and increase our wellbeing.

Research has shown compassion focused therapy to be helpful for many different kinds of people experiencing a range of difficulties, especially those who experience shame and self-criticism. Research has also shown that those who have higher levels of self-compassion in older age are happier. Memory problems can make us feel low and at times criticize ourselves. Therefore, this study is designed to find out if people with memory problems attending compassion-focused therapy experience improvements in their mood, anxiety, quality of life and self-compassion.

This study is a ‘pilot’. This means it is a small-scale study that will be used to prepare for a larger study. This pilot will help test out and improve the way future studies in this area are conducted.

What happens in Compassion Focused Therapy?

You and your family member/friend will be invited to attend up to 10 once-a-week sessions of compassion focused therapy. The sessions last up to an hour and will involve meeting with a therapist to talk about the person's mood, memory problems, and how they cope. During the sessions they will also do activities such as gentle breathing and self-compassion exercises.

Why have I been invited to take part?

Your family member/friend has been invited to take part because they are considered to be experiencing difficulties with their memory and mood. As a carer/family member of the person with memory problems we are also asking you to take part in the study as a 'supportive other'. This may involve attending all of or several of the compassion focused therapy sessions with them if they wish, and assisting them in-between sessions to try out home practice/s. Your involvement can be flexible and will depend on what your family member/friend finds useful. We will also invite both of you to attend an interview after the therapy to explore your experiences of the intervention.

Do I have to take part?

It is up to you and your family member/friend to decide whether or not you take part. If they would like a 'supportive other' during the therapy, you will be asked to sign a consent form. If you both do decide to take part together, you are still free to withdraw at any time without giving a reason. A decision to withdraw at any time, or a decision not to take part, will not affect the standard of care that either of you receive. If you do not decide to take part this will not prevent your family member/friend from taking part.

What will happen to me if I take part?

Following discussion of any questions you may have with a researcher, and signing the consent form, we will ask you to:

- Meet with a researcher for around one hour with your family member/friend to answer questions about their mood, anxiety, quality of life and thinking.
- Attend up to 10-weekly compassion-focused therapy sessions for your family member/friend as a 'supportive other'.
- The compassion focused therapy sessions will be audio recorded with consent from both parties and will be kept password protected.
- Meet with a researcher again after five sessions to answer the same questions as before, and again following completion of the therapy.
- You will be invited to attend an interview with your family member/friend to discuss both of your experiences of attending the compassion focused therapy sessions. Your family member/friend can choose if they would like to attend the interview with you or separately.

What do I have to do?

You can carry on your everyday activities as normal while participating in the study. If possible we would like you to support your family member/friend to attend the compassion-focused therapy sessions, and join them if they would find this helpful. We understand there may be times when you will be unable to attend a session. We may also ask you to help your family member/friend to try out home practice/s in between sessions.

What are the possible disadvantages and risks of taking part?

We appreciate that when your family member/friend is experiencing memory problems, it may be hard for both of you to talk about things like their memory difficulties, mood and quality of life. The researchers carrying out the assessments, intervention, and interviews have clinical experience and are working under supervision.

You and your family member/friend will be encouraged but never forced to take part in a particular activity during the sessions.

Overall the risks of taking part in this study are minimal. However, some people find that certain types of therapy do not help them or make them feel worse. If you or your family member/friend finds participating in the study distressing, either of you are free to withdraw at any point and other options of support can be discussed.

What are the possible benefits of taking part?

If you do decide to take part in the study we hope that attending the sessions is a helpful experience for both of you, although we cannot promise this. Previous research into compassion suggests that people can experience greater awareness, acceptance, control, improved coping and wellbeing. The information we get from this study may help us to support people with memory problems and their carers better in the future.

Will taking part in the study be kept confidential?

We will ask for your family member/friend's permission to send their GP a letter explaining that they will be taking part in the study. **We will not contact your GP.** All information collected about them over the course of the study will be kept confidential unless we became aware of something which made us worry about them or someone around them, in which case we will discuss the issue with them. All documents that leave the memory clinic will have their name removed with the exception of a consent form. Any quotes from interviews that are used for publication will be anonymised. Once the study has finished, University College London will keep the study data in a secure location.

What will happen if you or your family member/friend doesn't want you to continue as their 'supportive other'?

You will be free to withdraw from the study at any time, without giving a reason. This will not affect the standard of care your family member receives. We will need to use all data collected in the study, up to the point of withdrawal. If your family member prefers to continue the intervention alone we will respect their decision to do so.

What if something goes wrong?

Every care will be taken in the course of this study. However, in the unlikely event that you or your family member/friend is injured by taking part, compensation may be available.

If you/your family member/friend suspects that the injury is the result of the Sponsor's (University College London) or the memory clinic's negligence then you may be able to claim compensation. After discussing with the researcher, please make the claim in writing to Dr. Aimee Spector who is the Chief Investigator for the research and is based at University College London. Her details are provided at the end of this form. The Chief Investigator will then pass the claim to the Sponsor's Insurers, via the Sponsor's office. Your family member/friend may have to bear the costs of the legal action initially, and they should consult a lawyer about this.

Regardless of this, if your family member/friend wishes to make a complaint about any aspect of the way they have been approached or treated during the course of this study or if they are unhappy with anything about their participation, they can contact Dr Aimee Spector.

If your family member/friend has private medical insurance, they should inform their insurance company that they are intending to take part in this study.

Who is organising and funding the research?

The research is being organised and funded by University College London (UCL). The study will be conducted by Catrina Craig and Dr Syd Hiskey. Catrina works as a Trainee Clinical Psychologist, and the study will form part of an educational qualification (Doctorate in Clinical Psychology) at UCL. She is being supervised by Dr. Aimee Spector, who is a Clinical Psychologist at UCL, and Dr Lindsay Royan, who is a Consultant Clinical Psychologist working in the NHS. Dr Syd Hiskey is also a Consultant Clinical Psychologist working in the NHS.

What will happen to the results of the research?

The results will be published in health journals. No participants will be identified in any publication. Once the study has ended, you and/or your family member/friend can meet with a researcher to find out about the results, a written summary of the findings can also be requested.

Who has reviewed the study?

All NHS research is looked at by a group of people, called a Research Ethics Committee to protect your family member/friend's safety, rights, and dignity. This study has been cleared by London - Dulwich Research Ethics Committee.

Who can I contact for further information?

For more information about this research, please contact:

Catrina Craig
Department of Clinical,
Educational and Health Psychology
UCL Gower Street
WC1E 6BT
Email: Catrina.Craig.14@ucl.ac.uk

If you would like seek advice from an independent person who is not associated with the project, please contact:

Dr Will Mandy
Department of Clinical,
Educational and Health Psychology
UCL
Gower Street
WC1E 6BT
Email: w.mandy@ucl.ac.uk

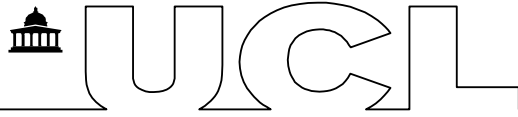
Or if you have any complaints about this study please contact:

Dr Aimee Spector

Department of Clinical,
Educational and Health Psychology
UCL
Gower Street
WC1E 6BT
Email: [REDACTED]
[REDACTED]

Thank you for thinking about taking part in this research study.

Appendix H – Participant Consent Form



Participant Consent Form

Study Title: Compassion Focused Therapy for people with Dementia: a pilot and feasibility study (Student Study)

Participant Number:

Name of Researcher: Catrina Craig

Please Initial Boxes

I confirm that I have read and understand the participant information sheet dated [date, version] for the above study, have had the opportunity to ask questions and have had these answered acceptably.	
I understand that my participation is voluntary and that I am free to withdraw at any time, without giving any reason, without my medical care or legal rights being affected.	
I understand that sections of any of my medical notes and data collected during the study may be looked at by individuals involved in the study, where it is relevant to my taking part in this research. I give my permission for these individuals to have access to my records	
I give permission for my GP to be informed of my participation in the study	
I understand that all information given by me or about me will be treated as confidential by the research team.	

PLEASE TURN OVER

I consent to the audio recording of the intervention sessions and post-intervention interview	
I agree to take part in the above study	

Name of participant	Date	Signature
Name of person taking consent (if different from the principal researcher)	Date	Signature
Principal researcher	Date	Signature

Appendix I – Carer Consent Form



Carer Consent Form

Study Title: Compassion Focused Therapy for People with Dementia: A Pilot and Feasibility Study (Student Study).

Participant Number:

Name of Researcher: Catrina Craig/Syd Hiskey

Please Initial Boxes

I confirm that I have read and understand the carer information sheet dated [date, version] for the above study, have had the opportunity to ask questions and have had these answered acceptably.	
I understand that my participation is voluntary and that I am free to withdraw at any time, without giving any reason, without my or my family member/patient's medical care or legal rights being affected.	
I understand that all information given by me or about me and my family member/patient will be treated as confidential by the research team.	
I consent to the audio recording of the intervention sessions and post-intervention interview	
I agree to take part as a 'supportive other' in the above study	

PLEASE TURN OVER

Name of participant	Date	Signature
Name of person taking consent	Date	Signature
Principal researcher	Date	Signature

Appendix J – GP Information Sheet



Department of Clinical, Educational and Health Psychology
University College London
Gower Street
London
WC1E 6BT
Phone: 020 7679 1897
Fax: 020 7916 1989

[Enter Name and Address of Recipient]

Dear [Enter Recipient's name]

GENERAL PRACTITIONER INFORMATION SHEET

Study Title: Compassion Focused Therapy for people with Dementia: a pilot and feasibility study (Student Study)

.....(Name of Participant) has been invited and consented to take part in a research study. Please let us know if you would like more information.

The study will be conducted by Catrina Craig and Dr Syd Hiskey, and possibly other qualified Clinical or Counselling Psychologists in North East London Foundation Trust (NELFT) and North Essex Partnership Foundation Trust (NEPFT). Catrina works as a Trainee Clinical Psychologist, and the study will form part of an educational qualification (Doctorate in Clinical Psychology) at University College London (UCL). She is being supervised by Dr. Aimee Spector, who is a Clinical Psychologist at UCL. Dr Syd Hiskey is a Consultant Clinical Psychologist working in the NHS.

This study is designed to find out if people with dementia and depression and/or anxiety in memory clinics who attend a compassion focused therapy intervention will experience improvements in their: mood, anxiety, quality of life, and self-compassion. The study is a 'pilot'. This means it is a small-scale study that will be used to prepare for a larger study. This pilot will help test out and improve the way future studies in this area are conducted.

The study will not affect your patient's current or future treatment.

The individual therapy sessions will last approximately one hour, and will occur weekly for up to ten sessions. The sessions involve participants meeting with a therapist to talk about their mood, memory problems, and how they cope. During the sessions they will also do activities such as gentle breathing and self-compassion exercises. Although the intervention is designed to help alleviate suffering, like any other psychological therapy it is possible that participants may become distressed during the process.

Participants will be assessed prior to the 10-week intervention, at five sessions in, and immediately following its completion. The assessment will take up to an hour to complete and will use outcome measures looking at: levels of self-compassion, mood, anxiety, and quality of life. Participants and their carers will also be invited to attend an interview following the intervention to explore their experience/s of the treatment.

The results of this study are expected to be published in relevant journals and at conferences. The information collected in the study will be anonymous and patients will not be identified in any report/publication. All treatment sessions and interviews are confidential and will not be disclosed to anyone else unless there is a concern about risk to the participant or someone around them. If this is the case, the researchers will discuss their concerns with the participant's care team.

All proposals for research using human subjects are reviewed by the local Ethics Committee before they can proceed. The appropriate permission has been granted by X Research Ethics Committee.

Thank you for reading this information sheet. Please do not hesitate to contact us at the above address or via email: catrina.craig.14@ucl.ac.uk if you need any further information.

