ACCEPTANCE AND COMMITMENT THERAPY FOR PEOPLE WITH DEMENTIA EXPERIENCING PSYCHOLOGICAL DISTRESS

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Thesis Abstract

Introduction: People with dementia can experience a high level of psychological distress (Muliyala & Varghese, 2010; Badrakalimuthu & Tarbuck, 2012). Although psychological approaches have been proposed as potential treatments for this population (NICE, 2018), there is indication that older adults (Laidlaw, 2013) and people with dementia have reduced opportunities for psychological treatments designed to improve their wellbeing. An increasing number of studies have evidenced the efficacy of Acceptance and Commitment Therapy (ACT) for anxiety, depression (Öst, 2014), distress in older adults (Gould et al., 2021; O'Keeffe et al., 2021) and illness-related distress (Mccracken & Gutiérrez-martínez, 2011). But, to date, no studies have investigated the effectiveness of ACT specifically for a dementia population, despite a conceptual case for its suitability, which is empirically supported by its use with parallel populations (other long-term and neurological conditions). Furthermore, no dementia studies involving therapeutic intervention have used a case series approach to explicitly examine change processes, integral for understanding and refining interventions. Therefore, the current research aims to investigate the effectiveness and acceptability of ACT for people with dementia.

Methods: A hermeneutic single case efficacy design (HSCED) series was used to analyse therapy process and outcome data to ascertain whether and how changes may have occurred over the ACT intervention. Three clients with a diagnosis of dementia, who experienced psychological distress, and their caregivers were recruited from a National Health Service (NHS) Memory Assessment Service (MAS) in Nottinghamshire and the Dementia Research UK website. Clients were offered 12 sessions of ACT. Quantitative and qualitative clinical data was collated ('rich case records') and subject to critical analyses by three independent psychotherapy experts who identified change processes and determined the outcome for each client.

Results: Adjudication concluded that one client made positive changes which were largely attributable to ACT, whilst two clients remained unchanged. Where change occurred, ACT-specific processes, namely values, committed action and acceptance, seemed to mediate change, alongside the client-carer relationship. Moderating factors included client willingness, resilience and perseverance, a history of values-based behaviour and established coping and hobbies.

Discussion/Conclusion: The HSCED enabled a dismantling of therapy components to understand change processes for people with dementia. For the client who demonstrated change, ACT processes and a strong working alliance between client and carer, in combination with existing client interests and individualised therapy adaptations, appeared to provide the setting in which an ACT intervention was effective. Reliable distress reduction occurred for this client without therapeutic aims to change their distressing thoughts, which has important theoretical implications for understanding the use of acceptance-based approaches for people with dementia. ACT may be a feasible, effective vehicle for therapeutic change by helping carers to better meet the needs of their loved ones. Based on the outcomes of the current study (one improved case and two cases of no change), future research to optimise ACT delivery in this population may be beneficial. Furthermore, to explore whether change processes occur by proxy, assessing carer factors (e.g., their psychological flexibility, the client-carer relationship) may enhance the evidence-base for systemic ACT-use.

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Statement of Contribution

Thesis	
Project Design	Amie Robinson; supervised by Dr Danielle De Boos and Dr Nima Golijani Moghaddam.
Literature Review	Amie Robinson; supervised by Dr Danielle De Boos and Dr Nima Golijani Moghaddam.
Application for Ethical Approval	Amie Robinson; supervised by Dr Danielle De Boos and Dr Nima Golijani Moghaddam.
Participant Recruitment	Belinda Baker (Memory Assessment Service Nurse) identified potential participants and administered screening measures. Amie Robinson also identified potential participants, administered screening measures, and gained informed consent.
Data Collection	Amie Robinson conducted the therapy intervention and collected data; supervised monthly by Dr Nima Golijani Moghaddam. Emma Garner, Fiammetta Rocca and Christopher Lambert conducted the change interviews with clients and their carers.
Data Analysis & Write up	Dr Nima Golijani Moghaddam assessed for ACT intervention fidelity. Dr Danielle De Boos and Dr Nima Golijani Moghaddam reviewed the rich case records and affirmative and sceptic briefs developed by Amie Robinson. Dr David Dawson, Dr Helen Philpott and Dr Sam Malins were independent psychotherapy judges who analysed the case records and provided their clinical opinion. Dr Danielle De Boos and Dr Nima Golijani Moghaddam reviewed draft versions of the journal paper by Amie Robinson.

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Systematic Literature Review

Psychological treatments and therapy adaptations for psychological distress in dementia and mild cognitive impairment: A systematic review and meta-analysis[1]

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Purpose: To evaluate the effectiveness of psychological treatments and identify required adaptations to increase acceptability and improve outcomes for people with dementia or mild cognitive impairment (MCI) who experience psychological distress. Methods: The Cochrane Dementia and Cognitive Improvement Group Specialized Register and other databases were searched for eligible studies. Inclusion criteria identified nine randomised controlled trials (RCTs) comparing a psychological intervention (cognitive behavioural therapy, relaxation training therapies, multimodal therapies, psychodynamic therapy, counselling, cognitive rehabilitation) with usual care, with measures of depression and/or anxiety as an outcome. The appraisal of papers was conducted using the Mixed Methods Appraisal Tool (MMAT). Data was analysed using meta-analysis. Results: Due to methodological limitations and a small number of studies evaluated, the quality of evidence was low for outcomes for depression and there were no significant outcomes in anxiety. Several therapy adaptations were identified. Conclusions: A small, significant effect size pre- to post-intervention was revealed, suggesting that psychological treatments may be effective in reducing psychological distress in people with dementia. Future studies should employ high-quality trials using standardised psychological interventions, of sufficient length, with long-term follow-up and offer of specific adaptations to increase accessibility and outcomes.

Keywords: dementia; psychological distress; psychological treatments; therapy adaptations; review; meta-analysis

Introduction

People with dementia commonly experience psychological distress. This can be defined as emotional suffering typified by clinical levels of depression and anxiety (Drapeau et al., 2012). It is possible that up to 68% of people with dementia have depression (Muliyala & Varghese, 2010) and up to 72% experience anxiety (Badrakalimuthu & Tarbuck, 2012). In mild cognitive impairment (MCI), the prevalence of depressive symptoms is estimated between 36% (Palmer et al., 2007) and 63% (Solfrizzi et al., 2007), and anxiety symptoms can range from 10% – 74% (Monastero et al., 2009). Depression and anxiety can considerably impact the course of dementia, resulting in reduced independence (Tonga et al., 2020), higher caregiver burden (Gonzalez-Salvador et al., 1999), institutionalisation (Stern et al., 1997), cost to society (Burns et al., 2005) and higher risk of dementia-related mortality when compared to people without psychological distress (Rosness et al., 2016). Whilst many people with mild dementia often report feeling lonely, distressed, depressed, and anxious, (Alzheimer's Association, 2014) and request individualised support (Waldorff et al., 2012), the needs of older people with mental health difficulties continue to be insufficiently met (Laidlaw, 2013). Hence, it is clearly an important clinical objective to support people to cope with any co-morbid depression and anxiety (Cheston, 1998; Moniz-Cook & Manthorpe, 2009). Pharmacological interventions, such as anti-depressants, are often used to treat depression and anxiety in dementia, despite posing serious side effects and evidence of poor efficacy (Banerjee, 2011). Psychological approaches have been recommended within clinical guidance as possible treatments in dementia (NICE, 2018) and there is evidence to suggest that non-pharmacological interventions are potentially cost-effective in improving psychological outcomes (Olazaran et al., 2010). The key psychotherapeutic approaches in treating depression and anxiety in adults are psychodynamic therapy (with a focus on past experiences and unconscious feelings), interpersonal therapy (to support positive interactions with others, considering relational issues such as conflict and loss; NICE), cognitive behavioural therapy (CBT; which aims to identify and challenge negative appraisals and behaviours) and supportive counselling (with advice, reassurance, and empathic listening) (WHO, 2007).

In Orgeta et al.'s (2015) systematic review, the results of six randomised controlled trials (RCTs) involving CBT, psychodynamic therapy, counselling and multimodal therapies indicated that treatments that applied a psychological model to primarily target depression and anxiety could promote psychological wellbeing in dementia. Results suggested that psychological treatments were superior to usual care in reducing distress, and as some control conditions were supplemented beyond usual care, the efficacy of the psychological therapies may have been underestimated (Orgeta et al.). In Teri et al.'s (1997) study involving dementia patient-caregiver dyads, it was also concluded that behavioural interventions, one emphasising patient pleasant events (e.g. being outside, shopping, being with family) and one emphasising caregiver problem-solving, significantly improved participants' depressive symptoms in comparison to the control, and these gains were maintained at six month follow-up. Furthermore, an RCT by Spector et al. (2015) found that depressive symptoms reduced following a 10-week CBT intervention for people with dementia, and improvements were maintained at six months. However, no significant difference was found in anxiety, possibly due to methodological weaknesses and inclusion of a limited number of trials. Nevertheless, concerns remain that people with dementia have fewer opportunities for psychological treatments aimed at improving their wellbeing (Laidlaw, 2013).

Several studies have investigated the benefit of therapy adaptations to compensate for age-related losses in sensory function and attention (Yost et al., 1986), which often involve emphasis on behavioural strategies, repetition of information (Grant & Casey, 1995) and relaxation practice (Stanley et al., 2004). Modifications to CBT, for example, focus on cognitive techniques in early-stage dementia and behavioural strategies in later stages (Orgeta et al., 2015). Further adaptations to reduce cognitive load such as simplifying communications (Robie, 1999), using concrete examples, checking clients' understanding throughout (Gellis et al., 2009) and generally slowing the pace of therapy have also proved useful. As such, CBT is considered feasible for people with dementia in terms of acceptability and effectiveness (Spector et al., 2015). However, as dementia causes cognitive decline beyond the expected course of normal ageing, it would be important to consider more specific and less ambiguous therapy adaptations required to improve acceptability and outcomes, not only to compensate for age-related clinical diversity but to also accommodate dementia-related cognitive decline.

In summary, people with dementia and MCI have a high prevalence of psychological distress but are inadequately served in terms of evidence-based interventions. Psychological treatments adapted for people with cognitive impairment may offer an alternative approach. As there appears to be efficacy of psychological interventions for dementia, and a convincing argument that any direct psychological intervention could be expected to be useful, further exploration of higher quality research is merited (Orgeta et al., 2015).

The main purpose of the current review is to extend Orgeta et al.'s (2015) review, a decision made based on the time elapsed since the review and the need to identify higher quality evidence that psychological treatments can effectively reduce depressive and anxiety symptoms in people with dementia and MCI. For example, there remain uncertainties about risk of bias in psychological treatments of depression and anxiety in dementia due to the use of combined, multimodal treatments, rather than one distinct psychological approach (Orgeta et al.). Hence, the current review will endeavour to identify studies involving well-defined psychological therapies. Moreover, the differences in duration and intensity of the interventions, as evaluated in Orgeta et al.'s review, caused difficulty in interpreting the data, thus intervention length may be a potential moderator.

The second aim of the review is to investigate and synthesise the specific adaptations made in intervention studies to increase acceptability and outcomes, which offers a novel focus in comparison to Orgeta et al.'s (2015) review. Therefore, the research question is, 'What adaptations must be made to psychological therapy to increase acceptability and improve outcomes for people with dementia and MCI who experience psychological distress?'

Methodology

Search Strategy

Prior to the data search, a check of the Prospero register confirmed no updates of Orgeta et al's (2015) review, thus the current review could proceed. Orgeta et al.'s original search strategy was replicated as far as possible in terms of access. The Cochrane Dementia and Cognitive Improvement Group (CDCIG) Specialized Register and ALOIS (https://alois.medsci.ox.ac.uk/) was searched. ALOIS contains dementia and cognitive impairment studies identified from the following (which were also searched individually):

(1) MEDLINE, CINHAL, PsycINFO, LILACS and EMBASE.

(2) Trial registers: The UKCTG for studies recruiting in the UK (data pooled from ISRCTN and ClinicalTrials.gov); Umin Japan Trial Register.

(3) Central Register of Controlled Trials (CENTRAL) in The Cochrane Library.

(4) A number of grey literature sources: ISI Web of knowledge Conference Proceedings; Index to Theses; Australasian Digital Theses.

Orgeta et al.’s (2015) original search terms were replicated. All "Treatment MCI" and "Treatment Dementia" studies were searched in combination with the following terms or phrases: Depression or Dysthymi* or "Adjustment Disorder/s" or "Mood Disorder/s" or "Affective Disorder/s" or "Affective Symptoms", Anxiety or Anxious or phobia/s or "Panic Disorder", psychotherapy, "cognitive therapy", "behaviour therapy", "cognitive behaviour therapy".

Study Selection

Following the removal of duplicates, titles and abstracts were screened using inclusion and exclusion criteria. Papers were excluded if they involved older adults without dementia or MCI, or involved only caregiver, spousal, or familial interventions. Thereafter, if papers were considered eligible (or potentially eligible but unable to be decided from the title and abstract), the full text was retrieved.

The population of interest was older adults with a diagnosis of dementia, Alzheimer’s Disease or organic brain syndrome, according to the American Psychiatric Association’s (APA, 2013) Diagnostic and Statistical Manual of

Mental Disorders 5th Edition (DSM-V), the World Health Organization's (WHO, 2018) International Statistical Classification of Diseases and Related Health Problems 11th Revision (ICD-11) or comparable, and participants with MCI, with any definition of MCI acceptable as long as there was evidence of objective cognitive impairment. The pragmatic decision was made to include papers on MCI as it could be argued there are many similarities in diagnosis and recognition of MCI and dementia (Knopman & Petersen, 2014) and are therefore only artificially separated.

In replication of Orgeta et al.'s (2015) review, studies were selected if they were RCTs with control group (usual care) and provided adequate information about the study design and results. Studies were included if they used a standardised measure of depression and/or anxiety as an outcome.

Psychological intervention was defined as an intervention designed to reduce depression and anxiety, improve adaptive functioning, or both, based on psychological theory and involving a structured interaction between a facilitator and participant (Orgeta et al., 2015). The following interventions were included:

(1) Cognitive behavioural therapies (e.g. CBT, behavioural therapy, problem-solving).
(2) Relaxation training therapies (e.g. progressive muscle relaxation, deep breathing, mindfulness).
(3) Psychodynamic therapies
(4) Supportive counselling therapies
(5) Cognitive rehabilitation

Interventions were also classed as ‘psychological’ if they involved an aspect of skills teaching to reduce psychological distress. Studies involving multimodal therapies (a combination of different psychological, pharmacological, or physical interventions) were included. Individual, dyad and group interventions were included. Interventions could be of any duration or frequency and conducted in any setting (e.g. home, community, institution). Studies solely involving medication, reminiscence, exercise, befriending, music therapy, or art or drama therapy were excluded.

Data Extraction

Data extraction was conducted by the first author. The following information was extracted from each paper; author(s), year and location, methodology (including analysis), sample characteristics (including population, sample size, gender and mean age), intervention (type, duration and modality), measures of depression and anxiety (including measurement time points), summary points and key findings, and intervention adaptations (where applicable to the review question, e.g. adaptations required to increase acceptability and improve outcomes).

Quality Appraisal

Due to the variety of recruitment methods, mixed methodologies, interventions, measures, measurement time points and power, the Mixed Methods Appraisal Tool (MMAT) Version 2011 (Pluye et al., 2011) was used to assess the methodological quality of included papers. The MMAT has been shown to have suitable validity and reliability (Pace et al., 2012) and was designed for use in systematic reviews of mixed methodologies. The MMAT enabled a thorough appraisal of studies and comparison between them.

As there were no qualitative studies in the current review, the MMAT was adapted for use by removing questions related to qualitative only methodologies. Questions regarding therapy fidelity and adaptations were added to capture this data. Responses to questions were either “yes”, “no” or “can’t tell”. However, in order to further operationalise these, the current review used “yes” when studies evidently met the criterion, “no” when they obviously did not, and “can’t tell” when there was not enough evidence to verify, or when criterion was only partly met. It was anticipated that due to adapting the MMAT, the scoring criteria would be invalidated, thus average quality scores were estimated to offer a quick indication of the quality of the studies. “No”, “can’t tell, and “yes” responses were appointed scores of ‘0’, ‘1’ and ‘2’ respectively (apart from question 4.6 which was reverse-scored). The scores were then totalled and divided by the number of relevant questions. Screening question scores were excluded. Questions regarding ‘complete outcome data’ were answered using the first available post-intervention or follow-up point for comparability. Questions concerning response rates mainly centred upon outcome and follow-up data.

Analysis

Review Manager 5.4 (The Cochrane Collaboration, 2020) was initially used to calculate the overall pooled effect size of changes in psychological distress between intervention and control groups. Post-intervention means, standard deviations and associated sample sizes were inputted into Review Manager

(The Cochrane Collaboration) for each study. Data was requested from authors when means and standard deviations were not reported. Papers were excluded from statistical analyses where data remained unavailable.

A forest plot of included studies was generated to review overall and individual effect sizes and confidence intervals. A funnel plot was produced to consider publication bias. The I^2 statistic was used to assess heterogeneity and a sensitivity analysis was conducted to determine the impact on heterogeneity when potentially heterogeneous studies were removed. Therefore, analyses were conducted with the removal of (1) the study of the lowest quality or (2) two studies involving the least common therapy modality (participant-carer dyads). Sensitivity analyses were also conducted in relation to outcome (separate pooled estimates for depression and anxiety), and for comparability, included the most used measure of depression (Cornell Scale for Depression in Dementia [CSDD]; Alexopoulos et al., 1988). A second meta-analysis was conducted to include those studies with longer-term follow-up data (6-12 months). Both meta-analyses utilised a random effects model (Higgins & Green, 2011) owing to clinical and methodological diversity often found in psychological intervention studies (Higgins et al., 2003). Furthermore, the use of standard mean difference (SMD) calculations produced pooled effect size estimates that were less susceptible to the effects of heterogeneity (French et al., 2017).

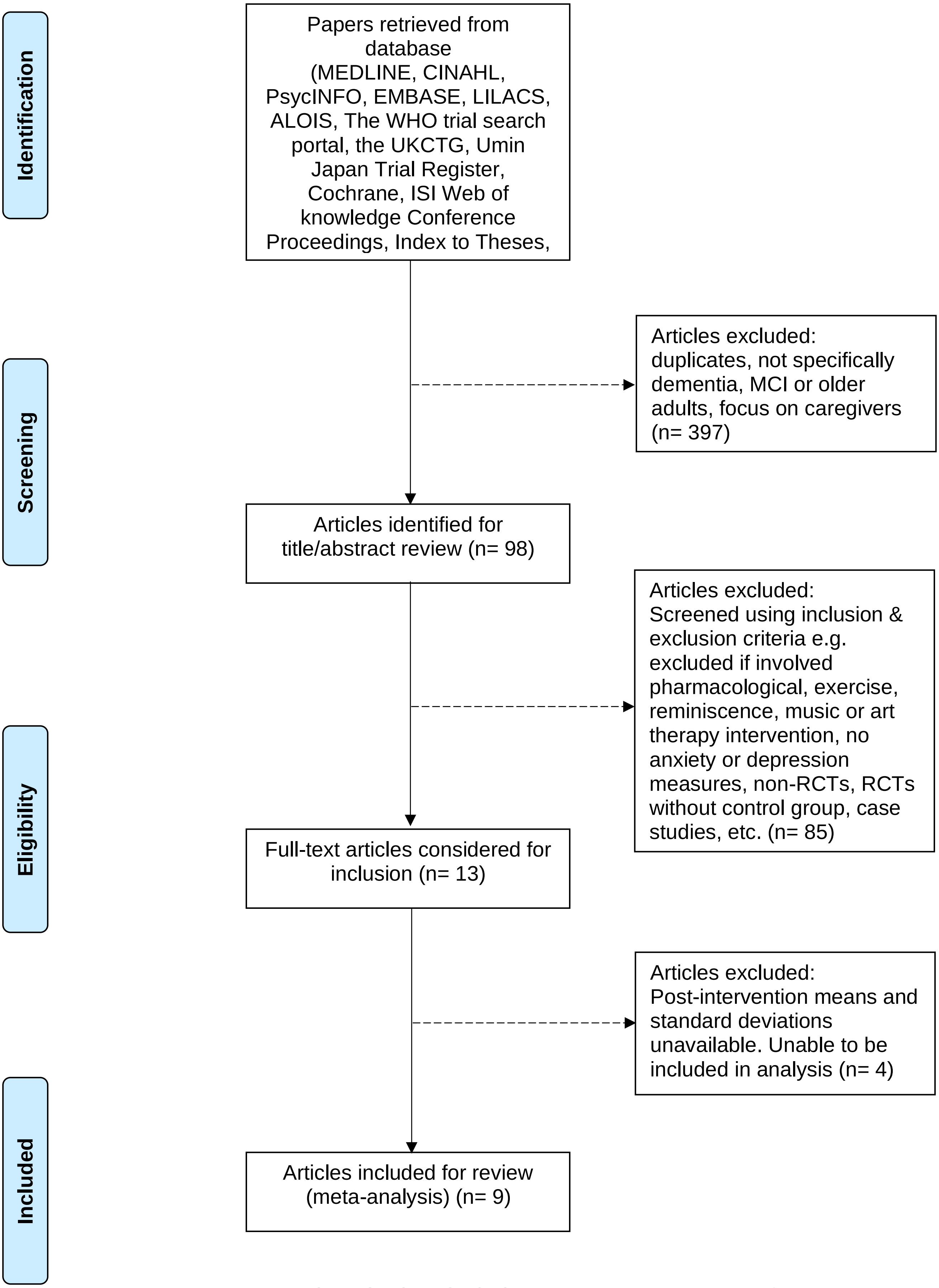
Overall pooled effect sizes were considered small at about <0.5, medium at 0.5 – 0.8 and large at ≥0.8. Heterogeneity using the I^2 statistic was regarded as insignificant (<40%), moderate (30 – 60%), substantial (50 – 90%), or considerable (>75%; Higgins et al. 2003).

Results

Search Strategy

A total of 495 results were identified through database searches conducted in June – July 2020. After the removal of duplicates and clearly irrelevant studies, 98 results remained, which were then screened by their titles and abstracts. Using inclusion and exclusion criteria, 85 results were excluded due to the use of pharmacological, reminiscence, exercise, music or art therapy interventions, omission of measures of depression and/or anxiety, RCTs without control group, and case studies or other methodologies that were not RCTs. This left 13 results for full-text review. However, data was unavailable from the authors of four papers, thus nine articles were included in the meta-analysis. Results are shown in a Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) flow diagram (Moher et al., 2009) in Figure 1.

Figure 1. PRISMA flow diagram outlining the selection process (Moher et al., 2009).



Study Characteristics

Study characteristics are provided in the Data Extraction table (Table 1). For ease of reading, studies will be referred to by the first author and year of publication for the remainder of the Results section.

Table 1. Data Extraction

Author(s) & Location	**Methodology**	**Sample Characteristics**	**Intervention**	**Measures of Depression & Anxiety**	**Summary Points & Key Findings**	**Intervention Adaptations**
1. Bailey, Stevens, LaRocca, & Scogin (2017) USA	**Quantitative** Questionnaires Observation RCT **Analysis** Inferential statistics (ANOVA)	**People with dementia and depression** (n=51) **Sample size** Experimental condition (n=26) Control condition (n=25) **Gender** Females (n= 51) Males (n=0) **Mean age** Experimental condition (84.35) Control condition (83.92)	6-week intervention. Two 30-minute group sessions per week involving question-asking reading (QAR), reminiscence, cognitive-behavioural therapy techniques, environmental supports and individualized behavioural activity programs. Assessed pre and post intervention.	Cornell Scale for Depression in Dementia (CSDD) Geriatric Depression Scale (GDS)	• Participants in the experimental condition showed significant improvement in depressive symptoms according to the CSDD. • Participants in the experimental group also exhibited significantly higher levels of expressive verbalisations, engagement with materials, and laughter. • There was non-significant change in quality of life. • The intervention structure may be suitable for older adults with cognitive impairment by distributing group tasks and providing external cognitive supports to positively impact participants' levels of depression.	• QAR reading passages adapted for age and interest e.g. Hobbies, Pets, World War II, The Depression, Childhood, Married With Children, Occupations, Favourite Holiday, Retirement, My Children Are Grown, Grandchildren and Great-Grandchildren, and Nursing Home Life.
2. Burgener, Yang, Gilbert, & Marsh-Yant (2008) USA	**Quantitative** Questionnaires Repeated measures RCT **Analysis** Inferential statistics	**People with dementia** (n=43) **Sample size** Experimental condition (n=24) Control condition (n=19)	20-week multimodal intervention. 60-minute Tai-chi classes (including 30 mins of relaxation)	Geriatric Depression Scale (GDS)	• Participants in the experimental group showed improved cognitive functioning following the intervention,	• Relaxation exercises encompassed approximately 30 minutes of the 60-minute class. • Tai-chi exercises consisted of strength and

	(independent samples t-test)	**Gender** Females (n=11) Males (n=13) **Mean age** Experimental condition (77.9) Control condition (76.0)	three times a week CBT group intervention for 90 minutes twice weekly. Support group for 90 minutes twice weekly. Assessed at baseline, 20 weeks (4.6 months) and 40 weeks (9.2 months).		with significant differences in MMSE scores in comparison to the control group. • Gains in MMSE scores at 40 weeks were not evident for the treatment group. • There was non-significant change in physical functioning in the experimental group. • Although further gains in balance and leg strength were not observed following intervention, physical functioning remained stable which may suggest Tai-chi exercise is beneficial for maintaining any prior gains in functioning. • The experimental group improved in self-esteem, but the control group declined. • Trends found in the stabilisation of depression were not significant. • There are potential benefits of an exercise intervention focusing on balance and strength training in older adults.; there are high adherence rates, potential for fall prevention, and benefits for cognitive functioning due to required motor and sequence learning.	balance training adapted for the PWD following a curriculum specifically for research on older adults).
3. Burns et al. (2005) UK	**Mixed methods** **Quantitative** Questionnaires	**People with Alzheimer's Disease** (n=40) **Carers** (n=40)	Six-week intervention. Weekly 50 minute 1:1	Cornell Scale for Depression in Dementia (CSDD)	• It is possible to adapt a model of psychotherapy	• Delivering the intervention in the individual's home.

	Repeated measures RCT **Qualitative** Semi-structured interview with 5 participants and their carers **Analysis** Inferential statistics (ANCOVA, Chi-squared) Clinician's Interview-Based Global Impression of Change	**Sample size** Experimental condition (n=20) Control condition (n=20) **Gender** Females (n=19) Males (n=21) **Mean age** Experimental condition (73.9) Control condition (77.7)	sessions of psychodynamic interpersonal therapy (with 10 minutes spent with the carer). Assessed at baseline, 3- and 6-month follow-ups.		for those with Alzheimer's disease. • No improvement was found on the majority of outcome measures in participants and their carers (e.g. cognitive function, activities of daily living, depression). • There was suggestion that the therapy had improved the carers' ways of coping with some of the symptoms of the disease. • The trend towards improvements in both carer and patient outcomes attests to the potential benefit of non-pharmacological interventions in this group.	• Involving carers in the treatment (therapist spent 10 minutes per session with the carer, listening to the carer's needs and informing the carer of therapeutic progress).
4. Churcher Clarke, Chan, Stott, Royan, & Spector (2017) UK	**Quantitative** Questionnaires Repeated measures Randomised controlled pilot study **Analysis** Inferential statistics (ANOVA)	**People with dementia** (n=31) **Sample size** Experimental condition (n=20) Control condition (n=11) **Gender** Females (n=15) Males (n=16) **Mean age** Experimental condition (81.3) Control condition (79.4)	10 session mindfulness intervention. Hourly group sessions, twice weekly for 5 weeks. Assessed at pre and post intervention.	Cornell Scale for Depression in Dementia (CSDD) Anxiety in Dementia Scale (RAID)	• There was a significant improvement in quality of life in the intervention group compared to controls. • There were no significant differences in depression, anxiety, cognitive functioning, stress, or mindfulness. • The adapted mindfulness intervention is feasible in terms of recruitment, retention, attrition, and acceptability for people with mild to moderate dementia. • Engagement and collaboration with managers is essential for the effective implementation of such interventions in care homes.	• Modification of scripts for the practices and the intervention structure was guided by systematic reviews of Mindfulness-Based Interventions for people with cognitive impairment and older adults. Practices were simplified, shortened, and used sensory elements that focused attention on one sense at a time. • A mindful warm-up activity was used to increase engagement and orient participants. • The number and frequency of sessions were increased, and group size was reduced. • There was increased use of modelling during intervention delivery and use

						of simplified language. Guidance and reminders were frequent to address confusion, and to monitor distress and physical discomfort.
5. Clare et al. (2019) UK	**Quantitative** Questionnaires RCT **Analysis** Inferential statistics (ANCOVA)	**People with dementia** (n=474) **Study partners** (n=474) **Sample size** Experimental condition (n=238) Control condition (n=236) **Gender** Females (n=226) Males (n=248) **Mean age** Experimental condition (78.3) Control condition (78.9)	10-week intervention. Hourly 1:1 sessions of goal-oriented cognitive rehabilitation (CR) and problem-solving over a 3-month period, followed by four 1-hour maintenance sessions over the subsequent 6 months. Assessed at baseline, 3- and 9-month follow-ups.	Hospital Anxiety and Depression Scale (HADS)	• Individualised, goal-oriented CR is an effective intervention for people with early stage Alzheimer's disease and vascular or mixed dementia wishing to improve aspects of their everyday functioning. • Outcomes from both participants and study partners indicated that CR significantly improved functioning in the areas targeted in the therapy at 3 months and was maintained at 9 months. • High levels of adherence and low attrition indicated that the intervention was acceptable to participants and study partners. • There were no significant differences in secondary outcomes, i.e. in cognitive function, anxiety, depression.	• Involvement of family members or other supporters to work collaboratively with the participant and therapist to choose personally relevant and meaningful goals relating to everyday activities. • Use of environmental adaptations and prompts. • Introduction of compensatory strategies and memory aids. • Use of procedural learning of skills for learning or relearning relevant information.
6. Hindle et al. (2018) UK	**Quantitative** Questionnaires RCT **Analysis** Inferential statistics (ANCOVA)	**People with dementia associated with Parkinson's** (n=29) **Carers** (n=26) **Sample size** Experimental condition Cognitive Rehabilitation (CR) (n=10) Experimental condition Relaxation	CR- 8-week intervention. Hourly 1:1 sessions of goal-oriented cognitive rehabilitation. RT- 8-week intervention. Hourly 1:1 sessions of progressive muscle relaxation and breathing exercises.	Hospital Anxiety and Depression Scale (HADS)-depression	• CR was superior to control group and relaxation therapy for primary outcomes in dementias associated with Parkinson's (goal attainment and satisfaction). • CR is a feasible and potentially effective	• Use of compensatory strategies and/or restorative approaches to circumvent difficulties relating to orientation, planning, the retention of learned information, and recall. • Participants were encouraged to practice their strategies

		Therapy (RT) (n=10) Control condition (n=9) **Gender** Females (n=226) Males (n=248) **Mean age** CR (75.8) RT (74.9) Control condition (78.6)	Assessed at baseline, 2- and 6-month follow-ups.		intervention for individuals with Parkinson's Disease Dementia and Dementia with Lewy Bodies. • Follow-up assessments at 2 months showed some positive effects for CR in ameliorating depression compared with the control group and/or relaxation therapy.	between therapy sessions with the assistance of the carer (where available). • Carers were invited to participate in the therapy sessions to support between-session implementation.
7. Stanley et al. (2013) USA	**Quantitative** Questionnaires Randomised controlled pilot study **Analysis** Inferential statistics (ANCOVA)	**People with dementia** (n=32) **Collaterals** (adult who spent at least 8 hours weekly with PWD) (n=32) **Sample size** Experimental condition (n=16) Control condition (n=16) **Gender** Females (n=19) Males (n=13) **Mean age** Experimental condition (77.6) Control condition (79.6)	Peaceful Mind: 12-week intervention in participant-carer dyads over 3 months followed by up to 8 brief telephone sessions from 3-6 months based on CBT and involving self-monitoring for anxiety, deep breathing, and optional skills (coping self-statements, behavioral activation and sleep management). Assessed at baseline, 3- and 6-month follow-ups.	Neuropsychiatric Inventory- Anxiety subscale Rating Anxiety in Dementia scale (RAID) Geriatric Anxiety Inventory Geriatric Depression Scale	• Feasibility was demonstrated with regards to recruitment, attrition, and treatment characteristics. • At 3 months, clinicians rated patients receiving Peaceful Mind as less anxious. • Collaterals reported less distress related to loved ones' anxiety. • There were no significant positive effects in other outcomes (self-reported worry, anxiety, depression, collateral depression) or at 6-month follow-up.	• Modifications made to content (simpler and fewer skills), learning strategies (e.g., increased repetition, spaced retrieval), and delivery (in-home care, involvement of a collateral and different learning strategies).
8. Tappen & Williams (2009) USA	**Quantitative** Questionnaires Repeated measures RCT **Analysis** Inferential statistics (ANCOVA)	**People with Alzheimer's Disease** (n=30) **Sample size** Experimental condition (n=15) Control condition (n=15) **Gender** Females (n=27) Males (n=3) **Mean age** Experimental condition (83.8) Control condition (90.3)	16-week intervention. 1:1 counselling sessions (therapeutic conversation) for 30 minutes, 3 times per week to reduce anxiety, form and maintain supportive relationships, and provide an opportunity for the individual to express his or her feelings. Assessed pre and post intervention.	Dementia Mood Assessment Scale (DMAS) Alzheimer's Disease and Related Disorders (ADRD) Mood Scale Montgomery-Asberg Depression Rating Scale (MADRS)	• The experimental group evidenced significantly less negative mood than the control group on the Montgomery-Asberg Depression Rating Scale and the Sadness and Apathy subscales of the Alzheimer's Disease and Related Disorders Mood Scale. • Differences approached significance on the Dementia	• Protecting from distractions • Adapting communication to the participant's cognitive ability • Accepting some misunderstandings • Focusing on the present • Asking general questions • Using non-verbal gestures and verbal encouragers • Allowing sufficient time for the participant to respond • Use of phase-specific strategies as tolerated by the participant.

					Mood Assessment Scale. • Results suggest that a therapeutic counselling approach can be effective in treating the dysphoria commonly found in individuals with Alzheimer's Disease.	• Verbal support and paraphrasing. • Therapist does not demonstrate impatience or frustration, correcting or pointing out errors, using diminutives or collective pronouns, and talking about the participant in his or her presence. Confrontational statements or questions such as those beginning with "Why?" are avoided.
9. Waldorff et al. (2012) Denmark	**Quantitative** Questionnaires RCT **Analysis** Inferential statistics (ANCOVA)	**People with Alzheimer's Disease** (n=330) **Carers** (who had at least weekly contact with the PWD) (n=330) **Sample size** Experimental condition (n=163) Control condition (n=167) **Gender** Females (n=179) Males (n=151) **Mean age** Experimental condition (76.5) Control condition (75.9)	Multimodal Danish Alzheimer Intervention Study (DAISY) for participant-carer dyads over 8-12 months with the aim to prevent or reduce depressive symptoms, impairments of health-related quality of life, and loss of social network. Up to 7 counselling sessions (two with the patient and caregiver; two with the patient; two with the caregiver; and an optional session with the patient, caregiver, and family network) to provide guidance with decision-making, advice and meaningful participant activities. Five 2hr educational courses on Alzheimer's Disease to establish a forum for patients' and caregivers. 3-8 telephone contacts with participants at 3-4-week	Cornell Scale for Depression in Dementia (CSDD)	• At 12 months, there were no significant differences between the experimental and control group in changes from baseline in the primary and secondary outcomes. • A small, non-significant difference was observed in Cornell depression scale scores in patients in the experimental group before and after. • For caregivers, outcomes changed from baseline in the geriatric depression scale score.	• Involvement of caregivers • Patients and caregivers were supplied with comprehensive written information to support the information given at counselling sessions and courses. • They were also provided with a logbook in which they could write information and thoughts about their daily life. • Activities and information in the intervention were specifically directed towards the patients and their caregivers. • Use of a semi-tailored design allowed for some components to be tailored for the needs of an individual patient or caregiver and with other components common for all participants. • The inclusion of the family network in one of the counselling sessions, at the discretion of the patient, was meant to ensure information was available to all, to prevent stigmatisation, to identify important resources in the network, and to enable the caregiver to recruit

			intervals focused on issues discussed at 1:1 sessions and education courses. Assessed at baseline, 6- and 12-month follow-ups.			a larger network when needed.

ADRD, Alzheimer's Disease and Related Disorders Mood Scale; ANCOVA, Analysis of covariance; ANOVA, Analysis of variance; CR, cognitive rehabilitation; CSDD, Cornell Scale for Depression in Dementia; DAISY, Danish Alzheimer Intervention Study; DMAS, Dementia Mood Assessment Scale; GAI, Geriatric Anxiety Inventory; GDS, Geriatric Depression Scale; HADS, Hospital Anxiety and Depression Scale; MADRS, Montgomery-Asberg Depression Rating Scale; MMSE, Mini-Mental State Examination; PWD, Person/people with dementia; QAR, Question-asking reading; RAID, Anxiety in Dementia Scale; RCT, Randomised controlled trial; RT, Relaxation Therapy; SLS, Single leg stance.