Yours sincerely,

Catrina Craig (Trainee Clinical Psychologist)

Appendix K – Self-Compassion Scale – Short Form

Running head: SELF-COMPASSION SCALE–Short Form (SCS–SF)

1

To Whom it May Concern:

Please feel free to use the Self-Compassion Scale – Short Form in your research (12 items instead of 26 items). The short scale has a near perfect correlation with the long scale when examining total scores. We do not recommend using the short form if you are interested in subscale scores, since they're less reliable with the short form. You can e-mail me with any questions you may have. The appropriate reference is listed below.

Best wishes,

Kristin Neff, Ph. D.

e-mail: kristin.neff@mail.utexas.edu

Reference:

Raes, F., Pommier, E., Neff, K. D., & Van Gucht, D. (2011). Construction and factorial validation of a short form of the Self-Compassion Scale. *Clinical Psychology & Psychotherapy*, 18, 250-255.

Coding Key:

Self-Kindness Items: 2, 6

Self-Judgment Items: 11, 12

Common Humanity Items: 5, 10

Isolation Items: 4, 8

Mindfulness Items: 3, 7

Over-identified Items: 1, 9

Subscale scores are computed by calculating the mean of subscale item responses. To compute a total self-compassion score, reverse score the negative subscale items - self-judgment, isolation, and over-identification (i.e., 1 = 5, 2 = 4, 3 = 3, 4 = 2, 5 = 1) - then compute a total mean.

HOW I TYPICALLY ACT TOWARDS MYSELF IN DIFFICULT TIMES

Please read each statement carefully before answering. To the left of each item, indicate how often you behave in the stated manner, using the following scale:

Almost never					Al most al ways
1	2	3	4	5	

_____ 1. When I fail at something important to me I become consumed by feelings of inadequacy.

_____ 2. I try to be understanding and patient towards those aspects of my personality I don't like.

_____ 3. When something painful happens I try to take a balanced view of the situation.

_____ 4. When I'm feeling down, I tend to feel like most other people are probably happier than I am.

_____ 5. I try to see my failings as part of the human condition.

_____ 6. When I'm going through a very hard time, I give myself the caring and tenderness I need.

_____ 7. When something upsets me I try to keep my emotions in balance.

_____ 8. When I fail at something that's important to me, I tend to feel alone in my failure

_____ 9. When I'm feeling down I tend to obsess and fixate on everything that's wrong.

_____ 10. When I feel inadequate in some way, I try to remind myself that feelings of inadequacy are shared by most people.

_____ 11. I'm disapproving and judgmental about my own flaws and inadequacies.

_____ 12. I'm intolerant and impatient towards those aspects of my personality I don't like.

Appendix L – Cornell Scale for Depression in Dementia

Cornell Scale for Depression in Dementia

Instructions to interviewer: Ratings should be based on symptoms and signs occurring the week prior to the interview. No score should be given if symptoms result from physical disability or illness.

Scoring system:

0. Absent 0. 1. Mild or Intermittent 1. 2. Moderate 2. 3. Severe 3. U. Unable to evaluate 3.

		Score
A.	Mood related signs	
1.	Anxiety, anxious expression, ruminations, worrying	
2.	Sadness, sad expression, sad voice, tearfulness	
3.	Lack of reactivity to pleasant events	
4.	Irritability, easily annoyed, short tempered	
B.	Behavioural disturbance	
5.	Agitation, restlessness, hand wringing hair pulling	
6.	Retardation slow movements, slow speech, slow reactions	
7.	Multiple physical complaints (score "Absent" if GI symptoms only)	
8.	Loss of interest, less involved in usual activities (score only if change occurred acutely, i.e. in less than 1 month)	
C.	Physical signs	
9.	Appetite loss, eating less than usual	
10.	Weight loss, (score "Severe" if greater than 5lbs in a month)	
11.	Lack of energy, fatigues easily, unable to sustain activities (score only if change occurred acutely, i.e. in less than 1 month)	
D.	Cyclic functions	
12.	Diurnal variation of mood symptoms worse in the morning	
13.	Difficulty in falling asleep falling asleep later than usual for this individual	
14.	Multiple awakenings during sleep	
15.	Early morning awakening, awakening earlier than usual for this individual	
E.	Ideational disturbance	
16.	Suicide, feels life not worth living, has suicidal wishes, or makes suicide attempt	
17.	Poor self esteem, self blame, self-deprecation, feelings of failure	
18.	Pessimism, anticipation of the worst	
19.	Mood-congruent delusions, delusions of poverty, illness, or loss	
Total		

Appendix M – Rating Anxiety in Dementia Scale

Rating Anxiety in Dementia (RAID)

Note to interviewer. Please interview the carer about each of the following 18 items relating to the participant. Ratings should be based on symptoms and signs occurring during two weeks prior to the interview. No score should be given if symptoms result from physical disability or illness.

Scoring system:

0. Absent 0. 1. Mild or Intermittent 1. 2. Moderate 2. 3. Severe 3. U. Unable to evaluate 4.

Participant Rating		Rating Anxiety in Dementia	Score
Worry	1	Worry about physical health	
	2	Worry about cognitive performance (failing memory, getting lost when goes out, not able to follow conversation)	
	3	Worry over finances, family problems, physical health of relatives	
	4	Worry associated with false belief and/or perception	
	5	Worry over trifles (repeatedly calling for attention over trivial matters)	
Apprehension & Vigilance	6	Frightened and anxious (keyed up and on the edge)	
	7	Sensitivity to noise (exaggerated startle response)	
	8	Sleep disturbance (trouble falling or staying asleep)	
	9	Irritability (more easily annoyed than usual, short tempered and angry outbursts)	
Motor Tension	10	Trembling	
	11	Motor tension (complain of headache, other body aches and pains)	
	12	Restlessness (fidgeting, could not sit still, pacing, wring hands, picking clothes)	
	13	Fatigueability, tiredness	
Autonomic Hypersensitivity	14	Palpitations (complains of heart racing or thumping)	
	15	Dry mouth (not due to medication), sinking feeling in the stomach	
	16	Hyperventilating, shortness of breath (even when not exerting)	
	17	Dizziness or light-headedness (complains as if going to faint)	
	18	Sweating, flushes or chills, tingling or numbness of fingers and toes	

Total Score: _____

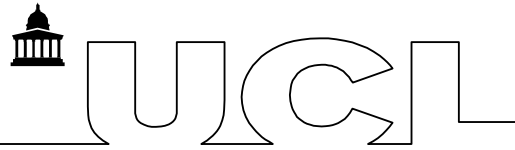
Appendix N – Quality of Life in Alzheimer’s Disease

Quality of Life in Alzheimer’s Disease cont’d

QOL-AD

UWMCI/ADPRI/QOL Aging and Dementia: Quality of Life in AD Quality of Life: AD (Participant Version)					Score (for clinician's use only)
ID Number □□□□□□		Assessment Number □□		Interview Date □□ □□ □□ Month Day Year	
Instructions: Interviewer administer according to standard instructions. Circle your responses.					
1. Physical health	Poor	Fair	Good	Excellent	
2. Energy	Poor	Fair	Good	Excellent	
3. Mood	Poor	Fair	Good	Excellent	
4. Living situation	Poor	Fair	Good	Excellent	
5. Memory	Poor	Fair	Good	Excellent	
6. Family	Poor	Fair	Good	Excellent	
7. Marriage	Poor	Fair	Good	Excellent	
8. Friends	Poor	Fair	Good	Excellent	
9. Self as a whole	Poor	Fair	Good	Excellent	
10. Ability to do chores around the house	Poor	Fair	Good	Excellent	
11. Ability to do things for fun	Poor	Fair	Good	Excellent	
12. Money	Poor	Fair	Good	Excellent	
13. Life as a whole	Poor	Fair	Good	Excellent	
Comments: _____ _____					Total

Appendix O – Participant Rating Form



Date completed:

Participant Rating Form

We want to develop these sessions so that they are as helpful as possible.

Please help us to improve these by answering the questions below:

1. How helpful did you find the session today?

1	2	3	4	5
Extremely Unhelpful	Somewhat Unhelpful	Neither Helpful nor Unhelpful	Somewhat Helpful	Extremely Helpful

2. What did you like about the session (if anything)? For example, was there anything you found helpful or enjoyable?

3. What did you not like about the session (if anything)? For example, was there anything you found unhelpful or not enjoyable?

Thank you for taking the time to complete the participant rating form.

Appendix P – Participant Change Interview

CFT Client Change Interview

What made you want to come to the therapy sessions? For example were there particular things they were struggling with, or things you wanted to change?

How are you doing now in general?

What changes, if any, have you noticed in yourself since therapy started? For example, are you feeling any differently since the therapy started? Or thinking any differently?

Since the sessions what are you doing differently in your day-to-day life?

- **How do you respond to yourself differently?** For example if you make a mistake, did something you regretted, if someone else upset/angered you.

- **Are you responding to others differently?** For example your loved ones – family, partner, friends. How about people you know less well or strangers? (scaffold with examples if needed, i.e. if a family member upset you, if a stranger bumped into you etc.)

- **Have others noticed if you're doing anything differently?** For example has anyone commented on anything different about how you respond to difficult situations?

What specific ideas, if any, have you gotten from therapy so far, including ideas about yourself or other people? i.e. what have you learnt about yourself and others? Or certain strategies you have learnt that help?

Has anything changed for the worse for you since therapy started?

Is there anything that you wanted to change that hasn't since therapy started?

Can you sum up what has been helpful about your therapy? Please give examples. (For example, general aspects, specific events)

What kinds of things about the therapy have been unhelpful, negative or disappointing for you? (For example, general aspects, specific events)

Do you have any suggestions for us, regarding the research or the therapy? Do you have anything else that you want to tell me?

Appendix Q – Carer Change Interview

CFT Client Change Interview – carer version

What made you want to come to the therapy sessions with your loved one/family member? For example were there particular things you or they were struggling with, or things you/they wanted to change?

How are you doing now in general? How is your family member doing?

What changes, if any, have you noticed in yourself or your family member since therapy started? For example, are you feeling any differently since the therapy started? Or thinking any differently?

Since the sessions what are you doing differently in your day-to-day life?

- **How do you respond to yourself differently?** For example if you make a mistake, can't manage something, did something you regretted, if someone else upset/angered you.

- **Are you responding to others differently?** For example your loved one (and family, partner, friends). How about people you know less well or strangers? (scaffold with examples if needed, i.e. if a family member upset you, if a stranger bumped into you etc.)

- Have others noticed if you're doing anything differently? For example has anyone commented on anything different about how you respond to difficult situations?

What specific ideas, if any, have you/your family member gotten from therapy so far, including ideas about yourself or other people? i.e. what have you learnt about yourself and others? Or certain strategies you have learnt that help?

Has anything changed for the worse for since the therapy started?

Is there anything that you or your family member wanted to change that hasn't since therapy started?

Can you sum up what has been helpful about the therapy? Please give examples. (For example, general aspects, specific events)

What kinds of things about the therapy have been unhelpful, negative or disappointing for you? (For example, general aspects, specific events)

Do you have any suggestions for us, regarding the research or the therapy? Do you have anything else that you want to tell me?

Appendix R – CFT for Dementia Manual

Compassion Focused Therapy for People with Dementia – an Individual Therapy

Table. Summary of Compassion Focused Therapy (CFT) for dementia intervention (guided by Charlesworth et al.'s (2014) phases of therapy in CBT)

Phase	Topic	Content
Phase 1 (Sessions 1-3)	Setting up: Introducing compassion focused therapy and engagement	<ul style="list-style-type: none"> - Psychoeducation - Experiencing/Developing mindful awareness - Collaborative formulation and goal setting - Developing physical self-soothing (soothing rhythm breathing) - Starting to experience compassion (flow)
Phase 2 (Sessions 4-7)	Developing compassion for the self	<ul style="list-style-type: none"> - Loving-kindness for the self - Fears and blocks to compassion - Imagery: safe-place, compassionate self - Compassion in everyday life - Compassionate letter/postcard
Phase 3 (sessions 8-10)	Managing difficult feelings Consolidating & ending	<ul style="list-style-type: none"> - Threat-based emotions - Soften, soothe, allow - Returning to key concepts/reflection on practices - Reviewing the therapy and compassionate future

‘Supportive other’: individuals will be asked if they would like a family member or friend to be involved in the therapy as a ‘supportive other’. This may involve attending sessions together (from one to all sessions; the whole session or 5-10 minutes at the beginning or end), and help with home practices.

Therapy Folders: All participants will be provided with a folder in which to keep all handouts and written information, which will be provided.

Session length: The sessions will last up to 50 minutes. It will be checked at the beginning of each appointment if this is manageable for them on that day and will be shortened if they prefer.

Below is a guide for potential content for each session across the intervention. It is the maximum amount that could be covered at each session. It will need to be adapted depending on the client’s cognitive ability and ‘openness’ to compassion. For example, more time may need to be spent on ‘fears and blocks to compassion’, and some opening practices may need to

be swapped to soothing-rhythm breathing to assist with learning, rather than introducing new practices. Further time/sessions may be needed on phase 1 (psychoeducation and formulation) if the individual struggles with identifying and expressing emotions. This may mean phase 2 and 3 are shortened. If the person would like more time to discuss and understand the dementia diagnosis ensure time is given for this at the beginning of the intervention. Tie in the response to the diagnosis and its implications to the theory and psychoeducation of CFT. Please see page 6 on adaptations to the process of delivering the intervention.

Initial meeting: nature of low mood and/or anxiety, impact of dementia diagnosis and cognitive decline, goals for therapy. Building the therapeutic relationship.

Brief explanation of compassion-focused therapy and compassion

Three components of self-compassion (Germer & Neff, 2012)

- 1) **Mindfulness** (noticing current bodily and emotional experiences, as they are, rather than avoid or suppression them)
- 2) **Common humanity** (suffering is part of the human experience, I am not alone in suffering, life is difficult for everyone of us)
- 3) **Self-kindness** (treating ourselves with care and understanding, soothing and comforting ourselves)

We give ourselves compassion not to feel better, but because we feel pain
Compassion 'a sensitivity of self and others, with a deep commitment to try and relieve it' *Dalai Lama*

Soothing Rhythm Breathing

Home practice: Soothing rhythm breathing, noticing sensations

Materials to support client:

- *Written handout of the three components of compassion*
- *Soothing rhythm breathing written instructions*
- *Written summary of the session*
- *audio of soothing rhythm breathing for home practice*

Second Meeting:

Opening practice: Mindful-attention exercise (5 minutes)

Review home practice and three components of compassion (from previous session)

Confirm goals (link to what the person values in life)

Psychoeducation on the 'tricky brain' (old brain, new brain, social brain), the wandering mind, doing vs. being modes, 'it's not your fault, but it is your responsibility'.

Three emotion regulation systems: threat, drive, and soothing

Dementia as a threat – exploring meaning of this and specific aspects that may trigger threat-based emotions. Reduces opportunity to use activation/drive as a coping strategy to down-regulate threat system. Can trigger feelings of ‘unsafeness’

Completion of three circles model for client’s experience (ensuring client’s strengths and existing self-soothing strategies are identified, as well as any self-critical thoughts). Depending on person’s cognitive ability consider breaking down the model into individual parts using examples from the person’s life.

Home practice: Mindful-attention exercise

Materials to support client:

- *Basic visual info on old/new brain*
- *Colour-printed three circles model to be completed*
- *Written summary of the session*
- *Sheet with goals written down*
- *Audio recording of mindful-attention for home practice*

Third Meeting

Opening practice: Affectionate breathing / soothing rhythm breathing (link to three-circles formulation – engaging soothing system and down-regulating threat system) (5 minutes)

(Weave in goals throughout session)

Review home practice

Attributes and qualities of compassion (sensitivity, sympathy, distress tolerance, empathy, non-judgment, care for wellbeing)

Flows of compassion: Loving-Kindness meditation (to loved one, to loved one and self, to self) (10 minutes)

Home practice: Affectionate breathing

Materials to support client:

- *Attributes and qualities of compassion sheet*
- *3 circles model*
- *Sheet with goals written down*
- *Written summary of session*
- *Audio recording of affectionate breathing for home practice*

Fourth Meeting

Opening practice: Loving-kindness for the self (5-10 minutes)

(Weave in goals throughout session)

Review home practice

Fears and blocks to compassion

Safe place imagery (using autobiographical memory) (5-10 minutes).

Home practice: Safe place imagery

Materials to support client:

- *Fears and blocks to compassion sheet*
- *3 circles model*
- *Safe place imagery sheet*
- *Sheet with goals written down*
- *Written summary of the session*
- *Audio recording of safe place imagery*

Fifth Meeting

Opening practice: Giving and receiving compassion (5-10 minutes)

(Weave in goals throughout session)

Review home practice

Compassion in every day life, looking after myself: compassionate attention, thoughts, actions/behavior, and emotions

Home practice: engaging in compassion in every day life

Materials to support client:

- *Compassion in everyday life sheet (to generate ideas)*
- *3 circles model*
- *Sheet with goals written down*
- *Written summary of session*
- *Sheet to support home practice of engaging compassion in everyday life*

Sixth Meeting

Opening practice: Compassionate body-scan (10 minutes)

(Weave in goals throughout session)

Review home practice

Soothing Rhythm Breathing (this is to ensure the individual is activating their soothing system prior to writing the compassionate letter/postcard)

Compassionate letter (or postcard, depending on cognitive ability) to self. If person does not have cognitive ability to write try to capture the person's thoughts and write this for them (with consent). Send to client at a later date in the post – consider length of time between the letter being written and it being posted. Ensure an initial outline is included at the top of the letter as a reminder as to why they are receiving the letter.

Home practice: Compassionate body-scan

Materials to support client:

- *Compassionate letter/postcard prompts*
- *3 circles model*
- *Sheet with goals written down*
- *Written summary of session*
- *Audio recording of compassionate body scan*

Seventh Meeting:

Opening practice: Loving-kindness meditation (10 minutes)

(Weave in goals throughout session)

Review home practice

Developing the compassionate self (imagery)

Home practice: developing the compassionate self

Materials to support client:

- *Developing the compassionate self prompt sheet*
- *3 circles model*
- *Sheet with goals written down*
- *Written summary of session*
- *Audio recording of developing compassionate self*

Eighth Meeting:

Opening practice: Soothing rhythm breathing (5 minutes)

(Weave in goals throughout session)

Review home practice

Managing difficult feelings/emotions (threat-based emotions: anger, fear, shame, disgust)

Soften, soothe, allow (5 minutes)

Home practice: Soften, soothe, allow

Materials to support client:

- *Sheet on managing difficult feelings*
- *3 circles model*
- *Sheet with goals written down*
- *Sheet outlining soften, soothe, allow*
- *Written summary of session*
- *Audio recording of soften, soothe, allow*

Ninth Meeting

Opening practice: Flow of compassion: giving and receiving compassion (10 minutes)

(Weave in goals throughout session)

Review home practice

Return to compassion in everyday life, compassionate self, safe place imagery

Home practice: Mindful compassion for self and others (flow of compassion in and out)

Materials to support client:

- *3 circles model*
- *Written summary of session*
- *Sheet with goals written down*
- *Audio recording of mindful compassion for self and others*

Tenth Meeting:

Opening practice: Affectionate breathing (5 minutes)

(Weave in goals throughout session)

Review home practice

Reviewing the therapy: what has worked for me and what do I want to continue?
Compassionate future.

Materials to support client:

- *Therapy review sheet*
- *3 circles model*
- *Sheet with goals written down*
- *Written summary of session*
- *Audio recordings of all practices*

CFT Process adaptations

Slow delivery of concepts

Checking-in if the concepts are making sense

Provide regular summaries (every 10-15 mins)

Regularly check understanding (after each novel concept)

Repeat main therapeutic concepts frequently

Provide written summary of the session

Provide visual handouts

Provide CDs/audio recordings of meditations/home practices

If possible use outcome of neuropsychological testing to adapt the sessions, i.e. make use of strengths and minimize demands on weaknesses. For example, if visual skills are strong use visual imagery more

Tape record session for client to listen to

Consider whether concepts from the previous session/s need to be returned to and prioritise these over introducing new concepts

Generate flashcards for client's chosen methods of coping/practices

Engage 'supportive other' – session material and home practice

Meditations/practices shortened, less silence

With imagery practices, determine if person is able to hold an image in mind for 5-10 minutes prior to the activity

Involvement of 'supportive other'/carer if desired (attending sessions, last 5 mins of session etc).

Ensure psychoeducation of CFT and formulation takes account of the person's religious and cultural beliefs

Tool Kit of Activities

Possible Opening Practices:

Soothing rhythm breathing
Affectionate breathing
Mindful attention
Loving Kindness Meditation (short)
Loving Kindness to the self (short)

Meditation activities:

Affectionate breathing
Loving Kindness Meditation
Loving Kindness to the self
Giving and receiving compassion
Compassionate body scan
Soften, soothe, allow

Other exercises:

Compassionate letter/postcard writing
Using reminiscence – list of things I am grateful for

Imagery Exercises:

Safe place imagery
Developing the compassionate self

This intervention has been developed using the following resources:

1. Content of the therapy:

Outline and Session-by-Session Record of Compassion Focused Group Therapy Module in the Context of a Local DBT Programme (Parker, Woods, & Gilbert, 2009)

An Introduction to the Theory and Practice of Compassion Focused Therapy and Compassionate Mind Training for Shame Based Difficulties (Gilbert, 2010)

Mindful Self-Compassion (Germer & Neff, 2012)

The Compassionate Mind Approach to Recovering from Trauma (Lee, 2012)

The Compassionate Mind (Gilbert, 2013)

The Mindful Path to Self-Compassion (Germer, 2009)

2. Process and adaptations of the intervention for cognitive impairment

Facing Degeneration with Compassion on your Side: Using Compassion Focused Therapy with People with a Diagnosis of a Dementia (Poz, 2014)

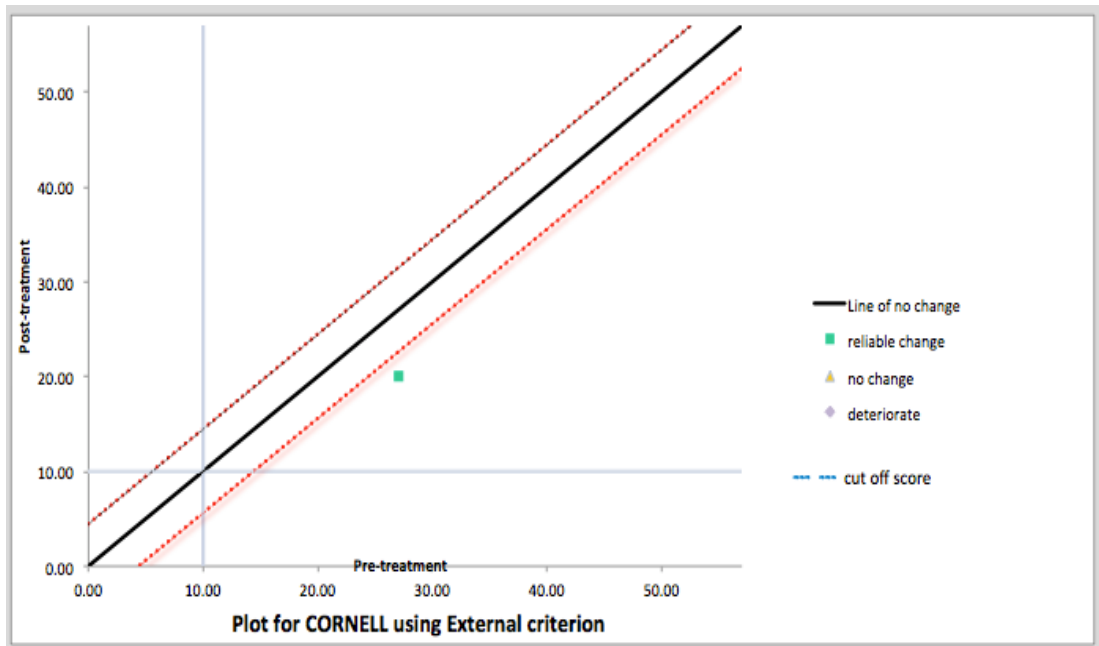
Cognitive Changes, Executive Functioning, Working Memory and Scripts: Their Relevance to Therapeutic Engagement (James, 2010), in Cognitive Behavioural Therapy with Older People.