All studies involved interventions for people with dementia. No identified studies involved MCI. Four studies (Burns, 2005; Churcher Clarke, 2017; Clare, 2019; Hindle, 2018) were conducted in the UK and four in the USA (Bailey, 2017; Burgener, 2008; Stanley, 2013; Tappen, 2009). Samples varied in recruitment method and setting, for example, included referrals from nursing home staff (Bailey, 2017), physicians and self- referrals (Burgener, 2008) and recruited from care facilities (Bailey, 2017), memory clinics (Burns, 2005; Hindle, 2018) and support groups (Clare, 2019). Sample size also varied from 29 (Hindle, 2018) to 474 participants (Clare, 2019). There were a total of 1010 participants, with 519 allocated to intervention conditions and 491 to control conditions. Two study interventions were identified as Cognitive Behavioural Therapies (Bailey, 2017; Stanley, 2013), two as counselling therapies (Tappen, 2009; Waldorff, 2012), two as cognitive rehabilitation (Clare, 2019; Hindle, 2018), one as relaxation therapy (Churcher Clarke, 2017), one as multimodal, combining Tai-chi exercises, CBT and support (Burgener, 2008), and one as psychodynamic therapy (Burns, 2005).

Intervention modalities varied, with four studies involving one-to-one interventions (Burns, 2005; Clare, 2019; Hindle, 2018; Tappen, 2009), three group therapy studies (Bailey, 2017; Burgener, 2008; Churcher Clarke, 2017) and two studies conducted in participant-carer dyads (Stanley, 2013; Waldorff, 2012). The duration of interventions varied from five (Churcher Clarke, 2017) to approximately 32 weeks (Waldorff, 2012), and almost nine weeks on average. All studies measured depression as an outcome, with the majority using the CSDD. Three studies measured anxiety as an outcome, using the Anxiety in Dementia Scale (RAID; Churcher Clarke, 2017; Stanley, 2013), Hospital Anxiety and Depression Scale (HADS; Clare, 2019), Neuropsychiatric Inventory Anxiety subscale (Stanley, 2013) and the Geriatric Anxiety Inventory (GAI; Stanley, 2013). Three studies used pre- and post-intervention measurement timepoints, however the other six other studies (Burgener, 2008; Burns, 2005; Clare, 2019; Hindle, 2018; Stanley, 2013; Waldorff, 2012) provided longer-term follow-up data (between 6-12 months).

Quality Appraisal

Quality appraisal is provided in Table 2. Quality scores varied from 0.79 (Burgener, 2008) to 1.79 (Clare, 2019). The lowest-scoring study lacked necessary information to draw conclusions about quality and potential bias, for example, regarding allocation to conditions, intervention fidelity, power, and drop-out rates.

Table 2. Quality Appraisal based on the Mixed Methods Appraisal Tool (MMAT)

Study	1. Bailey, Stevens, LaRocca, & Scogin (2017), USA	2. Burgener, Yang, Gilbert, & Marsh-Yant (2008), USA	3. Burns et al. (2005), UK	4. Churcher Clarke, Chan, Stott, Royan, & Spector (2017), UK	5. Clare et al. (2019), UK	6. Hindle et al. (2018), UK	7. Stanley et al. (2013), USA	8. Tappen & Williams (2009), USA	9. Waldorff et al. (2012), Denmark
Screening Q: Are there clear research questions (or objectives?	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes
Screening Q: Do the collected data allow to address the research questions?	Can't tell	Can't tell	Can't tell	Can't tell	Can't tell	Can't tell	Can't tell	Can't tell	Can't tell
2.1 Quantitative RCT- Is there a clear description of the randomisation (or an appropriate sequence generation)?	No	No	Yes	Yes	Yes	Yes	No	No	Yes
2.2 Quantitative RCT- Is there a clear description of the allocation concealment (or blinding when applicable)?	No	No	Yes	Yes	Yes	Yes	No	No	Yes
2.3 Quantitative RCT- Are there complete outcome data (80% or above)?	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes
2.4 Quantitative RCT- Is there low withdrawal/ drop-out (below 20%)?	Yes	No	Yes	Yes	Yes	Yes	Can't tell	Yes	Yes
3.1 Quantitative non-randomized- Are participants (organisations) recruited in a way that minimises selection bias?	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A
3.2 Quantitative non-randomized- Are measurements appropriate (clear origin, validity known, or standard instrument)?	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A
3.3 Quantitative non-randomized- In the groups being compared (intervention vs. without), are the participants comparable, or do researchers take into account (control for) the difference between these groups?	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A

Study	1. Bailey, Stevens, LaRocca, & Scogin (2017), USA	2. Burgener, Yang, Gilbert, & Marsh-Yant (2008), USA	3. Burns et al. (2005), UK	4. Churcher Clarke, Chan, Stott, Royan, & Spector (2017), UK	5. Clare et al. (2019), UK	6. Hindle et al. (2018), UK	7. Stanley et al. (2013), USA	8. Tappen & Williams (2009), USA	9. Waldorff et al. (2012), Denmark
3.4 Quantitative non-randomized- Are there complete outcome data (80% or above), and, when applicable, an acceptable response rate (60% or above)?	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A
4.1 Quantitative descriptive- Is the sampling strategy relevant to address the research question?	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes
4.2 Quantitative descriptive- Is the sample representative of the target population?	Yes	Yes	Yes	Yes	Yes	No	Yes	Yes	Yes
4.3 Quantitative descriptive- Are the measurements appropriate (clear origin, validity known, or standard instrument)?	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes
4.4 Quantitative descriptive- Is there an acceptable response rate (60% or above)?	Yes	Can't tell	Yes	Yes	Yes	Yes	Yes	Yes	Yes
4.5 Quantitative descriptive- Was the consistency of the intervention measured (fidelity)?	Yes	No	Yes	No	Yes	No	Yes	Yes	No
4.6 Quantitative descriptive- Is it likely that participants received an unintended intervention (contamination or co-intervention) that may influence the results?	Can't tell	Yes	Can't tell	Can't tell	Can't tell	Can't tell	Yes	Can't tell	Can't tell
4.7 Quantitative descriptive- Is the analysis performed by intervention allocation status (i.e. intention to treat) rather than the actual intervention received?	No	No	Yes	No	Yes	No	Yes	No	Yes

Study	1. Bailey, Stevens, LaRocca, & Scogin (2017), USA	2. Burgener, Yang, Gilbert, & Marsh-Yant (2008), USA	3. Burns et al. (2005), UK	4. Churcher Clarke, Chan, Stott, Royan, & Spector (2017), UK	5. Clare et al. (2019), UK	6. Hindle et al. (2018), UK	7. Stanley et al. (2013), USA	8. Tappen & Williams (2009), USA	9. Waldorff et al. (2012), Denmark
4.8 Quantitative descriptive- Were reasonable adjustments/ intervention adaptations aimed to increase accessibility provided throughout the trial?	Yes	Can't tell	Yes	Yes	Yes	Yes	Yes	Yes	Can't tell
4.9 Quantitative descriptive- Was the acceptability of the intervention considered/consulted with the participant?	Can't tell	Can't tell	No	Yes	Yes	Yes	Yes	Yes	Yes
4.10 Quantitative descriptive- Was the study sufficiently powered to detect an intervention effect on anxiety or depression (if one exists) and if so, what was the relative effect size?	Yes- large	No	No	No	No	Yes- large	Yes- medium-large	Yes- small	Yes- small
5.1 Mixed-methods- Is there an adequate rationale for using a mixed methods design to address the research question?	N/A	N/A	No	N/A	N/A	N/A	N/A	N/A	N/A
5.2 Mixed-methods- Is the integration of qualitative and quantitative data (or results) relevant to address the research question (objective)?	N/A	N/A	Can't tell	N/A	N/A	N/A	N/A	N/A	N/A
5.3 Mixed-methods- Is appropriate consideration given to the limitations associated with this integration, e.g. the divergence of qualitative and quantitative data (or results) in a triangulation design?	N/A	N/A	No	N/A	N/A	N/A	N/A	N/A	N/A

Potential areas of concern during quality assessment	Nursing home staff referred residents. Reductions in depression may have been attributable to additional staff time.	Overlap existed between the support group intervention and CBT. Also, significant interpersonal interactions were occurring in both the CBT and Tai-chi exercise sessions.	The therapist was clearly a major source of support for the carers and the patients.	Absence of recording and monitoring of pharmaco-logical treatment. Researchers delivered the intervention and collected acceptability data from participants (possibly introduced a social desirability bias).	Unable to conclusively demonstrate that benefits were due to the specific effects of CR rather than nonspecific effects of contact with a therapist.	The array of outcome measures is large, increasing the likelihood of type-1 error. No clinical instrument used to determine dementia stage and instead relied on the clinical judgement. Between session practice not monitored.	The control condition did not control for non-specific treatment factors, such as time and attention.	Small sample size including individuals with a wide range of MMSE scores from mild to severe impairment. Under-generalised men and minority groups.	Inclusion into the study was not restricted to patients and care givers actively seeking help. The logistics for participation in the study was quite demanding. Multiple primary outcomes were not adjusted for, under-powered.
Average Quality Score	1.43	0.79	1.41	1.50	1.79	1.50	1.50	1.50	1.71

Responses to questions on the MMAT may have increased the possibility of identifying bias or lower quality in the studies due to a lack of information about randomisation, allocation concealment or blinding, intervention fidelity, potential contamination of the intervention and thus results, and consideration of a mixed-method design where one was used. Overall, most studies had complete outcome data and low drop-out rates. Psychological distress measures involved a variety of completion methods within studies (self-report, carer-report and clinician-rated) which may have reduced the possibility of bias.

Besides the MMAT and quality scores, potential areas of concern were also noted. These included possible bias during recruitment (e.g. in Bailey's [2017] study, participants were referred by residential staff), interactions between groups outside of the study, the effect of non-specific therapy factors such as additional staff time, attention and contact with the therapist (Burns, 2005; Clare, 2019; Stanley, 2013), lack of monitoring of pharmacological treatment as an extraneous variable (Churcher Clarke, 2017) and the array of outcome measures in increasing the likelihood of Type 1 error (Hindle, 2018).

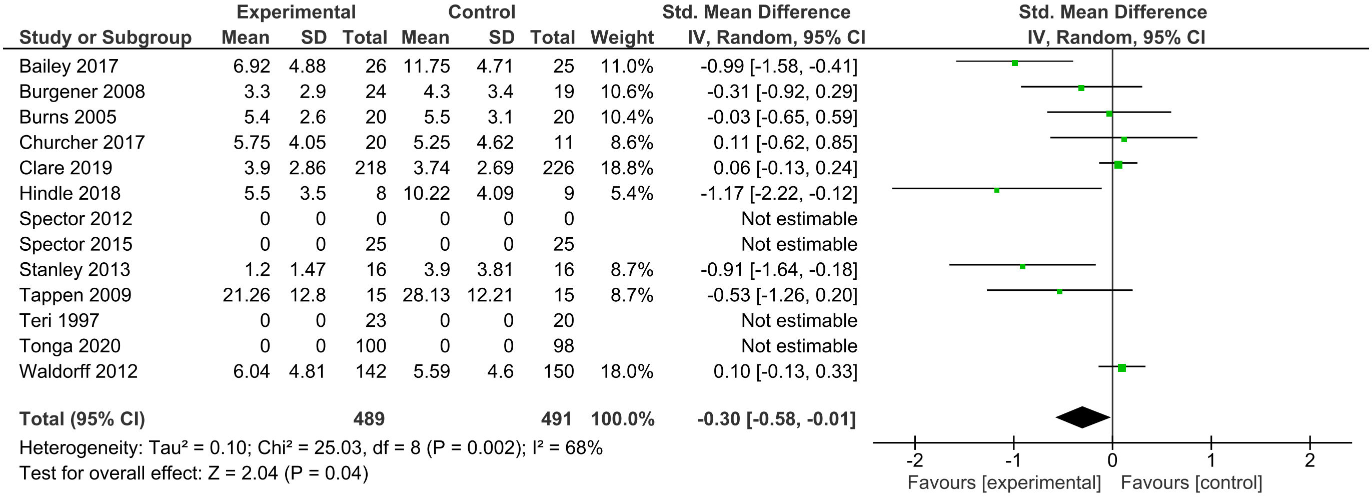
An independent rater quality appraised three papers chosen at random. Inter-rater reliability indicated ‘near perfect’ agreement (*k*= 0.89; Cohen, 1960).

Meta-Analysis

Summary of Overall Analysis

Studies were analysed using Review Manger 5.4 (The Cochrane Collaboration, 2020). The results showed a relatively small effect size for pre- to post-decrease in psychological distress following psychological interventions (*SMD*= -0.3, 95% CI [-0.58 – -0.01], *z*= 2.04, *p*= 0.04). Studies were shown to have substantial heterogeneity (I^2= 68%, *p*= 0.002). A forest plot (Figure 2) indicated that six studies favoured psychological intervention compared to control groups, but they had small effect sizes. The confidence interval of Hindle’s (2018) study was relatively large (-2.22 – -0.12), which may indicate that it lacked reliability. A funnel plot did not appear to show any issues with publication bias (Figure 3).

Figure 2. Forest plot for meta-analysis of pre- to post-change in psychological distress following psychological interventions

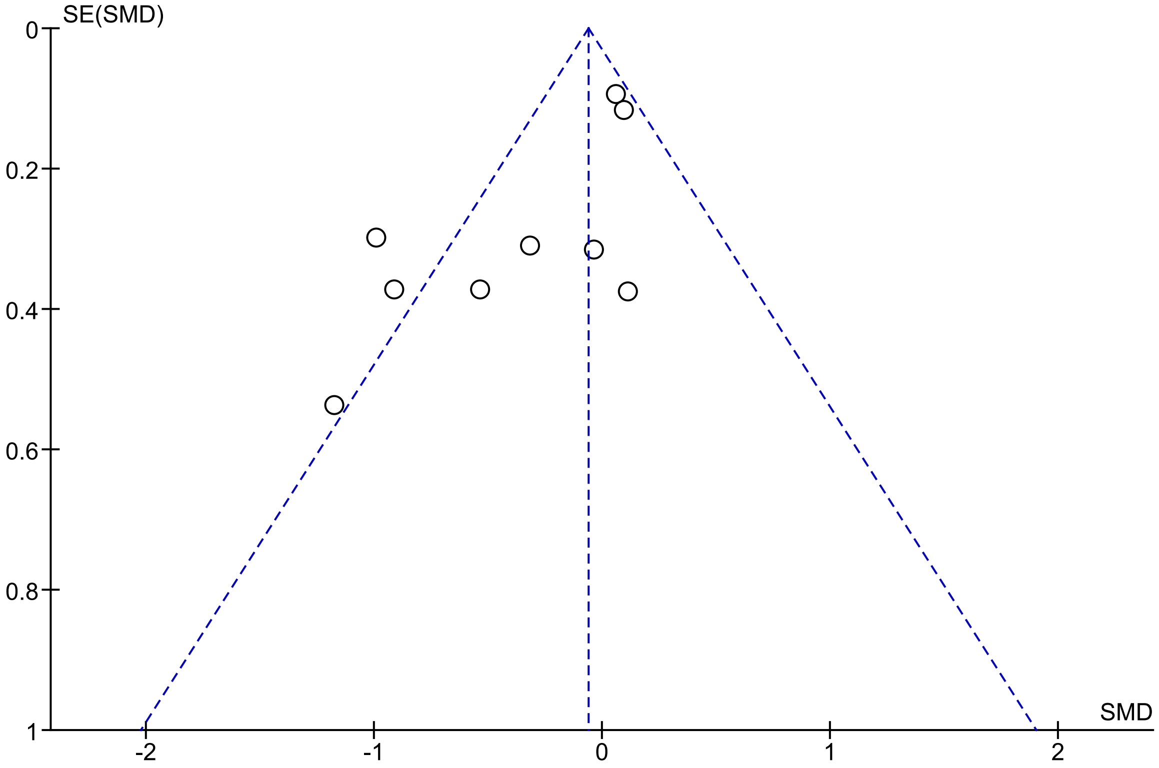


	Experimental			Control				Std. Mean Difference
Study or Subgroup	Mean	SD	Total	Mean	SD	Total	Weight	IV, Random, 95% CI
Bailey 2017	6.92	4.88	26	11.75	4.71	25	11.0%	-0.99 [-1.58, -0.41]
Burgener 2008	3.3	2.9	24	4.3	3.4	19	10.6%	-0.31 [-0.92, 0.29]
Burns 2005	5.4	2.6	20	5.5	3.1	20	10.4%	-0.03 [-0.65, 0.59]
Churcher 2017	5.75	4.05	20	5.25	4.62	11	8.6%	0.11 [-0.62, 0.85]
Clare 2019	3.9	2.86	218	3.74	2.69	226	18.8%	0.06 [-0.13, 0.24]
Hindle 2018	5.5	3.5	8	10.22	4.09	9	5.4%	-1.17 [-2.22, -0.12]
Spector 2012	0	0	0	0	0	0		Not estimable
Spector 2015	0	0	25	0	0	25		Not estimable
Stanley 2013	1.2	1.47	16	3.9	3.81	16	8.7%	-0.91 [-1.64, -0.18]
Tappen 2009	21.26	12.8	15	28.13	12.21	15	8.7%	-0.53 [-1.26, 0.20]
Teri 1997	0	0	23	0	0	20		Not estimable
Tonga 2020	0	0	100	0	0	98		Not estimable
Waldorff 2012	6.04	4.81	142	5.59	4.6	150	18.0%	0.10 [-0.13, 0.33]
Total (95% CI)			**489**			**491**	**100.0%**	**-0.30 [-0.58, -0.01]**

Heterogeneity: Tau² = 0.10; Chi² = 25.03, df = 8 (P = 0.002); I² = 68%

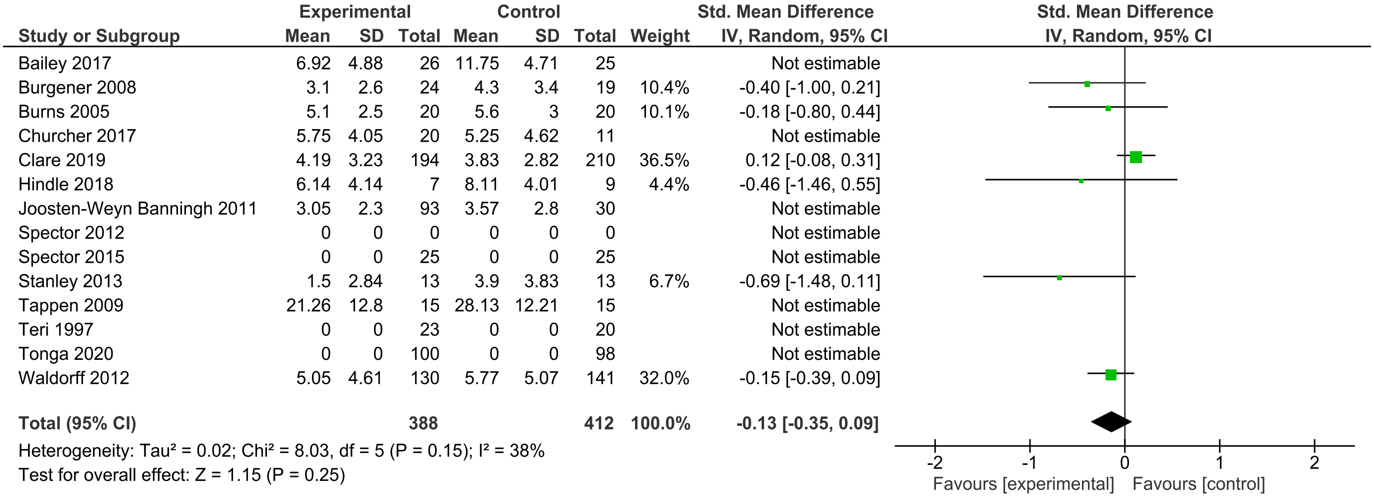
Test for overall effect: Z = 2.04 (P = 0.04)

Figure 3. Funnel plot representing publication bias of included studies



A second meta-analysis was conducted to include those studies with longer-term follow-up data (6-12 months). Results showed a non-significant decrease in psychological distress between pre-intervention and longer-term follow-up post-intervention (*SMD*= -0.13, 95% CI [-0.35 – 0.09], *z*= 1.15, *p*= 0.25). Heterogeneity between studies was moderate (I^2= 38%, *p*= 0.15). A forest plot (Figure 4) showed the overall effect size overlapped 0 and thus the possibility of no effect could not be ruled out.

Figure 4. Forest plot for second meta-analysis of studies with longer-term follow-up data (6-12 months)



Study or Subgroup	Experimental Mean	Experimental SD	Experimental Total	Control Mean	Control SD	Control Total	Weight	Std. Mean Difference IV, Random, 95% CI
Bailey 2017	6.92	4.88	26	11.75	4.71	25		Not estimable
Burgener 2008	3.1	2.6	24	4.3	3.4	19	10.4%	-0.40 [-1.00, 0.21]
Burns 2005	5.1	2.5	20	5.6	3	20	10.1%	-0.18 [-0.80, 0.44]
Churcher 2017	5.75	4.05	20	5.25	4.62	11		Not estimable
Clare 2019	4.19	3.23	194	3.83	2.82	210	36.5%	0.12 [-0.08, 0.31]
Hindle 2018	6.14	4.14	7	8.11	4.01	9	4.4%	-0.46 [-1.46, 0.55]
Joosten-Weyn Banningh 2011	3.05	2.3	93	3.57	2.8	30		Not estimable
Spector 2012	0	0	0	0	0	0		Not estimable
Spector 2015	0	0	25	0	0	25		Not estimable
Stanley 2013	1.5	2.84	13	3.9	3.83	13	6.7%	-0.69 [-1.48, 0.11]
Tappen 2009	21.26	12.8	15	28.13	12.21	15		Not estimable
Teri 1997	0	0	23	0	0	20		Not estimable
Tonga 2020	0	0	100	0	0	98		Not estimable
Waldorff 2012	5.05	4.61	130	5.77	5.07	141	32.0%	-0.15 [-0.39, 0.09]
Total (95% CI)			**388**			**412**	**100.0%**	**-0.13 [-0.35, 0.09]**

Heterogeneity: Tau² = 0.02; Chi² = 8.03, df = 5 (P = 0.15); I² = 38%
Test for overall effect: Z = 1.15 (P = 0.25)

Sensitivity Analysis

Sensitivity analysis was conducted to establish whether results were sensitive to the decisions made on study inclusion. When the lowest quality study was removed (Hindle, 2018), the overall effect size remained similarly small and significant (*SMD*= -0.24, 95% CI [-0.51 – 0.04], *z*= 1.68, *p*= 0.09), with a minor reduction in heterogeneity (I^2= 66%, *p*= 0.004).

Sensitivity analysis was also conducted to only include studies with the most prevalent therapy modality (one-to-one). Little change was noted in the effect size and this was found to be non-significant (*SMD*= -0.24, 95% CI [-0.69 – 0.20], *z*= 1.07, *p*= 0.28). Heterogeneity reduced but remained at a substantial level (I^2= 58%, *p*= 0.07).

A further sensitivity analysis was conducted to only include studies with the most used therapy models (Cognitive Behavioural Therapies, counselling, and cognitive rehabilitation). Results showed a small effect size (*SMD*= -0.42, 95% CI [-0.81 – -0.04], *z*= 2.14, *p*= 0.03), with heterogeneity increasing to a considerable amount (I^2= 79%, *p*= 0.0002).

A final sensitivity analysis was conducted to only include studies that used the most common measure of depression (CSDD). Results showed a small effect size which was non-significant (*SMD*= -0.19, 95% CI [-0.70 – 0.31], *z*= 0.74, *p*= 0.46), and heterogeneity remained at a substantial level (I^2= 74%, *p*= 0.009).

Separate pooled estimates were calculated for anxiety and depression outcomes. The inclusion of studies with a measure of anxiety indicated a small, non-significant effect size (*SMD*= -0.19, 95% CI [-0.75 – 0.38], *z*= 0.65, *p*= 0.52), with minimal difference in heterogeneity (I^2= 69%, *p*= 0.04). The inclusion of only depression measures showed a slightly larger effect size (*SMD*= -0.41, 95% CI [-0.84 – 0.02], *z*= 1.85, *p*= 0.06), but little variation in heterogeneity (I^2= 71%, *p*= 0.004). As heterogeneity remained high in both sub-groups, it may be inappropriate to consider these as distinct.

Moderator Analysis

In MetaEssentials 1.4 (Suurmond et al., 2017), intervention length was inputted as a moderator to examine whether study effect sizes correlated with the duration of the intervention, but this was revealed to be non-significant (β= 1.47, *p*= 0.682).

Therapy Adaptations

In response to the review question concerning the adaptations required for psychological therapy to increase acceptability and improve outcomes, two studies did not provide specific detail of therapy adaptations. Those that did, evidenced the following:

(1) Slowing the pace of therapy by increasing the number and frequency of sessions, which corroborated recommendations by Robie (1999).
(2) Using straightforward language to simplify communications (Robie), with communication adapted to the participants’ cognitive ability.
(3) Emphasising behavioural strategies, as suggested by Grant and Casey (1995), with use of procedural learning and modelling during intervention delivery.
(4) Using learning strategies such as increased repetition (Grant & Casey).

There were additional adaptations that had not previously been considered, including:

(5) Use of compensatory strategies and memory aids such as visual, written, and verbal information, and offer of guidance, reminders, and prompts.
(6) Making environmental adaptations, for example, reducing the size of therapy groups, delivering the intervention in participants’ homes, and protecting from distractions.
(7) Involving family members or carers to support in-session and with between-session tasks, according to client preference.
(8) A supportive therapist style using non-verbal gestures, verbal encouragers, and paraphrasing, and allowing sufficient time for participants to respond. Therapist impatience or frustration is discouraged and correcting or pointing out of any errors are avoided.

Discussion & Conclusions

People with dementia and MCI commonly experience psychological distress but are inadequately supported with evidence-based psychological interventions. The current review revealed a small but significant effect size pre- to post-intervention. This suggests that psychological treatments for people with dementia may be effective in reducing psychological distress, which supports the findings of Orgeta et al.'s (2015) review. Findings also compare favourably with the scarce evidence base for pharmacological approaches, such as antidepressants, for treating depression in dementia (Banerjee, 2011). Unfortunately, no trials of psychological treatment for people with MCI met the inclusion criteria, hence no conclusions can be made regarding MCI. The current meta-analysis has several strengths, such as the inclusion of a variety of therapies from different theoretical perspectives, with some using a combination of treatments, and the inclusion of only RCTs with the aim of minimising methodological bias. Furthermore, quality appraisal was considered thorough with the involvement of an additional, independent rater to decrease the likelihood of bias. Since no adverse events were reported in relation to the use of psychotherapeutic interventions, it is likely that the results are of important clinical benefit to people with dementia. Although depression and anxiety were primary outcomes for this review, only three suitable studies collected data for anxiety. Analysis of all available data demonstrated a small overall effect size, even when analysis was adjusted to exclude obvious sources of heterogeneity.

The main limitation of the current review was the inclusion of only a small number of interventional studies that substantially varied in terms of quality, modality, duration, outcome measures and overall heterogeneity. This caused difficulty in interpreting the data and in drawing conclusions about the best way to deliver psychological treatments. Hence, the studies in the current review only partially answered the research aims. However, it is recognised that psychotherapy can often be difficult to standardise due to the individualised approach needed for clients with differing needs and complexities (Christie & Fleischer, 2009). Therefore, some psychotherapies would not have met strict inclusion criteria for RCTs, which may explain the limited number of studies identified in the current review.

A review of forest plots showed that six studies (Burgener, et al., 2008; Burns et al., 2005; Churcher Clarke, et al., 2017; Clare et al., 2019; Tappen & Williams, 2009; Waldorff et al., 2012) were non-significant, with two studies delivering relatively brief interventions and five studies that used a single-item self-report measure of depression. Robustness of underlying psychological theory was also questionable, as three studies did not appear to measure the consistency of the intervention and there was insufficient information about the fidelity of the intervention in two more. In the absence of supplementary data from authors, quality appraisal may be criticised for assessing the quality of report-writing as opposed to methodological quality. In hindsight, the current review may have been improved by excluding psychosocial interventions, namely cognitive rehabilitation, which is not specifically aimed at depression or anxiety (Olazaran et al., 2010). Most studies were conducted in the UK or USA, potentially limiting the generalisability of results to the rest of the world or specifically to the UK. Furthermore, most were conducted in the community with people with mild dementia, thus it may be assumed that psychological talking therapies are not feasible for people with advanced dementia and uncertainty remains about the extent to which findings may be applicable to people living in care facilities. Only one study screened participants for clinical levels of depression at baseline, which may limit how far findings can be applied to people with a specific diagnosis of depression or anxiety. Interestingly, there was significant improvement in depression as measured using the Montgomery-Asberg Depression Rating Scale (MADRS) in Tappen and Williams' (2009) study and on the CSDD in Bailey et al.'s (2017) study, but no significant improvement on the CSDD in other studies. This may therefore relate to methodological differences between studies, model adherence or quality of the therapist as opposed to the psychometric properties of the measures used.

Tentative conclusions may be drawn about the use of specific adaptations in improving engagement with therapy, but no conclusions can be made regarding the impact upon intervention effectiveness and outcomes. The identified adaptations are vague thus cannot be reliably tested or causally linked to outcomes. Furthermore, therapy delivered with adaptations was not directly compared against therapy delivered without them. Although there is evidence to suggest that slowing the pace of therapy over additional sessions is helpful, some interventions in the review were considered brief. This is surprising as intervention length seems important for this client group. Presumably, sufficient time, based on individual clinical assessment, is required for participants with both cognitive impairments and mental health difficulties to understand the process and content of the intervention and become socialised to the therapeutic model.

Despite its limitations, the current review offers a unique contribution in identifying specific adaptations deemed helpful in improving the accessibility and acceptability of therapy for people with dementia, suggesting therapy can be adjusted enough to support favourable outcomes. These adaptations may also be valuable in therapy with populations with other long-term conditions or cognitive impairments.

Recommendations

People with dementia and MCI are an under-researched population whose needs remain inadequately met. There is low quality evidence that psychological treatments can reduce depressive symptoms in people with dementia and no significant outcomes were found in reducing anxiety.

However, a lack of evidence-based psychological treatments may not necessarily mean that they are invalidated, but that they require further validation. Hence, to promote choice, clinical efficacy and to support living well with dementia, there is a necessity is to develop the evidence-base by testing multiple intervention options. Future interventional studies should focus on standardised psychological therapies with high fidelity to the therapeutic model to further optimise therapy delivery in this population, and to reduce bias associated with combined, multimodal treatments (Orgeta et al., 2015). Studies should also comprise sufficient intervention length (minimum of nine weekly sessions according to the current review). As a non-significant decrease was found in psychological distress between pre-intervention and longer-term follow-up (6-12 months), it would also be important for future studies to investigate the longer-term effects of psychological treatments for people with dementia, possibly using a triangulation of direct and indirect methods such as self-report, and behavioural or observational measures.

Moreover, future studies should trial and assess the evidence for specific and reasonable adjustments to interventions with the aim of increasing accessibility for people with dementia, consulting with participants and their caregivers, and regularly inviting their feedback to improve acceptability, outcomes, and person-centred care.

It is hoped that by developing the therapeutic evidence base for people with dementia and MCI, ineffective interventions may be ruled out, which may have some bearing on important clinical outcomes such as dementia-related mortality (Rosness et al., 2016) and key relational and societal factors including caregiver burden (Gonzalez-Salvador et al., 1999), rates of institutionalisation (Stern et al., 1997) and cost to society (Burns et al., 2005).

Higher powered studies using better-defined psychological therapies may enable future reviews to overcome the current methodological shortcomings, with the prospect of producing higher quality evidence that psychological treatments can effectively reduce depression and anxiety in people with dementia and MCI.

Data Availability Statement

The data that supports the findings of this study is available from the corresponding author upon reasonable request.

Funding Source Declaration

There have been no funding or research grants received in the course of the study, research or assembly of the manuscript.

Declaration of Conflicts of Interest

None.

Systematic Literature Review References

Alexopoulos, G. S., Abrams, R. C., Young, R. C., & Shamoian, C. A. (1988). Cornell scale for depression in dementia. *Biological Psychiatry*, *23*(3), 271–284. https://doi.org/10.1016/0006-3223(88)90038-8

Alzheimer’s Association. (2014). 2014 Alzheimer’s disease facts and figures. *Alzheimer’s & Dementia, 10,* 47-92.

American Psychiatric Association. (2013). *Diagnostic and statistical manual of mental disorders* (5th ed.). Arlington, VA, US: American Psychiatric Publishing, Inc. https://doi.org/10.1176/appi.books.9780890425596

Badrakalimuthu, V. R., & Tarbuck, A. F. (2012). Anxiety: a hidden element in dementia. *Advances in Psychiatric Treatment, 18*(2), 119-128.

Bailey, E. M., Stevens, A. B., LaRocca, M. A., & Scogin, F. (2017). A randomized controlled trial of a therapeutic intervention for nursing home residents with dementia and depressive symptoms. *Journal of Applied Gerontology, 36*(7), 895-908.

Banerjee, S., Hellier, J., Dewey, M., Romeo, R., Ballard, C., Baldwin, R., et al. (2011). Sertraline or mirtazapine for depression in dementia (HTA-SADD): a randomised, multicentre, double-blind, placebo-controlled trial. *Lancet, 378,* 403-411.

Burgener, S. C., Yang, Y., Gilbert, R., & Marsh-Yant, S. (2008). The effects of a multimodal intervention on outcomes of persons with early-stage dementia. *American journal of Alzheimer's disease and other dementias*, *23*(4), 382-394. https://doi.org/10.1177/1533317508317527

Burns, A., Guthrie, E., Marino-Francis, F., Busby, C., Morris, J., Russell, E., et al. (2005). Brief psychotherapy in Alzheimer's disease: randomised controlled trial. *The British Journal of Psychiatry, 187,* 143-147.

Cheston, R. (1998). Psychotherapeutic work with dementia sufferers. *Journal of Social Work Practice: Psychotherapeutic Approaches in Health, Welfare and the Community, 12*(2), 199-207.

Churcher Clarke, A., Chan, J. M. Y., Stott, J., Royan, L., & Spector, A. (2017). An adapted mindfulness intervention for people with dementia in care homes: feasibility pilot study. *International Journal of Geriatric Psychiatry, 32*(12), 123-131.

Clare, L., Kudlicka, A., Oyebode, J. R., Jones, R. W., Bayer, A., Leroi, I., et al. (2019). Individual goal-oriented cognitive rehabilitation to improve everyday functioning for people with early-stage dementia: a multicentre randomised controlled trial (the GREAT trial). *International Journal of Geriatric Psychiatry, 34*(5), 709-721.

Cohen, J. (1960). A coefficient of agreement for nominal scales. *Educational and Psychological Measurement, 20*(1), 37-46. https://doi.org/10.1177/001316446002000104

Christie, C. A., & Fleischer, D. (2009). Social inquiry paradigms as a frame for the debate on credible evidence. In S. I. Donaldson, C. Christie, & M. M. Mark (Eds.), *What counts as credible evidence in applied research and evaluation practice?* (pp. 19-30). Thousand Oaks, CA: Sage Publications, Inc. https://doi.org/10.4135/9781412995634.d7

Drapeau, A., Marchand, A., & Beaulieu Prevost, D. (2012). Epidemiology of psychological distress. In L. LAbate (Ed.), *Mental Illnesses: Understanding, Prediction and Control* (pp. 105-124). Rijeka: InTech.

French, K., Golijani-Moghaddam, N., & Schröder, T. (2017). What is the evidence for the efficacy of self-help acceptance and commitment therapy? A systematic review and meta-analysis. *Journal of Contextual Behavioral Science, 6,* 360-374.

Gellis, Z. D., McClive-Reed, K. P., Brown, E. L. (2009). Treatments for depression in older persons with dementia. *Clinical Care and Aging, 17,* 29-36.

Gonzalez-Salvador, M. T., Arango, C., Lyketsos, C. G., Barba, A. C. (1999). The stress and psychological morbidity of the Alzheimer patient caregiver. *International Journal of Geriatric Psychiatry, 14,* 701-710.

Grant, R. W., & Casey, D. A. (1995). Adapting cognitive behavioural therapy for the frail elderly. *International Psychogeriatrics,* **7**(4), 561-571.

Higgins, J. P. T., & Green, S. (2011). Cochrane Handbook for Systematic Reviews of Interventions Version 5.1.0. The Cochrane Collaboration. Retrieved from https://handbook-5-1.cochrane.org/

Higgins, J. P. T., Thompson, S. G., Deeks, J. J., & Altman, D. G. (2003). Measuring inconsistency in meta-analyses. *BMJ (Clinical Research Ed.), 327*(7414), 557-560.

Hindle, J. V., Watermeyer T. J., Roberts, J., Brand, A., Hoare, Z., Martyr, A., et al. (2018). Goal-orientated cognitive rehabilitation for dementias associated with Parkinson's disease- a pilot randomised controlled trial. *International Journal of Geriatric Psychiatry, 33,* 718-728.

Knopman, D. S., & Petersen, R. C. (2014). Mild cognitive impairment and mild dementia: a clinical perspective. *Mayo Clinic proceedings, 89*(10), 1452-1459. https://doi.org/10.1016/j.mayocp.2014.06.019

Laidlaw, K. (2013). 'ViewPoint: a deficit in psychotherapeutic care for older people with depression and anxiety'. *Gerontology 59*(6): 549-556. https://doi:10.1159/000351439

Moher, D., Liberati, A., Tetzlaff, J., Altman, D. G., & The PRISMA Group. (2009). Preferred Reporting Items for Systematic Reviews and Meta-Analyses: The PRISMA Statement. *PLoS Med, 6*. https://doi.org/10.1371/journal.pmed1000097

Monastero, R., Mangialasche, F., Camarda, C., Ercolani, S., & Camarda, R. (2009). A systematic review of neuropsychiatric symptoms in mild cognitive impairment. *Journal of Alzheimer's Disease, 18,* 11-30.

Moniz-Cook, E, D., & Manthorpe, J. (Eds.). (2009). *Psychosocial interventions in early dementia: Evidence based practice.* London: Jessica Kingsley.