Cognitive Behavioural Therapy for People with Dementia: A Clinical Guideline for a Person-Centred Approach (Charlesworth, Sadek, Schepers, & Spector, 2014)

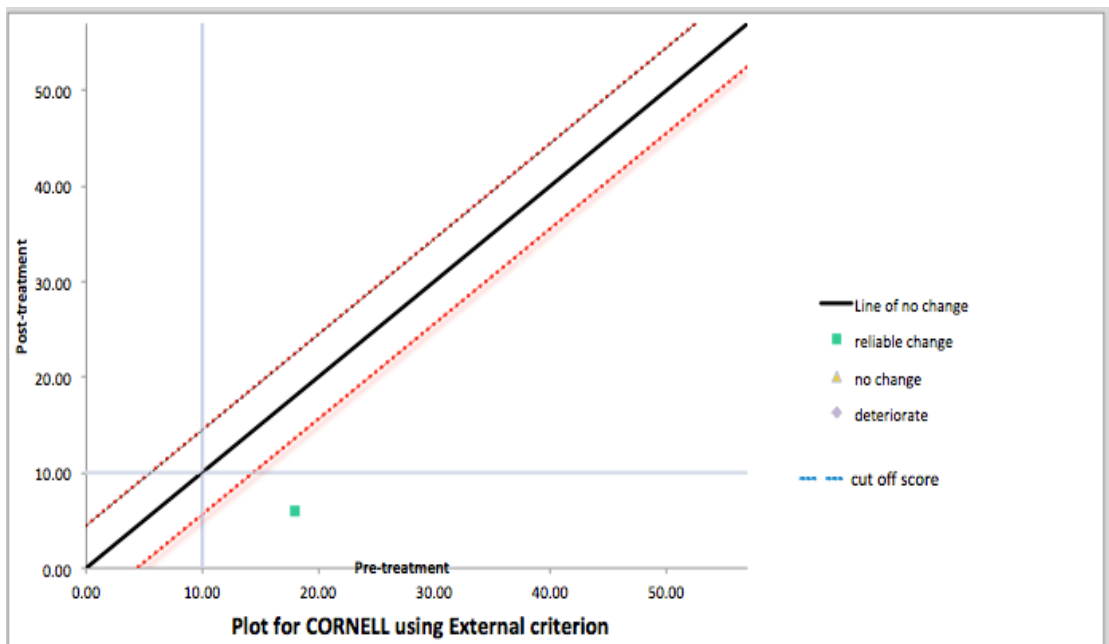
Psychotherapeutic Work with People with Dementia: a Review of the Literature Cheston (1998)

Appendix S – Reliable change graphical output for CSDD (Mood)