Muliyala K. P., & Varghese, M. (2010). The complex relationship between depression and dementia. *Annals of Indian Academy of Neurology, 13*(2), 69-73.

National Institute for Health and Care Excellence. (2018). Dementia: assessment, management and support for people living with dementia and their carers. Retrieved from https://www.nice.org.uk/guidance/ng97

Olazaran, J., Reisberg, B., Clare, L., Cruz, I., Pena-Casanova, J., Del Ser, T., et al. (2010). Nonpharmacological therapies in Alzheimer’s disease: a systematic review of efficacy. *Dementia and Geriatric Cognitive Disorders, 30,* 161-178.

Orgeta, V., Qazi, A., Spector, A., & Orrell, M. (2015). Psychological treatments for depression and anxiety in dementia and mild cognitive impairment: systematic review and meta-analysis. *The British Journal of Psychiatry: The Journal of Mental Science*, *207*(4), 293-298. https://doi.org/10.1192/bjp.bp.114.148130

Pace, R., Pluye, P., Bartlett, G., Macaulay, A. C., Salsberg, J., Jagosh, J., & Seller, R. (2012). Testing the reliability and efficiency of the pilot Mixed Methods Appraisal Tool (MMAT) for systematic mixed studies review. *International Journal of Nursing Studies, 49*(1), 47-53. https://doi.org/10.1016/j.ijnurstu.2011.07.002

Palmer, K., Berger, A. K., Monastero, R., Winblad, B., Backman, L., & Fratiglioni, L. (2007). Predictors of progression from mild cognitive impairment to Alzheimer disease. *Neurology, 68,* 1596-1602.

Pluye, P., Robert, E., Cargo, M., Bartlett, G., O'Cathain, A., Griffiths, F., et al. (2011). Proposal: A mixed methods appraisal tool for systematic mixed studies reviews. *Department of Family Medicine, McGill University, Montreal, Canada.* Retrieved from http://mixedmethodsappraisaltoolpublic.pbworks.com.

Robie, K. J. (1999). An exploration of psychologists' perceptions of the process of psychotherapy for the treatment of psychological concerns and mental disorders in elders who have concomitant dementia. *Dissertation Abstracts International, 59,* 5108.

Rosness, T. A., Strand, B. H., Bergem, A. L. M., Nafstad, P., Langballe, E. M., & Engedal, K. (2016). Association of psychological distress late in life and dementia-related mortality. *Aging & Mental Health, 20*(6), 603-610.

Solfrizzi, V., D'Introno, A., Colacicco, A. M., Capurso, C., Del Parigi, A., Caselli, R. J., et al. (2007). Incident occurrence of depressive symptoms among patients with mild cognitive impairment: the Italian longitudinal study on aging. *Dementia and Geriatric Cognitive Disorders, 24,* 55-64.

Spector, A., Charlesworth, G., King, M., Lattimer, M., Sadek, S., Marston, L., et al. (2015). Cognitive–behavioural therapy for anxiety in dementia: pilot randomised controlled trial. *The British Journal of Psychiatry, 206,* 509-516. https://doi.org/10.1192/bjp.bp.113.140087

Stanley, M. A., Calleo, J., Bush, A. L., Wilson, N., Snow, A. L., Kraus-Schuman, C., et al. (2013). The peaceful mind program: a pilot test of a cognitive-behavioral therapy-based intervention for anxious patients with dementia. *The American Journal of Geriatric Psychiatry: Official Journal of the American Association for Geriatric Psychiatry*, *21*(7), 696-708. https://doi.org/10.1016/j.jagp.2013.01.007

Stanley, M. A., Diefenbach, G. J., & Hopko, D. R. (2004). Cognitive behavioral treatment for older adults with generalized anxiety disorder: a therapist manual for primary care settings. *Behavior Modification, 28*(1), 73-117. https://doi.org/10.1177/0145445503259259

Stern, Y., Tang, M. X., Albert, M. S., Brandt, J., Jacobs, D. M., Bell, K., et al. (1997). Predicting time to nursing home care and death in individuals with Alzheimer disease. *JAMA, 277,* 806-812.

Suurmond, R., van Rhee, H., & Hak, T. (2017). Introduction, comparison and validation of Meta-Essentials: A free and simple tool for meta-analysis. *Research Synthesis Methods, 8*, 537-553. https://doi.org/10.1002/jrsm.1260

Tappen, R. M., & Williams, C. L. (2009). Therapeutic conversation to improve mood in nursing home residents with Alzheimer's disease. *Research in Gerontological Nursing, 2,* 267-275.

Teri, L., Logsdon, R. G., Uomoto, J., & McCurry, S. M. (1997). Behavioral treatment of depression in dementia patients: a controlled clinical trial. *The Journals of Gerontology Series B: Psychological Sciences and Social Sciences, 52*(4), 159-166.

The Cochrane Collaboration. (2020). Review Manager (RevMan) [Computer program]. Version 5.4. Copenhagen: The Nordic Cochrane Centre.

Tonga, J. B., Šaltytė Benth, J., Arnevik, E. A., Werheid, K., Korsnes, M. S., & Ulstein, I. D. (2020). Managing depressive symptoms in people with mild cognitive impairment and mild dementia with a multicomponent psychotherapy intervention: a randomized controlled trial. *Internal Psychogeriatrics,* 1-15. https://doi.org/10.1017/S1041610220000216

Waldorff, F. B., Buss, D. V., Eckermann, A., Rasmussen, M. L. H., Keiding, N., Rishøj, S., et al. (2012). EIicacy of psychosocial intervention in patients with mild Alzheimer's disease: the multicentre, rater blinded, randomised Danish Alzheimer Intervention Study (DAISY). *BMJ, 345,* 1-14.

World Health Organization. (2018). *International Statistical Classification of Diseases and Related Health Problems 11th Revision (ICD-11).* Retrieved from https://icd.who.int/browse11/l-m/en

World Health Organization, Regional Office for Europe, Health Evidence Network. (2007). *Evidence for decision makers.* Retrieved from http://www.euro.who.int/HEN/

Yost, E., Beutler, L., Corbishley, A., & Allender, J. (1986). *Group Cognitive therapy: A treatment approach for depressed older adults.* New York: Pergamon Press.

Journal Paper

Acceptance and Commitment Therapy (ACT) for people with dementia experiencing psychological distress: A hermeneutic single case efficacy design (HSCED) series[2]

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[2] This journal paper has been prepared for submission to the Journal of Counselling and Psychotherapy Research; Appendix Z shows Author Guidelines.

Biographical author notes

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Dr Danielle De Boos is an Associate Professor & Programme Co-Director at the Trent DClinPsy at the University of Nottingham. Danielle has conducted doctorate level research using qualitative and quantitative methods and a range of service evaluations and audits. She currently teaches qualitative research methods and supervises doctoral research projects on the Trent DClinPsy course.

Dr Nima Golijani Moghaddam is a Research Clinical Psychologist and Senior Lecturer at the Trent DClinPsy at the University of Lincoln. Nima has devised and worked on a succession of grant-awarded research projects with clients, carers, and professionals in NHS service-contexts. He has applied a broad range of research methods and is an accomplished quantitative data analyst, as well as experienced qualitative analyst. He currently teaches clinical research methods and supervises doctoral research projects on the Trent DClinPsy course.

Data availability statement

The data that supports the findings of this study is available from the corresponding author upon reasonable request.

Funding statement

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Conflict of interest disclosure

None.

Ethics approval statement

Ethical approval of this project was obtained on 2nd December 2020 by Wales Research Ethics Service 6 (REC reference: 20/WA/0317).

Patient consent statement

All participants provided written informed consent prior to enrolment in the study.

Written informed consent was obtained from all participants for the publication of this project.

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N/A

Clinical trial registration

www.clinicaltrials.gov (NCT04630912)

Implications of the findings

- When using Acceptance and Commitment Therapy (ACT) systemically with people with dementia, it may be important to support a strong client-carer working alliance, facilitate exposure to and acceptance of avoided or suppressed emotions, and plan value-driven behaviour (committed action).
- Use of weekly process measures and/or post-therapy change interviews may help to further monitor and understand change processes in clinical practice. However, due to uncertainties about the reliability of self-report measures in the context of memory difficulties, measure selection needs critical consideration. A combination of both quantitative and qualitative measures may be most beneficial.
- Future studies should optimise ACT delivery in dementia via a new case series. The carer-supported aspect highlighted in the current study is under-researched, which may be critical to working therapeutically with this population.
- To improve acceptability, the service pathway in older adult services, such as Memory Assessment Services (MAS), could offer increased flexibility and choice of therapy delivery (in-person or remote).

Abstract

Introduction: People with dementia have a high prevalence of psychological distress but are under-served with evidence-based psychological interventions. To promote choice and improve clinical outcomes, there is a necessity to test different psychological intervention options for this population. Purpose: To investigate the effectiveness and acceptability of Acceptance and Commitment Therapy (ACT) for people with dementia, considering carer-supported, remote delivery and necessary therapy adaptations. Methods: A hermeneutic single case efficacy design (HSCED) series was used to analyse therapy process and change for three clients with dementia and psychological distress. A matrix of quantitative and qualitative data was collated (‘rich case records’) and subject to critical analyses by three independent psychotherapy experts (‘judges’) who identified change processes and determined the outcome for each client. Results: Adjudication concluded that one client made positive changes, specifically reliable reductions in psychological distress, which were largely attributable to ACT. Two clients remained unchanged. Discussion/Conclusion: Where change was achieved, the ACT-specific processes of values, committed action and acceptance, in combination with non-specific therapy factors including a strong client-carer relationship, existing client interests and individualised therapy adaptations, were facilitative. Hence, ACT may be a feasible and effective vehicle for therapeutic change by helping carers to better meet the needs of their loved ones. Future research to optimise ACT delivery in this population may be beneficial. Furthermore, the assessment of carer factors (e.g., their psychological flexibility, the client-carer relationship) may strengthen the evidence-base for systemic ACT-use.

Keywords: dementia; psychological distress; psychological therapy; ACT; acceptability; HSCED

Introduction

Dementia is a chronic, progressive syndrome that causes cognitive decline beyond normal ageing, and can affect memory, learning, language, comprehension, judgement, and problem-solving abilities. In older adults worldwide, dementia is one of the leading causes of disability and dependency[3] (World Health Organization; WHO, 2019). By 2050, it is expected that global prevalence rates will increase to 152 million (WHO).

According to the National Institute for Health and Care Excellence (NICE, 2018), interventions for people with mild-moderate dementia with the aim of promoting cognition, independence, and wellbeing[4] include participation in activities tailored to personal preference, group reminiscence therapy, cognitive stimulation therapy, and pharmacological management. However, the needs of older people with mental health difficulties remain under-recognised and inadequately met (Laidlaw, 2013).

Psychological distress[5], defined as "emotional suffering characterised by clinical levels of depression and anxiety" (Drapeau et al., 2012, p. 105), is common in people with dementia (Muliyala & Varghese, 2010; Badrakalimuthu & Tarbuck, 2012). Furthermore, there is significant correlation between psychological distress and greater risk of dementia-related mortality compared to people without psychological distress (Rosness et al., 2016). Hence, helping people with early dementia manage co-morbid anxiety and depression is an important clinical objective (Cheston, 1998; Moniz-Cook & Manthorpe, 2009). Yet, although psychological approaches have been proposed (NICE, 2018) with the potential to enhance wellbeing (Orgeta et al., 2014), older people (Laidlaw, 2013) and those with dementia likely have reduced opportunities for psychological treatments.

Cognitive behavioural therapy[6] (CBT) is a leading psychological treatment for depression and anxiety in adults (WHO, 2007). Its effectiveness is measured

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[3] Extended Paper section 1.2; background information about dementia
[4] Extended section 1.3; further information about dementia treatments
[5] Extended sections 1.4 and 1.5; further information about psychological distress in dementia
[6] Extended section 1.6.1; further information about CBT and its evidence-base

via symptom reduction, acceptability, and attrition. However, adherence to CBT in dementia can be poor (Spector et al., 2012) and efficacy reduced in older adults in comparison to working age adults, particularly in treating generalised anxiety disorder (Kishita & Laidlaw, 2017). Therefore, psychological treatments for people with dementia merit further research (Orgeta et al., 2014).

Acceptance and Commitment Therapy[7] (ACT) offers a ‘third wave’, alternative approach to traditional CBT. Whilst CBT may offer help in exploring appraisals people make about their health prognosis in dementia (for example, considering the evidence for and against thoughts), ACT arguably offers a more nuanced position with less emphasis on cognitive change or mediation of psychological distress and greater emphasis upon how helpful these appraisals are in influencing the way people choose to focus their energies and lead their lives. ACT proposes that distress results from an individual’s unhelpful relationship with their cognitive, emotional, and behavioural processes[8]. ACT aims to foster acceptance of thoughts and separation from distress by changing how experiences are related to. Though distress may reduce secondarily, effectiveness is measured by the extent of re-engagement with a life of valued activities and functional improvement in the presence of symptoms, thoughts, and feelings typical of the condition (Gillanders & Laidlaw, 2014). ACT also aims to promote psychological flexibility (PF), an overarching process consisting of six interrelated processes[9]: being present, cognitive defusion, acceptance, self-as-context, values and committed action (Hayes et al., 2006). PF has been shown to facilitate good psychological health, with higher levels of PF related with lower distress (Hayes et al., 2013). However, there is limited understanding of the role PF may have in dementia.

An increasing number of studies have evidenced ACT for psychological distress in adults (Öst, 2014), older adults (Gould et al., 2021; O’Keeffe et al., 2021), illness-related distress (Mccracken & Gutiérrez-martínez, 2011) and dementia caregivers (Fowler et al., 2021). Valued action in ACT may aid living well with

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[7] Extended section 1.6.2; further information about ACT and its evidence-base
[8] Extended section 1.7; theoretical and philosophical basis of ACT
[9] Extended section 1.8; detailed information about ACT processes

dementia and thus provide a suitable intervention, but no studies have investigated ACT effectiveness specifically for dementia, despite a conceptual case for its suitability with parallel populations. Furthermore, no dementia therapeutic intervention studies have used a case series approach to examine change processes, integral for understanding and refining therapy. Hence, this study will use a hermeneutic single case efficacy design (HSCED) series[10],[11] to analyse therapy process and outcome data, with the prospect of producing findings that contribute to the seemingly limited evidence-base for effective psychological intervention for people with dementia.

Research Objective & Guiding Questions

In summary, people with dementia have a high prevalence of psychological distress but are under-served with evidence-based psychological interventions. To promote choice and clinical efficacy, there is necessity to test multiple intervention options for this population. The aim of this study is to investigate the effectiveness of ACT for supporting people with dementia experiencing psychological distress. A secondary aim is to investigate the acceptability of ACT with people with dementia, in which carer-supported, remote delivery and necessary therapy adaptations are considered.

Methods

Design

The adjudicated HSCED[12] is guided by three fundamental questions: (1) Did the client change over the course of therapy? (2) Is the therapy responsible for the observed changes? (3) What events or processes facilitated observed changes? A detailed matrix of quantitative and qualitative clinical data was collated ('rich case records') and affirmative and sceptic briefs developed. These were subject to critical analyses by three independent psychotherapy experts ('judges') who identified change processes and determined and

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[10] Extended section 2.1; systematic case series rationale
[11] Extended section 2.5; epistemological position
[12] Extended section 2.2; detailed description of HSCED development and procedures

attributed outcomes for each client.

Ethics

Ethical procedures[13] were approved by the NHS Local Research Ethics Committee (Appendices A and B) and locally within Nottinghamshire Healthcare NHS Foundation Trust's Research and Development Department.

Participants

The study involved a case series of three client-participants, who, for confidentiality purposes, chose the pseudonyms 'Minnie', 'Agatha' and 'Phyllis', and their respective carers (daughters) 'Mo', 'Jane' and 'Julie'. Minnie and Agatha were recruited from a National Health Service (NHS) Memory Assessment Service (MAS) in Nottinghamshire and screened using the Generalised Anxiety Disorder Questionnaire (GAD-7; Spitzer et al., 2006; Appendix L) and Patient Health Questionnaire (PHQ-9; Spitzer et al., 1999; Appendix M) by a MAS Nurse ('gatekeeper'). The gatekeeper used an informal crib sheet (Appendix C) to provide consistent study information to clients who expressed an interest. Clients and carers were then provided with Participant and Carer Information and Demographic Sheets (Appendices D, E, G, H) by the first author. Phyllis was recruited from the Dementia Research UK website and screened by the first author. All clients met inclusion criteria: (i) A diagnosis of dementia (any type) and (ii) A clinically significant level of psychological distress (scores of ≥8 on the GAD-7 and/or ≥10 on the PHQ-9). Clients would have been excluded if they: (i) Were already receiving psychotherapy, (ii) Had insufficient English or language abilities to engage in therapy or (iii) Were unable to consent to and/or engage in therapy. Consent was provided via written consent forms (Appendices F, I). Client-carer dyads completed all aspects of the study, except Agatha and Jane, who withdrew from therapy after six weeks, but consented to participate in a change interview and complete follow-up measures.

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[13] Extended section 2.7; further ethical considerations and procedures

Therapist & Intervention Integrity

The study utilised a practitioner-researcher model, meaning the first author was the simultaneous researcher and therapist[14] (McLeod, 2010; Elliott, 2002). The first author was a Trainee Clinical Psychologist who had undertaken advanced ACT training and received clinical supervision throughout intervention delivery. ACT fidelity was assessed via session audio recordings by the third author using the ACT Fidelity Measure (ACT-FM; O'Neill et al., 2019; Appendix S). Scores from a sample of three sessions indicated ACT-congruent behaviours were enacted (Total Consistency Score= 31/36), with extremely rare occasions of ACT-inconsistent behaviours (Total Inconsistency Score= 0.3/36).

Procedure & Intervention Content

The first author delivered the ACT intervention[15] following some pre-adaptational work for use with people with dementia (Appendix R). The intervention was delivered on an individual basis, accompanied by carers, via Microsoft Teams (MST), for up to 90-minute, 12 weekly sessions, which were reviewed at session six. An ACT protocol, ‘Better Living with Illness’ (Brassington et al, 2016), was used flexibly to guide the intervention. Experiential exercises, metaphors, and between-session tasks were integral. For example, to ensure internal consistency, the ‘beach ball’ metaphor was used with all clients with the aim of increasing acceptance. The first author took an active, responsive role in targeting inflexible processes ‘in flight’. According to process-led ideographic adaptations, less relevant or lengthy exercises were shortened or removed, whilst maintaining ACT fidelity.

Clients completed self-report measures at the beginning and end of sessions. Reported changes were also captured with informal ‘check-ins’, with clients sharing therapy reflections or changes between sessions.

Materials

Self-report measures were used to track change in variables of interest;

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[14] Extended section 2.4; additional therapist details
[15] Extended section 2.3; detail of ACT intervention and (pre)adaptational work

psychological distress (GAD-7 and PHQ-9), PF (Comprehensive assessment of Acceptance & Commitment Therapy- short form; Morris, 2019; Appendix N), wellbeing (Short Warwick-Edinburgh Mental Wellbeing Scale; Tennant et al., 2007; Appendix O), client problems (Personal Questionnaire; Elliott et al., 1999; Appendix P) and therapeutic alliance (Session Rating Scale; Duncan et al., 2003; Appendix Q), as shown in Table 3[16].

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[16] Extended sections 2.6 and 2.8; rationale for self-report measures used and methods of reducing client burden

Table 3. Summary of Measures

Measure & author	**Aim**	**Item scaling & directionality**	**Reliability & validity**	**Frequency of administration**
Generalised Anxiety Disorder Questionnaire (GAD-7); Spitzer et al. (2006)	Anxiety symptoms	7 items; 4-point Likert scale (range; 0-3); Higher scores indicate higher levels of anxiety: 5-10=mild 11-15=moderate 16-21=severe	IC; α= .92 High sensitivity and specificity (Spitzer et al., 2006)	Screening, Session 1, 6, 12, 1 and 3-month follow-up
Patient Health Questionnaire (PHQ-9); Spitzer et al. (1999)	Depressive symptoms	9 items; 4-point Likert scale (range 0-3); Higher scores indicate higher levels of depression: 5-9=mild 10-14=moderate 15-19=moderately severe 20-27=severe depression	IC; α= .89 Good validity (Kroenke et al., 2001)	Screening, Session 1, 6, 12, 1 and 3-month follow-up
Comprehensive assessment of Acceptance & Commitment Therapy- short form (CompACT-SF); Morris (2019)	Psychological flexibility	8 items; 7-point Likert scale; (range 1-7): Higher scores indicate greater PF	IC; α= .91 CompACT has good internal consistency (Francis et al., 2016).	Beginning of each session, 1 and 3-month follow-up
Short Warwick-Edinburgh Mental Wellbeing Scale (SWEMWBS); Tennant et al. (2007)	Wellbeing	7 items; 5-point Likert scale (range 1-5): Higher scores indicate higher positive mental wellbeing	IC; α= .83 Adequate internal consistency and reliability (Haver et al., 2015)	Session 1, 6, 12, 1 and 3-month follow-up
Personal Questionnaire (PQ); Elliott et al. (1999)	Client problems	Up to 10 client-generated problem statements, rated on a 7-point Likert scale (range 1-7): Higher scores indicate a greater problem	IC; α= .80 Strong correlations with standardised outcome measures (Elliott et al., 2016).	Session 1, Session 6, 12, 1 and 3-month follow-up
Session Rating Scale (SRS); Duncan et al. (2003)	Therapeutic alliance (therapist respect and understanding, relevance of topics, client-practitioner fit)	4-item visual analogue calculated (range 0-40): Higher scores indicate more effective relationship	IC; α= .93 Good concurrent validity (Campbell & Hemsley, 2009; Duncan et al., 2003)	End of each session
Change Interview; Elliott et al. (1999); Llewelyn et al. (1988)	To gather qualitative information about (extra)therapeutic factors			End of therapy

Change Interview (CI)

A semi-structured CI (Elliott et al., 1999; Appendix T) was used to obtain client and carer views about their therapy experience and change processes, including attributions of change and possible facilitators or hinderances. Interviews were conducted by an independent researcher a week post-therapy.

Analysis Team

The second and third authors, who were Clinical Psychologists with varied theoretical orientations and experienced in psychotherapy research, supervised the study, and approved the case records and affirmative and sceptic briefs.

Judges

Three independent Clinical Psychologists were invited to act as judges according to their interest in assessing psychotherapy effectiveness, varied theoretical orientations and clinical research prominence, which included specialist ACT research and psychotherapy in academia and in older adult and physical healthcare contexts. Judges were given information sheets and provided written consent to participate (Appendices J, K).

HSCED Analysis

Stage 1. Rich Case Records[17]

A comprehensive dataset was developed for each client, which involved:

i. Collating contextual client and therapist information.
ii. Analysing quantitative process and outcome data.
iii. Collating client's qualitative therapy descriptions into Elliott's (2002) categories of change.
iv. Gathering evidence for and against change in client goals using quantitative data, session recordings, therapist notes, CI transcripts and change rating sheets.
v. Gathering evidence for and against shifts in PF processes using quantitative data, session recordings, therapist notes, CI transcripts and

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[17] Extended section 2.9; Development of rich case records

change rating sheets.

In the case records, the affirmative case aimed to persuade the judges that clients changed substantially due to therapy (Elliott, 2002). The sceptic argument drew on alternative explanations, suggesting clients did not change substantially or that any changes were caused by extra-therapeutic factors (Elliott).

Stage 2. Adjudication

The first author emailed the case records to judges, including affirmative and sceptic briefs, CI transcripts and change rating sheets. Judges were asked to critically examine the case records and answer semi-structured adjudication questions about their views on the extent and type of client change and the evidence that most mattered in reaching their conclusions.

Results

Abridged Results for Minnie[18]

Context and Focal Problems

Minnie was a 71-year-old female who was diagnosed with Alzheimer's Disease in September 2020. She was a retired farmer's wife and widowed two years ago. Minnie had three adult children. One of her daughters, Mo, was in her fifties, married and a full-time carer for Minnie. Minnie was bereaved of her husband, sister, and mother-in-law in close succession in 2019, and experienced feelings of guilt, with beliefs about neglecting her sister who had dementia.

Minnie was prescribed Sertraline for depression and Galantamine for dementia. She had not previously had psychological therapy. A family informant, separate to the research, suggested Minnie may have had an undiagnosed mental health condition such as bipolar disorder, since her mood had 'always been very up and down'.

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[18] Paper section 3.1; Minnie's full rich case record

Major ACT Protocol Adaptations

Key aspects of the formulation were experiential avoidance of sadness and a fusion to controlling emotions. Whilst Minnie knew what was important to her (values), control-based coping strategies (e.g., distraction, avoiding unpleasant emotions) had become increasingly restrictive of valued-action. Therefore, the focus areas were acceptance and present-moment awareness. Thought defusion was not introduced due to Minnie's difficulties in identifying thoughts. Other adaptations included recapping the previous session, offering regular breaks, using visual prompts (Robinson & Moghaddam, 2022), providing concrete examples, and reducing session time from 90 to 60 minutes following the therapy review.

Quantitative Results[19]

Table 4. Minnie's psychological distress and PF ratings

Outcome Measure	**Clinical cut-off**	**RC min**	**Baseline**	**Pre**	**Post**	**1-month**	**3-month**
GAD-7	≥8	4 (↓)	0	3 (=)	1 (=)	3 (=)	0 (=)
PHQ-9	≥10	6 (↓)	**14**	9 (=)	6 (+)	7 (+)	0 (+)
SWEMWBS	≤17	4.35 (↑)	-	23	29 (+)	28 (+)	35 (+)
CompACT-SF	≤30	4.33 (↑)	-	**27**	43 (+)	38 (+)	46 (+)

Note. RC; reliable change (i.e., minimum change-score required to demonstrate statistically reliable change at 95% confidence); Clinical cut-off; caseness threshold for determining clinically significant symptoms; Values in bold fall within the clinical range; - signifies missing data; Arrows (↑/↓) indicate direction of desired change (improvement) for each measure; (+) denotes reliable improvement in relation to first available score; (=) denotes no change; and (-) denotes reliable deterioration.

Abridged Affirmative and Sceptic Briefs

The affirmative brief proposed Minnie made significant, reliable improvements in distress, problems and PF as indicated by quantitative data, which were maintained at follow-up. In the CI, Minnie reported feeling more relaxed and able to recognise and live in line with her goals, which she attributed to therapy ("I think the therapist certainly reminded me of ways forward and what I needed to do"). This was corroborated by Mo who stated that ACT techniques had been

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[19] Extended section 3.1.3; Minnie's full quantitative measures including SRS and PQ

useful and individually adapted to help Minnie plan committed action ("…the therapy has made me my mum realise that she's still got things she wants to do in life").

The sceptic case argued that Minnie's difficulties were unstable since her screening and pre-therapy scores were dissimilar, creating challenges in establishing whether her distress would have naturally improved without therapy. Some measures did not improve, suggesting ACT processes were less transferrable to Minnie. Furthermore, the stability of Minnie's answers was possibly state-dependent due to difficulties in recalling previous weeks, raising questions about the usefulness of self-report measures in the context of memory impairment. PQ scores and CI quotes provided evidence that positive changes were due to extra-therapeutic factors, such as Minnie's re-engagement with established coping rather than any new learning.

Adjudication

Table 5. Judicial results for Minnie

	Judge 1	Judge 2	Judge 3
	Client change		
Categorisation of outcome (certainty of decision as %)	Improved (60%)	Improved (80%)	Recovered (80%)
Extent of client change (certainty of decision as %)	Slightly (80%)	Moderately (80%)	Substantially (80%)
	Attribution		
Due to therapy (certainty of decision as %)	Moderately (80%)	Considerably (80%)	Substantially (80%)
Mediating Factors	• Behavioural activation • Behavioural awareness • Therapeutic relationship • Re-establishing a strong working client-carer relationship	• Mindfulness exercises • Acceptance • Values • Committed action • Therapy adaptations	• Mindfulness exercises • Present-moment awareness • Therapeutic relationship • Therapy adaptations

Moderating Factors	• History of values-based behaviour • Past experiences provided a basis for psychological mindedness.	• Resourcefulness with established hobbies and coping strategies. • Familiarity with mindfulness • Carer support	• Pre-existing interests and hobbies. • Pre-existing experience of therapeutic activities • Carer support
Certainty that ACT processes contributed to change	60%	60%	80%
ACT-specific processes that contributed to therapy-related change	• Behavioural awareness • Committed action	• Acceptance • Values • Committed action	• Acceptance • Committed action • Cognitive defusion • Present-moment awareness
Generic therapy processes that contributed to therapy-related change	• Improved client-carer bond • Exposure to and discussion of feelings	• Carer support within and outside of therapy. • Season change	• Therapeutic alliance • Therapy structure • Therapy adaptations
Overall attribution of change to therapy (ACT vs Other Factors)	60/40	80/20	40/60

All judges concluded with confidence that Minnie improved over the intervention, however, the extent varied between slightly and substantially. All judges largely attributed improvements to therapy over non-therapy factors. Two judges were confident that ACT-specific processes were responsible for more than half of the therapy-related change and all judges determined that committed action significantly contributed to positive change. Two judges also identified the client-carer relationship as a generic contributor.

The evidence that mattered most to the judges were:

- Reliable and significant change in quantitative measures
- Engagement in values-based behaviours

- Minnie and Mo's account (changes noted in the CI and change rating sheets, with attribution to specific techniques).

Abridged Results for Agatha[20]

Context and Focal Problems

Agatha was an 85-year-old female who was diagnosed with Mixed-Type Dementia in March 2021. She was a retired clerical worker and lived with her husband. She had three adult children, one of whom, Jane, was in her fifties and married with her own business, which she balanced with carer responsibilities for her parents.

Prior to her dementia, Agatha reported she had 'always been a worrier', with thoughts 'all waking hours' about harm coming to her family. Agatha was prescribed Donepezil for dementia. She had not previously had psychological therapy. She was hard of hearing and wore hearing aids.

Major ACT Protocol Adaptations

The main features of Agatha's formulation were fusion to thoughts about dementia-related difficulties and narratives about the person she 'should be'. Agatha seemed to have identity difficulties due to changes in her abilities (self-as-content), often stating, "When I was normal, …" Whilst Agatha knew what was important to her (values), getting caught up in thoughts (an 'internal monologue') was acting as a barrier to committed action. Thus, there was a focus on present-moment awareness, acceptance and thought defusion. Other adaptations included summarising the previous session, offering regular breaks, using visual prompts (Robinson & Moghaddam, 2022), providing more directive communication (Robie, 1999), using shorter dialogue and repetition, and reducing session time from 90 to 60 minutes.

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[20] Extended section 3.2; Agatha's full rich case record

Quantitative Results[21]

Table 6. Agatha’s psychological distress and PF ratings

Outcome Measure	**Clinical cut-off**	**RC min**	**Baseline**	**Pre**	**Post**	**1-month**	**3-month**
GAD-7	≥8	4 (↓)	**18**	**17** (=)	**18** (=)	**21** (=)	**12** (+)
PHQ-9	≥10	6 (↓)	9	9 (=)	**10** (=)	8 (=)	5 (=)
SWEMWBS	≤17	4.35 (↑)	-	19	20 (=)	22 (=)	23 (=)
CompACT-SF	≤30	4.33 (↑)	-	**21**	**24** (=)	**28** (+)	**25** (=)

Note. RC; reliable change (i.e., minimum change-score required to demonstrate statistically reliable change at 95% confidence); Clinical cut-off; caseness threshold for determining clinically significant symptoms; Values in bold fall within the clinical range; - signifies missing data; Arrows (↑/↓) indicate direction of desired change (improvement) for each measure; (+) denotes reliable improvement in relation to first available score; (=) denotes no change; and (-) denotes reliable deterioration.

Abridged Affirmative and Sceptic Briefs

The affirmative brief stated there was evidence of some change in PF according to the CompACT-SF (Morris, 2019) and in anxiety and frustration as indicated on the GAD-7 (Spitzer et al., 2006) and PQ (Elliott et al., 1999), assuming the intervention was responsible when changes occur in chronic difficulties, such as longstanding anxiety. However, Agatha could find wording in the measures confusing, which may explain why significant change was absent in some measures.

The sceptic argument claimed that any changes were minor and not maintained post-therapy. In the CI, neither Agatha nor Jane reported changes or acknowledged ACT processes. Due to Agatha’s recent dementia diagnosis, the sceptic case also questioned the timeliness of the intervention, and that Agatha’s level of impairment and hearing difficulties likely hindered any positive outcomes, resulting in her early withdrawal from therapy.

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[21] Extended section 3.1.3; Agatha’s full quantitative measures including SRS and PQ

Adjudication

Table 7. Judicial results for Agatha

	Judge 1	Judge 2	Judge 3
	Client change		
Categorisation of outcome (certainty of decision as %)	Unchanged (80%)	Unchanged (100%)	Unchanged (80%)
Extent of client change (certainty of decision as %)	No change (80%)	No change (100%)	No change (60%)

Judges unanimously concluded that Agatha remained unchanged (hence, verdicts on attribution of change were not applicable, nor tabulated). Whilst quantitative measures implied some improvement in the following months, it was doubtful this could be attributed to therapy.

Abridged Results for Phyllis[22]

Context and Focal Problems

Phyllis was a 90-year-old female who was diagnosed with Vascular Dementia in July 2020. Phyllis was a retired civil servant and widowed 11 years ago. She had two adult children. Her daughter, Julie, was a married teacher in her fifties. Julie lived elsewhere in the UK and visited Phyllis as often as possible. Phyllis was also supported by a next-door neighbour on an almost daily basis. Phyllis said she had been ‘a procrastinator a long time’ and found it helpful to think things over from different angles to enable her to do something in an easier or time-efficient way.

Phyllis took statins and a daily aspirin. She was not prescribed dementia medication, nor previously had psychological therapy. She was hard of hearing and wore hearing aids.

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[22] Extended section 3.3; Phyllis’ full rich case record

Major ACT Protocol Adaptations

Important aspects of Phyllis' formulation were experiential avoidance of sadness and embarrassment about her physical health difficulties and a fusion to thoughts about how she should be spending her time doing household chores. Whilst Phyllis knew what was important to her (values), 'procrastination', distractibility and avoidance of difficult thoughts and feelings had become increasingly restrictive of valued action. Hence, the intervention focused on present-moment awareness, thought defusion and the workability of some of Phyllis' behaviours to promote committed action. Other adaptations included flexibility with session start time, recapping the previous session, offering regular breaks, using visual prompts (Robinson & Moghaddam, 2022), concrete examples, directive communication (Robie, 1999) and repetition (Grant & Casey, 1995).

Quantitative Results[23]

Table 8. Phyllis' psychological distress and PF ratings

Outcome Measure	**Clinical cut-off**	**RC min**	**Baseline**	**Pre**	**Post**	**1-month**	**3-month**
GAD-7	≥8	4 (↓)	**9**	4 (+)	4 (+)	2 (+)	3 (+)
PHQ-9	≥10	6 (↓)	**12**	3 (+)	5 (+)	5 (+)	6 (+)
SWEMWBS	≤17	4.35 (↑)	-	27	24 (=)	25 (=)	23 (=)
CompACT-SF	≤30	4.33 (↑)	-	**21**	**20** (=)	**24** (=)	**22** (=)

Note. RC; reliable change (i.e., minimum change-score required to demonstrate statistically reliable change at 95% confidence); Clinical cut-off; caseness threshold for determining clinically significant symptoms; Values in bold fall within the clinical range; - signifies missing data; Arrows (↑/↓) indicate direction of desired change (improvement) for each measure; (+) denotes reliable improvement in relation to first available score; (=) denotes no change; and (-) denotes reliable deterioration.

Abridged Affirmative and Sceptic Briefs

The affirmative case emphasised statistically reliable, significant improvements in anxiety and depression on quantitative measures. Evidence from the CI suggested Phyllis became more skilled at mindfulness and in noticing thoughts

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[23] Extended section 3.1.3; Phyllis' full quantitative measures including SRS and PQ

without getting caught up in them. Phyllis' ability to discuss her feelings openly was also markedly improved ("…I'm not used to people asking sort of personal questions…but I got used to it as time went on"). Julie reported Phyllis seemed able to defuse from the thought that 'people will see me hobbling' to enable her to ask her neighbour for help according to the PQ (Elliott et al., 1999) and re-engage in things she enjoyed ("I think that helped my mum a lot more…I think she'd been focusing…about her mobility and what people would think").

The sceptic brief proposed that Phyllis' problems were unstable since her screening scores improved considerably by the first session, indicating that her distress could have changed without therapy. Moreover, Phyllis' working alliance with Julie was helpful in sharing the management of Phyllis' distress, similar to real-life clinical practice and the context in which Phyllis was living. There were evidently between-session processes with facilitative conversations about therapy, and support from Julie with between-session tasks. Thus, relational factors may have resulted in improvements.

Adjudication

Table 9. Judicial results for Phyllis

	Judge 1	Judge 2	Judge 3
	Client change		
Categorisation of outcome (certainty of decision as %)	Unchanged (60%)	Improved (60%)	Unchanged (60%)
Extent of client change (certainty of decision as %)	Slightly (40%)	Slightly (60%)	Moderately (60%)
	Attribution		
Due to therapy (certainty of decision as %)	Slightly (40%)	Moderately (80%)	Moderately (60%)
Mediating Factors	• Identifying values • Committed action • Increased emotional openness	• Mindfulness exercises • Remote therapy delivery	• Committed action

Moderating Factors	• Positive client-carer relationship • Embedded in a community • Willingness to engage with others and technology. • Resilience and perseverance	• Carer support • Facilitative conversations with carer	• Carer support • Willingness to engage in therapy • Availability of online groups and community events. • Supportive neighbour
Certainty that ACT processes contributed to change	40%	20%	20%
ACT-specific processes that contributed to therapy-related change	• Values • Committed action	• Values • Committed action • Acceptance • Defusion	• Committed action
Generic therapy processes that contributed to therapy-related change	• Therapist empathy (alliance) • Client-carer alliance • Goal consensus	• Therapeutic alliance • Timing of therapy • Remote therapy delivery	• Therapeutic alliance • Therapy adaptations
Overall attribution of change to therapy (ACT vs Other Factors)	20/80	60/40	20/80

Two judges concluded that Phyllis remained unchanged whilst one judge felt she had improved to a slight degree. The extent of change attributed to therapy varied from slightly to moderately. There was mixed opinion regarding mediating factors, however, judges agreed that the client-carer relationship was helpful, as were the ACT-processes of values and committed action. Judges' certainty that ACT had led to change varied from 20-40%.