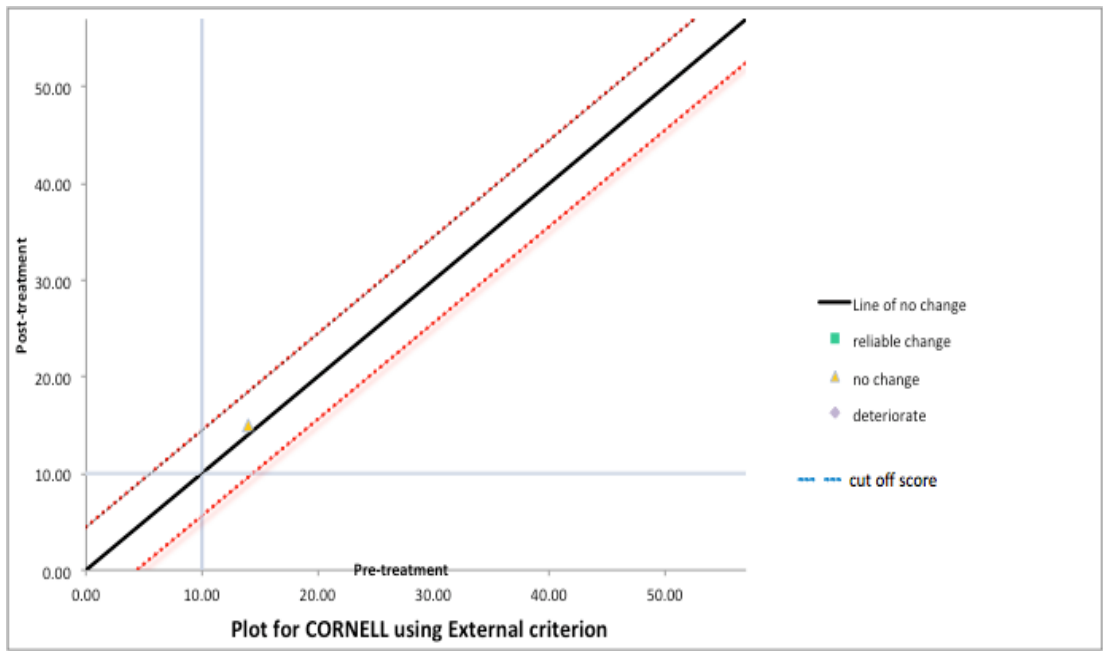
Participant 1



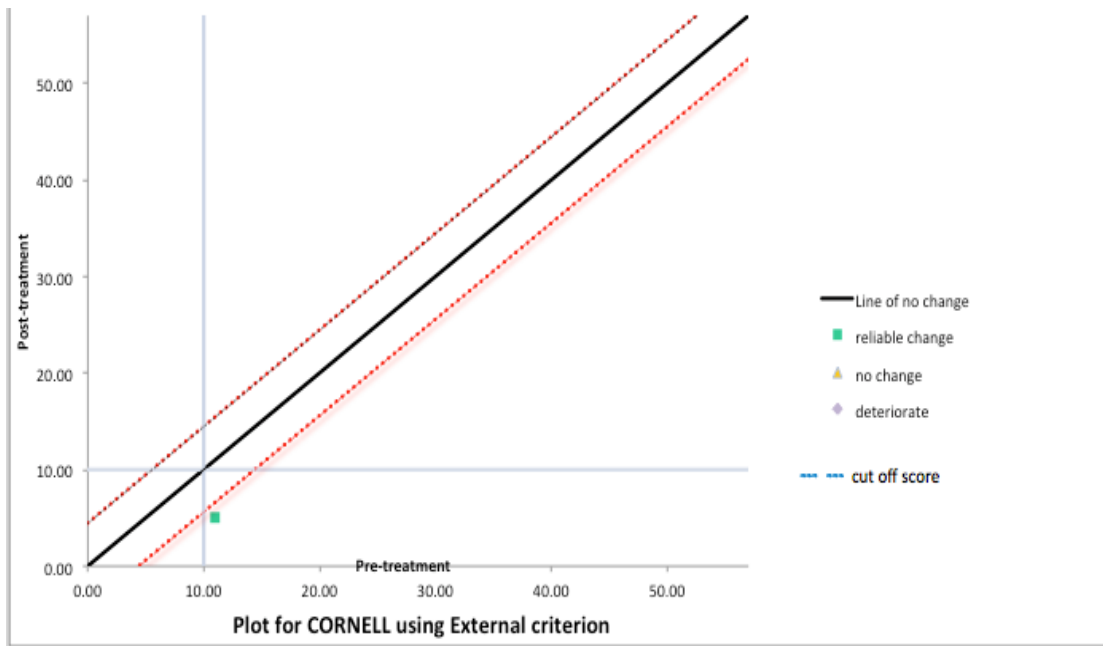
Participant 2



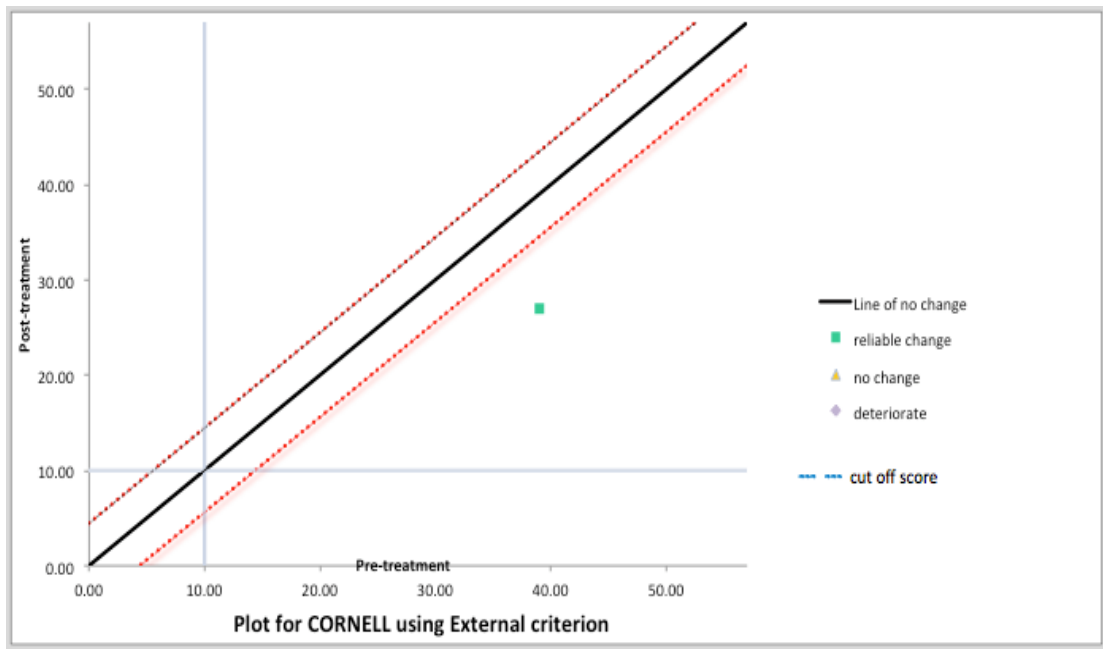
Participant 3



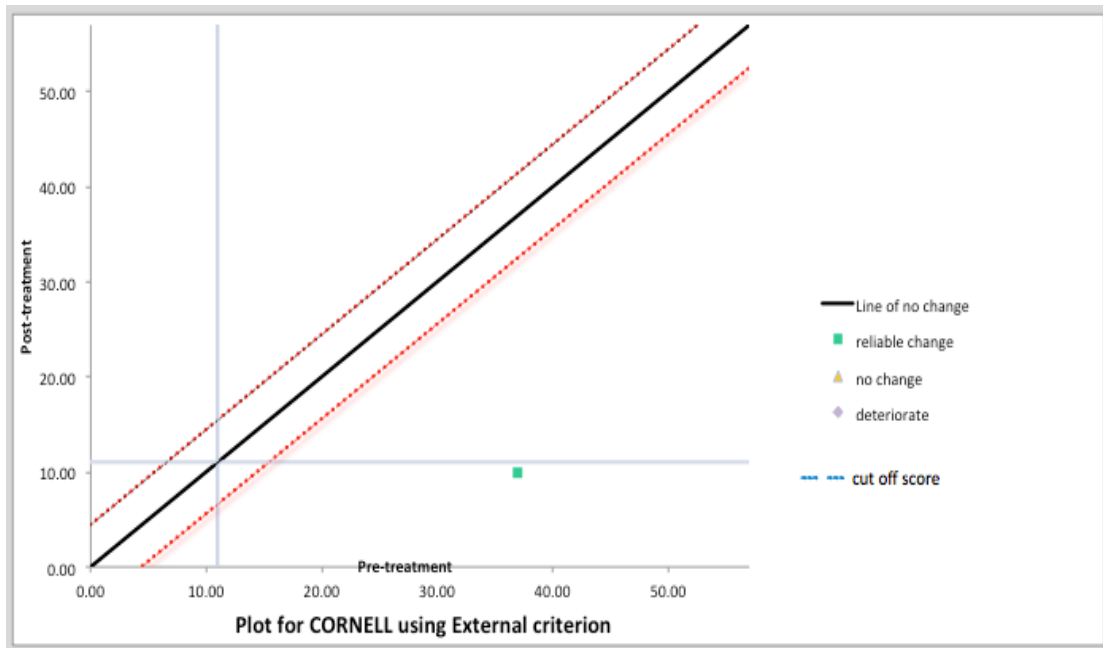
Participant 4



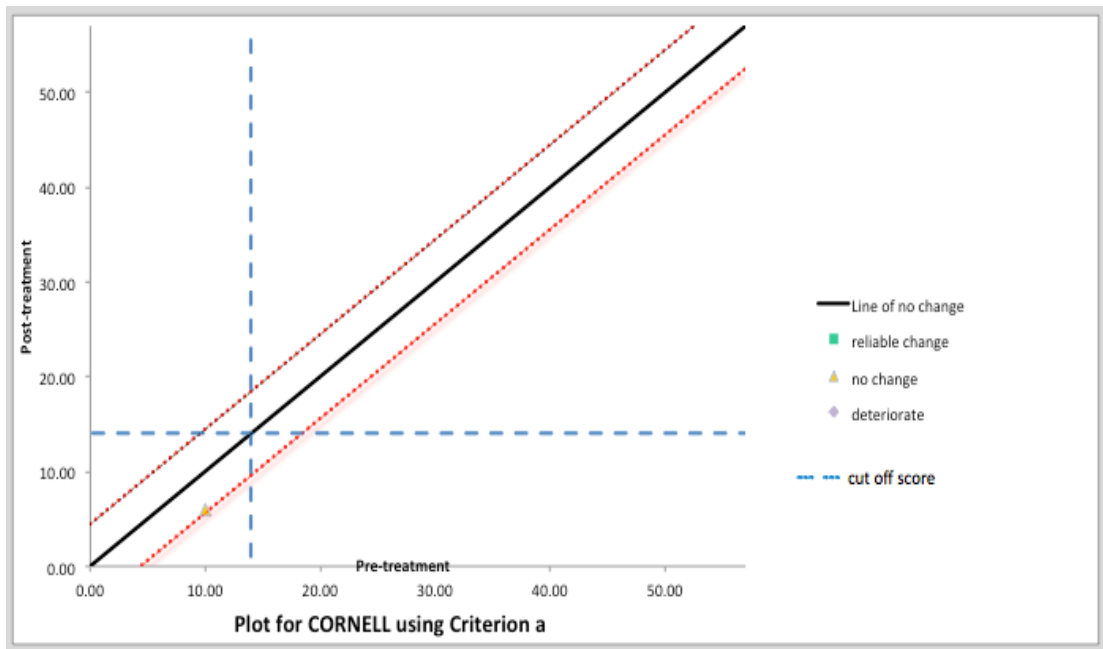
Participant 5



Participant 6

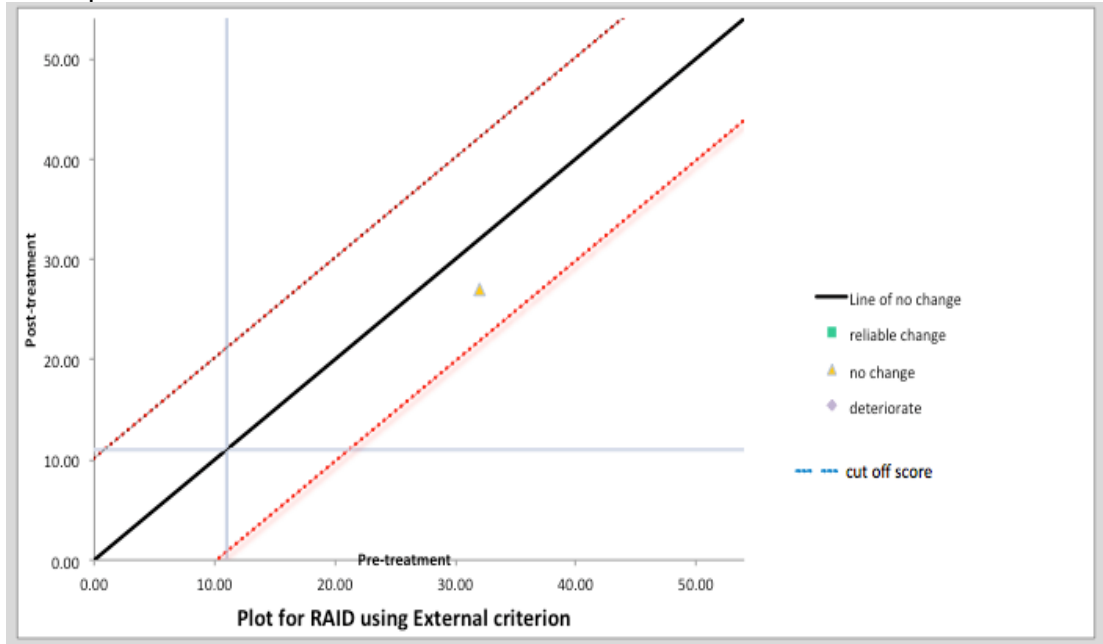


Participant 7

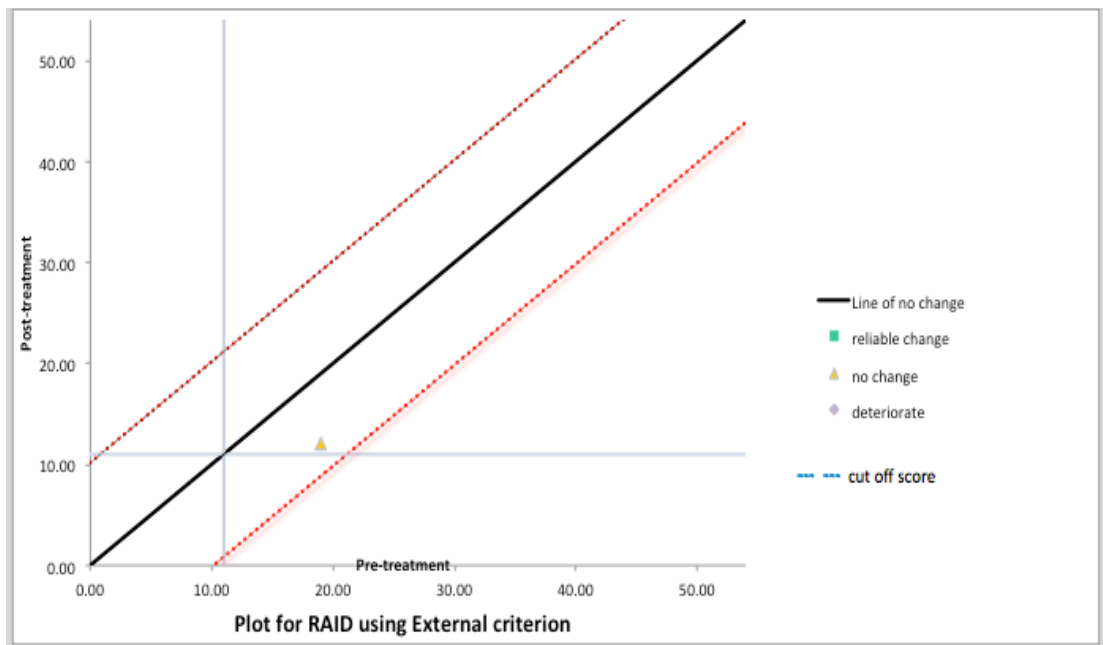


Appendix T - Reliable change graphical output for RAID (Anxiety)

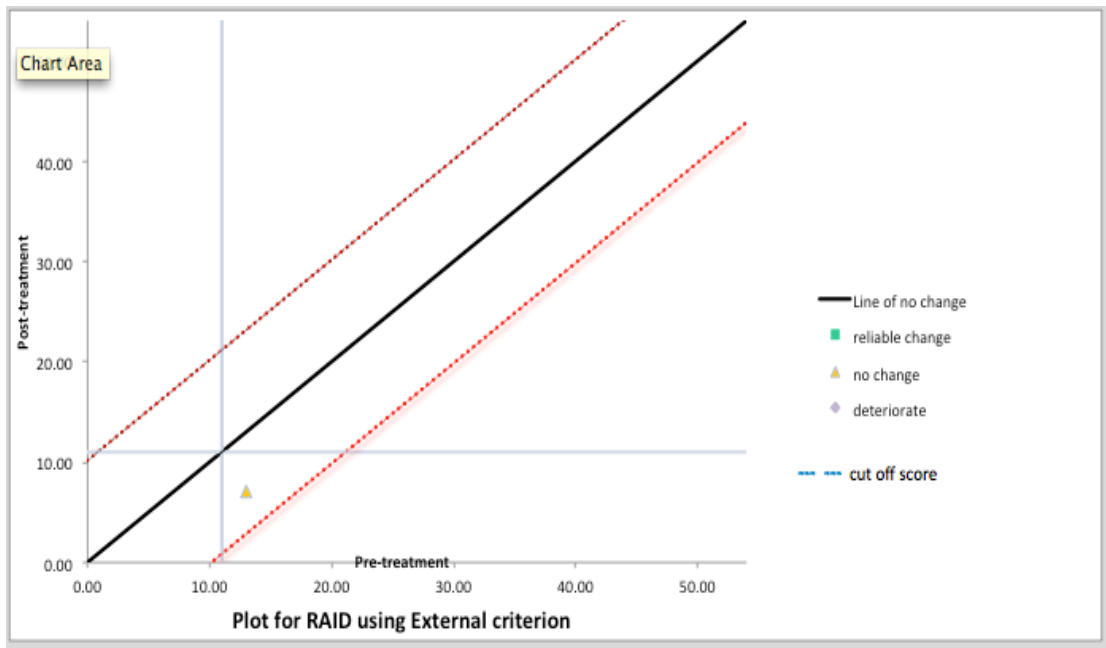
Participant 1



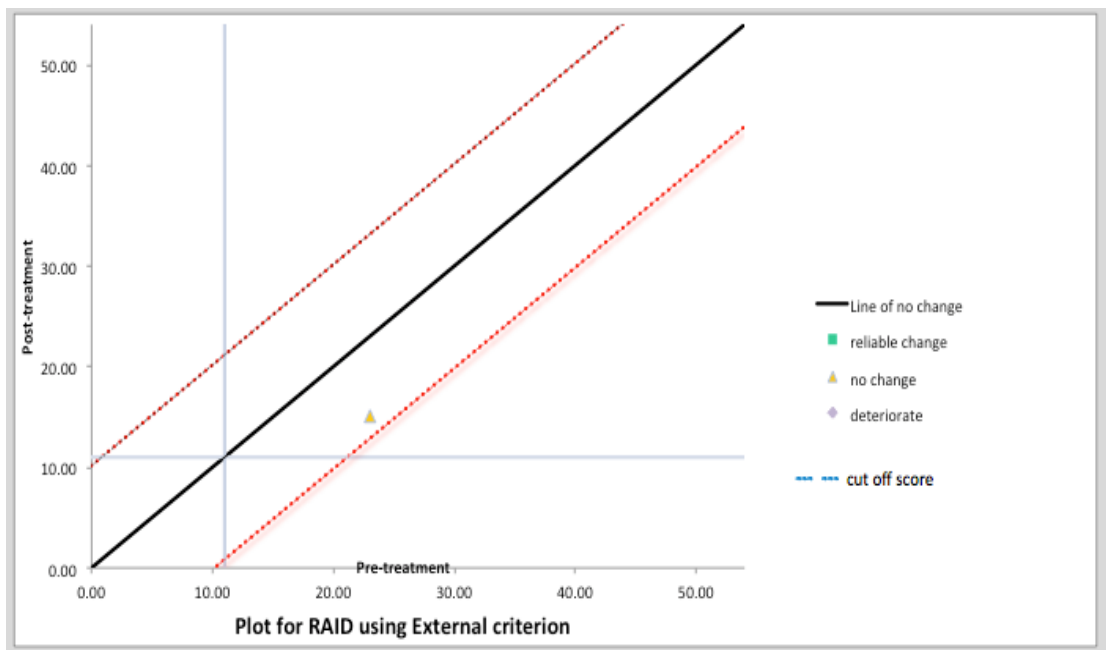
Participant 2



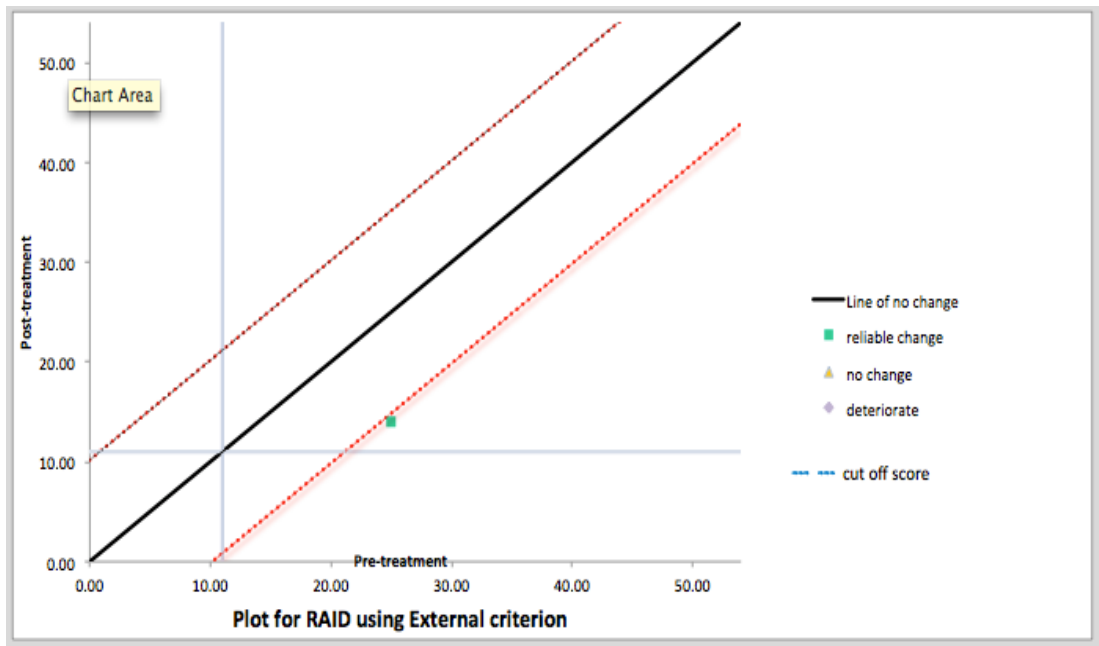
Participant 3



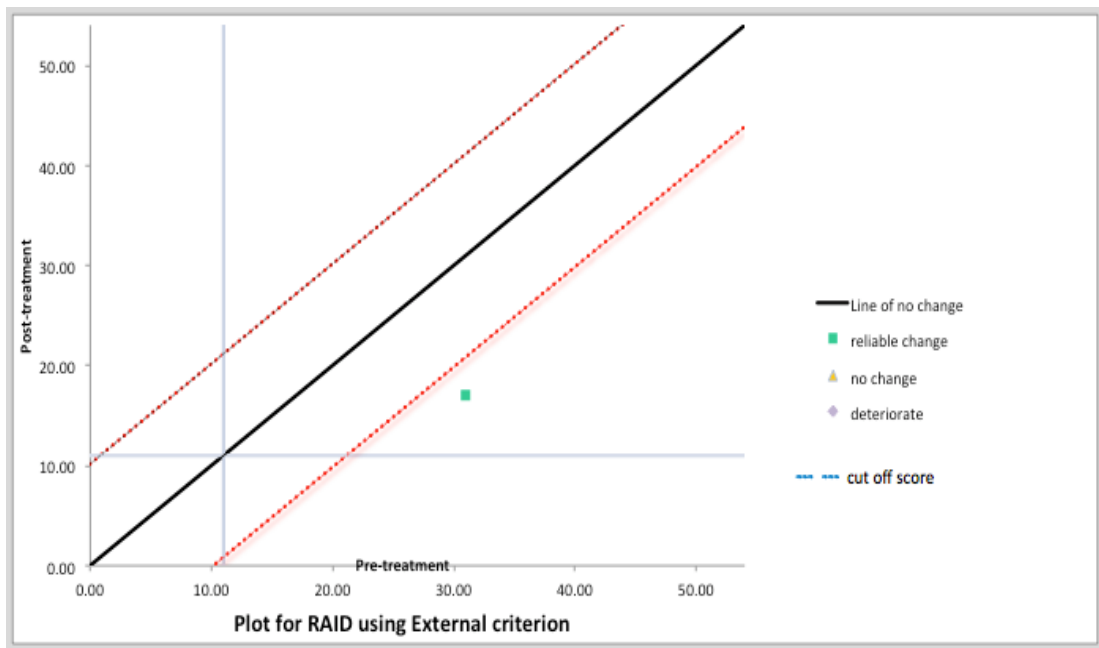
Participant 4



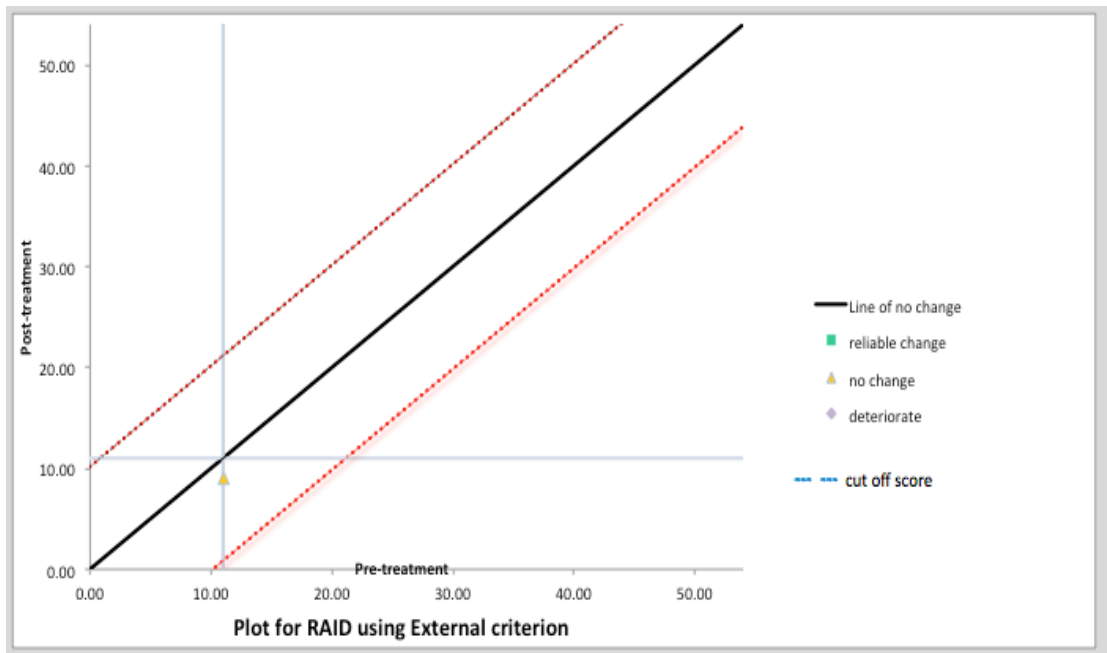
Participant 5



Participant 6

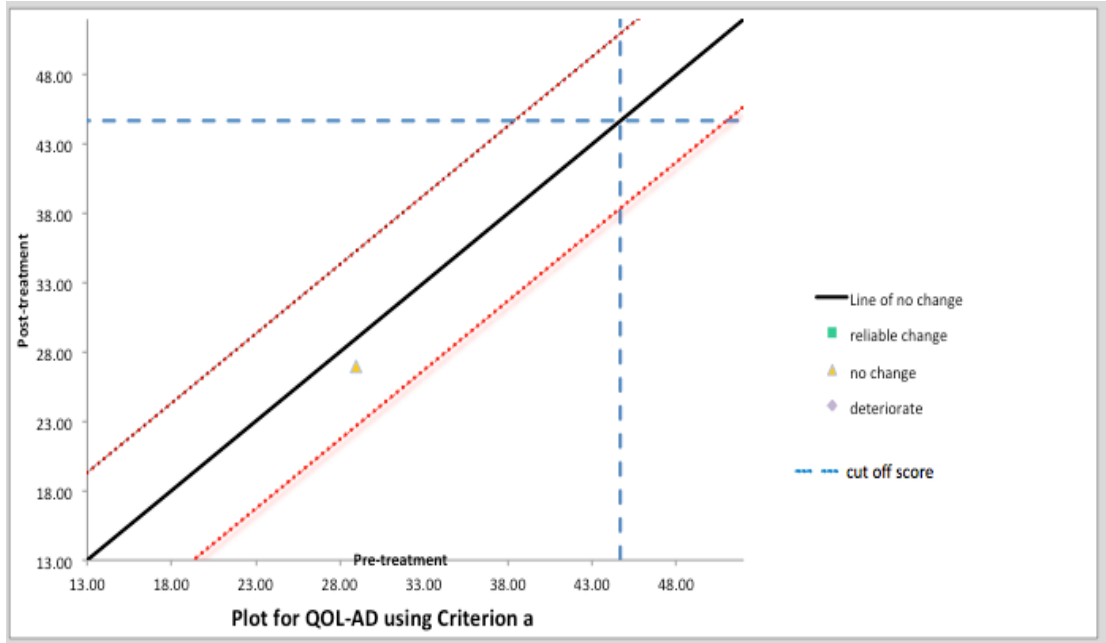


Participant 7

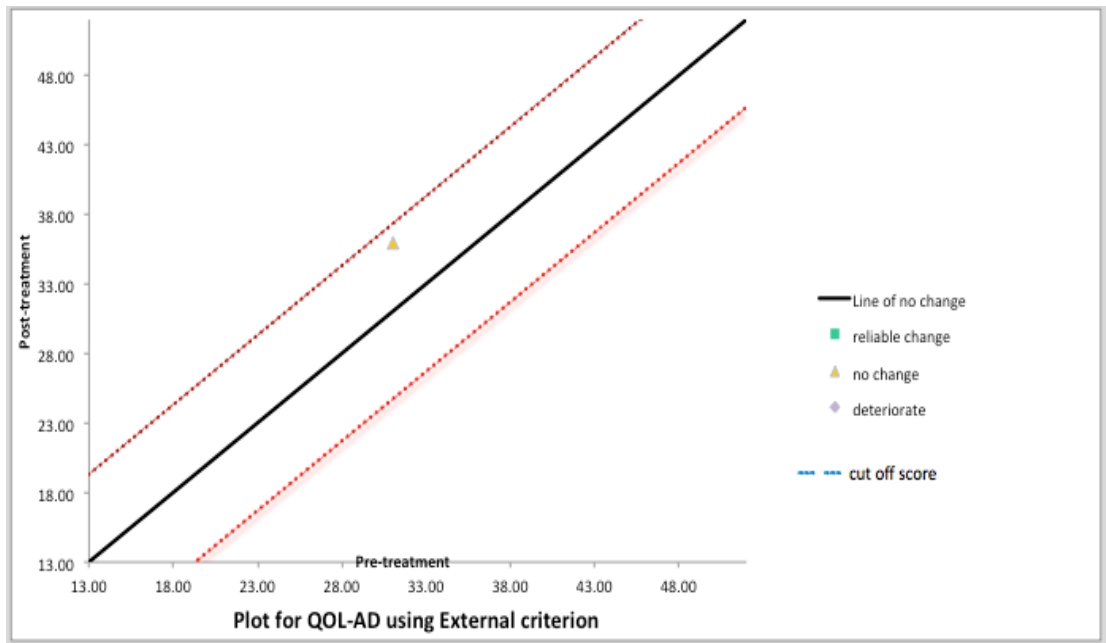


Appendix U - Reliable change graphical output for QoL-AD (Quality of life)