Cross-Case Synthesis

Across the three cases, the following patterns were identified:

- ACT processes thought to partially mediate outcomes were values identification, committed action and acceptance.
- The working alliance between client and carer was also a likely mediator of therapeutic change.
- Moderating processes included client willingness, engagement, resilience, perseverance, pre-existing therapeutic experience and established coping and hobbies. Conversely, clients with progressed dementia or with less facilitative carers were met with extra challenges.
- One judge highlighted that some processes were not necessarily ACT-specific but evident in other therapeutic approaches (e.g., ‘committed action’ in ACT and ‘behavioural activation’ in CBT).

Discussion

This study aimed to investigate the effectiveness and acceptability of ACT for people with dementia experiencing psychological distress. The study evaluated ACT for this population using a case series approach to examine change processes and address questions of causality, mediation, and moderation. Rich case records from three client-participants were examined by an expert panel of Clinical Psychologists to conclude upon the efficacy of the intervention.

Findings showed one client (Minnie) improved at least slightly, and at most, recovered substantially in key problem areas, whilst two (Agatha and Phyllis) remained unchanged. Though one judge indicated that Phyllis had improved slightly, it was hard to attribute this to therapy due to unclear evidence that ACT processes were key over and above relational and structural therapy aspects[24].

Clinical and Theoretical Implications[25]

Effectiveness

Despite mixed conclusions between and within cases, two of the three clients

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[24] Extended section 4.1; relationship between study findings and extant literature

[25] Extended sections 4.2 and 4.3; detailed discussion of clinical, theoretical and research implications

demonstrated reliable improvement in anxiety and depression at one and three-month follow-up. Judicial outcomes suggested both ACT-specific processes (values, committed action and acceptance) and generic therapy factors (particularly the client-carer relationship) facilitated change for one client. This may suggest that psychological distress was sensitive to increases in PF, as well as differences in the client-carer relationship and client ability to adopt an ACT-consistent understanding of their internal world. Targeting psychological inflexibility via ACT techniques, such as the ‘beach ball’ metaphor to increase acceptance, seemed to contribute to change in this client. Two clients could commit to value-congruent behaviours during therapy (e.g., socialising), however, this may have been as a result of continued carer support. Hence, carers’ ability to facilitate values-based action seemed important towards therapeutic change. A combination of remote therapy, technical issues, hearing difficulties, level of impairment and variable carer support likely acted as extra-therapeutic moderators, resulting in the judicial conclusions of no change for two clients. Yet, distress reduction occurred for one client without therapeutic aims to change their distressing thoughts. This has important theoretical implications for understanding the use of acceptance-based approaches that genuinely validate people with dementia and support re-engagement with valued activities despite symptoms, thoughts, and feelings that may be typical of the condition (Gillanders & Laidlaw, 2014).

Acceptability

In most cases, using ACT systemically in the triad between client, carer and therapist appeared to facilitate a strong client-carer working alliance, akin to the child and adolescent literature in which parents act as co-therapists (Barmish & Kendall, 2005; Manassis et al., 2014). The client-carer relationship, in combination with existing client interests and hobbies (values-driven behaviour) and therapy adaptations, appeared to provide the setting for an effective ACT intervention. However, results suggested that common factors alone did not account for the full extent of therapy-related change, with ACT processes playing a varying role for two of the three clients. Still, it is challenging to assess the role of model-specific versus generic, non-therapy processes due to their degree of interdependence (Laska & Wampold, 2014).

Though all clients met inclusion criteria, they were heterogenous in a variety of ways. For example, differences in individual traits, skills and experiences, cognitive ability, time since diagnosis and carer relationships possibly limited cross-case comparisons. Judging when and how to introduce concepts was individualised, but there were commonalities in which ACT metaphors did not achieve the intended outcome versus those that were better understood and engaged with, namely those shorter, more immediate, and less abstract exercises. Therefore, whilst an ACT intervention may be acceptable for people with a milder level of cognitive impairment, receipt of a dementia diagnosis should not be a barrier to accessing therapy.

Whilst remaining aware not to stereotype people with dementia with what they are able to comprehend (Gillanders & Laidlaw, 2014; Harris, 2013), there were similar adaptations required to aid engagement, not only to the intervention, but also for remote and carer-assisted delivery. These included offer of regular breaks, use of visual prompts (e.g., screen sharing; Robinson & Moghaddam, 2022), providing directive communication (Robie, 1999), repetition (Grant & Casey, 1995), and tangible examples (Table 10) to support ACT concepts and negotiating time for clients and carers to share their perspectives.

Table 10. Examples of therapy techniques used to target psychological inflexibility processes

Psychological Flexibility Term	**Process of psychological inflexibility**	**Examples of techniques used in therapy to target processes of psychological inflexibility**
Defusion	Cognitive fusion	Leaves on a stream Labelling thoughts
Acceptance	Experiential avoidance	Pushing away paper Passengers on a bus Beach ball
Noticing self (self-as-context)	Over attachment to self-content (self-as-content)	General discussion about important roles (e.g., wife, mother)
Contact with the present moment	Past or future dominated attention	Three-minute present moment awareness exercise Mindfulness of breath
Values clarity	Remoteness from values	80th birthday party Values circle
Value committed action	Unworkable action	Goal setting Assertiveness

The current study used an ACT-consistent intervention and benefitted from a high level of ecological validity in the presentations encountered. Thus, results can support clinical decisions for the treatment of people with dementia experiencing distress, particularly those referred to MAS. But, due to the small sample size and inconsistent outcomes, such considerations are tentative.

Limitations

Whilst the dual role of the first author enabled generation of knowledge in context and captured complexity in the therapy process (McLeod, 2010), a major criticism is of the associated researcher bias[26]. Although potential bias was reduced with the involvement of independent judges to cross-examine the case records, judges likely had their own biases according to theoretical orientation and clinical experience. It seemed judges drew upon different evidence to form their conclusions, and one judge appeared more optimistic about change in Phyllis' case, possibly indicating greater reflection of achievable change in a real-life setting (Elliott, 2002; Elliott et al., 2021). Hence, the study may have benefitted from joint adjudication, with judges acting as a jury to provide one conclusion per client (Bohart et al., 2021).

A further limitation was the study's reliance on self-report measures[27] owing to clients' reduced reflective capabilities, recollection of previous weeks and understanding the wording in some measures, which risked negotiation of scores with their carers. The inclusion of behavioural measures could have helped with process-outcome mapping over the course of therapy (Newsome et al., 2019).

Finally, all clients and carers were White-British, mother-daughter dyads. Whilst this may illustrate how carer responsibilities typically fall to female family members (Alzheimer's Research UK, 2015), this may reduce result applicability to more diverse populations[28].

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[26] Extended sections 4.5.1 and 4.5.4; critique of design and potential bias sources
[27] Extended section 4.5.2; critique of measurement
[28] Extended section 4.5.3; critique of sample characteristics

Recommendations

- Therapy components important to consider when using ACT systemically with people with dementia include supporting a strong client-carer working alliance, facilitating exposure to and acceptance of avoided, suppressed emotions, and planning value-driven behaviour, with less reliance on memory by using shorter, immediate, and less abstract ACT metaphors.
- Weekly behavioural and process measures and/or post-therapy CIs may help to monitor and understand change processes in real-life clinical practice if this does not increase client burden.
- Therapist process notes, including reflections upon alliance, formalised therapist ratings and monitoring completion of between-session tasks could be beneficial in examining other non-specific therapy factors.
- Whilst ACT may be acceptable to those with a milder level of cognitive impairment, receipt of a dementia diagnosis should not be a barrier to accessing therapy.
- To improve acceptability, older adult service pathways, such as MAS, could offer increased flexibility and choice of therapy delivery (in-person or remote).
- Future studies should optimise ACT delivery in dementia via a new case series. Though ACT is mainly delivered individually or in groups, the carer-supported aspect is currently under-studied and may be critical to working therapeutically with this population. Hence, the inclusion of a companion may be important for clinical practice.

Conclusion

This study applied a therapeutic intervention to an under-researched, dementia population using a methodology that enabled exploration of complex therapy processes and contributes to the limited psychotherapy evidence-base for people with dementia.

The client-carer relationship in this study was revealed to be a mediator of therapeutic outcomes, which offers a novel contribution to the literature. ACT can be used systemically to support values-based behaviours and favourable outcomes for some, thus, may be a feasible and effective vehicle for therapeutic change by helping carers to better meet the needs of their loved ones[29]. This may offer a finding generalisable to populations supported by companions, such as those with other long-term conditions or cognitive impairments.

There was one case of positive change and two cases of no change. The critical differentiators were deemed to be extra-therapeutic. Considering the intervention, inclusion criteria, and measurements used, future research may benefit from further optimising ACT delivery in this population via a new case-series. Furthermore, to explore whether change processes occur by proxy (with the carer as a co-client) or co-facilitation (with the carer as co-therapist), assessing the carers' PF and client-carer relationship may enhance the evidence-base for systemic ACT-use.

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[29] Extended section 1.8; contribution towards the literature

Journal Paper References

Alzheimer’s Research UK. (2015). *Women and dementia: A marginalised majority.* Retrieved from https://www.alzheimersresearchuk.org/about-us/our-influence/policy-work/reports/women-dementia/

Badrakalimuthu, V. R., & Tarbuck, A. F. (2012). Anxiety: A hidden element in dementia. *Advanced Psychiatric Treatment, 18*(2), 119-128. https://doi.org/10.1192/apt.bp.110.008458

Barmish, A. J., & Kendall, P. C. (2005). Should parents be co-clients in cognitive–behavioral therapy for anxious youth? *Journal of Clinical Child & Adolescent Psychology, 34,* 569-581. https://doi.org/10.1207/s15374424jccp3403_12

Bohart, A. C., Shenefiel, L., & Alejandro, M. (2021). What can we learn about therapeutic change from case history data? The case of “Carl” and “Sandra.” *Pragmatic Case Studies in Psychotherapy, 17*(2), 210-234. https://doi.org/10.14713/pcsp.v17i2.2096

Brassington, L., Ferreira, N. B., Yates, S., Fearn, J., Lanza, P., & Kemp, K. (2016). Better living with illness: A transdiagnostic acceptance and commitment therapy group intervention for chronic physical illness. *Journal of Contextual Behavioral Science, 5*(4), 208-214. https:/doi.org/10.1016/j.jcbs.2016.09.001

Campbell, A., & Hemsley, S. (2009). Outcome Rating Scale and Session Rating Scale in psychological practice: Clinical utility of ultra-brief measures. *Clinical Psychologist, 13*(1), 1-9. https://doi.org/10.1080/13284200802676391

Cheston, R. (1998). Psychotherapeutic work with dementia sufferers. *Journal of Social Work Practice: Psychotherapeutic Approaches in Health, Welfare and the Community, 12*(2), 199-207. https://doi.org/10.1080/02650539808415149

Drapeau, A., Marchand, A., & Beaulieu Prevost, D. (2012). Epidemiology of psychological distress. In L. LAbate (Ed.), *Mental Illnesses: Understanding, Prediction and Control* (pp. 105-124). Rijeka: InTech. https://doi.org/10.5772/30872

Duncan, B. L., Miller, S. D., Sparks, J., Claud, D., Reynolds, L., & Brown, J. (2003). The session rating scale: Preliminary psychometric properties of a “working” alliance measure. *Journal of Brief Therapy, 3,* 3-12. Retrieved from https://www.scottdmiller.com/wp-content/uploads/documents/SessionRatingScale-JBTv3n1.pdf

Elliott, R. (2002). Hermeneutic single-case efficacy design. *Psychotherapy Research*, *12*(1), 1-21. https://doi.org/10.1016/j.buildenv.2006.10.027

Elliott, R., Mack, C., & Shapiro, D. (1999). *The simplified personal questionnaire procedure*. University of Toledo: Toledo.

Elliott, R., Stephen, S., Robinson, A. (2021). Extending the boundaries of systematic case study research: Conceptual and methodological issues. *Pragmatic Case Studies in Psychotherapy, 17*(2), 235-254. https://doi.org/10.14713/pcsp.v17i2.2097

Elliott, R., Wagner, J., Sales, C., Rodgers, B., Alves, P., & Café, M. J. (2016). Psychometrics of the personal questionnaire: A client-generated outcome measure. *Psychological Assessment*, *28*(3), 263-278. https://doi.org/10.1037/pas0000174

Fowler, N. R., Judge, K. S., Lucas, K., Gowan, T., Stutz, P., Shan, M., et al. (2021). Feasibility and acceptability of an acceptance and commitment therapy intervention for caregivers of adults with Alzheimer’s disease and related dementias. *BMC Geriatrics, 21,* 127. https://doi.org/10.1186/s12877-021-02078-0

Francis, A., Dawson, D., & Moghaddam, N. (2016). The development and validation of the comprehensive assessment of acceptance and commitment therapy processes (CompACT). *Journal of Contextual Behavioral Science*, *5*(3), 134-135.

Gillanders, D., & Laidlaw, K. (2014). ACT and CBT in older age: Towards a wise synthesis. In N. Pachana and K. Laidlaw (Eds.) *The Oxford handbook of clinical geropsychology*. Oxford: OUP.

Gould, R. L., Wetherell, J. L., Kimona, K., Serfaty, M. A., Jones, R., Graham, C. D., et al. (2021). Acceptance and commitment therapy for late-life treatment-resistant generalised anxiety disorder: A feasibility study. *Age and Ageing, 50*(5), 1751-1761. https://doi.org/10.1093/ageing/afab059

Grant, R. W., & Casey, D. A. (1995). Adapting cognitive behavioural therapy for the frail elderly. *International Psychogeriatrics, 7*(4), 561-571. https://doi.org/10.1017/s1041610295002298

Harris, R. (2013). *Getting unstuck in ACT: A clinician's guide to overcoming common obstacles in acceptance and commitment therapy.* Oakland, CA: New Harbinger Publications.

Haver, A., Akerjordet, K., Caputi, P., Furunes, T., & Magee, C. (2015). Measuring mental well-being: A validation of the short warwick-edinburgh mental well-being scale in Norwegian and Swedish. *Scandinavian Journal of Public Health*, *43*(7), 721-727. https://doi.org/10.1177/1403494815588862

Hayes, S. C., Levin, M. E., Plumb-Vilardaga, J., Villatte, J. L., & Pistorello, J. (2013). Acceptance and commitment therapy and contextual behavioral science: Examining the progress of a distinctive model of behavioral and cognitive therapy. *Behavior Therapy, 44,* 180-198. https://doi.org/10.1016/j.beth.2009.08.002

Hayes, S. C., Luoma, J. B., Bond, F. W., Masuda, A., & Lillis, J. (2006). Acceptance and commitment therapy: Model, processes and outcomes. *Behaviour Research and Therapy*, *44*(1), 1-25. https://doi.org/10.1016/j.brat.2005.06.006

Kishita, N., & Laidlaw, K. (2017). Cognitive behaviour therapy for generalized anxiety disorder: Is CBT equally efficacious in adults of working age and older adults? *Clinical Psychology Review, 52,* 124-136. https://doi.org/10.1016/j.cpr.2017.01.003

Kroenke, K., Spitzer, R. L., & Williams, J. B. W. (2001). The PHQ-9: Validity of a brief depression severity measure. *Journal of General Internal Medicine*, *16*(9), 606-613. https://doi.org/10.1046/j.1525-1497.2001.016009606.x

Laidlaw, K. (2013). ViewPoint: A Deficit in Psychotherapeutic Care for Older People with Depression and Anxiety. *Gerontology 59*(6), 549-556. https://doi.org/10.1159/000351439

Laska, K. M., & Wampold, B. E. (2014). Ten things to remember about common factor theory. *Psychotherapy, 51*(4), 519-524. https://doi.org/10.1037/a0038245

Llewelyn, S. P., Elliott, R., Shapiro, D. A., Firth, J., & Hardy, G. (1988). Client perceptions of significant events in prescriptive and exploratory periods of individual therapy. *British Journal of Clinical Psychology, 27,* 105-114. https://doi.org/10.1111/j.2044-8260.1988.tb00758.x

Manassis, K., Lee, T. C., Bennett, K., Zhao, X. Y., Mendlowitz, S., Duda, S., et al. (2014). Types of parental involvement in CBT with anxious youth: A preliminary meta-analysis. *Journal of Consulting and Clinical Psychology, 82,* 1163–1172. https://doi.org/10.1037/a0036969

Mccracken, L. M., & Gutiérrez-martínez, O. (2011). Behaviour research and therapy processes of change in psychological flexibility in an interdisciplinary group-based treatment for chronic pain based on acceptance and commitment therapy. *Behaviour Research and Therapy*, *49*(4), 267-274. https://doi.org/10.1016/j.brat.2011.02.004

McLeod, J. (2010). Case study research in counselling and psychotherapy. London: Sage Publications.

Moniz-Cook, E, D., & Manthorpe, J. (Eds.). (2009). Psychosocial interventions in early dementia: Evidence based practice. London: Jessica Kingsley.

Morris, J. (2019). *Development and validation of a short form of the comprehensive assessment of acceptance and commitment therapy processes (CompACT-SF)* (Doctoral dissertation). University of Nottingham, Nottingham.

Muliyala K. P., & Varghese, M. (2010). The complex relationship between depression and dementia. Annals of Indian Academy of Neurology 13(2), 69-73. https://doi.org/10.4103/0972-2327.74248

National Institute for Health and Care Excellence. (2018*). Dementia: assessment, management and support for people living with dementia and their carers.* Retrieved from https://www.nice.org.uk/guidance/ng97

Newsome, D., Newsome, K., Fuller, T. C., & Meyer, S. (2019). How contextual behavioral scientists measure and report about behavior: A review of JCBS. *Journal of Contextual Behavioral Science, 12,* 347-354. https://doi.org/10.1016/j.jcbs.2018.11.005

O’Keeffe, J. R., Golijani-Moghaddam, N., Burrell, R., & De Boos, D. (2021). *Acceptance and Commitment Therapy for older adult clients experiencing psychological distress: a hermeneutic single case efficacy design (HSCED) series* (Unpublished doctoral dissertation). University of Nottingham, Nottingham.

O'Neill, L., Latchford, G., McCracken, L. M., & Graham, C. D. (2019). The development of the acceptance and commitment therapy fidelity measure (ACT-FM): A delphi study and field test. *Journal of Contextual Behavioral Science, 14,* 111-118. https://doi.org/10.1016/j.jcbs.2019.08.008

Orgeta, V., Qazi, A., Spector, A. E., & Orrell, M. (2014). Psychological treatments for depression and anxiety in dementia and mild cognitive impairment. *The Cochrane database of systematic reviews*, *2014*(1), CD009125. https://doi.org/10.1002/14651858.CD009125.pub2

Öst, L.G. (2014). The efficacy of acceptance and commitment therapy: An updated systematic review and meta-analysis. *Behaviour Research and Therapy*, *61*, 105-121. https://doi.org/10.1016/j.brat.2014.07.018

Robie, K. J. (1999). An exploration of psychologists' perceptions of the process of psychotherapy for the treatment of psychological concerns and mental disorders in elders who have concomitant dementia. *Dissertation Abstracts International, 59,* 5108.

Robinson, A., & Moghaddam, N. (2022). Psychological treatments and therapy adaptations for psychological distress in dementia and mild cognitive impairment: A systematic review and meta-analysis. *Mental Health Review Journal.* Advanced online publication. https://doi.org/10.1108/MHRJ-05-2021-0043

Rosness, T. A., Strand, B. H., Bergem, A. L. M., Nafstad, P., Langballe, E. M., & Engedal, K. (2016). Association of psychological distress late in life and dementia-related mortality. *Aging & Mental Health, 20*(6), 603-610. https://doi.org/10.1080/13607863.2015.1031639

Spector, A, Orrell, M, Lattimer, M, Hoe, J, King, M, & Harwood, K. (2012). Cognitive behavioural therapy (CBT) for anxiety in people with dementia: Study protocol for a randomised controlled trial. *Trials, 13,* 197. https://doi.org/10.1186/1745-6215-13-197

Spitzer, R. L., Kroenke, K., & Williams, J. B. (1999). Patient health questionnaire primary care study group, validation and utility of a self-report version of PRIME-MD: The PHQ primary care study. *JAMA, 28*(2), 1737-1744. https://doi.org/10.1001/jama.282.18.1737

Spitzer, R. L., Kroenke, K., Williams, J. B. W., & Löwe, B. (2006). A brief measure for assessing generalized anxiety disorder. *Archives of Internal Medicine*, *166*(10), 1092. https://doi.org/10.1001/archinte.166.10.1092

Tennant, R., Hiller, L., Fishwick, R., Platt, S., Joseph, S., & Weich, S. (2007). The warwick-edinburgh mental well-being scale (WEMWBS): Development and UK validation. *Health and Quality of Life Outcomes 5,* 63. https://doi.org/10.1186/1477-7525-5-63

World Health Organization. (2007). *Evidence for decision makers.* Retrieved from http://www.euro.who.int/HEN/ 2007 2007.

World Health Organization. (2019). *Dementia.* Retrieved from https://www.who.int/news-room/facts-in-pictures/detail/dementia

Extended Paper

1.0 Extended Introduction

1.1 Chapter Introduction

This extended Introduction offers the study context and provides information about dementia and its treatment, psychological distress and evidence-based therapies, and further exploration of the theoretical underpinnings of Acceptance and Commitment Therapy (ACT).

1.2 Dementia

Dementia is a chronic and progressive syndrome (or group of related symptoms) associated with an ongoing decline of brain functioning. Dementia symptoms may include memory loss, slower thinking speed, reduced mental sharpness and quickness, language difficulties or trouble speaking, problems with understanding, judgement, mood, movement, and difficulties with daily activities (National Health Service; NHS, 2020).

1.2.1 Dementia Epidemiology

Dementia is currently the seventh leading cause of death amongst all diseases and one of the major causes of disability and dependency in older people globally (World Health Organization; WHO, 2021a). At present, more than 55 million people live with dementia worldwide and there are nearly 10 million new cases every year (WHO). Alzheimer's Disease is thought to be the most common form of dementia and may contribute to 60-70% of cases (WHO).

It is claimed that dementia has a disproportionate impact on women. Globally, 65% of dementia-related deaths are women and disability-adjusted life years due to dementia are roughly 60% higher in women than in men (Centers for Disease Control and Prevention, 2019).

Dementia can have a physical, psychological, social, and economic impact, not only for people living with dementia, but also for their carers, families, and society at large (WHO, 2021a). Women seem to provide the majority of informal care for people living with dementia, accounting for 70% of carer hours (Centers for Disease Control and Prevention, 2019).

1.2.2. Dementia Risk Factors

The strongest known risk factor for dementia is increasing age, with most cases affecting those of 65 years and older (Centers for Disease Control and Prevention, 2019). However, dementia is not an inevitable consequence of ageing, as young-onset dementia (defined as the onset of symptoms before the age of 65 years) accounts for up to 9% of cases (WHO, 2021a). A family history of dementia can also be a risk factor, as can race and ethnicity. Older African American people are considered twice more likely and Hispanic people 1.5 times more likely to develop dementia than Caucasian people (Centers for Disease Control and Prevention). High blood pressure, cholesterol, and smoking can increase the risk of dementia and for people who have experienced a traumatic brain injury, especially if the brain injury is severe or has occurred repeatedly (Centers for Disease Control and Prevention). Additional risk factors include depression, social isolation, low educational attainment, cognitive inactivity, and air pollution (WHO).

Studies have shown that people can reduce their risk of cognitive decline and dementia by remaining physically active, not smoking, avoiding harmful use of alcohol, controlling their weight, eating a healthy diet, and maintaining a healthy blood pressure, cholesterol, and blood sugar levels (WHO, 2021a).

1.3 Dementia Treatment

To date, there is no cure for dementia. However, there are treatments that can help people with dementia to live well with the condition, with the aim of promoting cognition, independence, and wellbeing. Treatments include medication, participation in a range of activities, or a combination of both. Treatment should be person-centred so that it focuses on an individual's needs and preferences (Alzheimer's Society, 2021).

1.3.1 Medication

Acetylcholinesterase inhibitors may offer temporary help with memory, motivation, concentration, and daily living and slow the progression of dementia. In more moderate cases, medication may also ease distress or behaviours that challenge, such as those related to agitation or aggression. Namely, Donepezil, Rivastigmine and Galantamine are recommended as options for managing mild to moderate dementia (National Institute for Health and Care Excellence; NICE, 2018).

A wide range of other medications may be prescribed at different times for a person with dementia, including antipsychotics, sleeping tablets or medications to treat anxiety and depression, despite indication of poor efficacy and side effects associated with anti-depressants (Banerjee et al., 2011). Not all are recommended for all types of dementia (Alzheimer’s Society, 2021).

1.3.2 Cognitive Rehabilitation

Cognitive rehabilitation can help a person with dementia to engage in meaningful activity and stay physically, mentally, and socially active, with a view to retaining skills and improving coping.

Occupational therapy can be used to support functional ability (NICE, 2018) by building on the person's strengths and finding ways to compensate for impairments and support independence. For example, using pill boxes, calendar clocks, or offering practical advice on how to develop routines or break tasks into simpler steps (Alzheimer’s Society, 2021).

People with dementia may also enjoy life story work, in which the person is encouraged to share their life experiences and memories. This can also be facilitated as part of a group with reminiscence therapy (NICE, 2018) to support mood, wellbeing, and mental abilities. Other popular activities include music, singing or art.

1.3.3 Cognitive Stimulation Therapy (CST)

CST usually occurs as part of a group, where a person with dementia engages in a range of themed activities and discussions over several weeks, with the aim of improving or maintaining cognitive and social functioning (NICE, 2018).

Evidence on the effectiveness of these psychosocial interventions, however, remains inconclusive, possibly due to the diverse target population, dementia severity, and the need for different intervention designs considering factors such as individual insight and ability to understand verbal communication (Leung et al., 2021).

1.4 Psychological impact of dementia

People with dementia can be vulnerable to experiencing psychological distress. It is estimated that up to 68% of people with dementia have depression (Muliyala & Varghese, 2010) and up to 72% experience anxiety (Badrakalimuthu & Tarbuck, 2012). In a recent meta-analysis, the prevalence rates of depressive symptoms in mild, moderate, and severe dementia were 38%, 41%, and 37% respectively, and corresponding prevalence for anxiety was 38%, 41%, and 37% (Leung et al., 2021), indicating that affective symptoms were an important treatment target throughout the course of dementia. Furthermore, there is a significant correlation between psychological distress and greater risk of dementia-related mortality in comparison to people without psychological distress (Rosness et al., 2016)

1.5 Psychological distress in dementia

Psychological distress is defined as a state of emotional suffering characterised by clinical features of anxiety and depression (Drapeau et al., 2012) which impacts daily functioning (Wheaton, 2007), and is often used as an indicator of mental health. For the purposes of this study, psychological distress refers to the presentation of anxiety and/or depression.

1.5.1 Anxiety

The emotion of anxiety is characterised by physiological, cognitive, and behavioural symptoms. Anxiety has an evolutionary purpose; it is a survival instinct to help recognise danger and prepare the body to respond. When placed in a feared situation, the amygdala in the brain is activated, which sends a signal to the hypothalamus and triggers the sympathetic nervous system. Epinephrine (adrenaline) is then pumped around the body, which induces physiological changes, such as increased heart rate, to pump blood to the muscles and vital organs. Breathing becomes quicker and shallower, sight, hearing, and other senses become sharper, muscles become tense, and a person may experience a dry mouth, perspiration, or feelings of nausea.

However, anxiety may be experienced in the absence of real threat or danger (but when perceived as such). Hence, anxiety may become problematic when it habitually occurs without a real threat.

If relevant criterion is met, clinically significant levels of anxiety may be categorised into psychiatric diagnostic groups using tools such as the American Psychiatric Association’s (APA, 2013) Diagnostic and Statistical Manual of Mental Disorders 5th Edition (DSM-5) and the World Health Organization’s (WHO, 2018) International Statistical Classification of Diseases and Related Health Problems 11th Revision (ICD-11). The DSM-V and ICD-11 incorporate various types of anxiety disorders based on their onset, developmental progression, severity, and topography. According to large population-based surveys, up to 33.7% of the UK population is affected by an anxiety disorder during their lifetime (Bandelow & Michaelis, 2015), however, it is likely that there is considerable under-recognition of anxiety disorders, possibly due to overlapping symptoms with other diagnoses and differences in diagnostic criterion.

For example, Generalised Anxiety Disorder (GAD) is typified by marked symptoms of anxiety that persist for at least several months, for more days than not, resulting in significant distress or impairment in personal, family, social, educational, occupational, or other important areas of functioning. According to the ICD-11 (WHO, 2018), the following features must be present for a diagnosis:

- General apprehension (i.e., ‘free-floating anxiety’) or;
- Excessive worry focused on several everyday events, most often concerning family, health, finances, and school or work, with;
- Symptoms such as muscular tension or motor restlessness,
- Sympathetic autonomic over-activity,
- Subjective experience of nervousness,
- Difficulty maintaining concentration,
- Irritability or;
- Sleep disturbance

- The symptoms are not a manifestation of another health condition, nor due to substance or medication effects on the central nervous system.

1.5.2 Depression

Sadness is a natural emotion following the loss of valued objects, events, personal characteristics, skills, or relationships (Carr, 2001). However, according to the ICD-11 (WHO, 2018), depression is characterised by near daily low mood, reduced energy, concentration, interest in activities and fatigue, alongside feelings of guilt, worthlessness and repeated thoughts of death or suicide.

Depressive disorders are thought to affect 322 million people worldwide (WHO, 2017). In England, approximately 4-10% of people will experience depression in their lifetime (McManus et al., 2009). Increased risk is associated with being female (24% prevalence versus 13% for males; Mental Health Statistics, 2020), adverse life events, such as psychological trauma (WHO, 2021b), a family history of depressive disorders, lack of social support, low socio-economic status, insomnia, sleep disorders (Martin, 2021), physical health conditions and chronic pain (WHO, 2021b).

Recurrent Depressive Disorder is characterised by a history of, or at least two, depressive episodes, separated by at least several months without significant mood disturbance. According to the ICD-11 (WHO, 2018), the following symptomology should occur almost daily for at least two weeks to meet the criteria for Recurrent Depressive Disorder:

- Depressed mood or diminished interest in activities,
- Difficulty concentrating,
- Feelings of worthlessness or;
- Excessive or inappropriate guilt,
- Hopelessness,
- Recurrent thoughts of death or suicide,
- Changes in appetite or sleep,
- Psychomotor agitation or retardation,
- Reduced energy or fatigue with;

- No prior manic, hypomanic, or mixed episodes, which would indicate the presence of a bipolar disorder.

Formal diagnoses can be valuable in reassuring that an individual’s difficulties are not inexplainable (Craddock & Mynors-Wallis, 2014) and may mean there is an evidence-base and experience to be drawn upon to offer the best care (McLaughlin, 2006). Diagnoses can also help to formulate the correct care pathway to enable access to support, interventions, or financial benefits (Equality Act, 2010). However, as some symptoms can overlap with different diagnoses, there is risk of misdiagnosis (Cook, 2008). Furthermore, classification systems are supported by research that has sought homogeneity (Craddock & Mynors-Wallis) which can obscure the effects of diversity on mental health (McLaughlin), oversimplify the complexities of human experience, and scrutinise an individual’s difficulties at the expense of their assets and abilities for growth (Hubble et al., 1999). There may also be associated ethical implications, such as stigmatisation (Johnstone, 2014), symptom exacerbation, feelings of disempowerment, poorer treatment adherence (Sowislo et al., 2017), and exclusion from other services.

1.5.3 Psychological measures

Psychometrics (self-report questionnaires) are often used within mental health services to provide indication of psychological difficulties as a criterion to access services. Standardised measures can also be used to assess treatment engagement and response to psychological treatment to help improve outcomes. The Generalised Anxiety Disorder questionnaire (GAD-7; Spitzer et al., 2006; Appendix L) and Patient Health Questionnaire (PHQ-9; Spitzer et al., 1999; Appendix M) was used in this study according to routine measures used at a recruitment site (Memory Assessment Service; MAS) in Nottinghamshire and acceptability for use with older adults.

1.5.4 Comorbidity

Though diagnostic criteria assume anxiety and depression are distinct difficulties, there is evidence to suggest that the two are interrelated and co-exist (Coplan, 2015). Hence, many people who experience severe anxiety are likely to experience clinical levels of depression and vice versa.

1.5.5 Models of anxiety and depression

There are various theoretical models that can be used to explain the development and maintenance of anxiety and depression, and therefore several treatment approaches. For example, anxiety may be explained using:

(i) The cognitive avoidance theory (Borkovec et al., 2004). This proposes that worrying is used to prepare oneself in the event of perceived future threats, however, also acts as avoidance and therefore maintains the anxiety.

(ii) The metacognitive model (Wells, 1999). This suggests that negative patterns of responding develop, such as worrying, ruminating and hypervigilance, which is maintained by negative beliefs (e.g., “I can’t control my thoughts) and over-reliance on positive beliefs surrounding worry (e.g., “It’s useful to prevent bad things from happening”).

(iii) The intolerance of uncertainty theory (Dugas et al., 1998). This purports that negative beliefs about uncertainty serve to maintain excessive worry.

(iv) The emotional dysregulation model (Suveg et al., 2010). This proposes that anxiety is related to one’s family environment and high levels of reactivity.

Depression is commonly explained using:

(i) The Cognitive Model (Beck et al., 1979). This suggests that individuals develop core beliefs about themselves, others, and the world, starting in childhood (‘the cognitive triad’; Beck et al.). Adverse life experiences can lead to negative core beliefs and trigger negative automatic thoughts and cognitive distortions (inaccurate, negatively biased thoughts). The model also highlights the primacy of cognition, suggesting that feelings and behaviours are mostly determined by one’s appraisal of events (Beck et al.).

(ii) Behavioural models such as operant conditioning (Skinner, 1953). This proposes that the frequency of behaviour is controlled by its consequences. Behaviours are reinforced, either positively or negatively, when a consequence increases the frequency of that behaviour, so that it is more likely to be repeated in the future. Hence, depression may be developed and maintained through a lack of reinforcement of previously reinforced behaviours (Skinner, Ferster, 1966; Lewinsohn, 1975) and a lack of positive reinforcement in the environment (Ferster).

1.6 Evidence-based therapies for adults with anxiety and depression

According to Orgeta et al.’s (2014) systematic review, evidence from six randomised control trials (RCTs) showed that psychological treatments that used a psychological model to predominantly target anxiety and depression could have the potential to enhance the psychological wellbeing of people with dementia. Hence, there is a need to demonstrate psychotherapy effectiveness in order to develop evidence-based treatments (Wampold, 2013). However, there is contention as to whether psychotherapy effectiveness operates through model-specific factors (ACT in this case) or through non-specific factors common to all therapies, such as therapeutic alliance or client expectations of treatment (Mulder et al., 2017), as well as extra-therapeutic factors (life events outside of therapy), such as loss. As previously discussed, there can be high comorbidity between conditions, for example, in treating anxiety, there can be reductions in depression (Tsao et al., 2005). Therefore, transdiagnostic approaches can offer a way of conceptualising mental health difficulties across different diagnoses and populations by identifying the common factors between them (Hofmann & Hayes, 2019). However, it is argued that some of these factors may be less transferrable or ‘common sense’ to a dementia population, and therefore, further research into psychotherapy acceptability was required.

1.6.1 Cognitive behavioural therapy (CBT)

CBT is a recommended, evidence-based treatment for anxiety and depression in adults, according to the National Institute for Clinical Excellence (NICE, 2011; 2009). CBT, an amalgamation of both cognitive and behavioural perspectives, proposes that a cycle of unhelpful thoughts, feelings and behaviours are generated, which remain unchallenged and so keep the individual depressed and anxious. Intervention from a CBT perspective would target these maintaining factors. For example, via a range of behavioural and cognitive techniques, clients would be encouraged to identify their negative appraisals or ‘faulty information processing’ (Beck et al., 1979), before confronting them with the evidence for and against (Kennerley et al., 2017). This should enable the client to gain disconfirmatory evidence which helps modify the content of their thoughts by obtaining an alternative view and therefore reduce distress. Whilst CBT may be helpful in exploring how individuals make sense of or appraise their health prognosis and, in turn, modify maladaptive or biased cognitions, adherence to CBT has been found to be poor in dementia. For example, in Spector et al.’s (2012) study, only 56% of 50 participants completed all 10 sessions of CBT available to them (Orgeta et al., 2014). There were also uncertainties about risk of bias due to the use of multimodal psychological approaches that combined a variety of treatments, rather than one well-defined psychological approach. Despite the large evidence base for CBT effectiveness, there is limited indication that findings are accounted for by the mechanisms of change proposed by CBT (Burns & Spangler, 2001). Furthermore, in comparison to working age adults, there is evidence to suggest that CBT efficacy is reduced in older adults, particularly in treating GAD (Kishita & Laidlaw, 2017). An RCT by Spector et al. (2015) found that depressive symptoms reduced following a 10-week CBT intervention for people with dementia, and improvements were maintained at six months, but no significant difference was found in anxiety, possibly due to methodological weaknesses and inclusion of a limited number of trials. A systematic review of therapeutic interventions did not find consistent evidence for the efficacy of CBT for people with dementia and mild cognitive impairment (MCI) with anxiety and depression (Orgeta et al., 2014).

According to the Alzheimer’s Society (2021), CBT for depression or anxiety is most suitable for people in the earlier stages of dementia due to fewer difficulties with their memory, communication, reasoning, and insight. It is likely sessions would need to be adapted for the specific needs of each individual, for example, offering shorter sessions, using memory aids and summarising concepts or recapping past sessions, and involving a companion to support with CBT strategies outside of sessions (Alzheimer’s Society; Robinson & Moghaddam, 2022).

1.6.2 Acceptance and Commitment Therapy (ACT)

ACT offers a’ third wave’, behavioural, contextual approach in comparison to traditional CBT, and is considered transdiagnostic (Hayes et al., 1999).

ACT proposes that distress, such as depression and anxiety, is normal and inevitable but that it does not inherently cause psychological difficulty (Harris, 2006). It is reported that by way of trying to avoid or control pain that suffering can ensue. An unwillingness to experience such difficulties can be defined as ‘experiential avoidance’ (Hayes et al., 1996). The context in which unhelpful relationships between cognitive, emotional, and behavioural processes develop can provide information about the behaviour’s underlying function (Hayes et al., 2012; Vilardaga et al., 2007).

ACT aims to promote acceptance of all thoughts, detachment from distress and reduction of experiential avoidance by changing how an individual interacts with their thoughts. ACT also seeks to encourage psychological flexibility (PF) to connect with the present-moment and engage in behaviours that are consistent with one’s values (Hayes et al., 1999). An acceptance approach, as offered by ACT, whereby individuals are encouraged to foster PF and focus on their remaining resources, may be useful in considering the helpfulness or workability of individual appraisals upon valued action and hence lead to behavioural change.

A growing number of studies have evidenced the efficacy of ACT for anxiety and depression in adults (Öst, 2014), anxiety in older adults (Gould et al., 2021) and illness-related distress (Mccracken & Gutiérrez-martínez, 2011). At present, there is little evidence for ACT for people with dementia, despite a conceptual case for its suitability, which is empirically supported by its use with parallel populations.

As there are conceptual strengths within ACT and given that there is a rationale for examining ACT as a possible treatment option, further investigation using a methodologically sound design was required to examine whether the efficacy of ACT extended to those with dementia and, crucially, investigate the processes by which change may occur.

1.7 Theoretical and Philosophical Basis of ACT

ACT is based upon the philosophy of functional contextualism, which states that behaviour must in understood in relation to the context in which it happens and that the function of the behaviour must be identified to understand or influence it (Gifford & Hayes, 1999). Contextualism proposes that thoughts, emotions, and internal bodily sensations are not inherently dysfunctional or problematic, rather it depends on the context in which they occur. Hence, ACT views distress as a function of context; There is nothing faulty or maladaptive ‘inside’ the client (Dawson & Golijani Moghaddam, 2015).

ACT has theoretical underpinnings in Relational Frame Theory (RFT; Roche et al., 2002). RFT explains how, through human language, we create associations between events and concepts, which leads to the development of vast relational networks, showing us how things are related to each other. Relationships between events and concepts derive from experience; they are not directly trained or taught and are not based solely on physical properties (e.g., appearance) of the concept but by specific contextual cues (Garcia & Benjumea, 2001). Thus, relating is contextually established through language. RFT can inform clinical practice when understanding how ‘private events’ may lead to psychological distress (Hayes et al., 2011).

1.8 ACT Processes

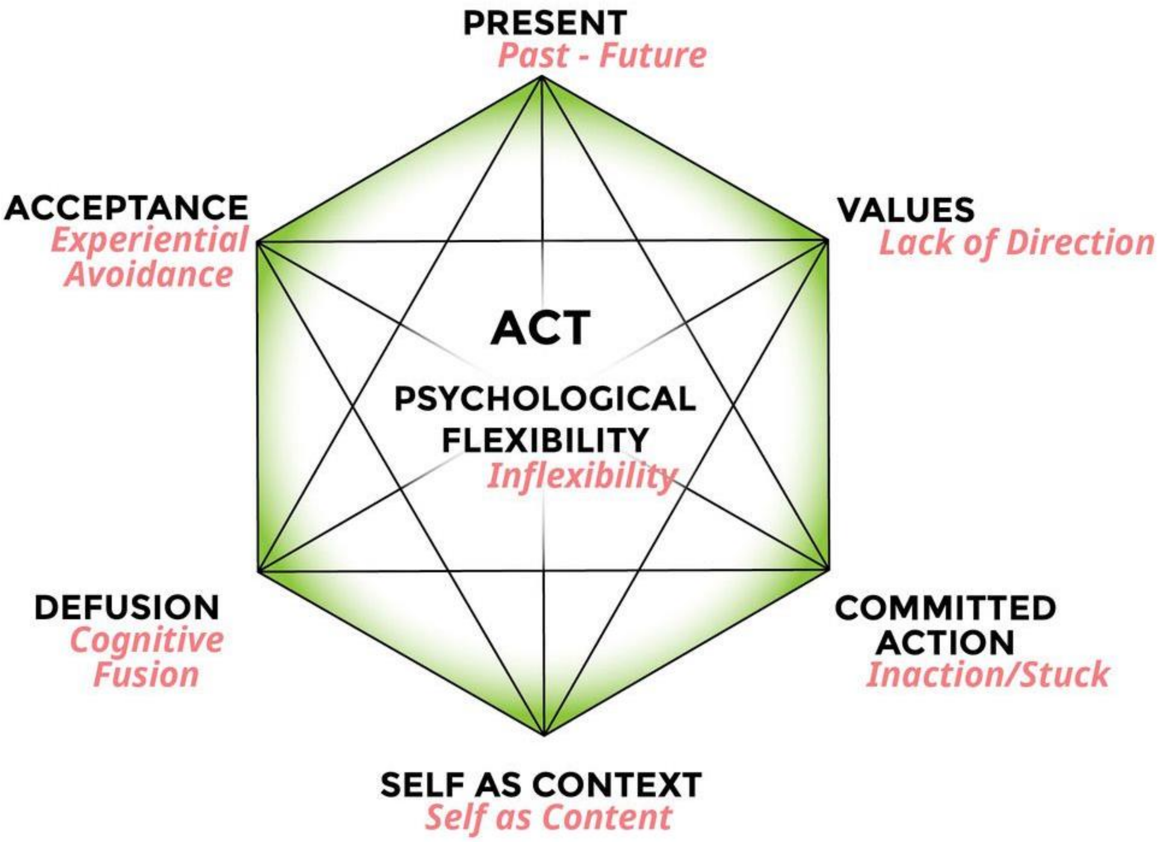
The main aim of ACT is to increase PF. PF can be defined as the capability to make contact with the present moment, pay full attention to the here-and-now experience and enable a change or persistence in behaviour that serves valued living (Hayes et al., 2006), thereby encouraging acceptance of all experience, rather than attempting to regulate emotional or cognitive content (Hayes, 2008). Though distress may reduce from altering the way an individual relates to their cognitions, the aim of ACT is to foster value-directed behaviour in the presence of distress (Gillanders & Laidlaw, 2014), hence its effectiveness is measured by how much an individual re-engages with a life of valued activity and improvements in functional wellbeing.

PF is an overarching process that consists of six interrelated processes (Table 11), referred to as the ACT ‘hexaflex’ (Figure 5): being present, cognitive defusion, acceptance, self-as-context, values and committed action (Hayes et al., 2006). The inverse of these processes comprises psychological inflexibility.

Table 11. The six ACT processes and the inverse processes and definitions adapted from Francis et al. (2016) and Hayes et al. (2012)

Psychological Flexibility Term	**Process of psychological inflexibility**	**Definition of psychological inflexibility**
Defusion	Cognitive fusion	Accepting and fixating on cognitions as ‘truths’.
Acceptance	Experiential avoidance	Attempting to reduce the form or frequency of unwanted internal or external experiences.
Noticing self (self-as-context)	Over attachment to self-content (self-as-content)	Fixed view of ‘who’ oneself is/over-attachment to the self-narrative.
Contact with the present moment	Past or future dominated attention	Rigid focus on past or future events.
Values clarity	Remoteness from values	Unclear or vague idea of what aspects of life are personally important.
Value committed action	Unworkable action	Action/inaction that is incongruent with one’s values.

Figure 5. ACT Hexaflex (Hayes et al., 2006)



(i) Cognitive Defusion

Since dementia is progressive, people may be more inclined to believe thoughts about losses and disablement as truths, with fusion to such thoughts possibly impacting their level of distress and functioning. For example, fusion to terms such as ‘illness’ may have a functional impact upon wellbeing. Cognitive defusion aims to create separation or distance from the content of one’s unpleasant thoughts, images, or memories, by learning to step back or detach from them, rather than get caught up in them. The aim is for the person to notice their thoughts for what they are to reduce their power upon their mood or wellbeing. Techniques include phrases such as, “I’m having the thought that…” or repeating thoughts aloud, which has been found to reduce believability and subjective distress experienced from negative self-relevant phrases (Masuda et al., 2004).

(ii) Acceptance

People may become more aware of difficult thoughts and feelings as they are put in touch with the challenges that dementia can bring in everyday life. Older adults who repeatedly use avoidance or unworkable actions to control unsolvable difficulties are reportedly more vulnerable to mental health difficulties (Isaacowitz & Seligman, 2002). ACT aims to foster acceptance, which can be described as a willingness to make room for painful feelings, sensations and urges instead of trying to resist, control or eliminate them (Harris, 2006). One may learn that avoidance is unworkable, since trying to control aversive events can get in the way of living a valued life. Therefore, acceptance does not mean necessarily wanting to experience aversive private events, but involves actively embracing them, in the pursuit of engaging in a life of valued activity.

(iii) Self-as-context

Older adults may be more inclined to be wedded to stories about themselves, which have developed across the lifespan. For example, in Agatha's case, she stated she was a 'wordsmith' who loved reading books. However, reading was becoming increasingly difficult due to her dementia and was causing feelings of sadness at her reduced abilities. Furthermore, fusion to this self-narrative may have acted as a barrier to adjusting to a life with cognitive impairment. Self-as-context is used as a way to help people to view their inner experiences as separate from themselves, in other words, that they are greater than their experiences. The aim is to seek separation from the person's attachment to their conceptualised self or 'self-as-content'. It proposes an observer stance; the observing self never changes; you have been the same 'you' all your life, irrespective, in this case, of the dementia.

(iv) Present moment awareness

Present moment awareness requires one to connect with private experiences non-judgementally (Harris, 2006). Mindfulness exercises can be used to orient to the present moment and experiential practice can be used to help accept and make room for both negative and positive experiences (Hayes et al., 1999). Mindfulness has been associated with improved wellbeing for people with various physical health conditions (Piet et al., 2012).

(v) Values

Values can be described as personally chosen, desired life directions. Values are thought to guide behaviour, rather than something that can be achieved, like a goal. Often, people can become disconnected from their values and recognise discrepancies between their current lifestyle and how they wish to live their life. Identifying what really matters in life can provide a salient purpose to the way in which we choose to behave.

(vi) Committed action

Once values have been identified, specific, meaningful, and time-specific goals can be set and achieved to help one act in congruence with their values, with a view to living a more fulfilling, meaningful life.

The way a person with dementia understands their difficulties may impact their level of distress, experiential avoidance, fusion to particular terms or thoughts, or overall functioning. ACT uses mindfulness, metaphors, and experiential exercises to encourage behaviour change in line with one’s values.

1.8 Contribution towards the Literature

Recent literature suggests that PF can be effectively promoted, even in populations with longstanding difficulties, such as those with treatment-resistant panic disorder (Gloster et al., 2015). PF is also helpful in reducing the negative effects of stress by increasing present-moment awareness to enable people to notice and non-judgementally acknowledge any anxiety or other uncomfortable emotions and experiences (Hofer et al., 2018). PF has been widely investigated in physical health conditions, such as cancer and chronic pain, but there is limited understanding of the role PF may have in dementia. This experimental study provides an original contribution as it applies an under-researched therapeutic intervention (ACT) to an under-researched population (people with dementia), and uses a methodology to explore complex therapy processes, which, to date, has not been used to investigate ACT with people with dementia experiencing psychological distress.

2.0 Extended Methods

2.1 Rationale for Systematic Case Study Series

There is a necessity to establish effective, evidence-based psychotherapeutic interventions. RCTs are deemed the ‘gold standard’ in demonstrating intervention effectiveness by comparing active treatments with control groups. When conducted well, RCTs provide valuable information about therapy outcomes (Carey & Stiles, 2016). However, in real-life clinical practice, psychotherapy can be difficult to standardise between individuals due to differences in engagement and adaptations required within an intervention (Christie & Fleischer, 2009). Some psychotherapies would not meet strict inclusion criteria for RCTs due to the varied, individualised approach needed for clients with complex needs. Hence, RCTs fail to offer conditions under which causal inferences can be made about individual cases and are thus inappropriate for evaluating complex change processes (Carey & Stiles, 2016; Wall et al., 2017). Case study series are not subject to the limitations of RCTs and can be used to effectively investigate change processes.

2.2 Hermeneutic Single Case Efficacy Design (HSCED) Development

A HSCED is a systematic, pragmatic, mixed-methods approach used to critically examine therapy process and outcome data on a case-by-case basis to ascertain whether and how changes may have occurred. A matrix of qualitative change process data about significant events, quantitative outcome measures and direct information about therapy process is systematically analysed (Elliott, 2009) to measure the various contributing factors of change within psychotherapy research, including model-specific, non-specific, and extra-therapeutic factors (Elliott, 2002).

The HSCED accommodates three clients within one investigation (Elliott, 2015) to enable cross-synthesis and generalisability of potential mediators and moderators of change between participants (Wall et al., 2017). The adjudication method allows a greater level of interpretative analysis by experts separate to the research team. However, consensus between judges can be conflicting

(Elliott et al., 2021), leading to possible difficulties in determining a clear answer to the research questions (Elliott et al., 2021). Nonetheless, a HSCED can offer explanation of causality though interpretation, particularly for under-researched interventions or populations, such as those with dementia.

2.2.1 Philosophical Underpinnings of HSCED

HSCED is based upon pragmatic constructivism, which proposes that quantitative and qualitative methods can be utilised collectively to enable researchers to draw upon methods with complementary strengths (Tashakkori & Teddlie, 1998; Brewer & Hunter, 1989). Constructivism, as asserted by Kuhn (1970), takes the view that knowledge is a construction created by individuals in relation to current context, rather than representing some correspondence to external reality. Thus, we cannot seek an absolute truth but instead seek feasible explanations in the world as we understand it, hence, the essence of meaning is situated in context.

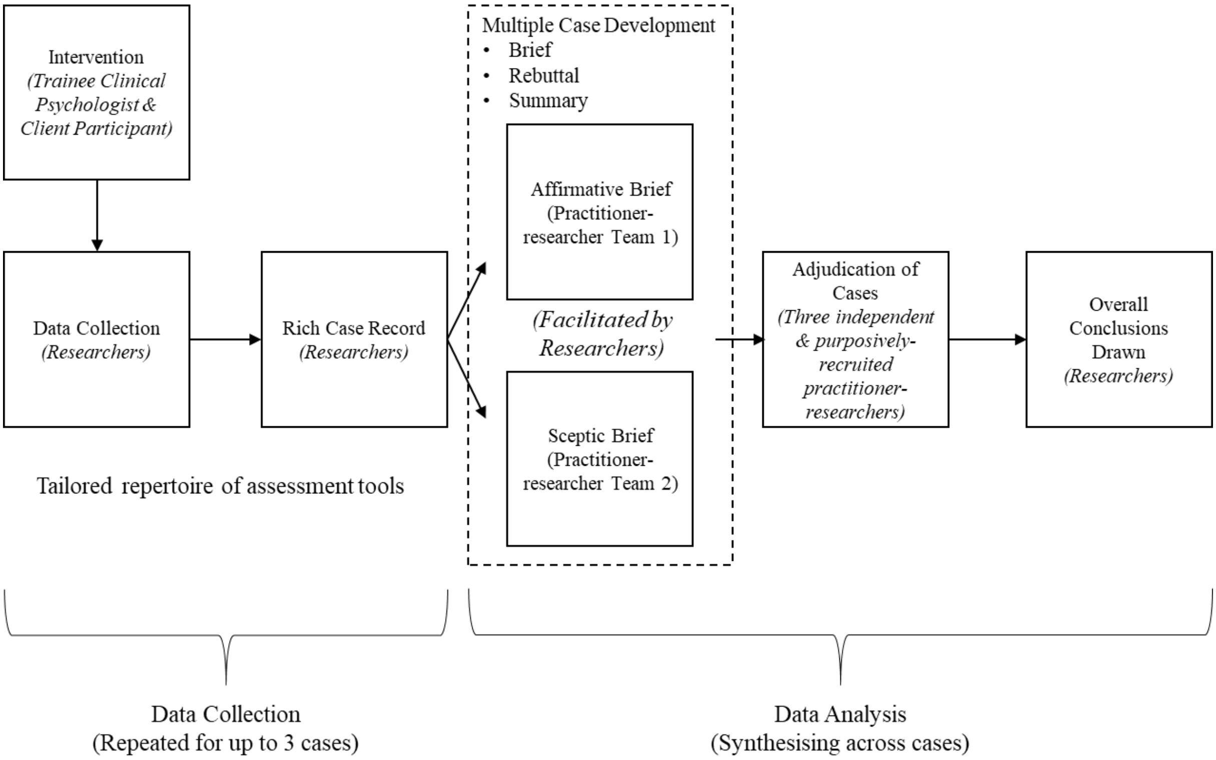
Case study research takes an interpretive, as opposed to experimental, stance, emphasising thick descriptions from rich pools of information of qualitative and quantitative data. Narrative causality is used to develop probabilistic knowledge claims should therapy be deemed responsible for, facilitative of, or influencing change on the part of participants, rather than purport absolute knowledge claims (Elliott, 2015).

2.2.3 HSCED Procedure

The HSCED included baseline and intervention phases. As participants were recruited to the study at different times, baseline lengths varied which may have strengthened the design by reducing the possibility of any observed changes being attributed to time-based effects after a duration of monitoring.

The HSCED analysis involved two stages, as illustrated below in Figure 6.

Figure 6. The Enhanced HSCED Protocol (Wall et al., 2017, p. 542)



Analysis

At the first stage, ‘rich case records’, a comprehensive exhibition of quantitative and qualitative clinical data, was developed for each participant. The case records included affirmative and sceptic arguments, as developed by the research team, regarding client change based upon the data collected over the intervention. The affirmative case offered a persuasive argument that the client changed over the course of therapy and that the change was mainly attributable to therapy. The affirmative case drew upon various types of evidence, including (i) retrospective attribution, (ii) process-outcome mapping, (iii) within therapy process-outcome correlation, (iv) early change in stable problems, and (v) event-shift sequences (Elliott, 2002). The sceptic case proposed alternative interpretations of the data in the case records and served to undermine the affirmative case. The sceptic case suggested changes could be attributed to (i) non-improvements, (ii) statistical artefacts (iii) relational artifacts (iv) client expectations, (v) self-correction (vi) extra-therapy life events, (vii) psychobiological factors, and/or (viii) reactive effects (Elliott).

Adjudication

The second stage involved the rich case records being subject to critical analysis or ‘adjudication’ by three independent psychotherapy experts (or ‘judges’) to identify change processes and ascribe outcomes (the extent to which any observed changes could be attributed to therapy versus non-therapy, and whether therapy-attributable changes were model-specific or therapy-generic).

Judges were emailed with each client’s case records, affirmative and sceptic briefs, and change interview (CI) transcripts, and asked to read them in a unique order to reduce order effects. Judges were then asked to respond to a series of semi-structured adjudication questions regarding the extent and type of client change and provide conclusions about the effectiveness of the intervention. The Adjudication Interview Schedule is summarised below in Table 12.

Table 12. Adjudication Questions

Client Change	**Response Options**
How would you categorise the outcome for this client?	Deteriorated Unchanged Improved Recovered
How certain are you?	0% 20% 40% 60% 80% 100%
What evidence presented in the rich case record mattered most to you in reaching this conclusion? How did you make use of this evidence?	
To what extent did the client change over the course of therapy?	No Change (0%) Slightly (20%) Moderately (40%) Considerably (60%) Substantially (80%) Completely (100%)
How certain are you?	0% 20% 40% 60% 80%

	100%
What evidence presented in the rich case record mattered most to you in reaching this conclusion? How did you make use of this evidence?	
If you indicated that the client did not change over the course of therapy, in your view, why did the client remain unchanged?	
To what extent is the client's change due to therapy?	No Change (0%) Slightly (20%) Moderately (40%) Considerably (60%) Substantially (80%) Completely (100%)
How certain are you?	0% 20% 40% 60% 80% 100%
What evidence presented in the rich case record mattered most to you in reaching this conclusion? How did you make use of this evidence?	
Which therapy processes (mediator factors) do you feel were helpful to the client?	
Which characteristics and/or personal resources of the client (moderator factors) do you feel enabled them to make the best use of therapy?	
How strong is your belief that ACT-specific processes contributed to therapy-related change for the client?	0% 20% 40% 60% 80% 100%
Which ACT-specific processes and techniques, if any, do you feel were helpful to the client?	
How strong is your belief that other (generic) therapy processes contributed to therapy-related change for the client?	0% 20% 40% 60% 80% 100%
Which generic therapy processes, if any, do you feel were helpful to the client?	
Overall, as a percentage, what proportion of the client's therapy-related change was due to ACT-specific processes vs Other therapy processes?	*(ratio)*

2.3 ACT Intervention

As there was no ACT protocol for use with people with dementia, the ‘Better Living with Illness’ (Brassington et al., 2016) protocol was chosen as most suitable to guide the intervention. This ACT protocol was initially developed for use in a group setting of people with chronic physical health conditions, comprising of six weekly sessions lasting up to 2.5 hours. Hence, the protocol had to be somewhat adapted for use in individual therapy, with a different population and via remote delivery, and was extended over 12 weeks to support with cognitive impairment. The manual was used flexibly according to individual client need so that the first author could model an active and responsive role in targeting psychological inflexibility ‘in flight’ (Hayes et al., 1999). Experiential exercises, metaphors, discussions, and between-session tasks were integral aspects of the intervention. To ensure internal consistency, psychological inflexibility was targeted using the same ACT metaphors between clients. Each session began with a mindfulness exercise to support present-moment awareness. Initial sessions focused on the unworkability of some behaviours. Mid-sessions began to consider values and committed action. Thought defusion and self-as-context exercises were introduced depending upon the clients’ cognitive ability. The final sessions considered setbacks and ongoing valued action. Clients completed a battery of psychometric measures at session 1, 6 and 12. Table 13 outlines the protocol structure and Table 14 offers examples of therapy techniques used to target psychological inflexibility.

Table 13. General Protocol Structure

Session number	Session objectives
1, 2	• Exploring the client’s experiences of dementia and coping strategies (distinguishing between control and non-control strategies) • Distinguishing between primary and secondary suffering
3, 4	• Learning about thoughts, emotions, behaviour, and physiology • Understanding how strategies like suppression can be unhelpful • Introducing concept of values • Learning about mindfulness as an awareness technique

5, 6	• Understanding what values are and begin to identify them • Practising mindful awareness
7, 8	• Learning about and practising defusion from thoughts • Practising mindful awareness and introducing self-as-context perspective
9, 10	• Discussing valued action and setting goals • Reviewing and consolidating previous sessions
11, 12	• Learning about pacing • Preparing for setbacks

Table 14. Examples of therapy techniques used to target psychological inflexibility processes

Psychological Flexibility Term	**Process of psychological inflexibility**	**Examples of techniques used in therapy to target processes of psychological inflexibility**
Defusion	Cognitive fusion	Leaves on a stream Milk, milk, milk Labelling thoughts
Acceptance	Experiential avoidance	Pushing away paper Walking in the rain Passengers on a bus Beach ball Tug of war White rabbit
Noticing self (self-as-context)	Over attachment to self-content (self-as-content)	General discussion about important roles (e.g., wife, mother) “You are more than your dementia”
Contact with the present moment	Past or future dominated attention	Three-minute present moment awareness exercise Mindfulness of breath Body scan Mindful acceptance
Values clarity	Remoteness from values	Famous faces 80th birthday party Values circle
Value committed action	Unworkable action	Values and goals worksheet (setting short, medium, and long-term goals and planning committed action) Assertiveness

ACT fidelity was assessed via session audio recordings by the third author using the Acceptance and Commitment Therapy Fidelity Measure (ACT-FM; O'Neill et al., 2019; Appendix S). A sample (10%; 3 session recordings) of the 30 sessions were assessed (purposively selected to represent at least one recording from each client, and sessions from early-, mid-, and late-therapy). Sample sessions were judged to be largely ACT consistent (Total Consistency Score= 31 out of 36, Total Inconsistency Score= 0.3 out of 36).

2.3.1 (Pre)adaptational work

Whilst remaining attuned with individual needs and maintaining ACT fidelity, there were commonalities in the adjustments made (Appendix R). Adaptations not only involved modifications to the ACT protocol to support cognitive impairment, but also used to support remote, carer-assisted delivery. However, it is likely difficult to distinguish which adjustments supported which aspect of therapy or whether there was overlap. Common adjustments made in the current study are listed below, some of which were supported by the literature:

(i) Slowing the pace of therapy by increasing the number and frequency of sessions (Robie, 1999) and offering regular breaks.
(ii) Using straightforward language to simplify communications (Robie), with communication adapted to the clients’ cognitive ability.
(iii) Checking understanding throughout.
(iv) Emphasising behavioural strategies, as suggested by Grant and Casey (1995), with use of procedural learning and modelling during intervention delivery.
(v) Using learning strategies, such as increased repetition (Grant & Casey).
(vi) Use of compensatory strategies and memory aids, such as visual (e.g., screen sharing), written, and verbal information, and offer of guidance, reminders, and prompts (Robinson & Moghaddam, 2022).
(vii) Making environmental adaptations, for example, delivering the intervention in clients’ homes, protecting from distractions, and using headphones to reduce any background noise (Robinson & Moghaddam).

(viii) Involving family members or carers to support in-session and with between-session tasks, according to client preference, using written and audio recorded exercises (Robinson & Moghaddam).

(ix) A supportive therapist style using non-verbal gestures, verbal encouragers, and paraphrasing, and allowing sufficient time for clients to respond (Robinson & Moghaddam).

2.4 Additional Therapist Details

The first author (lead researcher and simultaneous therapist) was a Trainee Clinical Psychologist, employed by Nottinghamshire Healthcare NHS Foundation Trust, and in her second year of a Doctoral Programme in Clinical Psychology (DClinPsy) at the time of therapy delivery to the three client-participants. At the time, the first author had completed placements in Adult, Older Adult and Child and Adolescent Mental Health services. The first author attended a one-day ACT workshop (100 Key Points & Techniques in ACT) led by Dr Joe Oliver and Dr Richard Bennett, who are prominent Clinical Psychologists in the field. She also chose ACT as a specialist option as part of her DClinPsy training, which involved four weeks of teaching and ten weeks of reflective practice groups, used to apply theory to practice via formulation and intervention planning. The first author used ACT with clients on clinical placements and had weekly clinical supervision with her placement supervisors, as well as monthly research supervision with the third author.

2.5 Epistemological Position

The epistemological position of this study is pragmatic constructivism. Pragmatism was developed to challenge the extreme positions of positivism and constructivism, rejecting the forced choice between incompatible methodologies, and instead, proposed that both quantitative and qualitative methods could be utilised in unison (Tashakkori & Teddlie, 1998). This enables researchers to address research questions using methods that have no overlapping weaknesses and to draw upon their corresponding strengths (Brewer & Hunter, 1989).

Constructivism takes the view that knowledge is a construction created by individuals in relation to current context, rather than representing some correspondence to external reality (Kuhn, 1970). This also fits with ACT’s functional contextual underpinning, which takes a pragmatic view of how ‘truth’ (of an observed behaviour) relies upon interpretation and the context in which it occurs (Hayes et al., 2013). Therefore, we cannot seek an absolute truth but instead seek reasonable explanations in the world as we understand it, so that the essence of meaning is situated in context. In both pragmatism and constructivism, interpretation is considered inherent to identifying causal relationships, and so both viewpoints are consistent with the interpretive and pragmatic approach of the HSCED. When therapy is described as responsible for bringing about, facilitating, or influencing change on the part of clients, narrative causality is used to develop probabilistic knowledge claims, rather than purport absolute knowledge (Elliott, 2015).

However, it is recognised there may be possible conflict between the epistemological positions of pragmatic constructivism of the HSCED and critical realist position of ACT, which sits between the ideas that knowledge is measurable through scientific enquiry (positivism) and that no single knowledge exists (social constructionism). To resolve this conflict in this case, a pragmatic approach was taken to prioritise the position of the HSCED to address the research questions.

2.6 Rationale for Self-Report Measures

The GAD-7 and PHQ-9 are brief clinical measures of anxiety and depression, and both have shown good construct validity (Spitzer et al., 2006; Spitzer et al., 1999). A score of 15 or above on the GAD-7 and 20 or above on the PHQ-9 indicate ‘severe’ levels of anxiety and depression. However, the current study used ‘caseness’ scores as a threshold for suitability of treatment, which was 8 or above on the GAD-7 (Spitzer et al., 2006) and/or 10 or above on the PHQ-9 (Kroenke et al., 2001). Both measures were used as a routine screening tool within the MAS service from which Minnie and Agatha were recruited, therefore, showing utility with older adults with memory difficulties and a reduced burden on clients to screen for the study.

Though the Acceptance and Action Questionnaire (Bond et al., 2011) is used in most of the literature as a measure of PF, it has been criticised for focusing too heavily on acceptance and defusion (Francis et al., 2016). Whilst the Comprehensive assessment of Acceptance & Commitment Therapy (CompACT; Francis et al.) is considered a more robust measure of ACT processes, it may be criticised for its weakness in measuring self-as-context. This is important to acknowledge, since older adults may be more inclined to be attached to their conceptualised selves or self-stories, which may indicate increased psychological inflexibility. When Agatha referred to herself as a 'worrier' and Phyllis to herself a 'procrastinator', the first author did not interpret this as a 'truth' from a realist position, but as a possible indication of psychological inflexibility (namely self-as-content, fusion to thoughts and lack of valued action). The CompACT- short form (CompACT-SF; Morris, 2019; Appendix N), the shorter version of the CompACT (Francis et al.), was chosen to better account for more of the ACT processes, as well as reduce client burden. Since qualitative data was also prioritised in the study design, the assessment of self-as-context and changes in psychological flexibility was supplemented with information gathered at informal 'check-ins' at the beginning of each therapy session and change interviews, as well as the Personal Questionnaire (Elliott et al., 1999).

To assess wellbeing, the Short Warwick-Edinburgh Mental Wellbeing Scale (SWEMWBS; Tennant et al., 2007; Appendix O), a simplified version of the Warwick-Edinburgh Mental Wellbeing Scale (WEMWBS; Tennant et al.) was used, owing to adequate internal consistency and reliability (Haver et al., 2015).

The Personal Questionnaire (PQ; Elliott et al., 1999; Appendix P) is a measure designed to assess changes in specific problems according to the client and has good internal consistency (Elliott et al.). The focus of therapy (changes of interest) is therefore specific to the personal concerns and goals of each client, reflected in an individually adapted PQ (Elliott et al.). The current study used a shortened version, consisting of up to 10 problem statements which the client rated on a 7-point Likert scale.

The Session Rating Scale (SRS; Duncan et al., 2003; Appendix Q) is used as a measure of therapeutic alliance and was administered weekly to track the client-therapist relationship over time. The SRS has been shown to have good internal consistency and validity (Duncan et al.).

As part of the HSCED, CIs, based on The Helpful Aspects of Therapy framework (Llewelyn et al., 1988), were used to gain qualitative information from the client and their carer about their views and experience of therapy. The CIs included the following questions:

(i) How are you doing now in general?
(ii) What has therapy been like for you? How has it felt to be in therapy?
(iii) What changes, if any, have you noticed in yourself since therapy started?
(iv) Has anything changed for the worse since therapy started?
(v) Is there anything that you wanted to change that hasn't since therapy started?
(vi) Can you sum up what has been helpful about therapy? Please give examples (e.g., general aspects, specific events).
(vii) In general, what do you think has caused the various changes you described? What do you think might have brought them about, including things both outside of therapy and in therapy?
(viii) What personal strengths do you think have helped you make use of therapy to deal with your problems (what you're good at; personal qualities)?
(ix) What things in your current life situation have helped you make use of therapy to deal with your problems (family, relationships, living arrangements)?
(x) What kinds of things about the therapy have been hindering, unhelpful, negative, or disappointing for you (general aspects or specific events)?
(xi) Were there things in therapy which were difficult or painful but still OK or perhaps helpful? What were they?
(xii) Has anything been missing from treatment? What would have made therapy more effective or helpful?
(xiii) Are there things about you that you think have made it harder for you to use therapy to do deal with your problems? If so, what?

(xiv) Are there things in your life situation that have made it harder for you to use therapy to deal with your problems (family, relationships, living arrangements etc.)?

(xv) Do you have any suggestions for us, regarding the research or the therapy?

(xvi) Do you have anything else that you want to tell me?

2.7 Ethical considerations and procedures

To ensure scientific and ethical rigour, the current study went through a number of stages. The project was developed via a research proposal panel, research proposal presentation and protocol, as well as ongoing research supervision as part of the first author’s DClinPsy training. Ethical approval was granted by Wales Health Research Authority (Appendix A) and at a local level via Nottinghamshire Healthcare NHS Foundation Trust’s Research and Development department.

The initial focus of the research was the dementia population. However, according to feedback from the gatekeepers (MAS nurses), a potential barrier to recruitment may have been excluding those with MCI. Hence, due to recruitment difficulties, as well as a strong clinical argument, a substantial ethical amendment was approved to include people with MCI, if required (Appendix B). It was argued that an MCI diagnosis likely had a similar psychological impact to that of dementia, since both are characterised by objective evidence of cognitive impairment and represent markedly heightened risk of worsening over time. However, this amendment was not used and the inclusion of people with MCI did not transpire due to recruiting enough numbers.

2.7.1 Informed consent

Having met inclusion criteria, the first author provided potential clients with a Participant Information Sheet (Appendix D) and Participant Demographic Sheet (Appendix E), and if they shared a preference for the involvement of a companion, their carers were also provided with a Carer Information Sheet (Appendix G) and Carer Demographic Sheet (Appendix H). Both were given a few days to consider study participation. The first author then made telephone contact with both client and carer and gave the opportunity to answer questions. Once clients and their carers verbally consented to participate, they were asked to provide written consent by signing and returning the consent forms (Appendices F and I) via email. The first author reminded that participation was entirely voluntary and that one or both were free to withdraw at any time but that any data collected so far could not be deleted and would be used in the final analyses.

2.7.2 Confidentiality & Data Protection

The first author used an NHS Trust encrypted laptop to store confidential personal data in line with Nottinghamshire NHS Foundation Trust's Information Governance Policy. This included client and carer contact details, session audio recordings, therapist notes, completed outcome measures and CI transcripts and recordings. All data to be used for analysis was anonymised and all documents were password protected. Participants were given the opportunity to choose a pseudonym for themselves to be used in any publications (e.g., electronic documents, written notes, and transcripts) to prevent identification and references to personal information (e.g., other people's names, locations) were altered. Where information was shared within the research team, clients and carers were referred to either by number or their pseudonym.

2.7.3 Managing Risk

Clients were informed of confidentiality and its limits. For example, should they have disclosed criminal or risky behaviours, or if there was concern for theirs or others' wellbeing, the first author would have had an obligation to share concerns with the clients' carers or care team (GP or MAS) so that it could be appropriately managed. Minnie and Agatha were still open to MAS and were informed that they could contact MAS for support or the crisis team if outside of working hours. Any Coronavirus (COVID-19) related risks were minimised by conducting the intervention remotely.

2.8 Methods of reducing client burden

No intervention which would normally be considered part of routine care was withheld because of research participation. However, the research intervention required the repeated completion of numerous measures which could have caused client burden.

This was minimised by ensuring that potential client-participants were fully aware of the necessity to assess therapeutic change by completing an extra amount of outcome measures, as stated on the Participant Information Sheet, and of their right to withdraw at any time, without affecting their future care or benefits to which they were otherwise entitled. The study intended to reflect usual clinical practice, hence, the burden to clients was of a similar level to treatment as usual, for example, the two mood measures used in the study were routinely used for Minnie and Agatha as part of their care in MAS. To reduce burden, short-form outcome measures were chosen, where possible, and clients were offered regular breaks in session and support in completing measures by the first author or carer, if required.

As with any psychological therapy, there was an expectation that a working alliance would be developed between client and therapist from which to explore often personal content, some of which may have risked clients feeling upset or uncomfortable. Clients reserved the right to decline answering a question without reason, any non-verbal behaviour indicative of distress was continually monitored, and the first author intervened where necessary.

2.9 Development of rich case records

The rich case records for each client varied in length from 40 – 51 pages, depending on the amount of data collected over the course of therapy. Agatha's rich case record was shortest. Due to her early withdrawal from therapy, she completed fewer outcome measures than Minnie and Phyllis, and offered less therapy feedback at the change interview, resulting in a shorter interview transcript. Therefore, there was less evidence to draw upon when populating her rich case record.

All rich case records followed the same framework, as outlined by Elliott (2002):

(i) Contextual information about the client and carer
(ii) Adaptations to the ACT protocol
(iii) Client and therapy goals

(iv) Quantitative outcome measures

(v) Evidence for and against ACT-specific processes

- Do changes occur over the course of therapy?
- Are changes attributable to ACT?
- What factors, within ACT or outside of it, contribute to the observed changes?