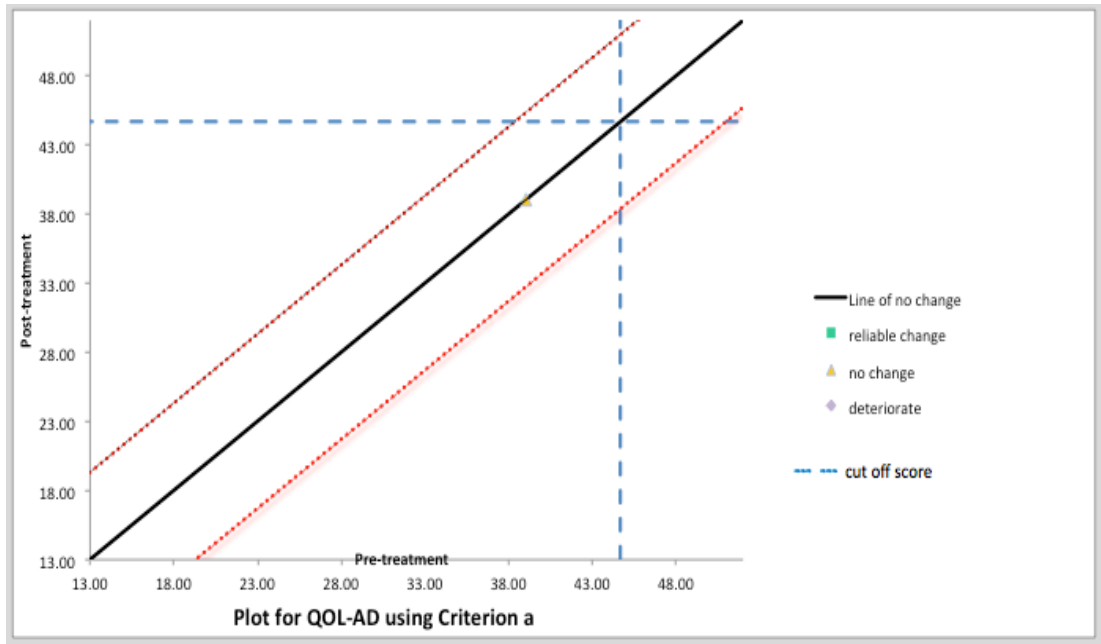
Participant 1



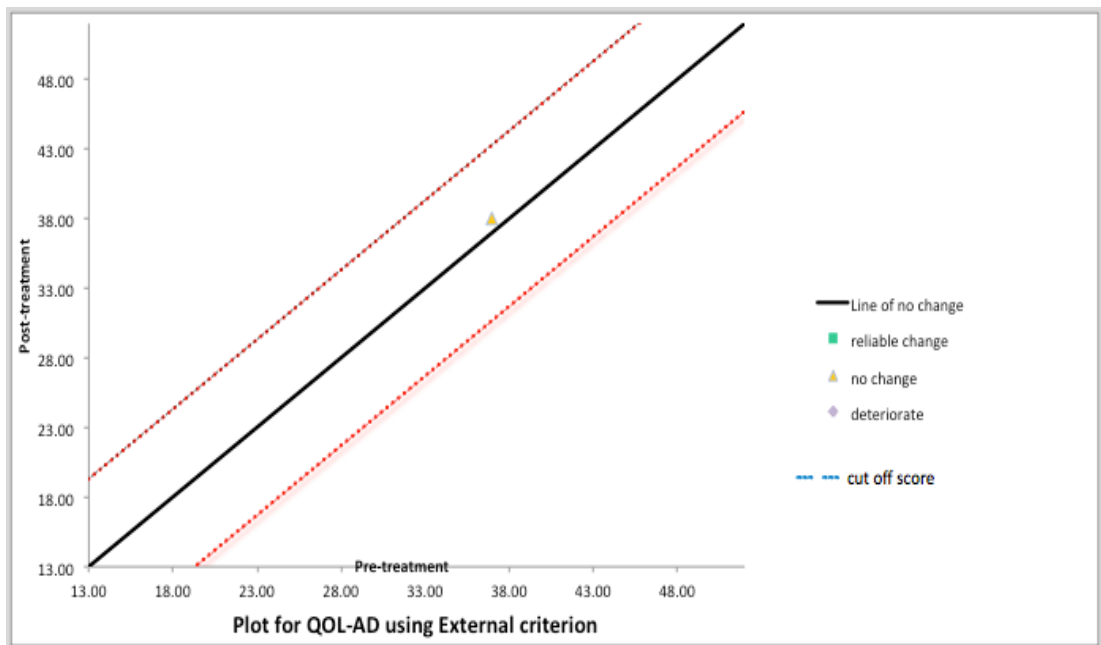
Participant 2



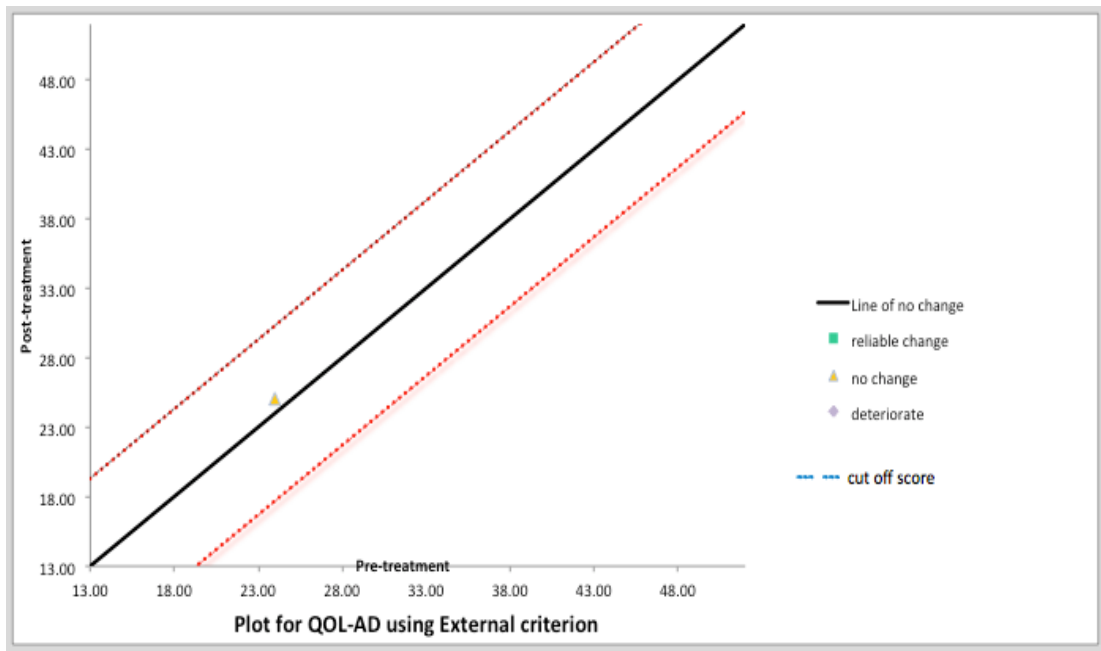
Participant 3



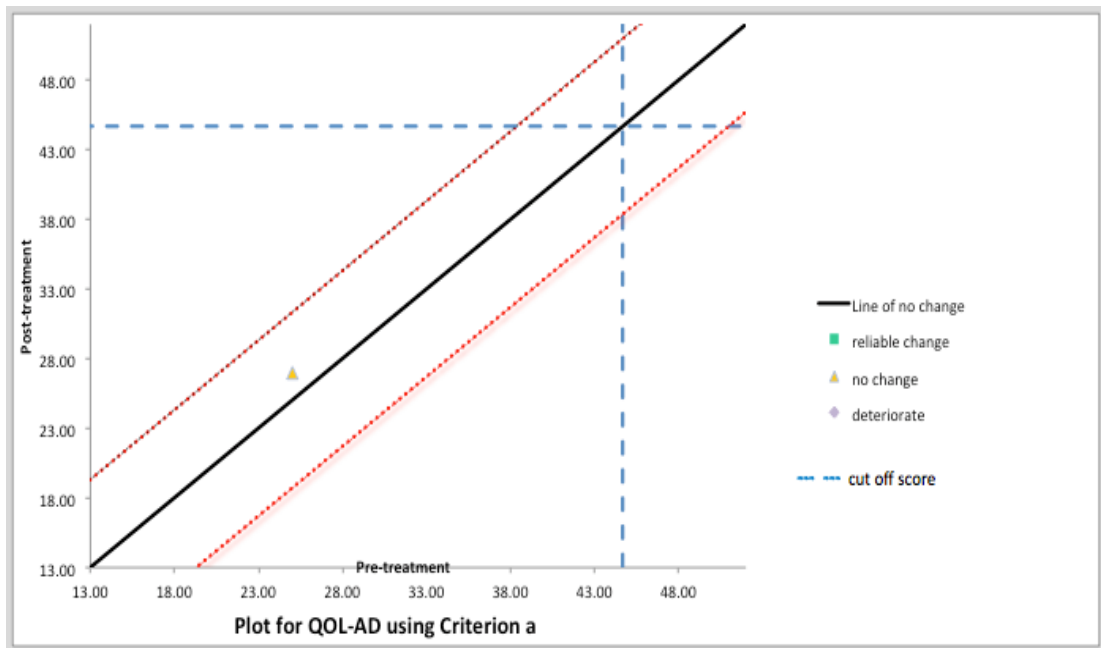
Participant 4



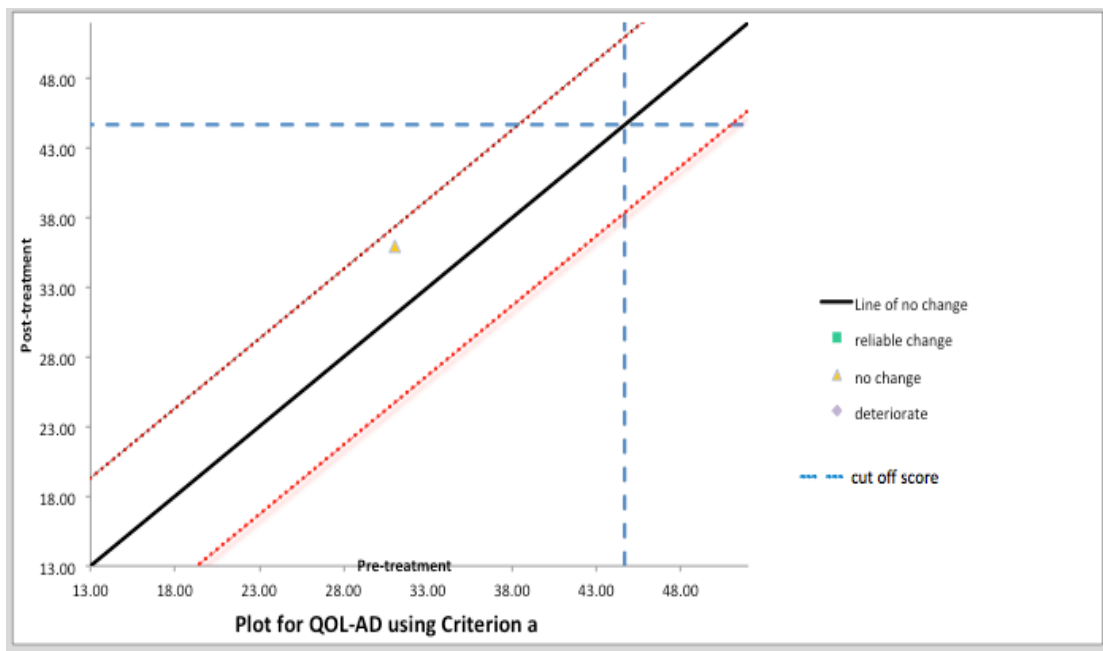
Participant 5



Participant 6

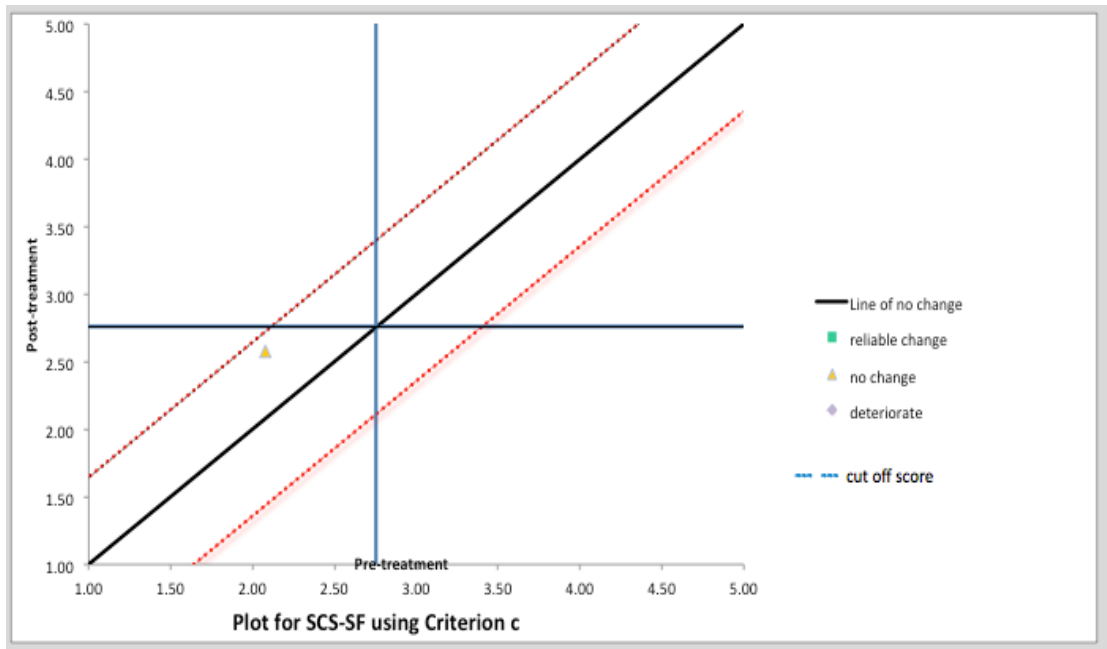