(vi) Arguments- Affirmative and sceptic cases

(vii) Appendices

- ACT processes of psychological flexibility
- Intervention details
- Change Interview transcript
- Change Rating sheets

The HSCED allowed judges to attend to both confirmatory and disconfirmatory evidence, and the structure of the rich case records enabled judges to make cross-case comparisons and answer questions about causality, mediation, and moderation. However, categorising data into Elliott's (2002) framework may have been viewed as restrictive of naturally occurring themes. To address potential bias and ensure balanced data, the research team reviewed the reliability of the case records before they were sent to the judges. Raw data (interview transcripts and change rating sheets) were added as appendices for judges to view outside of the framework of the case records. As an example, Minnie's rich case record, as received by the judges, is shown in Appendix U.

3.0 Extended Results

The journal paper provides summarised versions of the rich case records sent to judges, including contextual information about clients and carers, therapy adaptations, therapy process, outcome and qualitative data and abridged versions of the affirmative and sceptic briefs. This extended Results section provides the full rich case records, which include therapist suggested attributions, evidenced in the CIs, change rating sheets, therapist notes and outcome scores, as well as full affirmative and sceptic briefs and CI transcripts.

3.1 Minnie's Full Rich Case Record

3.1.1 Minnie's Goals

Using the PQ (Elliott et al., 1999), Minnie generated personal goals for therapy which were as follows:

(i) To improve low mood (due to feelings of isolation, bereavements, and fleeting thoughts that life is not worth living).
(ii) To decrease worry about long-term coping.

3.1.2 Minnie's Therapy Adaptations

To aid engagement and understanding, the following therapy adaptations were made:

- Offer of regular breaks.
- Use of visual prompts (e.g., screen sharing the measures and materials from previous sessions).
- Providing prompting, scaffolding and concrete examples to Minnie when completing measures. Whilst it was recognised this risked asking loaded questions and may have been ACT-inconsistent, this was balanced with a need to give additional support and direction to help (re)orient Minnie to the questions.
- At Minnie and Mo's request, the first author recorded a reading of a mindfulness script and emailed this to Mo so she could support Minnie with between-session practice.
- Following the therapy review at session six, it was agreed that session time would be reduced from 90 to 60 minutes.
- Negotiating and protecting time for both Minnie and Mo to share their perspectives and feelings (the first author debriefed with Mo a couple of days after the first session).

3.1.3 Outcome Measures

Table 15. Minnie's process ratings

Process Measure	**S1**	**S2**	**S3**	**S4**	**S5**	**S6**	**S7**	**S8**	**S9**	**S10**	**S11**	**S12**
SRS	-	36	36	36	36	36	36	36	36	32	36	40

Note. S; session; - signifies missing data; maximum score of 40, with score of less than 36 indicating potential concern in the therapeutic relationship.

Table 16. Minnie's problem ratings

Personal Questionnaire	**Clinical cut-off**	**RC min**	**S1**	**S6**	**S12**	**1-month**	**3-month**
1. Feeling frustrated/fed up	>3.25	1.67 (↓)	2	**4** (-)	1 (=)	1 (=)	1 (=)
2. Feeling upset	>3.25	1.67 (↓)	1	1 (=)	1 (=)	2 (=)	1 (=)
3. Remembering bereavements	>3.25	1.67 (↓)	**7**	1 (+)	1 (+)	3 (+)	1 (+)
4. Feeling isolated	>3.25	1.67 (↓)	2	1 (=)	1 (=)	2 (=)	1 (=)
5. Having thoughts that life's not worth living	>3.25	1.67 (↓)	**5**	1 (+)	1 (+)	1 (+)	1 (+)
6. Feeling worried about going out	>3.25	1.67 (↓)	**5**	3 (+)	2 (+)	2 (+)	1 (+)

Note. S; session; Likert scale range 1-7; higher scores indicate a greater problem; Values in bold fall within clinical range; (+) denotes reliable positive change in relation to first available score; (=) denotes no change; and (-) denotes reliable negative change.

Minnie's overall outcome measures and weekly session measures are presented in Table 17 below. There was reliable improvement in depression scores from baseline to the end of the intervention according to the PHQ-9 (Spitzer et al., 1999), which was maintained at one and three-month follow-up. There was also reliable improvement in wellbeing according to the SWEMWBS (Tennant et al., 2007) from the first to the twelfth session, which again, was maintained at one and three-month follow-up. There was reliable improvement in PF pre- and post-intervention, according to the CompACT-SF (Morris, 2019). On the PQ (Elliott et al., 1999), Minnie's problems with distress caused by memories of bereavements, thoughts that life was not worth living and worries about going out also seemed to reliably improve across the intervention period and was maintained at follow-up. According to SRS (Duncan et al., 2003) scores, therapeutic alliance was generally stable, apart from at session 10, when Minnie gave a lower score owing to topics covered in session and stated that she felt sad when she mentioned her bereavements. Unfortunately, the SRS (Duncan et al.) data from the first session is missing as time constraints meant it could not be administered.

Table 17. Minnie's Therapy and Process Measures

Measure	**Timepoint**														
	Screen	Session 1	Session 2	Session 3	Session 4	Session 5	Session 6	Session 7	Session 8	Session 9	Session 10	Session 11	Session 12	1-month follow-up	3-month follow-up
GAD-7 (clinical cut-off 8)	0	3					4						1	3	0
PHQ-9 (clinical cut-off 10)	14	9					9						6	7	0
SWEMWBS		23					26						29	28	35
PQ (out of 42)		22					11						7	11	6
CompACT-SF		27	38	37	45	37	36	45	43	32	37	39	43	38	46
SRS		x	36	36	36	36	36	36	36	36	32	36	40		

3.1.4 Minnie’s Rich Case Summary

Do (meaningful) changes occur for Minnie over the course of (and after) the ACT intervention?

Table 18. Evidence For and Against Meaningful Change- Minnie

Therapeutic goals	**Supporting evidence** *(meaningful change did occur)*	**Refutational evidence** *(meaningful change did not occur)*
Change generally	**Change interview** “I think not being frightened to admit that, yes, I have got problems, you know, and accept that because I am who I am, I can always divert my thoughts and needs to a hobby, a sort, whether it's just researching history…”. “Well, I suppose since then I've lost my mother [in law], sister and husband, so you learn to actually cope with this and yeah, you accept that it's happened, you can't change it, so you’ve got to learn to live with the losses you’ve got. But that shouldn't overcome the other interests in life and ways of moving forward… I don't feel guilty about moving forward now”. **Change rating sheet** When asked, ‘What was the change?’ Minnie identified she was giving herself more time and understanding. She rated this change as neither expected nor surprising but that it was personally ‘very important’ to her.	**Change interview** “Have I [noticed any changes], Mo? I don't know” “I don't think I can tell you very much, no not really” **Therapist notes** Minnie often stated that she could not recall last week’s session or discussions. Minnie did not appear to understand some metaphors and exercises, therefore, required re-explaining or reframing; “I don’t get that Amie, it’s going over my head” (session 9). Minnie reported feeling guilty and that her confidence had reduced due to fears of falling and feeling scared and unsafe about going out due to COVID-19 (sessions 4, 7, 8). It seemed internal control strategies were generally working well for Minnie. She stated, “I get on with life, I always have done, I don’t sit and brood or feel sorry for myself as then you’re not in control of your emotions and I’d have to claw back control… I have to shut them out or push them away and do something

	Minnie also identified feeling more relaxed, which she said she was somewhat surprised by and was an 'extremely important' change for her. Finally, Minnie identified a positive change of recognising her goals and living in line with them which she rated as being 'somewhat surprised' by and 'extremely important'. **Therapist notes** Minnie reported therapy had offered a reminder of techniques to use and that she had found it helpful "just talking and listening to your ideas that aren't far from mine". Minnie said she had learned to take time out and evaluate what we had been talking about. She reported feeling more confident. Mo said Minnie was more relaxed (session 12).	else. I don't indulge them" (sessions 2, 3). Minnie identified no costs to this. Minnie reported difficulties in planning steps towards committed action during COVID-19, for example, said she wanted to go on holiday or to the garden centre but could not (session 2).
To improve low mood	**Therapist notes** When reminded that, at session 1, Minnie had identified thoughts of not wanting to be here anymore, she appeared surprised and in disbelief that she had said this (session 12). Minnie stated, "Dementia doesn't stop me from doing things although I'm less active now [in researching archaeology and sharing knowledge with others]" (session 2). Both Minnie and Mo seemed to use and responded well to humour in session.	**Therapist notes** Minnie continued to become tearful when thinking about or discussing the people she had lost (sessions 3, 9 and 10). Mo and a family informant reported Minnie's moods had 'always been up and down'. Mo stated she had noticed that some weeks Minnie was in a good mood and relaxed following the session, but at other weeks, she could find it very hard and was mentally exhausted. Mo reported Minnie was, in general, 'constantly tired' (session 6).

	PQ scores Reduction in PQ ratings of this problem. Pre-therapy: score of 5 (feeling isolated), 7 (memories of bereavements) End of therapy: both a score of 0 **PHQ-9 scores** Overall reduction across intervention. Pre-therapy: score of 14 Session 1: score of 9 Session 6: score of 9 Session 12: score of 6 1 month follow-up: score of 7 3 month follow-up: score of 0 **Change interview** Mo stated, "'Cause there was a point you would sit in your chair and just zone out with the telly but you are doing a lot more things even though the collecting the pebbles winds me up, but yeah, you like collecting your pebbles".	Mo said Minnie had opportunities to engage with others and activities but did not take them up due to tiredness and lack of motivation (session 7).
To decrease worry	**Therapist notes** When practising the mindful breathing both in session and between sessions, Minnie and Mo described this as helping Minnie to feel relaxed and she could notice the changes in her body.	**GAD-7 scores** Appeared to remain stable across the intervention. Pre-therapy: score of 0 Session 1: score of 3 Session 6: score of 4 Session 12: score of 1 1 month follow-up: 3 3 month follow-up: 0

	Minnie appeared to engage well with mindfulness, which she said helped her feel more relaxed. Minnie commented, “I’m remarkedly content” (session 6). Minnie said a bonfire had reignited in her garden and she had telephoned Mo, despite noticing thoughts about ‘not being very good’ on the phone (session 12). **PQ scores** Reduction in PQ ratings of this problem. Pre-therapy: score of 5 Session 12: score of 1	**Therapist notes** Minnie reported concerns about slipping outside (sessions 4, 7, 8). Mo anticipated Minnie would be ‘stuck to my side’ when they went to the supermarket once COVID-19 restrictions were lifted (session 5). When discussing thoughts that may act as a barrier to valued living (to advocate), Minnie stated, “I can’t face being in a group of people [archaeologists], I don’t want to be a burden… they’re awfully busy” (session 9). Mo said Minnie did not want others to perceive her as pestering. Minnie seemed to have difficulty keeping in mind what her experience told her; “I love *[archaeologist],* he’s interested in the project, he agreed with me” (session 11).

Are observed changes broadly attributable to the ACT intervention?

Table 19. Evidence For and Against Changes attributable to therapy- Minnie

Supporting evidence *(change is due to therapy)*	**Refutational evidence** *(change is due to external factors)*
Change interview/rating sheet Giving herself more time and understanding was a change Minnie seemed to attribute to therapy, rating this as 'very unlikely without therapy (clearly would not have happened)'. The change of feeling more relaxed and the change of recognising her goals and living in line with them were both rated as 'somewhat unlikely without therapy (probably would not have happened)'. Mo stated, "Amie's helped you to realise your goals… you've been obviously contacting the archaeologists about the stones and the pebbles you keep collecting and stuff like that. So, Amie's sort of, which we wouldn't have done, if we'd not been seeing Amie, I don't think we would have gone down that route". Minnie said, "… it's [therapy's] not something that I would have thought was necessary, but I can see the positive in it". "I think the therapy reminded me of methods that I could use to get to a stable place where I was alright". "I think having therapy it sort of nudged me into a position that I realised I could take control of what was happening to me and to understand the reasoning and what was happening to me".	**Change interview** Minnie reported, "I'm a creature of the 60s so, you know, some of the exercises are quite transferable from the 60s… I always say I was a creature of the 60s and the breathing and all those exercises were all very reminiscent of a 60s lifestyle". *Attribution- personal attributes/established coping skills.* "I think I realised that I'd got to move on, that it's no good sat there brooding about what you've lost. So, I grow things. I have done in the past. When I lost [mother-in-law], [husband]'s mum, that put me into a terrible depression. But by growing things, by keeping things moving, you claw back, you get at least some peace… And it's technique I've had to use two or three times in my life". *Attribution- established coping skills.* **PQ scores** Minnie stated that she used to practise breathing as a teenager as a 'hippy'. Mo said Minnie could do this quite automatically (session 12). *Attribution- established coping skills.* When asked why they thought Minnie's PQ scores had changed over time, Minnie attributed this to the season and improved weather in enabling her to engage in her hobbies; "…When stuff starts growing and I'm gardening, being busy and occupied". Mo also said, "Winter

“I think the therapist certainly reminded me of ways forward and what I needed to do”. “I think in actual fact, I did recognise that therapy could be a good thing because it does make you order your thoughts, it does make you understand”. Mo stated, “In your first few sessions you were really low and like I say, the therapy steered you into something you wanted to do so that gave you the positivity and that there is life with the Alzheimer’s, about taking control and doing what you want to do”. “… but the therapy has gave us some techniques, even down to the carer, I can use some of them techniques to zone out a bit. It was that ‘river’ one, I loved that river one”. **Therapist notes** Mo said, “It’s [therapy’s] highlighted we’re in a fortunate place” (session 12). She added that the questions and techniques used had been “pure genius, bloody brilliant” and had been adapted for Minnie as an individual; “I totally commend you for how you’ve dealt with us, we’re not the easiest of families. Thank you for trying to understand us” (session 12).	months have always been hard for Mum, she becomes more positive when the weather improves” (session 12). *Attribution- time of year.*

What specific factors (within ACT or outside of it) contribute to observed changes?

Table 20. Evidence For and Against Therapy as a Mechanism of Change- Minnie

Supporting evidence *(contributing internal factors)*	**Refutational evidence** *(contributing external factors)*
Therapeutic Alliance **Therapist notes** Mo stated, “You’ve said more to Amie than you have to me”, Minnie replied, “You’ve never wanted me to” (session 12). “It was good to have given opportunities for a break and reading the situation at the time, you were fast thinking” (session 12). Minnie stated, “Just talking and listening to your ideas that aren’t far from mine [was helpful]… I’m grateful for what you’ve done, it’s been good” (session 12). **SRS scores** Most weeks, Minnie provided a score of 36 out of 40 on the SRS, apart from session 10 when she reported it had been hard (becoming tearful when thinking of bereavements) and rated the session at 32 out of 40. Minnie rated session 12 as 40 out of 40, indicating satisfaction with her relationship with the therapist, therapist approach and the goals and topics covered. ACT Techniques **Therapist notes** When mindful breathing both in session and between sessions, Minnie and Mo described this as helping her to	Family support **Therapist notes** Mo reported she was worried that there was a genetic link with developing dementia and the reason for agreeing to participate in therapy was to help their family and others in the future to see if this therapy was effective (session 1). When reviewing between-session tasks on committed action (contacting archaeologists), Mo stated, “She [Minnie] wouldn’t have done it without me” (session 9). **Change interview** Mo said, “…I'm having to support you [Minnie] more and more and my brain capacity’s obviously trying to understand what you want to say and do, so yeah it’s a hard process…”. Time of year **Therapist notes** Mo said, “Winter months have always been hard for Mum, she becomes more positive when the weather improves” (session 12). Minnie said, “But then it got warmer, and I could start and grow things and… nature’s wonderful”. Personal attributes/established coping strategies **Therapist notes**

feel relaxed and that she could notice the changes in her body. Mo reported, “You’ve adapted it for Minnie as an individual” (session 12). **Change interview** Mo said, “But she [therapist] was spot on, she’d go away after each session and then come back the following session and I used to think, yeah, you're spot on here. That’s what I think”. “…the therapy has made me my mum realise that she’s still got things she wants to do in life”. “Amie, like I’ve told her, she's been spot on, she's understood my mum and she’s made it quite individual to you and that was just spot on”.	Minnie stated that she used to practise breathing as a teenager as a ‘hippy’. Mo said Minnie could do this quite automatically (session 12). Mo reflected that ladies in the family were ‘tough cookies’ and that Minnie had been brought up not to show any feelings (session 12). **Change interview** Minnie referred to established, helpful coping strategies; “So I grow things. I have done in the past… And it's technique I've had to use two or three times in my life”. “It’s hard work! It really is hard work. I usually go from these sessions home… exhausted”.

3.1.5 Minnie’s Briefs

3.1.5.1 Minnie’s Affirmative Case

The affirmative case proposes that there are clear links between therapy process and outcome, and requires at least two of the following pieces of evidence, as outlined by Elliott (2002):

1) change in stable client problems (client experiences changes in longstanding or chronic difficulties)
2) retrospective attribution
3) outcome-process mapping (content of the CI plausibly matches specific events, aspects, or processes within therapy)
4) event-shift sequences (significant therapy events are followed forward in time for evidence of their later effects e.g., stable shifts in client distress).

Changes across therapy

Minnie’s scores changed on the PHQ-9, PQ, and CompACT-SF. Though not the primary aim of ACT, this indicates symptoms reduced over the course of the intervention. This may be attributed to Minnie’s increased PF in enabling her to become more open to the experience of difficult thoughts and feelings, increased behavioural awareness and improvements in functional ability through re-engaging in meaningful, value-led activity. Though distraction and keeping busy appeared to be a pervasive coping strategy, arguably in the guise of experiential avoidance, Minnie chose to engage in valued action such as gardening (in line with her value of enjoyment) and liaising with ex-colleagues about archaeology projects (value of advocating) which may have resulted in improvements in her mood and problems as indicated in the PQ. Minnie always appeared to engage well in mindfulness and the weekly three-minute present moment awareness exercise, reflecting that she was able to stay with it, found it calming and did not notice any thoughts or feelings crop up. Though this may have been the case, she was given regular opportunity to notice and experience thoughts and feelings rather than to distract from them. Over the course of therapy, it was acknowledged that Minnie’s ability to discuss her experiences and feelings openly was a huge improvement. Therefore, ACT could have been a vehicle for therapeutic change for Minnie.

Retrospective attribution

Retrospective attribution requires Minnie to attribute any changes she noticed to therapy, which is highlighted in the CI and change rating sheets when asked how likely she thought the identified changes would have been without therapy. Minnie reported in the CI that she had noticed positive changes which would have been ‘extremely’ or ‘somewhat’ unlikely without therapy.

Therapist attributed these changes to the therapy

It may be helpful to consider whether the therapist attributed any changes to the therapy using knowledge of Minnie, her presentation and through discussion within sessions. With Mo’s support, Minnie was observed to engage in planned committed action exercises as between-session practice and her reactions of sadness to any intrusive thoughts about her bereavements seemed to become less evident over time. Understandably, it is recognised that Minnie may have had difficulty in reflecting upon therapy and identifying changes without support, as mentioned in the CI. GAD-7 scores pre-therapy to session one worsened, which may indicate that improvements were not made prior to therapy.

Process-outcome mapping

Process-outcome mapping refers to Minnie’s CI information about significant events corresponding with aspects or processes within therapy. In the CI, Minnie stated that therapy had helped her to recognise her goals and live in line with them and this was demonstrated in therapy with between-session practice of committed action tasks (session eight onwards). Therefore, it would be expected that Minnie’s scores on the valued action subscale of the CompACT-SF, for example, may have improved after session eight. However, scores remained somewhat stable at 16-18, which may query the reliability or sensitivity of self-report measures in the context of memory difficulties.

Change in stable problems

Information from the MAS gatekeeper highlighted that Minnie’s life was ‘chaotic’ and that she had ‘good and bad days’. This was corroborated by Mo and the family informant. It may be assumed that the therapeutic intervention is responsible for change when this occurs in chronic, pervasive difficulties. Minnie described experiencing a change in giving herself more time and understanding and feeling more relaxed. Minnie's PQ scores regarding low mood due to feeling isolated and her bereavements appeared to change considerably.

Changes not due to relational artefacts

It did not appear that changes were due to relational artefacts (the client emphasising change to please the therapist) as the first author and therapeutic relationship was mentioned more by Mo during the CI. It felt as though the therapeutic relationship could fluctuate (e.g., "I don't get that Amie"), especially if Minnie interpreted questions as testing or exposing. However, SRS scores suggest that the therapeutic relationship remained strong throughout therapy. Scores remained stable and were not shown to increase steadily over time. Furthermore, there may have been some internal consistency in Minnie and Mo's relationship as Mo tended to 'chip in' to discussion as she would in day-to-day life and helped to prompt Minnie's recall. Moreover, it is unknown whether the therapeutic relationship and Minnie's engagement in therapy may have increased if therapy had taken place in person rather than online. Therefore, relational factors between the first author and Minnie and Mo and Minnie cannot fully account for the improvements identified over the course of the therapy.

Changes not due to expectancy artefacts

This pertains to whether changes occurred due to Minnie's expectations or hopes for change. Minnie identified two changes that she was surprised by (feeling more relaxed and living in line with her goals). She also said that therapy was not something she thought necessary but could see the positive in it, indicating she did not have particular expectations or hopes for therapy. Therefore, changes are unlikely due to expectancy artefacts.

Statistical artefacts

All clinical cut-off scores are approximate and have been calculated using existing means for clinical and/or non-clinical populations. Therefore, the affirmative case suggests that Type II errors could be responsible for lack of significant change in measures. Furthermore, due to Minnie's attention and memory difficulties, she could find some of the wording in the questionnaires confusing and at times, required a lot of scaffolding and examples to aid her understanding, which may explain why significant change was absent in some measures. The sensitivity of the measures may also be questionable when used with older adults with memory difficulties.

Conclusion

This affirmative case stipulates that:

- Minnie demonstrated substantial change in her problems.
- Minnie attributed these changes to therapy, even if her psychometric scores did not correspond with sessions.
- The therapist attributed most of these changes to therapy.
- This evidence contradicts sceptic non-therapy reasons for change and/or lack of change.

This evidence provides a basis for you to support the case that Minnie changed substantially during the period of therapy and infer that this change was caused by her participation in the ACT intervention.

3.1.5.2 Minnie’s Sceptic Case

This sceptic brief describes a good attempt to counter the argument that Minnie changed substantially during therapy and that this change was due to the intervention. As suggested by Elliott (2002), the sceptic case will examine Minnie’s case record for evidence of alternative explanations.

The following explanations suggest that any observed changes do not represent clinical improvement due to:

1) trivial or negative changes on measurement
2) statistical artefacts
3) relational artefacts
4) expectancy artefacts

Trivial or negative changes on measurement

Minnie’s problems were not stable since her screening scores and pre-therapy scores (session one) were dissimilar. Therefore, it is difficult to establish whether the distress she experienced would have remained stable over time or naturally improved without therapy. Though some measures showed improvement, others did not, which may suggest that ACT processes were less transferrable to older adults with dementia and hence did not result in symptom reduction.

Statistical artefacts

Statistical errors cannot be ruled out and relies on primary analysis being accurate. Therefore, the presence of a change in PQ, PHQ-9 and CompACT-SF scores could be due to statistical inaccuracy. Furthermore, Minnie may have misinterpreted or misunderstood the questions. At times, there also seemed to be a negotiation in given answers on measures with Mo, which therefore questions the extent to which Mo’s presence was helpful or hindering. If the intervention had been truly effective, it would be expected that stable changes would have occurred as indicated on the measures.

Furthermore, the reliability and validity of the measures was queried as it was felt that the stability or consistency of Minnie’s answers were possibly state-dependent due to her difficulties in recalling or reflecting upon the past week. Though measures were used to assess change, they must also be conceptualised, thus questions were raised regarding the usefulness of self-report measures in the context of memory difficulties. For example, at session eight, Minnie disagreed with the CompACT-SF statement, ‘I go out of my way to avoid situations that might bring difficult thoughts, feelings, or sensations’ but later in the session said, “I’m keen to avoid situations that would cause upset, I’d distract from or ignore them”, indicating agreement with the statement. Without confidence in self-report measures, it is hard to detect clinically significant improvement. A family informant reported Minnie’s difficulties were not likely reflected in the measures, nor changes sustained after therapy, which again, queries the accurateness of self-report measures in this case.

Relational artefacts

Elliott (2002) suggests this can be evaluated by careful assessment of specific changes in Minnie’s experiences and whether changes were identified due to a desire to impress or reassure the first author. Not only should Minnie’s relationship with the first author be considered (which was seemingly strong according to SRS scores), but also her working alliance and relationship with Mo since ACT was used systemically in the triad between therapist, client, and carer. Mo's involvement was deemed helpful since the management of Minnie's distress became shared, similar to real life clinical practice and the context in which Minnie was living (becoming more reliant upon Mo). Moreover, there were likely between-session processes with facilitative conversations about therapy outside of sessions and with Mo prompting and supporting Minnie with between-session tasks. Thus, relational factors may have resulted in the identified improvements.

Expectancy artefacts

Though not particularly verbalised by Minnie, Mo appeared to have expectations about therapy in helping their family to see if ACT was effective for people with dementia. Mo shared upsetting memories of caring for family members with dementia, prior to caring for her mother, and tangible fears about developing dementia herself in the future. Since Mo was involved in the intervention and spoke of her motivations for participating in therapy in Minnie's presence, this may have influenced Minnie's expectations or hopes for therapy.

The following explanations, as suggested by Elliott (2002), stipulate that change has occurred but not due to therapy and is therefore as a result of the following factors:

5) self-correction
6) life events
7) psychobiological factors
8) reactive effects of research participation

Self-correction and other factors

This potential reason for change suggests that any improvement is caused by self-help outside of therapy. As previously discussed, consideration should be given to between-session processes and facilitative conversations about therapy between Minnie and Mo, with Mo supporting Minnie with between-session tasks. Furthermore, Minnie referred to mindfulness exercises, especially mindful breathing, as reminiscent of practices in the 1960s, indicating that this skillset was already established and that prompting and opportunity alone enabled Minnie to re-engage with and develop her skills in mindfulness. Over the course of therapy, Minnie also increased her engagement in established hobbies and interests.

Life events

Minnie did not experience any major life events over the three months of therapy; however, it is recognised that her abilities may have reduced according to the progressive nature of her dementia. Minnie’s certainty in whether or not things had changed as a result of therapy varied since she had difficulty in reflecting upon and recalling previous sessions, and therefore required support from Mo to do this. Hence, Minnie’s level of impairment likely acted as a barrier to getting the most from therapy.

Furthermore, changes to one’s life during COVID-19 restrictions likely brought additional challenges which could understandably affect mood and wellbeing, rendering the intervention less effective. Alternatively, some improvements in mood may have been as a result of lighter nights and better weather, enabling Minnie to re-engage in interests that may have been harder to do in winter months. This was reported by both Minnie and Mo in the CI and in therapy.

Psychobiological factors

Although not reported by Minnie, changes in hormones, such as melatonin, may have improved Minnie’s circadian rhythm and contributed to fluctuations in her mood or distress. Minnie did report fluctuations in physical discomfort and chronic fatigue which may have accounted for variation in her scores, particularly as fluctuations indicating improvement were not statistically significant week-to-week. Minnie’s dementia medication may have also affected her mood or sense of wellbeing.

Reactive effects of research participation

Mo reported that Minnie had spoken more to the first author about her feelings than she had to her her whole life. She also said that Minnie had enjoyed the first author’s attention and in talking about her interests. The overall positive experience of therapy may therefore explain the positive changes identified.

Lack of event-shift sequences

Any changes were not sustained as Minnie's scores across all measures appeared to fluctuate throughout the intervention. It would be expected that significant therapy events would result in significant shifts in difficulties, yet only weak evidence exists for event-shift sequences because reliable shifts did not occur when coinciding with helpful events as per Minnie's CI.

Conclusion

This sceptic case stipulates that:

- Minnie did not make significant changes
- Minnie did not attribute changes to therapy
- Any minor changes made were due to extra-therapeutic factors
- This evidence contradicts evidence presented by the affirmative case

This evidence provides a basis for you to reject the case that Minnie changed substantially during therapy and infer that any change was caused by extra-therapeutic factors.

3.2 Agatha's Full Rich Case Record

3.2.1 Agatha's Goals

Using the PQ (Elliott et al., 1999), Agatha generated personal goals for therapy which were as follows:

(i) To decrease anxiety and frustration (due to difficulties remembering, having problems with reading, worries about getting things wrong and getting caught up in my thoughts and rushing through things without paying attention).
(ii) To decrease sadness due to problems with reading.

3.2.2 Agatha's Therapy Adaptations

To aid engagement and understanding, the following therapy adaptations were made:

- Offer of regular breaks.
- Use of visual prompts (e.g., screen sharing the measures, materials from previous sessions, pictures when introducing exercises and metaphors and typing questions as they were asked so Agatha could read them and then respond).
- Providing options when asking questions as Agatha could struggle with several choices or open-ended questions.
- Providing more directive communication to aid understanding, for example, suggesting Agatha close her eyes during mindfulness exercises as she could get caught up in thoughts about whether to do so if given the option. Whilst this may have been inconsistent with ACT language, it was balanced with a need to give additional support and direction.
- Use of shorter dialogue and repetition.
- Checking understanding throughout (“Does that make sense?”)
- Slowing speech, for example, during mindfulness scripts.
- Keeping the camera on during exercises so Agatha could lip read.
- Using headphones to reduce any background noise.
- At Jane’s request, the first author recorded a reading of a mindfulness script and emailed this to Jane so she could support Agatha with between-session practice.
- Emailing the link of a present-moment awareness exercise to Jane to see if it could be played louder through a speaker in person, rather than through the first author’s laptop.
- Attempting to build rapport and encourage Jane’s participation in therapy in session and via email.
- Following feedback, sessions were reduced from 90 to 60 minutes.

3.2.3 Outcome Measures

Table 21. Agatha's process ratings

Process Measure	**S1**	**S2**	**S3**	**S4**	**S5**	**S6**
SRS	36	33.5	39	37	40	40

Note. S; session; - signifies missing data; maximum score of 40, with score of less than 36 indicating potential concern in the therapeutic relationship.

Table 22. Agatha's problem ratings

Personal Questionnaire	**Clinical cut-off**	**RC min**	**S1**	**S6**	**1-month**	**3-month**
1. Feeling confused	>3.25	1.67 (↓)	**5**	**5** (=)	**4** (=)	**4** (=)
2. Difficulties remembering and getting frustrated	>3.25	1.67 (↓)	**7**	**5** (+)	**5** (+)	**5** (+)
3. Feeling sad that I have problems with reading	>3.25	1.67 (↓)	**6**	**5** (=)	**6** (=)	**5** (=)
4. Feeling frustrated that I have problems with reading	>3.25	1.67 (↓)	**5**	**5** (=)	**6** (=)	**5** (=)
5. Feeling more anxious than usual, worrying about getting things wrong	>3.25	1.67 (↓)	3	**5** (-)	**4** (=)	**4** (=)
6. Difficulties concentrating due to getting caught up in my thoughts	>3.25	1.67 (↓)	**6**	**5** (=)	**5** (=)	**5** (=)
7. Rushing through things without paying attention	>3.25	1.67 (↓)	**5**	**4** (=)	3 (+)	**4** (=)

Note. S; session; Likert scale range 1-7; higher scores indicate a greater problem; Values in bold fall within clinical range; (+) denotes reliable positive change in relation to first available score; (=) denotes no change; and (-) denotes reliable negative change.

Agatha's overall outcome measures and weekly session measures are presented in Table 23 below. There was reliable improvement in anxiety scores at three-month follow-up in comparison to baseline, and reliable improvement in PF at one month follow-up in comparison to baseline, however, these did not appear to be maintained over time. There did seem to be reliable improvement on the PQ (Elliott et al., 1999) regarding Agatha's frustration with her memory difficulties, which was maintained at follow-up. But generally, Agatha's quantitative outcomes remained unchanged. According to SRS (Duncan et al., 2003) scores, therapeutic alliance was generally stable, apart from at session two, when Agatha gave a lower score, stating she found the SRS (Duncan et al.) questions difficult to answer.

Table 23. Agatha's Therapy and Process Measures

Measure	**Timepoint**								
	Screen	Session 1	Session 2	Session 3	Session 4	Session 5	Session 6	1-month follow-up	3-month follow-up
GAD-7 (clinical cut-off 8)	18	17					18	21	12
PHQ-9 (clinical cut-off 10)	9	9					10	8	5
SWEMWBS		19					20	22	23
PQ (out of 49)		37					34	33	32
CompACT-SF		21	19	20	20	19	24	28	25
SRS		36	33.5	39	37	40	40		

3.2.4 Agatha’s Rich Case Summary

Do (meaningful) changes occur for Agatha over the course of (and after) the ACT intervention?

Table 24. Evidence For and Against Meaningful Change- Agatha

Therapeutic goals	**Supporting evidence** *(meaningful change did occur)*	**Refutational evidence** *(meaningful change did not occur)*
Change generally	**Change interview** “…maybe that I do sometimes tell myself I should calm down a bit. I try to make myself calm down and be a bit less manic…”. “I think it's got slightly worse… I think I have got worse, yes, I think I have... I don't think there's anything in particular, just that I know I'm so confused”. **Change rating sheet** When asked, ‘What was the change?’ Agatha identified one change which was telling herself to calm down. She rated this change as neither expected nor surprising and that it was personally ‘moderately important’ to her.	**Change interview** “I am undoubtedly confused… it [dementia] just made life certainly more difficult for me. I take longer to do things and I get things wrong quite frequently I would say, and I just can't retain things”. “It's really difficult to know how much it [therapy] helped”. “I suddenly realised that I didn't feel I was going to be getting anything out of that which was probably because of how I am”. Jane denied noticing any changes over the course of the intervention; “Yeah, we haven't noticed anything… So, it’s about two months” which was corroborated by Agatha. When asked about any helpful changes through therapy, Jane replied, “Nothing”. “I think it's just how I am, perhaps how I've always been, but I'm not sure about that”. Agatha said throughout that nothing had changed.

		Therapist notes Agatha could become easily confused and it seemed effortful for her to hear and comprehend. This, understandably, may have caused her and Jane frustration. Agatha did not appear to understand some metaphors and exercises, therefore, required re-explaining or reframing; “I’m not sure where this is going to lead to” (session 4). It seemed external control strategies (distraction) were quite pervasive and generally worked well for Agatha. She stated, “I’ve always enjoyed walking, making a cup of coffee, doing a puzzle book, code words, and watching Coronation Street” (session 1). Agatha said, “I’m anxious, I’m that sort of person, I don’t think therapy would change it, I might be wrong… I don’t look forward to it, feel like it’s another thing I’ve got to do” (session 6). Jane stated that Agatha did not enjoy therapy and that it caused her more anxiety; “The costs are outweighing the benefits” (session 6).
To decrease anxiety and frustration	**Therapist notes** Agatha stated that dementia did not stop her from doing what she wanted (session 1). At times, both Agatha and Jane seemed to use and responded well to humour in session.	**Change Interview** “I don't think anything's changed”. “…everybody would have found it easier if we hadn't had COVID and they could have come in and done a normal face to face conversation… everybody would have found it less stressful, wouldn't they? Probably”.

	Agatha said she was not fraught but not relaxed either (session 5). **PQ scores** Reduction in PQ ratings of this problem. Pre-therapy: score of 7 (due to difficulties remembering) End of therapy: score of 5 Reduction in PQ ratings of this problem. End of therapy: score of 5 (due to worries about getting things wrong) 1 month follow-up: score of 4 **GAD-7 scores** Reduction following intervention. 1 month follow-up: score of 21 3 month follow-up: score of 12	“I just found it [therapy] quite stressful”. Jane mentioned a particular question (on the CompACT-SF) that Agatha struggled with each week. **Therapist notes** Agatha stated on several occasions throughout therapy that she felt ‘fraught’ (‘hot and bothered’) and ‘frazzled’ (sessions 2, 5). Agatha said, “I’m anxious, I’m that sort of person, I don’t think therapy would change it” (session 6). **GAD-7 scores** Scores appeared to remain stable over the course of the intervention. Pre-therapy: score of 18 Session 1: score of 17 Session 6: score of 18
To decrease sadness	**PHQ-9 scores** Reduction in scores following intervention. 1 month follow-up: score of 8 3 month follow-up: score of 5	**Change Interview** “I don't think anything's changed”. **PQ scores** PQ ratings of this problem (due to problems with reading) appeared to remain stable. Session 1: score of 6 Session 6: score of 5 1 month follow-up: score of 6 3 month follow-up: score of 5 **Therapist notes**

	Agatha stated she felt sad and did not want to rely on her daughters all the time (session 1). Agatha reported feeling sad when she became aware of her difficulties (session 2).

Are observed changes broadly attributable to the ACT intervention?

Table 25. Evidence For and Against Changes attributable to therapy- Agatha

Supporting evidence *(change is due to therapy)*	**Refutational evidence** *(change is due to external factors)*
Change interview “Well, it [therapy] was certainly interesting”. **Therapist notes** Though seemingly difficult, Agatha was able to engage with mindfulness at times. During one exercise, with prompting, she was able to identify thoughts and judgements such as, ‘How quiet it is, how peaceful it is, there aren’t any noises’ (session 3). Following introduction of ‘Leaves on a Stream’, Agatha said she liked the picture (visual prompt), that it was nice and that she could follow the exercise. She was able to identify thoughts such as, ‘I’m not sure where this is going to lead to’ (session 4). Agatha stated that she found therapy challenging but interesting as she had never done it before (session 6). Agatha persevered with therapy despite losing track at times and feeling confused, which was reflected back to her (session 6).	**Change interview/rating sheet** “Well, I think I am doing reasonably well but this is because I have, we have, a lot of help from our lovely family so I'm not sure how I would manage otherwise”. *Attribution- family support.* “Oh, it was the mindfulness. I'm afraid I just, I just couldn't, it wasn't me if you like, I couldn’t switch onto it and I think I suddenly realised that I didn't feel I was going to be getting anything out of that which was probably because of how I am. I think that's all I can say on that”. *Attribution- not due to therapy.* “I don't feel that anything has helped me. I can't think of anything. The mindfulness was interesting, and I know it's something I could do, but I also know it's most unlikely that I will. I just feel that I'm not that kind of person really”. *Attribution- not due to therapy.* “…it wasn't a good fit for me because I'm not a mindlessness kind of person”. *Attribution- not due to therapy.* “…everybody would have found it easier if we hadn't had COVID and they could have come in and done a normal face to face conversation… everybody would have found it less stressful, wouldn't they? Probably”. *Attribution- not due to therapy.*

Jane stated she did not think Agatha had used therapy to deal with her problems; “I think you didn't know what was happening a lot of the time. You didn’t really understand it, did you?” *Attribution- not due to therapy.*

Agatha felt that the identified change of telling herself to calm down would have been very likely without therapy (would have happened anyway). *Attribution- personal attributes/established coping skills.*

Therapist notes

Due to the progressive nature of dementia, Agatha’s level of impairment may have hindered her ability to engage in the intervention; “I don’t know what I’m meant to be doing” (session 3).

In repeating parts of the mindfulness exercises and ACT metaphors due to Agatha’s comprehension and hearing difficulties, it was felt that they likely lost meaning. In trying hard to concentrate and lip read, this may have acted as a barrier to enabling Agatha to close her eyes and engage fully. This meant interactions became far more dyadic and directive than experiential.

Agatha was offered opportunities to notice her bodily sensations during a conversation about worrying about her family but stated she had not noticed anything (session 5).

Agatha appeared to get caught up in thoughts, for example, at the beginning of a mindfulness exercise, she noticed thoughts about whether or not to close eyes which then caused her panic because she thought she might have missed part of the exercise (session 5).

	Agatha stated that she did not like the present-moment awareness exercise and did not know how it was helping (session 6).

What specific factors (within ACT or outside of it) contribute to observed changes?

Table 26. Evidence For and Against Therapy as a Mechanism of Change- Agatha

Supporting evidence *(contributing internal factors)*	**Refutational evidence** *(contributing external factors)*
Therapeutic Alliance **Therapist notes** Agatha used humour at times, possibly to deflect from her difficulties; “I’m OK when I’m asleep” (session 6). Agatha said she had concerns about withdrawing from therapy as she wanted to help the therapist with her course (session 6). The therapist, during her Older Adult placement, conducted neuropsychological testing with Agatha and disclosed the dementia diagnosis, therefore there may have been an alliance prior to the research intervention. **Change interview** Agatha agreed that she was satisfied with the content of the sessions and the therapist’s style. “…I thanked her [therapist] very much for her patience and then I had to explain to her the reasons for finishing. I don't think I've got anything else to add to that”. **SRS scores** Agatha provided scores between 33.5 and 40 out of 40 on the SRS, indicating satisfaction with her relationship with the therapist, therapist approach and goals and topics covered.	Family support **Change interview** “Well, I think I am doing reasonably well but this is because I have, we have, a lot of help from our lovely family so I'm not sure how I would manage otherwise”. Role/family relationships **Change interview** Agatha said, “But I think at the end of the day, which is why I told Amie not to continue, it, well, yes, I did feel, I think I felt it wasn't for me and that I perhaps couldn't spare the time”. “I thought it was taking up too much time that I hadn't got to spare and also, I felt my daughter hadn't got time spare”. Personal attributes/established coping strategies **Therapist notes** Agatha appeared impassioned when discussing her love of the environment during a values-identification exercise and continued to engage in things she enjoyed (session 5). **Change interview** Jane stated, “You didn't find it [therapy] very helpful, did you? I don't want to put words in your mouth, but I didn't think you’d found it very helpful from what you’d said before”.

ACT Techniques

Change interview

“…I know it’s [therapy’s] not been hindering”.

“Well, nothing was unhelpful”.

“Well, nothing difficult or painful”.

Interest in research

Change interview

Agatha denied having expectations of the therapy, but then said she must have had to agree to it and hoped she would maybe get something out of it.

“I just thought it sounded interesting and worth a try, I think that's what I thought”.

“I was just curious, and I suppose I must have been thinking if there's anything that might help, I should give it a try”.

3.2.5 Agatha’s Briefs

3.2.5.1 Agatha’s Affirmative Case

The affirmative case proposes that there are clear links between therapy process and outcome, and requires at least two of the following pieces of evidence, as outlined by Elliott (2002):

1) change in stable client problems (client experiences changes in longstanding or chronic difficulties)
2) retrospective attribution
3) outcome-process mapping (content of the CI plausibly matches specific events, aspects, or processes within therapy)
4) event-shift sequences (significant therapy events are followed forward in time for evidence of their later effects e.g., stable shifts in client distress).

Changes across therapy

Agatha’s scores changed on the PHQ-9, GAD-7 and PQ. Though not the primary aim of ACT, this may indicate some symptoms reduced over the course of the intervention. Although not shown by changes in scores, Agatha’s valued action score on the CompACT-SF indicated that despite challenges brought about by her dementia, she continued to engage in meaningful, value-led activity. Although distraction and keeping busy appeared to be a pervasive coping strategy, arguably in the guise of experiential avoidance, Agatha chose to engage in valued action such as gardening and reading (in line with her value of enjoyment), which may have resulted in improvements in her mood and problems as indicated in the PQ. Though she appeared to struggle to engage with mindfulness, in therapy, Agatha was given regular opportunity to notice and experience difficult thoughts and feelings rather than to distract from them.

Retrospective attribution

Retrospective attribution requires Agatha to attribute any changes she noticed to therapy. In the CI, Agatha identified a change in being able to tell herself to calm down, yet, according to the change rating sheet, she did not attribute this change to therapy but something she most likely did previously. However, at the same time, Agatha stated that therapy had not been hindering or unhelpful.

Therapist attributed these changes to the therapy

It may be helpful to consider whether the therapist attributed any changes to the therapy using knowledge of Agatha, her presentation and through discussion within sessions. However, as Agatha withdrew from therapy before values and committed action work, she did not have full opportunity to benefit from therapy and make changes. GAD-7 scores pre-therapy to session one worsened, which may indicate that improvements were not made prior to therapy.

Process-outcome mapping

Process-outcome mapping refers to Agatha's CI information about significant events corresponding with aspects or processes within therapy. In the CI, Agatha stated that therapy had not been hindering, unhelpful, difficult, or painful. However, no significant events were identified.

Change in stable problems

Agatha and Jane informed that Agatha had 'always been a worrier' and Agatha said this was her 'default'. It may be assumed that the therapeutic intervention is responsible for change when this occurs in chronic, pervasive difficulties. Agatha described experiencing a change in telling herself to calm down. Agatha's PQ scores regarding anxiety and frustration, due to her difficulties remembering and worries about getting things wrong, appeared to improve.

Changes not due to relational artefacts

It did not seem that changes were due to relational artefacts (the client emphasising change to please the first author) as the therapeutic relationship was not explicitly mentioned by Agatha or Jane during the CI, and SRS scores showed some fluctuation in the therapeutic relationship. Whilst Agatha reported a concern about helping the first author by participating in the research, she made the decision to prematurely withdraw from therapy. Furthermore, there may have been some internal consistency in Agatha and Jane's relationship in therapy and in their day-to-day life. Jane's support to Agatha in therapy may have been perceived as limited at times and the first author was unsure about the extent of between-session processes, for example, whether any facilitative conversations about therapy took place. Moreover, it is unknown whether the therapeutic relationship and Agatha's engagement in therapy may have increased if therapy had taken place in person rather than online, as she indicated in the CI. Therefore, relational factors between the first author and Agatha and Agatha and Jane cannot fully account for improvements in therapy.

Changes not due to expectancy artefacts

This pertains to whether changes occurred due to Agatha's expectations or hopes for change. Agatha stated she did not have expectations of therapy but was curious to participate. This was corroborated by Jane. Therefore, changes are unlikely due to expectancy artefacts. Moreover, Agatha's ambivalence towards therapy and overall adverse experience of therapy may explain the lack of changes identified.

Statistical artefacts

All clinical cut-off scores are approximate and have been calculated using existing means for clinical and/or non-clinical populations. Therefore, the affirmative case suggests that Type II errors could be responsible for lack of significant change in measures. Due to Agatha's difficulties with attention and memory, she could find some of the wording in the questionnaires confusing and, at times, required a lot of scaffolding and examples to aid her understanding, which may explain why significant change was absent in some measures. It is queried whether another, more suitable metric to measure functioning, for example, may have been more useful, since mood scores and the impact on daily functioning may have differed. The sensitivity of the measures may also be questionable when used with older adults with memory difficulties.

Conclusion

This affirmative case stipulates that:

- Agatha demonstrated substantial change in her problems, even if she did not explicitly attribute them to therapy and her psychometric scores did not correspond with sessions.
- The therapist attributed most of these changes to therapy.

- This evidence contradicts sceptic non-therapy reasons for change and/or lack of change.

This evidence provides a basis for you to support the case that Agatha changed substantially during the period of therapy and infer that this change was caused by her participation in the ACT intervention.

3.2.5.2 Agatha's Sceptic Case

This sceptic brief describes a good attempt to counter the argument that Agatha changed substantially during therapy and that this change was due to the intervention. As suggested by Elliott (2002), the sceptic case will examine Agatha's case record for evidence of alternative explanations.

The following explanations suggest that any observed changes do not represent clinical improvement due to:

1) trivial or negative changes on measurement
2) statistical artefacts
3) relational artefacts
4) expectancy artefacts

Trivial or negative changes on measurement

Agatha's problems were not stable since her scores post-therapy (from session six to follow-up) were dissimilar. Agatha and Jane both reported Agatha experienced longstanding anxiety. Therefore, it is difficult to establish whether the distress she experienced would have stayed the same or naturally improved without therapy. Though some measures showed improvement, others did not, which may suggest that ACT processes were less transferrable to older adults with dementia and thus did not result in symptom reduction.

Statistical artefacts

Statistical errors cannot be ruled out and relies on primary analysis being accurate. Therefore, the presence of changes in PHQ-9, GAD-7 and PQ scores could be due to statistical inaccuracy. Furthermore, Agatha may have misinterpreted or misunderstood the questions. At times, there also seemed to be a negotiation in given answers on measures with Jane, which may have resulted in inaccuracy in capturing Agatha's experiences. If the intervention had been truly effective, it would be expected that stable changes would have occurred as indicated on the measures.

Relational artefacts

Elliott (2002) suggests this can be evaluated by careful assessment of specific changes in Agatha's experiences and whether changes were identified due to a desire to impress or reassure the first author. Agatha said she was concerned about helping the first author by participating in the research and may have been subject to some type of social desirability bias, since the first author was known to Agatha prior to starting the intervention through Agatha's neuropsychological testing. Not only should Agatha's relationship with the first author be considered (which was seemingly strong according to SRS scores), but also her working alliance and relationship with Jane since ACT was used systemically in the triad between therapist, client and carer. The presence of Jane may have impacted the effectiveness of therapy. Thus, relational factors may have resulted in the identified changes.

Expectancy artefacts

Agatha reported hopes that therapy may be helpful to her which may have led to a strong motivation for improvement.

The following explanations, as suggested by Elliott (2002), stipulate that change has occurred but not due to therapy and is therefore as a result of the following factors:

1) self-correction
2) life events
3) psychobiological factors
4) reactive effects of research participation

Self-correction and other factors

This potential reason for change suggests that any improvement is caused by self-help outside of therapy, therefore, consideration should be given to between-session processes and facilitative conversations about therapy between Agatha and Jane, with Jane supporting Agatha with between-session tasks. Whilst it is evident that Agatha struggled with parts of the intervention, her perseverance meant she continued with the intervention until session six and could continue to engage in established hobbies and interests. Conversely, withdrawing early from the intervention meant she did not have full opportunity to benefit from it.

Life events

Agatha had been assessed and diagnosed with dementia just one month before starting the intervention, therefore the timeliness of the intervention may have been inappropriate, and any adjustment difficulties may have impacted its effectiveness. Furthermore, it is recognised that Agatha's abilities may have reduced according to the progressive nature of her dementia. It is queried whether her level of impairment and hearing difficulties acted as a barrier to her engagement with the intervention.

Moreover, changes to one's life during COVID-19 restrictions likely brought additional challenges which could understandably affect mood and wellbeing, rendering the intervention less effective.

Psychobiological factors

At the time of therapy, Agatha reported that she was often confused, did 'a lot of milling around' and stated that difficulties related to her dementia had worsened. As stated in the CI, Agatha had begun taking Donepezil just two weeks prior to starting therapy. Therefore, any positive changes identified (such as improvement in GAD-7 and PHQ-9 scores at one and three-month follow-up), may have been due to the medication reaching titration. Agatha also listed physical health difficulties and the many other medications she took during the CI, which may have had an influence upon her mood and sense of wellbeing.

Reactive effects of research participation

Agatha reported that she found therapy interesting and wanted to take part to see if it would be helpful to her. In wanting to help the first author by participating in the research, Agatha was subject to social desirability bias.

Lack of event-shift sequences

Changes were not sustained as Agatha's scores across all measures appeared to fluctuate throughout the intervention. It would be expected that significant therapy events would result in significant shifts in difficulties, but no reliable shifts were reported, nor helpful events in therapy according to the CI.

Conclusion

This sceptic case stipulates that:

- Agatha did not make any significant changes, hence, in this case, ACT was not a vehicle for therapeutic change.
- Any minor changes Agatha did identify were not attributed to therapy and were instead due to extra-therapeutic factors.
- This evidence contradicts evidence presented by the affirmative case

This evidence provides a basis for you to reject the case that Agatha changed substantially during therapy and infer that any change was caused by extra-therapeutic factors.

3.3 Phyllis' Full Rich Case Record

3.3.1 Phyllis' Goals

Using the PQ (Elliott et al., 1999), Phyllis generated personal goals for therapy which were as follows:

(i) To decrease frustration (due to tiredness, reduced mobility and difficulties finding things).
(ii) To decrease worry about asking for help.

3.3.2 Phyllis' Therapy Adaptations

To aid engagement and understanding, the following therapy adaptations were made:

- At Julie’s request, therapy was conducted via Zoom as Phyllis was familiar with using this platform, however, as there was a 40-minute time limit, sessions were moved to Microsoft Teams (MST).
- To support accessibility, at Julie’s request, a new MST link was sent in the morning before each session so that the email invite would appear at the top of Phyllis’ and Julie’s email inboxes.
- Flexibility with the starting time due to Phyllis’ difficulties with time management.
- Offer of regular breaks.
- Use of visual prompts (e.g., screen sharing the measures and materials from previous sessions).
- Providing more directive communication at times to aid concentration, for example, suggesting Phyllis close her eyes during mindfulness exercises as she could get caught up in thoughts about whether to do so if given the option. Whilst this may have been ACT-inconsistent, it was balanced with a need to give additional support and direction.
- At Phyllis’ and Julie’s request, the first author recorded a reading of a mindfulness script and emailed this to them both so Julie could support Phyllis with between-session practice.
- Emailing Phyllis and Julie materials used in session as a prompt for between-session tasks.
- Using repetition, especially on weeks where Phyllis was not wearing her hearing aid.
- Using concrete examples, provided by Phyllis, to support with ACT exercises.
- Negotiating and protecting time for both Phyllis and Julie to share their perspectives and feelings whilst maintaining a structure to sessions.
- At the end of the session, ending the MST meeting for all as Phyllis could not always successfully exit the meeting.

3.3.3 Phyllis’ Outcome Measures

Table 27. Phyllis’ process ratings

Process Measure	S1	S2	S3	S4	S5	S6	S7	S8	S9	S10	S11	S12
SRS	34	36	33	32	35	35	35	36	36	35	36	36

Note. S; session; - signifies missing data; maximum score of 40, with score of less than 36 indicating potential concern in the therapeutic relationship.

Table 28. Phyllis’ problem ratings

Personal Questionnaire	Clinical cut-off	RC min	S1	S6	S12	1-month	3-month
1. Feeling tired gets in the way of getting done what I want to or used to do (household chores), which makes me feel frustrated.	>3.25	1.67 (↓)	**5**	**5** (=)	**4** (=)	**5** (=)	**4** (=)
2. Feeling frustrated because I’m not as fast as I used to be on my legs.	>3.25	1.67 (↓)	**5**	**4** (=)	**5** (=)	**6** (=)	**6** (=)
3. Not wanting to ask my neighbour for help as they will be too busy.	>3.25	1.67 (↓)	**4**	**5** (=)	**4** (=)	**6** (-)	2 (+)
4. Feeling frustrated when I can’t find things.	>3.25	1.67 (↓)	**5**	**5** (=)	**5** (=)	**7** (-)	**4** (=)

Note. S; session; Likert scale range 1-7; higher scores indicate a greater problem; Values in bold fall within clinical range; (+) denotes reliable positive change in relation to first available score; (=) denotes no change; and (-) denotes reliable negative change.

Phyllis’ overall outcome measures and weekly session measures are presented in Table 29 below. There was reliable improvement in both anxiety and depression scores from baseline to the end of the intervention, according to the GAD-7 (Spitzer, et al., 2006) and PHQ-9 (Spitzer et al., 1999), which was maintained at one and three-month follow-up. Some of Phyllis’ problems, as identified on the PQ (Elliott et al., 1999), appeared to show fluctuations in reliable shifts in both directions (improving and worsening), such as difficulties with distress at asking her neighbour for help and feelings of frustration when misplacing belongings. However, these changes did not appear to be maintained over time. According to SRS (Duncan et al., 2003) scores, therapeutic alliance was generally stable, apart from at sessions three and four, when Phyllis gave lower scores due to some technical difficulties and connection issues with trialling Zoom and its time limit, meaning session content was disrupted and took time away from the session.

Table 29. Phyllis' Therapy and Process Measures

Measure	**Timepoint**														
	Screen	Session 1	Session 2	Session 3	Session 4	Session 5	Session 6	Session 7	Session 8	Session 9	Session 10	Session 11	Session 12	1-month follow-up	3-month follow-up
GAD-7 (clinical cut-off 8)	9	4					8						4	2	3
PHQ-9 (clinical cut-off 10)	12	3					7						5	5	6
SWEMWBS		27					25						24	25	23
PQ (out of 28)		19					19						18	24	16
CompACT-SF		21	21	21	26	22	19	21	22	18	20	23	20	24	22
SRS		34	36	33	32	35	35	35	36	36	35	36	36		

3.3.4 Phyllis’ Rich Case Summary

Do (meaningful) changes occur for Phyllis over the course of (and after) the ACT intervention?

Table 30. Evidence For and Against Meaningful Change- Phyllis

Therapeutic goals	**Supporting evidence** *(meaningful change did occur)*	**Refutational evidence** *(meaningful change did not occur)*
Change generally	**Change interview** “I have sort of made myself go out more and I've been going over to the Parish Hall to have lunches… I'm going to go to the [location] which is another community place for lunch, see if I can meet people and see people there”. Phyllis said she liked attending a local community centre and that it had given her other things to think about besides her own worries and problems. Both Phyllis and Julie seemed to recognise Phyllis’ increased openness and ability to discuss difficult thoughts and feelings; “It [therapy] felt alright, it's just that I'm not used to people asking sort of personal questions, so… but I got used to it as time went on, you know?” Julie reported a change she had noticed in Phyllis was that she was better able to ask for help; “…she'd [Phyllis had] been in the garden but then she said that she'd asked [neighbour], one of the girls that lives	**Change interview** “The thing that gets me is that I was unaware that I had any problems at the start, I thought I was perfectly normal and so when somebody starts talking about problems, I think, what problems?” “I don't think I have any problems, but I guess I have!” **Therapist notes** Phyllis stated she felt uncomfortable and embarrassed when others helped her. She said she did not have much opportunity to be helpful to others (session 6). Phyllis said maintaining her independence was getting harder and harder due to her physical abilities (‘leg trouble’) (session 6). Phyllis said she was not good with vocalising her gratitude to others and tended to be ‘grumbly’ to her children (session 6). Phyllis reported difficulties in planning steps towards committed action during COVID-19, for example, with meeting people in-person and said she did not email or phone enough (session 6).

	next door, if she would come and help. So, I said to her, "Well, that's really great", because that's something that we've talked about in the meetings with Amie is that, umm, asking for help… so, I was pleased that she'd done that because that's something we've been discussing over the weeks". Julie also recognised Phyllis had been attending more online classes such as therapy on Thursdays, a cafe on Wednesdays, a reading/art group on Tuesdays, and a singing group. Phyllis said she had enjoyed getting to know people at these online groups. Julie said Phyllis had also maintained regular contact with her family during COVID-19 via Zoom and FaceTime. **Change rating sheet** When asked, 'What was the change?' Phyllis identified she was going out more to the Parish Hall and community centre. She rated this change as being somewhat expected and that it was personally 'very important' to her. Phyllis also identified attending online groups more regularly and meeting people, which she said she was very much surprised by and was a 'very important' change for her.	Phyllis sometimes struggled to take planned steps towards committed action and stated that watching TV had got in way; "I haven't been working on it" (session 9). It seemed that a pervasive barrier to being mindful was ongoing, intrusive thoughts about housework; "It [untidiness of my house] is shameful" and Phyllis appeared to seek reassurance from Julie that the untidiness of her home could not be seen on the camera (session 11). Phyllis reported feeling 'stiff and sore' after doing lots of laundry the previous day and had chosen not to wait for her neighbour to help her with this (session 8).
To decrease frustration	**Therapist notes** Phyllis stated that dementia did not stop her from doing what she wanted to do (session 1).	**Therapist notes** Phyllis sometimes reported feeling 'rushed', 'harassed' and 'grumpy' on starting the session (sessions 2, 3, 10).

	Phyllis reported she had practised mindfulness before art class and found it relaxing (session 12). **PQ scores** Reduction in PQ ratings of this problem. Pre-therapy: score of 5 (feeling frustrated due to fatigue) End of therapy: score of 4 **Change interview** Julie reported a change she had noticed in Phyllis was that she was better able to ask for help, rather than struggle on her own.	Phyllis occasionally seemed to communicate frustration towards the therapist; “Amie, you ask some questions!” (session 11). Phyllis sometimes appeared frustrated and angry towards Julie; “You’re wasting our lesson time”, “Leave me alone, I can look after myself!” and seemed exasperated with Julie buying tickets for them both for an online event; “I’ve got jobs to do” (sessions 7, 8, 10).
To decrease worry	**Therapist notes** Phyllis appeared to engage well with mindfulness over time. Both Phyllis and Julie seemed to use and responded well to humour in session. **Change interview** Julie reported she had noticed Phyllis was better able to ask for help, despite ongoing worries about not wanting to bother people. **GAD-7 scores** Reduction across the intervention. Session 6: score of 8 Session 12: score of 4 1 month follow-up: score of 2	**Therapist notes** Phyllis identified barriers to working towards her goals, including ‘being down in the dumps’ (lacking motivation), staying up too late (tiredness), thoughts about what others would think of her and feelings of embarrassment (“People will see me hobbling along”) (session 9).

	PQ scores The PQ rating of worry (due to asking for help) seemed to become less bothersome over time. 1 month follow-up: score of 6 3 month follow-up: score of 2

Are observed changes broadly attributable to the ACT intervention?

Table 31. Evidence For and Against Changes attributable to therapy- Phyllis

Supporting evidence *(change is due to therapy)*	**Refutational evidence** *(change is due to external factors)*
Change interview/rating sheet The change of attending regular online groups was rated as ‘somewhat unlikely without therapy (probably would not have happened)’. Regarding going out more, Phyllis said, “…the therapy actually reminded me that it was there, whereas I think if I had been left on my own, I wouldn't even have thought about it, you know, I would have just stayed home reading a book or watching television, but because it was brought to my attention, then I ventured out”. When asked what she attributed changes to, Phyllis stated, “Well, I suppose it was someone else, like Amie, making the suggestions or just pointing out suggestions”. “Well, I think it's brought it to the foreground and I'm more aware of sort of going out and, talking to people or just observing what they do and trying to help if help is needed… yeah”. “Well, I think it's made me aware of sort of going out and making an effort to go out and mix with people”. Julie stated, “I really liked the fact that we got to talking about what her [Phyllis’] values are and then reflecting on what she was doing to, does that reflect your values? If it doesn't reflect your values, what could you	**Change interview/rating sheet** Going out more was a change Phyllis rated as ‘somewhat likely without therapy (probably would have happened)’. *Attribution- established coping skills.* “Well, I have been going to them [Parish Hall and community centre] before, but I haven't been going often enough, so I decided to go maybe twice a week instead of once a week… or whenever I feel like it”. *Attribution- established coping skills.* “… yes, because you get to see that everybody's got sort of their little worries or concerns, not just you, some of them have worse concerns than your own, so you sort of think, well, maybe I'm not so bad after all”. *Attribution- attending groups.* **Therapist notes** When feeling frustrated about not being able to do all that she wanted, Phyllis said she told herself she could not do it now or that ‘there’s always another day’. When reporting difficulties in accessing iPlayer on the TV, Phyllis said she was not bothered and would find another programme to watch (sessions 1, 2). *Attribution- established coping skills.* Phyllis said, “If I see a paper, I pick it up and read it even if I’m on my way to do a job… always hated housework… don’t appreciate being

do? It doesn't have to be big things, what small things could you do to live a life nearer to your values?"

She added, "And therefore, by doing the therapy we have been doing with Amie, we've had these kinds of conversations, whereas so by working with Amie, she's acted like, I suppose, a person who allows those conversations to happen because of the questions that she asked, whereas normally you would struggle to have the conversation with my mum"

Julie reported Phyllis was better able to defuse from thoughts; "…we had a conversation with Amie on the 1st July and in there we discussed about my mum going out and she talked about her thoughts about if she goes to the Parish Hall thinking about, 'Oh, people will see me hobbling', and that was one of the reasons that kind of put her off because of her mobility. But then we talked about how to defuse the thoughts and need to create distance from them. And I think that helped my mum a lot more 'cause I think she'd been focusing for quite a few weeks about her mobility and what people would think so I actually think by discussing that, she then started to go more regularly to the Parish Hall, to the cafe there, she'd been dwelling more on her mobility".

Julie felt that online therapy had worked well; "I think the fact that it's taken place on Zoom is good in a way, it is good, because if my mum would have to actually physically go somewhere to meet Amie, then that would have been a big barrier to her accessing it".

Therapist notes

in the house all day, I go to the [community centre] where people come and go where I can have a conversation with someone or just be around people" (session 4). *Attribution- established coping skills, committed action.*

Phyllis informed she had not practised mindfulness often as it was hard to do on her own; Julie had been unable to support Phyllis with it one week due to other commitments (session 5). *Attribution- family support.*

Phyllis stated she procrastinated, for example, she asked herself whether to book a hairdressers' appointment due to concerns about the price (session 2). However, by session 3, she had made an appointment and told herself, "I'm just going to do it". She said the therapist had made her more ruthless! Phyllis said it had been good to bring things up to think about [in therapy] so that if it cropped up in real life, she would have already given some thought to it (session 6). Phyllis was observed to engage well in an acceptance mindfulness exercise, was able to notice thoughts without acting on them and could describe her experience in visual terms (e.g., a 'feeling' in her calf which was pear-shaped and caused tension but had no colour) (session 11).	

What specific factors (within ACT or outside of it) contribute to observed changes?

Table 32. Evidence For and Against Therapy as a Mechanism of Change- Phyllis

Supporting evidence *(contributing internal factors)*	**Refutational evidence** *(contributing external factors)*
Therapeutic Alliance **SRS scores** Phyllis provided scores between 32 and 36 out of 40 on the SRS. Her lowest scores of 32 and 33 at sessions 3 and 4 were as a result of less satisfaction with the goals and topics covered. However, overall, she appeared satisfied with her relationship with the therapist and the therapist approach. **Change interview** Julie appeared to find sessions useful and supportive; “Yes, it was, that's a good way of saying it, as a nice conversation, but along the way, a supportive conversation, nice, supportive and making suggestions and lots of things to try… I think Amie did a really good job and she did meet with us and did talk to us…” Julie also mentioned adaptations made by the therapist; “I think she's [the therapist’s] worked round lots of ways like she emails me and my mum the link in the morning of Thursday mornings because she was emailing them a week before the session but then my mum couldn't find it on her emails. She made that adaptation… We were doing it on Zoom to begin with because that's what my mum was used to but then you’re timed out after 45 minutes… so that was a dilemma so then we moved to Teams, so I think she's adapted the technology as we've gone through to help my	Family/carer support **Change interview** “I appreciate my next-door neighbour more because she's always popping in and she will mail a letter or do bits of shopping, you know, she's very helpful”. Julie stated, “I realised that actually me being part of it [therapy] was a key part of the therapy because we have that conversation with Amie and then my conversations with my mum on the phone or face to face, if I was there, in the following weeks, I would say, “Right, so we've said that you were going to try this. Have you done it, or have you been out?” She added; “A conversation would go on after the meeting with Amie, you know. It's a catalyst… “Oh, remember, we said we're going to do this, or you were going to try that””. Personal attributes/established coping strategies **Therapist notes** Phyllis said she had learned to use Zoom during COIVD-19 (session 2) and had also learned to use MST to access therapy sessions. This new skill enabled her to join other online meetings. **Change interview**

mum access it more. She's made accommodations that way. Then, like the mindfulness, I asked her if she would record it and she recorded it and sent it as a link so then that we could practise it in between different times. ACT Techniques **Therapist notes** It seemed Phyllis referred to an increase in committed action when she said that she had realised that rather than sitting at home with books and the TV, that being with others was just as important and that she needed to make herself get out or call others (session 12). Julie said it had been helpful to have the therapist as an intermediary and taking conversation to a deeper level than they would have done on their own. She also said she had learned strategies to use in her own life (session 6). **Change interview** “Well, I think she [therapist] made me think of a lot of other aspects of what you could do to motivate yourself or to help yourself”. Julie reported that thought defusion was useful; “Amie was really good at trying to get my mum to like, have that distance between, what was the phrase? ‘I'm having the thoughts that’ to put a distance between your thought rather than, you know, put that distance in and think well, ‘I'm thinking that’ but try to overcome that thought to then enable you to go out”.	Phyllis reported she found the use of technology (using the iPad to join online meetings) relatively easy since she and her husband had attended computer courses from the 1980s. Phyllis stated she had used the local community centre for many years; “Well, it's been very fortunate that we've had this [community centre] because we're not too far away from it, it's close at hand and it gave us something to do”. Julie reported Phyllis liked to help, was very interested in ideas, reading and discussions and that she had chosen to take on the challenge of therapy.

Julie also appeared to find the values-work helpful; “I think the looking at values and what my mum’s values are, see, she's touched about that about going out, talking about that, but we had lots of discussions about, you know, she wants to be helpful or being grateful or being independent”.

She added; “… like the discussions we had about thoughts, you can accept that thought, but think about what you might do or other ways you can change to like what your values are to meet those core values that you might have”.

Julie also appeared grateful for facilitative conversation in a way that may not have been achieved alone; “…so I suppose it explores the dynamics between your relationship as well”.

3.3.5 Phyllis' Briefs

3.3.5.1 Phyllis' Affirmative Case

The affirmative case proposes that there are clear links between therapy process and outcome, and requires at least two of the following pieces of evidence, as outlined by Elliott (2002):

1) change in stable client problems (client experiences changes in longstanding or chronic difficulties)
2) retrospective attribution
3) outcome-process mapping (content of the CI plausibly matches specific events, aspects, or processes within therapy)
4) event-shift sequences (significant therapy events are followed forward in time for evidence of their later effects e.g., stable shifts in client distress).

<u>Changes across therapy</u>

Phyllis' scores changed on the PHQ-9 and GAD-7. Though not the primary aim of ACT, this indicates symptoms reduced over the course of the intervention. This may be attributed to Phyllis' increased PF in enabling her to become more open to the experience of difficult thoughts and feelings, increased behavioural awareness and improvements in functional ability through re-engaging in meaningful, value-led activity. Though not necessarily reflected in Phyllis' CompACT-SF scores, Phyllis engaged in valued action such as going to the Parish Hall and community centre (in line with her value of connectedness with others) which may have resulted in improvements in her mood. Lack of significant improvement in other areas, according to the other measures, may owe to Phyllis' difficulties in recalling the past week.

Over time, Phyllis appeared to engage well in mindfulness and the weekly three-minute present moment awareness exercise, reflecting that she was becoming more skilled at mindfulness and able to notice thoughts without using experiential avoidance to distract from them. Furthermore, through therapy, it was acknowledged by both Phyllis and Julie that Phyllis' ability to discuss her experiences and feelings openly was a huge improvement. Therefore, ACT could have been a vehicle for therapeutic change for Phyllis.

Retrospective attribution

Retrospective attribution requires Phyllis to attribute any changes she noticed to therapy, which is highlighted in the CI and change rating sheets when asked how likely she thought the identified changes would have been without therapy. Phyllis reported in the CI that she had noticed the positive change of attending online meetings, which would have been ‘somewhat’ unlikely without therapy.

Therapist attributed these changes to the therapy

It may be helpful to consider whether the therapist attributed any changes to the therapy using knowledge of Phyllis, her presentation and through discussion within sessions. With Julie’s support, Phyllis was observed to engage in planned committed action exercises between sessions. Understandably, it is recognised that Phyllis may have had difficulty in reflecting upon therapy and in identifying changes without support, as mentioned in the CI. However, Phyllis seemed to respond very positively to therapy and was able to make quick and effective changes in her daily life.

Process-outcome mapping

Process-outcome mapping refers to Phyllis’ CI information about significant events corresponding with aspects or processes within therapy. In the CI, when discussing the positive change of attending online groups, Phyllis said that this had occurred over the past two or three months, which maps onto the same timeframe as the therapy took place (May-July 2021).

The first author and Julie noticed Phyllis could maintain her concentration for longer periods, not only in therapy, but according to Julie, outside of therapy, for example, during their online art class. Therefore, it would be expected that Phyllis’ CompACT-SF scores would increase from session four onwards when mindfulness was introduced. CompACT-SF scores were highest at session four, however this was not maintained over time, which may highlight potential reliability issues when using self-report measures in the context of memory difficulties.

Change in stable problems

Phyllis informed she had been ‘a procrastinator a long time’ which could act as a barrier to committed action and negatively impact her mood. It may be assumed that the therapeutic intervention is responsible for change when this occurs in chronic, pervasive difficulties. In the CI, Phyllis described how therapy had made her realise she should make an effort to go out and mix with people. Julie also reported that Phyllis seemed to be able to defuse from the thought that ‘people will see me hobbling’ and so was able to re-engage in things she enjoyed (going to the Parish Hall).

Changes not due to relational artefacts

It did not appear that changes were due to relational artefacts (the client emphasising change to please the first author) as the first author and therapeutic relationship was not mentioned by Phyllis during the CI but more so by Julie. It seemed Phyllis could occasionally communicate frustration to the first author, possibly if she felt her cognitive difficulties had been exposed (e.g., “Amie, you ask some questions!”), which may have affected the therapeutic relationship. However, SRS scores suggest that the therapeutic relationship remained strong throughout therapy. Scores remained stable and were not shown to increase steadily over time. Furthermore, there may have been some internal consistency in Phyllis and Julie’s relationship as Julie tended to ‘chip in’ to discussion as she would in day-to-day life and helped to prompt Phyllis’ recall. Moreover, it is unknown whether the therapeutic relationship, Phyllis’ engagement or therapy effectiveness may have increased if therapy had taken place in person rather than online. Therefore, relational factors between the first author and Phyllis and Phyllis and Julie cannot fully account for the improvements identified over the course of the therapy.

Changes not due to expectancy artefacts

This pertains to whether changes occurred due to Phyllis’ expectations or hopes for change. Phyllis identified the change of attending more online groups as very surprising to her. She also said that she did not know what she was entering into when starting therapy and both Phyllis and Julie denied they had any preconceived ideas or expectations for therapy, instead, felt it was an exploration (“No, I don't think I particularly wanted to change anything 'cause

I'm, I just didn't think about it that way”). Therefore, changes are unlikely due to expectancy artefacts.

Statistical artefacts

All clinical cut-off scores are approximate and have been calculated using existing means for clinical and/or non-clinical populations. Therefore, the affirmative case suggests that Type II errors could be responsible for lack of significant change in measures. Due to Phyllis’s attention and memory difficulties, she could find some of the wording in the questionnaires confusing and required prompting to aid her understanding, which may explain why significant change was absent in some measures. The sensitivity of the measures may also be questionable when used with older adults with memory difficulties.

Conclusion

This affirmative case stipulates that:

- Phyllis demonstrated substantial change in her problems .
- Phyllis attributed these changes to therapy, even if her psychometric scores did not correspond with sessions.
- The therapist attributed most of these changes to therapy.
- This evidence contradicts sceptic non-therapy reasons for change and/or lack of change.

This evidence provides a basis for you to support the case that Phyllis changed substantially during the period of therapy and infer that this change was caused by her participation in the ACT intervention.

3.3.5.2 Phyllis’ Sceptic Case

This sceptic brief describes a good attempt to counter the argument that Phyllis changed substantially during therapy and that this change was due to the intervention. As suggested by Elliott (2002), the sceptic case will examine Phyllis’ case record for evidence of alternative explanations.

The following explanations suggest that any observed changes do not represent clinical improvement due to:

1) trivial or negative changes on measurement
2) statistical artefacts
3) relational artefacts
4) expectancy artefacts

Trivial or negative changes on measurement

Phyllis' problems were not stable since her screening scores had improved considerably by session one. This may indicate that the distress she experienced would have naturally improved without therapy. Though some measures showed improvement, others did not, which may suggest that ACT processes were less transferrable to older adults with dementia and thus did not result in symptom reduction.