Participant 7

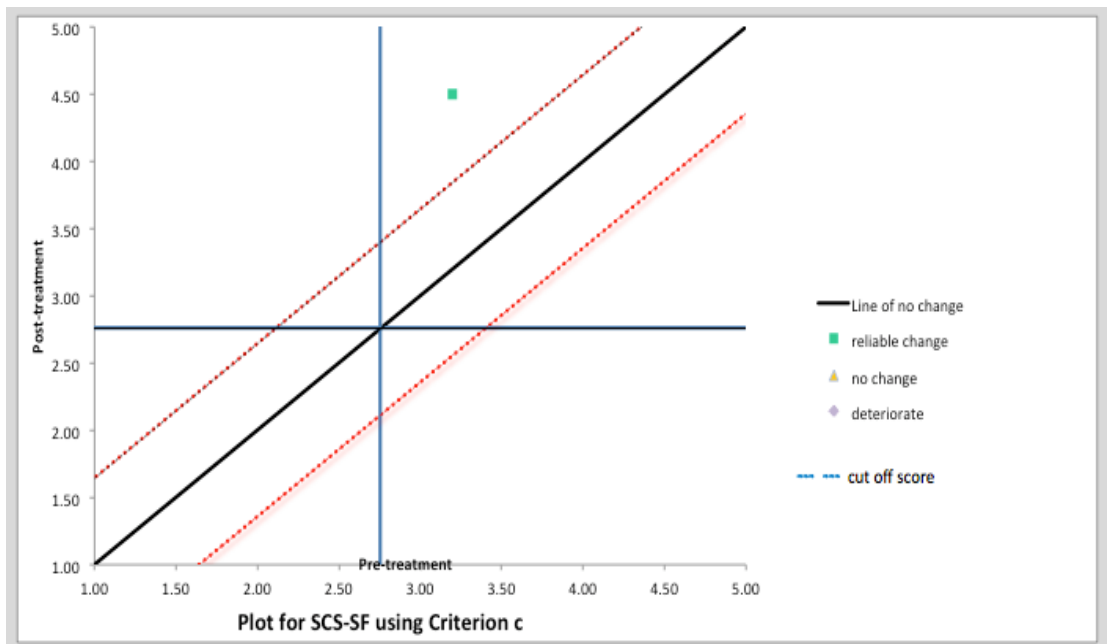


Appendix V - Reliable change graphical output for SCS-SF (Self-compassion)

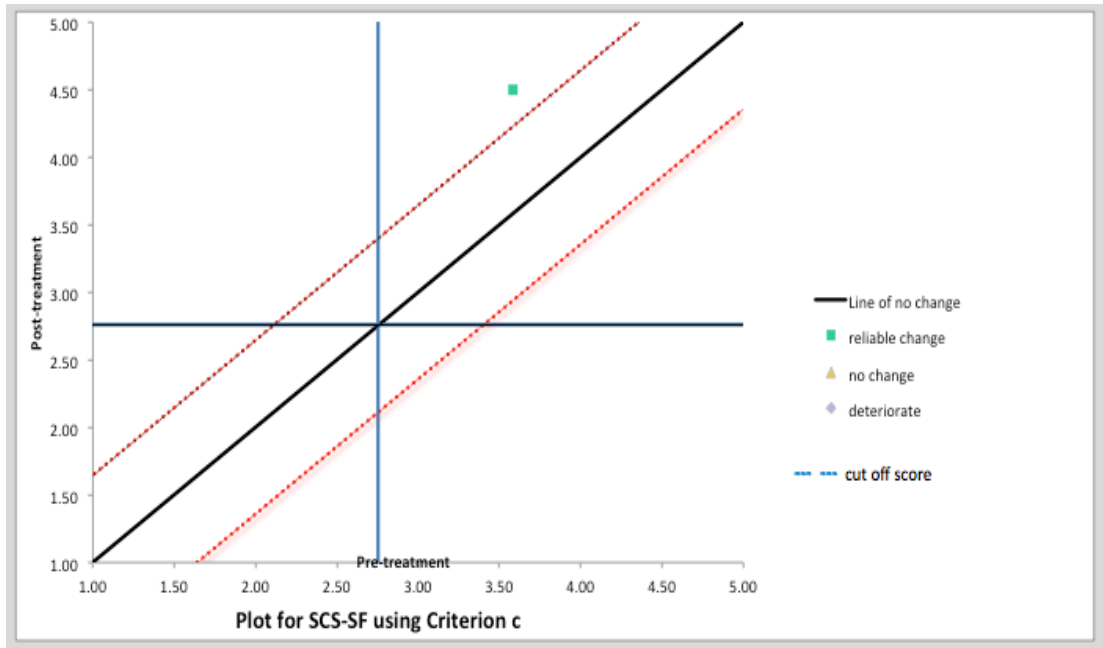
Participant 1



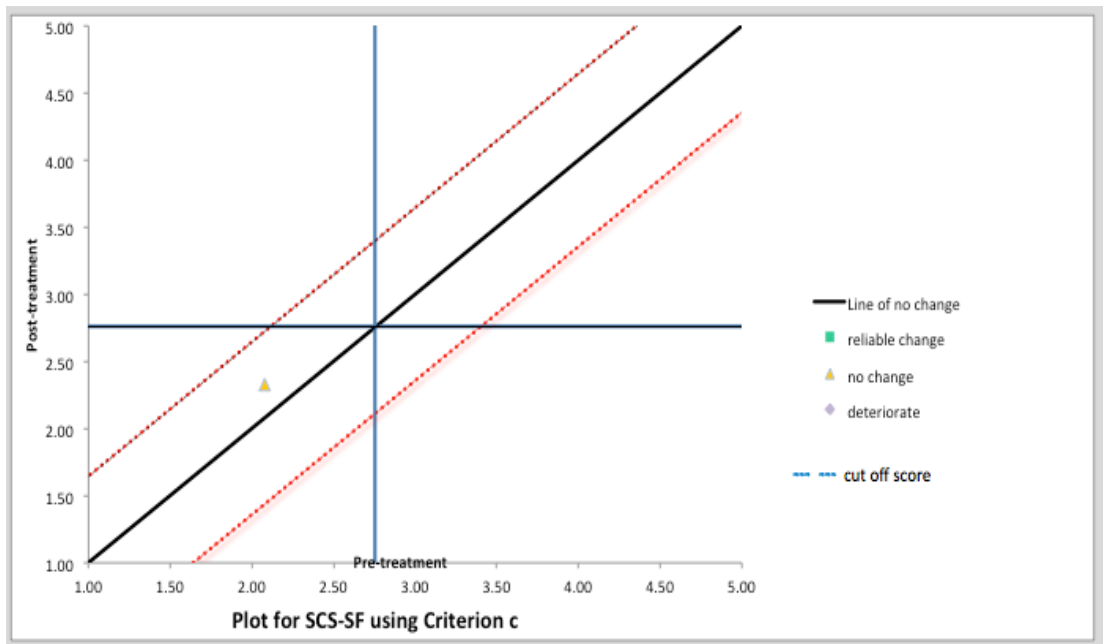
Participant 2



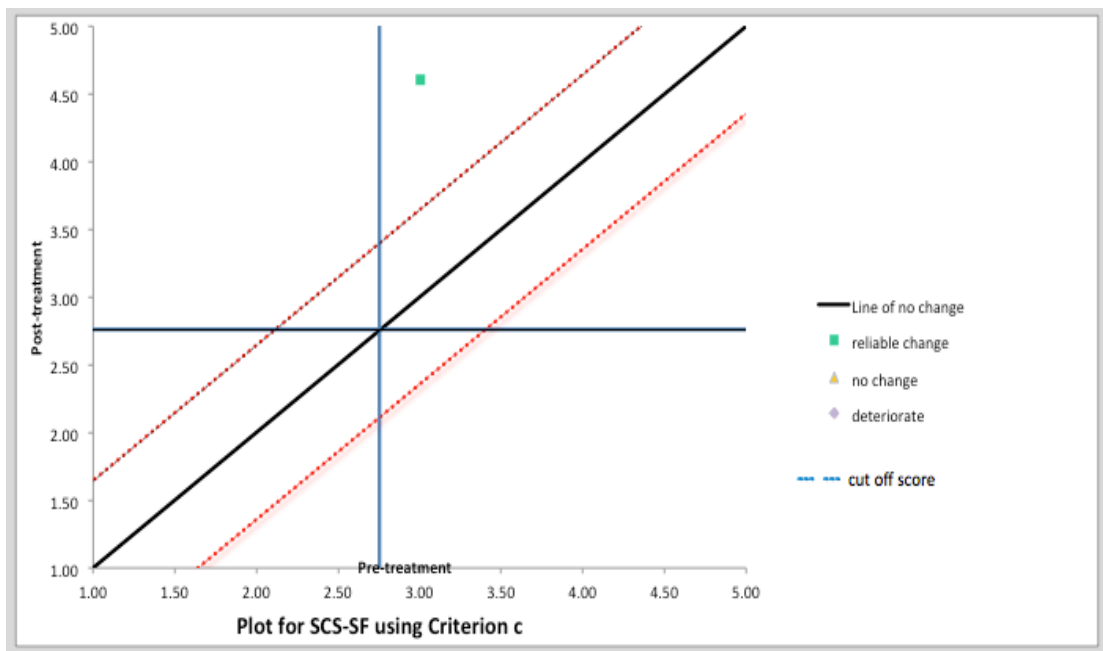
Participant 3



Participant 5



Participant 6



Participant 7