Statistical artefacts

Statistical errors cannot be ruled out and relies on primary analysis being accurate. Therefore, the presence of a change in PHQ-9 and GAD-7 scores could be due to statistical inaccuracy. Furthermore, Phyllis may have misinterpreted or misunderstood the questions and had difficulties reflecting upon previous weeks due to her dementia, rendering scores invalid. At times, there also seemed to be a negotiation in given answers on measures with Julie, which therefore questions the extent to which Julie's presence was helpful in these instances. If the intervention had been truly effective, it would be expected that stable changes would have occurred as indicated on the measures.

Relational artefacts

Elliott (2002) suggests this can be evaluated by careful assessment of specific changes in Phyllis' experiences and whether changes were identified due to a desire to impress or reassure the first author. Not only should Phyllis' relationship with the first author be considered (which was seemingly strong according to SRS scores), but also her working alliance and relationship with Julie since ACT was used systemically in the triad between therapist, client and carer. Julie's involvement was generally deemed helpful since the management of Phyllis' distress became shared, similar to real life clinical practice and the context in which Phyllis was living. Moreover, there were evidently between-session processes with facilitative conversations about therapy outside of sessions, with Julie prompting and supporting Phyllis with between-session tasks. Thus, relational factors may have resulted in the identified improvements.

Expectancy artefacts

Though not particularly verbalised by Phyllis, Julie appeared to have expectations about therapy in helping others by investigating whether ACT was effective for people with dementia. She said, "We got involved through Dementia Research, so I said to my mum, "Well, if by being involved you help somebody else, you know, further down the line or help somebody else in the same situation as you…"". Since Julie was involved in the intervention and spoke of her motivations for participating in therapy in Phyllis' presence, this may have influenced Phyllis' expectations or hopes for therapy.

The following explanations, as suggested by Elliott (2002), stipulate that change has occurred but not due to therapy and is therefore as a result of the following factors:

5) self-correction
6) life events
7) psychobiological factors
8) reactive effects of research participation

Self-correction and other factors

This potential reason for change suggests that any improvement is caused by self-help outside of therapy. As previously discussed, consideration should be given to between-session processes and facilitative conversations about therapy between Phyllis and Julie, with Julie supporting Phyllis with between-session tasks. Over the course of therapy, Phyllis also increased her engagement in established hobbies and interests.

Life events

Phyllis did not experience any major life events over the three months of therapy; however, it is recognised that her abilities may have reduced according to the progressive nature of her dementia. Phyllis had difficulty in reflecting upon and recalling the detail of previous sessions, and therefore required support from Julie to do so.

Furthermore, changes to one's life during COVID-19 restrictions likely brought additional challenges which could understandably affect mood and wellbeing, rendering the intervention less effective. Alternatively, some improvements in mood may have been as a result of lighter nights and better weather, enabling Phyllis to re-engage in interests that may have been harder to do in winter months, such as travelling to the Parish Hall.

Psychobiological factors

Phyllis reported fluctuations in physical discomfort and chronic fatigue which may have accounted for variation in her scores, particularly as fluctuations indicating improvement were not statistically significant week-to-week. Phyllis took medications for her blood and muscles and vitamins for her general health, all of which may have had an effect on her mood or sense of wellbeing.

Reactive effects of research participation

Julie reported that she and Phyllis had had more open conversations in therapy than in normal day-to-day life. Phyllis and Julie's overall positive experience of therapy may therefore explain the positive changes identified.

Lack of event-shift sequences

Any changes were not sustained as Phyllis' scores across all measures appeared to fluctuate throughout the intervention. It would be expected that significant therapy events would result in significant shifts in difficulties, yet only weak evidence exists for event-shift sequences because reliable shifts did not occur when coinciding with helpful events, as per Phyllis' CI.

Conclusion

This sceptic case stipulates that:

- Phyllis did not make significant changes
- Phyllis did not attribute changes to therapy
- Any minor changes made were due to extra-therapeutic factors

- This evidence contradicts evidence presented by the affirmative case

This evidence provides a basis for you to reject the case that Phyllis changed substantially during therapy and infer that any change was caused by extra-therapeutic factors.

4.0 Extended Discussion

4.1 Current Study Findings within the Extant Literature

4.1.1 Effectiveness of ACT

The efficacy of ACT for anxiety and depression is supported by meta-analyses which have shown large effect sizes pre- to post-intervention and at follow-up (Hacker et al., 2016; Ruiz, 2010). The efficacy of ACT in treating psychological difficulties with comorbid physical health problems is also evidenced (Gaudiano, 2011; Hann & McCreacken, 2014). However, the methodological rigour of ACT trials has been criticised for using treatment-as-usual rather than control comparison groups (Öst, 2008). In dementia meta-analyses, there remain uncertainties about risk of bias in psychological treatments of depression and anxiety due to the use of combined, multimodal treatments, rather than one distinct psychological approach (Orgeta et al., 2014). Hence, the current study used a well-defined psychological therapy with robust underlying psychological theory and its consistency and fidelity were measured throughout.

Since no single-case designs had been employed to assess the effectiveness of ACT, the examination of ideographic level change in the current study provided useful data for understanding active processes in psychotherapy.

In the current study, on balance and drawing upon all available evidence, it was concluded that one client changed and two did not. Where change occurred, this was largely attributed to ACT processes, specifically the mediating roles of values, committed action and acceptance. This finding is supported by the literature, which suggests values work can mediate change and support increased committed action (Bacon et al., 2014; Ren et al., 2019; Smith, 2017). Furthermore, acceptance as an underlying mechanism of change in ACT and its role in improving outcomes in the current study is also supported by systematic reviews, meta-analysis (Ren et al.) and qualitative analysis (Smith). Moreover, the role of acceptance in outcomes has been demonstrated in parallel populations, such as those with chronic physical conditions (Åkerblom et al., 2015).

Similar to previous literature using ACT with older adults (Karlin et al., 2013), where higher levels of PF were related with lower distress (Hayes et al., 2013), increased PF in the current study seemed to be associated with improvements in psychological distress, mainly depression. This also supports ACT process literature, which implies PF strongly mediates symptom improvement and client functioning. This may suggest that distress is state-dependent rather than static or chronic, and sensitive to increases in PF in this population. Moreover, distress reduction occurred for these clients without therapeutic aims to change or alter their distressing thoughts.

However, arguably most importantly, the mediating role of the client-carer relationship and presence of the carer as both co-therapist and co-client was necessary to support the client to facilitate values-based action and overall therapeutic change. Hence, the current study supports the systemic use of ACT in this population, which is consistent with some of the child and adolescent literature when a parent is present and acts as a co-therapist (Barmish & Kendall, 2005; Manassis et al., 2014). Results also showed that additional client factors partially moderated therapeutic outcomes, including client willingness and engagement, resilience, and perseverance, and established coping and hobbies (values-driven behaviour). These findings lend themselves to the debate about common versus specific factors (Wampold, 2015), with disagreements related to the client-carer relationship, client expectancy, and process (common factors) and procedural techniques (specific factors; Mulder et al., 2017) on therapeutic change. For example, some clients may have embarked on therapy with an established, strong working alliance with their carer and, thus, the characteristics of their relationship had an extra-therapeutic influence on outcomes, rather than something that the therapist or intervention provided. In comparison, advocates of the specific factors argument may purport that some therapies with the most powerful specific ingredients, depending on the psychological difficulty or population, would be more effective than others. There is evidence of some case-to-case transferability of positive outcomes in ACT in the current study, since there was notable client heterogeneity (e.g., level of cognitive impairment, type of and time since diagnosis, individual traits). Two of the three clients demonstrated reliable improvement in anxiety and depression at one and three-month follow-up, with both ACT-specific processes and generic therapy factors considered facilitative of change, which indicates that effects were not confined to one case or homogenous cases.

The timing of the offered intervention likely mirrored challenges in real-life clinical practice because although Agatha received her dementia diagnosis a short time before embarking on therapy, it could be argued that she had already been processing and reconciling her memory difficulties in advance of the diagnosis. Moreover, individual traits that seemed to strengthen engagement in therapy included increased openness, a history of values-based behaviour, resourcefulness, longstanding helpful coping strategies and personal resilience and perseverance. Hence, for people with dementia, it seemed more important to build upon pre-existing resources, understandings, and behavioural repertoires, rather than new learning. Conversely, considering the lifespan, perhaps cohort beliefs and lived historical changes may have served to engrain longstanding behavioural repertoires, such as experiential avoidance, self-as-content, and fusion to thoughts, which caused difficulty in learning, integrating, and applying ACT concepts to daily living to evoke behaviour shifts. ACT challenges many commonly held assumptions about thoughts, emotions, and behaviours and, thus, requires people to be open to a different and often counterintuitive way of viewing their inner world.

In the context of the sample, it may be speculated that Minnie was the most likely to benefit from any therapy given she was the youngest and with one impact event (bereavement) affecting her mood, in comparison to Agatha and Phyllis, who were between 14-19 years older with arguably more chronic or trait-dependent mood difficulties. However, judges were provided with a comprehensive dataset for each client and when the rich case records were analysed on an individual basis, neither age nor the nature of impact events were highlighted as distinctively mediating or moderating change. Therefore, these factors may or may not relate to outcome. Overall, the current study showed that ACT could be a vehicle of change for some, which is supported by older adult research suggesting ACT is suitable based on older adults' diverse difficulties (Petkus & Wetherell, 2013).

4.1.2 Acceptability of ACT in dementia

4.1.2.1 Carer-supported delivery

The client-carer relationship in this study was revealed to be a mediator of therapeutic outcomes, which offers a novel contribution to the literature. Those with a strong, at least, working alliance with their carer, separate to their personal relationship, appeared to benefit more from therapy. In some ways, carer involvement meant that the management of the clients' distress in therapy became shared, mirroring the context in which clients were living, by becoming more reliant on others due to the progressive nature of their dementia.

The role of the carer likely began at recruitment, by supporting the research team's access to clients, meaning clients with a range of ability participated. Two carers informed that they had wanted to participate in the study to help others in their situation in the future, indicating some personal expectations of the research. Once therapy had begun, two of the carers alluded to between-session processes with ongoing facilitative conversations about therapy outside of sessions with the person they cared for. There may have been some internal consistency in carer behaviours, such as prompting the clients' recall and supporting with between-session tasks.

Clients' cognitive ability and reflective capacity was not explicitly measured in the current study, however, previous studies have proposed that cognitive processes, such as attention, information processing and memory, can influence therapy outcomes (Green et al., 2004), with more self-reflective people more likely to benefit from insight-based approaches (Beutler, et al., 2006). This, understandably, can prove difficult for people with dementia, hence, the role of the carer in the study likely enabled the clients to better integrate ACT into their lives to encourage behavioural shifts and build upon pre-existing resources. Thus, acceptability was improved by carers in better meeting the needs of their loved ones.

4.1.2.2 Remote delivery

For some, it was indicated that therapy by videocall enabled improved accessibility so that clients could remain in their own or family's homes, especially in the context of COVID-19 and for those whose carers did not live locally. It seemed engagement in remote therapy was influenced by the client or carers' willingness and aptitude to use technology. For some, online-delivered ACT was effective in reducing symptoms of psychological distress (Pots et al., 2016). Conversely, for other clients, the contextual complexities of remote therapy likely hindered their engagement and they stated they would have preferred therapy in person. This supports the literature that remote-ACT may be associated with increased disengagement (Herbert et al., 2017). Though there is evidence to suggest that ACT via videocall is comparable to face-to-face delivery, there may be associated increased attrition rates with remote therapy (Herbert et al.), which was true of one client-carer dyad.

4.1.2.3 Therapy adaptations

Psychotherapy can be difficult to standardise because there is a level of responsiveness and adaptation needed based on clients' progress and engagement (Christie & Fleischer, 2009). Therefore, to support both client cognition, remote delivery and engagement, several common adaptations were made before and during therapy. This included offer of regular breaks, use of visual prompts (Robinson & Moghaddam, 2022), repetition (Grant & Casey, 1995), directive communication (Robie, 1999), tangible examples and negotiation of time between clients and carers.

To slow the pace of therapy and offer an increased number of sessions, the 'Better Living with Illness' (Brassington et al., 2016) protocol was extended to 12 weeks, as suggested by previous literature (Robie, 1999; Robinson & Moghaddam, 2022). Intervention length was deemed important to this client group as sufficient time was required for clients with both cognitive impairment and mental health difficulties to understand the process and content of the intervention and become socialised to the therapeutic model to offer adequate time for reliable, psychological shifts. Furthermore, behavioural strategies were emphasised, with use of procedural learning and modelling during intervention delivery (Grant & Casey, 1995).

Even with adaptations, it was observed that some ACT metaphors were less transferrable to an older adult population with dementia, such as the ‘80th Birthday Party’ and ‘Passengers on a Bus’ metaphors (Hayes et al., 1999). It seemed clients could get caught up in thoughts about the practicalities or physical properties of the metaphors (e.g., the appearance of passengers on the bus). Shorter and more immediate exercises, rather than more cognitively taxing or abstract exercises, such as the ‘beach ball’ metaphor, which were less reliant upon retention and memory, were found to be more useful in introducing concepts and may have offered support for those less able to generate ideas independently.

4.2 Clinical Implications

The current study provides some evidence that ACT is a feasible intervention for reducing psychological distress in people with dementia and evidence for use of indirect ACT with carers. The current study identified specific therapy components that may be important to consider when using ACT systemically with people with dementia. These include supporting a strong working alliance between client and carer, facilitating exposure to and acceptance of avoided or suppressed emotions, and identifying values and planning value-driven behaviour to support engagement and motivation in therapy. There would also be value in considering individual client characteristics for assessing suitability and possible benefit from therapy, including client willingness, resilience, perseverance, and readiness for therapy. Whilst there was a likely client burden in completing extra outcome measures, there may be utility in weekly process measures and/or post-therapy CIs to further monitor and understand change processes in real-life clinical practice. However, due to queries about the reliability of self-report measures in the context of memory difficulties, the selection of measures would need critical consideration. For example, in the current study, there were noticeable difficulties for at least two of the clients in completing the CompACT-SF (Morris, 2019). More abstract constructs, like PF, may be harder to conceptualise for people with dementia, hence, assessment using standardised measures alone may not be suitable. A combination of both quantitative and qualitative data and use of behavioural and observational measures may be more beneficial.

Finally, due to the variance in the utility of remote-ACT between clients in this study, the service pathway in older adult services, such as MAS, may need to offer increased flexibility regarding therapy delivery (in-person or video) to accommodate cognitive and sensory impairments and improve therapy acceptability.

4.3 Theoretical Implications

In this study, reliable distress reduction occurred for one client. It was concluded that this outcome was largely as a result of the clients' experience of therapy and process-outcome links inferred that ACT processes had a partial mediating role. Results indicated increased value-driven behaviour, irrespective of continuing unpleasant thoughts and feelings. Although there was a lack of significant improvement on the CompACT-SF (Morris, 2019), this finding may suggest that PF did, in fact, increase. Corroborated by their carers in the CIs, clients seemed better able to cope with painful inner experiences so that they could engage in what was important to them. Furthermore, symptom reduction may have occurred secondarily to increased PF (Harris, 2006). Positive outcomes for some in this study indicates the potential utility of acceptance-based approaches to authentically validate the experience of people with dementia, and can seemingly be adapted enough so that, with carer support, ACT concepts can be applied to make a difference to the way a person with dementia lives their life. The dyadic change processes between client and carer, evident in the current study, is thought to fit conceptually with PF.

4.4 Research Implications

This study shows tentative but promising findings for the clinical use of ACT for some people with dementia experiencing psychological distress. With carer assistance, people with dementia can be encouraged to become accepting of the distress often associated with their condition, in the service of engaging in meaningful and valued living using their remaining resources for as long as they are able. The current study contributed to the scarce evidence-base by examining ideographic level changes through the use of a multiple case series approach, providing findings that were highly relevant to clinical practice. Moreover, the current study highlighted the difficulties of unpicking common therapy from non-therapy processes on psychotherapy effectiveness more broadly, particularly the role of the client-carer relationship in facilitating change.

Although not an aim of the current research, questions regarding whether client change occurred by proxy (via change in the carer as a co-client in therapy) or co-facilitation (with the carer acting as co-therapist) remain unanswered and would require further exploration. Therefore, future systemic ACT studies may benefit from additional measures of carer factors to develop understanding around active-therapeutic ingredients. For example, using alliance or observational measures to gather independent ratings of the client-carer relationship in therapy, or assessing the PF of carers alongside the PF of the people they cared for.

Moreover, there is scope to optimise ACT delivery considering the intervention, inclusion criteria, and measurements used, with a view to delivering a new case-series in future research.

4.4.1 Improvement rates

It is useful to consider the improvement/recovery rates in this study in reference to rates in psychotherapy more broadly. In Phyllis' case, her quantitative data, as compared with NHS data on recovery rates (NHS Digital, 2018), would suggest she fell within the 'recovered' bracket. Thus, overall, two of the three cases in this study were in a non-clinical, recovered range for distress after receiving the intervention. This compares well with recovery rates in Improving Access to Psychological Therapy (IAPT; ~50%; NHS Digital) and naturalistic therapy settings (~20%; Hansen et al., 2002). However, it is unclear whether change in Phyllis' case was stable and therapy-mediated, owing to the change in scores from baseline to first session. This makes it difficult to show reliable or clinically significant change in distress on anxiety and depression measures, meaning this study could only fully assess change in two cases, where it was concluded Minnie changed and Agatha did not.

4.5 Extended Critique

4.5.1 Design

A strength of the HSCED used in this study was that it drew upon multiple types and sources of data and analysis to investigate change for three clients with dementia experiencing psychological distress. It provided insight into ACT, the client group and change processes, offering research-practice links.

Nonetheless, HSCEDs are infrequently used in research studies, possibly due to their complexity and high resource demand, with the involvement of an analysis team and independent judges. A limitation of the HSCED is its reliance on the judges in influencing the outcomes of the research. In the current study, judges appeared to use different pieces of evidence in the rich case records to draw conclusions about the effectiveness of the intervention, likely influenced by their clinical area of expertise, theoretical orientation and understanding of what client change looked like. This indicates that the burden of proof may be different for each judge and reflective of their own experience and biases (Elliott et al., 2021), highlighting possible differences between statistical differences in theory versus more achievable differences in practice (Ranganathan et al., 2015).

4.5.2 Measurement

Quantitative measures used in the study were chosen due to their psychometric properties, utility with older adults and to reduce client burden as much as possible. However, one limitation was the variance in baseline measures, suggesting a lack of pre-intervention stability. Therefore, it was difficult to be sure whether psychological difficulties would have naturally improved without therapy.

The use of the PQ (Elliott et al., 1999), in particular, may have been ACT-incongruent. It may have miscommunicated to clients that the aim of therapy was to help minimise their identified problem areas, when the aim of ACT was, instead, to try to alter how they perceived and responded to their difficulties (Hayes et al., 2013). Problem areas identified by clients on the PQ (Elliott et al.) were mostly related to the removal of aversive experiences associated with their memory difficulties, which could have served to reinforce psychological inflexibility (experiential avoidance).

In general, there is uncertainty in the reliability of self-report measures in the context of memory difficulties due to reduced reflective capacity and comprehension. Hence, the stability or consistency of given answers were possibly state-dependent. Furthermore, due to attention and memory difficulties, some of the wording in the measures were not easily understood by all clients, and so required scaffolding and examples to aid understanding. This then risked negotiation of answers with their carers, which questioned the accuracy of capturing client experiences. Therefore, without confidence in self-report measures, it would be hard to detect clinically significant improvement and a lack of significant change in measures may have masked the full effects of the intervention. Commenting on client engagement with between-session tasks and therapy process notes regarding behavioural change in the rich case records may have supported judicial outcomes (Benelli et al., 2015).

4.5.3 Sample Characteristics

The HSCED often requires researchers to address complexities, ambiguities, and contradictions ignored in traditional designs and raises broader questions about external validity and causality in psychotherapy (Elliott, 2002). Hence, the HSCED is interpretive in making logical inferences between cases and focuses upon detail and process, rather than offering statistical generalisability. For example, the HSCED enabled understanding of the mediators and moderators of change in this study, and why particular processes were more or less important in one case than in another, rather than focusing on the presence or absence of an effect. If this was the case, there would have likely been an issue of replication in the current study since Minnie improved over therapy, but Agatha and Phyllis did not. The role of consensus in this type of research takes a functional contextual position, hence, agreement about the presence or absence of an effect between cases is less important.

In line with best practice standards, in HSCEDs, there is a convention of three clients per case series to be able to offer transferability of effects between cases. Other HSCEDs (Morris et al., 2018; O’Keeffe et al., 2021) have used this sample size to address questions about the applicability of ACT in other populations. Despite differences in the holistic outcomes of the judges in the current study, there was evidence of case-to-case transferability of ACT processes and generic therapy factors between Minnie and Phyllis. This indicates the sample size was suitable in demonstrating similar processes. However, there may also be benefit to a larger sample without undermining the epistemological position of the HSCED. Looking across more cases would likely offer increased variation in therapy, non-therapy and individual factors over different contexts and a larger data set from which to make interpretative inferences between cases.

All clients and carers in the current study were White-British females. Clients were between the ages of 71-90 years old and supported by their adult daughters in therapy. This was a natural consequence of the study method, which initially aimed to recruit all clients from a MAS in Nottinghamshire. These demographics are consistent with those of dementia populations, since estimates indicate 65% of people living with dementia in the UK are female (Prince et al., 2014) and 60-70% of carers for people with dementia are women (Alzheimer’s Research UK, 2015).

There were no formal criteria regarding clients’ cognitive ability, however, the gatekeeper and first author used the inclusion/exclusion criteria and clinical judgement to consider clients’ functional ability, likelihood of engaging in therapy and of understanding the consent process.

There was heterogeneity between the clients (e.g., level of cognitive impairment, type of and time since diagnosis, individual traits) which may limit cross-case comparisons. Conversely, the transdiagnostic nature of ACT may enable findings to be extended across heterogenous groups.

4.5.4 Potential sources of bias

In the current study, there were initial recruitment difficulties. It is questioned whether a barrier to recruitment was sending the Participant Information Sheet remotely to clients and their carers, rather than going through it with them together. This may have led to misconceptions about ACT, for example, if a client was experientially avoiding unpleasant experiences, whether that meant they were less willing to participate. Moreover, choosing from a pool of people who recently received a diagnosis in MAS brought into question the timeliness of therapy in their dementia journey. Furthermore, in her CI, Agatha alluded to concerns about the burden of time therapy would have on her daughter, which may have been a factor in deciding to withdraw early from therapy. However, these recruitment issues may be more general to therapy research rather than to an ACT interventions per se. In line with HSCED guidance, recruitment from MAS was used to mirror ‘real-life’ care as closely as possible to increase the ecological validity of the study.

Regarding data collection, clients received the ACT intervention from the same therapist (first author) and given that the first author had a degree of investment in the study continuation, it may be that additional effort was made to support clients through therapy. Moreover, the completion of self-report measures in the presence of the first author may have increased the risk of social desirability or self-presentational bias, but this was a practical decision to minimise the chance of missing data.

Tentative conclusions may be drawn about the use of specific adaptations in improving engagement with therapy for people with dementia, but those identified are vague and so cannot be reliably tested or causally linked to outcomes. Furthermore, therapy delivered with adaptations was not directly compared against therapy delivered without them.

In relation to analysis, though systematic and self-reflective, the use of expert judges was arguably a source of bias, according to their own preconceptions, interests and assumptions when analysing client data. Though judges were invited to participate based on their specialist knowledge of delivering and researching ACT in older adult and physical healthcare contexts, they were not completely ‘independent’ since one worked within Nottinghamshire, and all had varying professional links to the first author’s doctoral programme. However, the aim in HSCED is not to exert high levels of control to reduce all bias. Its underlying theory suggests that probabilistic knowledge claims are derived from a subjective, interpretative stance, rather than to purport declarations of absolute knowledge (Elliott, 2015).

5.0 Critical Reflective Section

I have always had a passion for working with older adults. Pre-training, I worked in a MAS, administering cognitive assessments and facilitating CST groups. However, at that time, I had not had the opportunity to deliver therapy with older adults with memory difficulties.

I had not heard of HSCED before considering doctoral project ideas but was interested in how it could support an investigation into therapy effectiveness. I had come across ACT in the first year of training, though had next to no experience of using it clinically and was interested to investigate if it could be applied to people with dementia. The underlying theory of ACT states that psychological pain is a normal and inevitable part of life, but that it does not inherently cause psychological difficulty (Harris, 2006). This resonated with me. I figured there were conceptual reasons for trialling ACT with people with dementia. Perhaps with a theoretical focus on PF and acceptance, a person with dementia could be encouraged to focus on their remaining resources and continue to lead a meaningful life, despite the challenges and losses along the way? I wondered if ACT could be particularly beneficial for those trying to adapt to living with cognitive impairment but using the same control-based coping strategies, with regular attempts to lead their lives as they had prior to their diagnoses, illustrative of some older adults who use unworkable actions (Isaacowitz & Seligman, 2002). I could understand how trying to avoid or control difficulties brought by dementia may have developed in the context of one's life but recognised that this could lead to further suffering. Despite its transdiagnostic approach with promising evidence in parallel populations (such as those with long-term physical health difficulties), I was unsure of the natural transferability of ACT to a dementia population due its very nature of progressive cognitive impairment.

5.1 Recruitment

The inclusion/exclusion criteria used for recruitment were chosen as a resemblance of service criteria, to identify the target population and to ensure the intervention had the best chance of evoking improvement. However, I underestimated the time it would take to recruit appropriate people to the study.

My understanding was that the usual care in MAS, from which I was recruiting, generally involved pharmacological treatment. However, if medication was deemed inappropriate, many people with dementia were often referred back to the care of their GP, unless they had any additional support needs, in which case, they may be signposted to third sector organisations, such as the Alzheimer's Society or their Local Mental Health Team, and then discharged. Psychological intervention was not routinely offered following a dementia diagnosis and I, thus, believed that study participation would not interfere with, but add to, the clients' usual treatment.

Possibly due to the reliance on gatekeepers in identifying appropriate participants and natural through-fare of referrals to MAS, recruitment took longer than anticipated. I then took to the Dementia Research UK website to recruit and sent many emails with the current study's details to people with dementia and their carers if they had shown an interest in the type of research I was offering. Due to recruitment difficulties, I also submitted a major amendment for ethics approval to include people with MCI, if necessary, with a clinical rationale, but did not need to use this in the end. I was very aware of what delayed recruitment might mean for my research timescale. I have since learned that I should have, ideally, started recruitment sooner, however, I am unsure whether I could have done much differently due to the underestimated, lengthy ethics process.

5.2 Dual role of therapist & researcher

As I felt a responsibility for my project, to resemble clinical practice and in order to ensure adherence to the ACT model, I suggested to the research team that I deliver the ACT intervention. I was certainly anxious about managing the pressure of delivering a research intervention but felt confident that by increasing my competence in ACT through formal training, reading and regular supervision from the research team, I could achieve this. Attending ACT training, particularly university teaching, enthused me and I became more convinced of the ability of ACT to help people live a more meaningful life. I believed that acceptance might help clients to make room for difficult feelings in the service of pursuing what was important to them.

Prior to the research intervention, I had begun to use ACT with a client on my Older Adult placement. This was a steep learning curve because I found that it was easy to get caught up in talking and explaining, rather than ‘doing ACT’ (Brock et al., 2015). For example, I found that the use of the Personal Values Card Sort (Miller et al., 2011) risked intellectualising with a client who was already emotionally-avoidant. From this, I learned that the most effective, process-oriented way to identify one’s values was to simply have a conversation about important areas of their life and used this, alongside a values circle, with my research clients. I also shared the rationale that acceptance might help clients to make room for difficult feelings in the service of pursuing what was important, which helped to prepare them for potentially difficult experiences elicited in therapy which they may not have anticipated or welcomed (Read, 2013). By the time I started the intervention with my research clients, I had more familiarity with and experience of using ACT and believed I could pay better attention to the hexaflex and inverse psychological inflexibility processes as they occurred in session, rather than strictly adhere to the protocol, which enabled me to be adaptive in my approach. Over time, my confidence grew, and I was able to draw upon my existing therapeutic skills and knowledge to engage and support clients and their carers to develop new understandings.

The use of a treatment integrity adherence scale (ACT-FM; O'Neill et al., 2019) ensured the intervention was competently implemented with fidelity to ACT and its processes (Plumb & Vilardaga, 2010). The frequency and depth of coverage of major ACT components and non-adherent components were rated on a 5-point scale (Plumb & Vilardaga; Twohig et al., 2010), where higher ratings indicated greater competence and adherence. Average ACT consistency was rated as 31 out of 36 with a median of 3 (maximum possible), indicating I enacted ACT-congruent behaviours most of the time. ACT inconsistency was rated as 0.3 out of 36, with extremely rare occasions of ACT-inconsistent behaviours. Whilst this was reassuring, some literature suggests a distinction between adherence (fidelity) and competence (skill), with reports that adherence is unrelated to treatment outcome (Zarafonitis-Müller et al., 2014). Nevertheless, I believe the adherence scale provided me with guidance throughout and I often referred to it on the wall in front of me when delivering the intervention.

I was also able to use ACT myself. For example, in learning more about ACT, I found I could become attached to my self-content of being a Trainee Clinical Psychologist and novice ACT therapist wanting to get things ‘right’. The process of learning about the ‘thinking self’ and ‘observing self’ enabled me to gain perspective and helped to develop my self-awareness, especially of my emotional states. I could practise mindful breathing to pause, anchor to the breath, notice when my mind had wandered and encourage it back to the breath (Bennett & Oliver, 2019).

Although there could have been inherent biases by my dual role of lead researcher and therapist, I feel this was sufficiently managed through the use of reflection, transparency and the adjudication panel to decide on change within clients. The strength of my dual role was evident at the analysis stage when collating data in the rich case records where I used a critical-reflective stance to apply my knowledge of the clients and carers from both positions. I realised that my understanding of the data was enhanced because of my role as the therapist, as I could understand the context of the clients’ lives, the client-carer relationship, and the context in which clients’ dementia diagnoses and difficulties had ensued, and therefore the process of changes in therapy. Hence, my dual role added to the contextual richness and quality of the data. I probably anticipated it would be awkward and exposing to develop sceptic briefs and critically analyse my therapeutic skills and abilities but found this relatively easy to do so. For any thoughts I did notice about being an incompetent therapist, I was able to defuse from them using ACT techniques.

5.3 ACT Intervention

5.3.1 ACT-inconsistent goals

The PQ (Elliott et al., 1999) was used for clients to identify their own problem statements and develop therapy goals. However, I found there was a tendency for clients to generate problem statements that may have been viewed as inconsistent with ACT by identifying difficulties according to their condition. For example, difficulties in remembering, concentrating, and feeling confused. It seemed challenging for clients to link these difficulties to other possible causes instead of the dementia (e.g., difficulties concentrating due to getting caught up in thoughts). When this occurred, I made a clinical judgement not to contest the client or ask that they changed their goal but remained curious and tried to tease out the context in which this was problematic. Direct challenge would have likely felt invalidating and risked rupturing the therapeutic alliance in its infancy. I was aware that, via experiential means, clients may have wanted to adapt their goals in a more naturalistic and ideographic way as the intervention progressed.

5.3.2 Therapy adaptations

Though I was aware that therapy would likely need to be adapted for the dementia population, for remote-delivery and for carer-assisted delivery, I did not anticipate how long pre-therapy adaptions would take (i.e., adapting the protocol). I overcame the challenges, posed by COVID-19, by recognising there was an opportunity to investigate how remote-ACT sessions, rather than face-to-face sessions, worked with people with dementia. However, this likely brought extra challenges for those with limited technical skill and confidence, which was somewhat moderated by carers' abilities.

Overcoming the sometimes jargonistic nature of ACT was also challenging at times. I found that longer utterances risked confusing clients and I found myself becoming more directive. I was aware that communication should be as clear and concise as possible for this population, which was not always adherent to ACT-consistent language, hence, I found myself trying to balance the two.

On reflection, I probably used a far more flexible approach in therapy with my research clients than in therapy with clients in clinical practice on placement. For example, because I was trying to maintain engagement and rapport, I was less boundaried with start times. As Phyllis was not accompanied by her carer in person, she did well to navigate technology independently, however, this, alongside her difficulties with getting up in a timely manner, meant we often started some sessions much later than planned.

The heterogenous nature of all three clients meant I was able to develop my meta-competencies, build confidence in using ACT and in managing obstacles in therapy. For example, judging when, where and how to introduce concepts, reflecting on which of these were engaged with well and those that did not achieve the intended outcome.

With regards to Agatha, I continue to feel sadness and regret about her early withdrawal from therapy. Her initial commitment to sessions was encouraging and she continued to persevere even when feeling confused, which was commended in session. Regrettably, the extent of her communication difficulties, hearing difficulties, level of impairment, and technology seemed to hinder her ability to engage in the intervention. For example, in repeating parts of the mindfulness exercises and ACT metaphors to aid Agatha's comprehension and hearing, it was felt that they likely lost meaning. ACT-consistent language could also be perceived as lengthy and confusing. Therefore, communication became shorter and more directive, meaning interactions appeared to be far more dyadic than experiential, which was inconsistent with ACT. Furthermore, there were challenges in slowing communication and balancing the time and space offered with having too big a gap and risking Agatha forgetting the task at hand. After much reflection upon whether I could have done more as a therapist, I believe that I could not have adapted therapy any further to benefit Agatha. However, I do wonder whether Agatha may have felt able to give the intervention longer had she not have been bothered by thoughts about Jane (carer) giving up her time to attend therapy, and whether Jane could have offered a more active, supportive role to enable her mother to engage with therapy.

5.3.3 Importance of a facilitative carer

Mo (Minnie's carer) and a family informant, separate to the research, had informed of complex dynamics in their relationships with Minnie. However, Minnie and Mo appeared to develop a strong working relationship, with Mo prompting and supporting Minnie within and outside of therapy. Similarly, it was evident that Julie (Phyllis' carer) and Phyllis had a strong working relationship, separate to their personal relationship. Whilst designing the study and prior to starting the intervention, I very much underestimated the role of the carer in therapy, nonetheless, soon learned of their importance, with findings indicating their presence likely mediated therapeutic client change.

In Agatha and Jane's case, whilst Jane supported with technology (i.e., setting up the laptop, playing the present-moment awareness exercise through her phone or speaker to support with Agatha's hearing difficulties), it was queried whether support extended to in-session engagement with ACT metaphors and exercises. Whilst both used humour, Jane's communication with Agatha may have been perceived as quite abrupt at times, which may have shown some internal consistency in their relationship outside of therapy. I was unsure of Jane's engagement in therapy as she was often observed to sit out of line of the camera.

In Agatha's CI, I observed a good rapport between the independent interviewer and Jane and wondered how I might have adapted my approach to develop something similar. I, understandably, was very invested in the study and was vexed to watch and transcribe Agatha's CI, as I felt Jane was particularly scathing about missing aspects of therapy. I understand that unfortunately, in Agatha's case, therapy did not appear beneficial, but this, to me, confirmed the importance of the research being conducted. I also wondered whether it was easier for Jane to project potential feelings of anger about her mother's dementia towards the intervention. Although initially disappointed, I was quickly able to separate myself and recognise that there was no personal attack on me. From this, I was able to include a balance of hindering events within Agatha's rich case record.

5.4 Ethical issues & decision-making

I was acutely aware of client burden, firstly, in consenting to participate in 12 weeks of therapy, as well as the quantity of measures required to track variables of interest at several time points. The balance of measures was considered carefully with my research supervisors. I reduced client burden by choosing routine, 'treatment-as-usual' anxiety and depression measures used in the MAS from which Minnie and Agatha were recruited. I also used short-version forms, where possible, to reduce cognitive load. However, the downside was that the measures were brief and not specific to health-related psychological distress. A pragmatic decision was made to use a simple, short measure of therapeutic relationship and alliance (SRS; Duncan et al., 2003), one measure of wellbeing (SWEMWBS; Tennant et al., 2007) and one measure of PF (CompACT-SF; Morris, 2019), and for these to be completed in session to reduce the risk of missing data. Though possibly limiting the depth of quantitative data, rich information was generated via other means, particularly in the CIs.

Whilst an ACT protocol was used to increase the consistency of therapy between clients and an ACT-fidelity measure used to assess this, it was agreed that the protocol would also be used flexibly. This was necessary according to the heterogeneity between clients, for example, with differences in pacing therapy and the ability of clients to grasp concepts. Hence, clinical judgement was most important to identify and address ACT processes ‘in flight’ (Hayes et al., 1999) to offer an appropriate, client-centred ACT intervention. Details of therapy adaptations were explicitly outlined in the rich case records, journal paper and extended paper to enable cross-comparisons.

5.5 Personal learning points

Overall, learning about ACT has enabled me to develop new insights. For instance, the ACT therapist’s flexible and responsive stance has encouraged me to make changes to my professional practice. I am now mindful to take opportunities to model ACT processes, such as self-disclosure of noticing during therapy and introducing new concepts by invitation. Formulating with and applying ACT in clinical practice has facilitated awareness of my own psychological inflexibility at times.

5.5.1 Research preconceptions

Prior to this study, I held assumptions about the general effectiveness of psychotherapy but little experience of using ACT in clinical practice. I also likely had preconceptions that dementia would be the most problematic issue in clients’ lives, above all others. However, this idea was challenged. For example, Phyllis said she was more concerned with her physical health difficulties than any further cognitive decline. I also found existing relationship difficulties, anxiety, and unresolved trauma in some cases, more problematic than the dementia per se. Concerns about being a novice therapist were also challenged by some of the wonderful feedback I received from carers in the CIs about both therapy-specific and non-therapy qualities. For example, the use of some ACT techniques was described by Mo as “pure genius, bloody brilliant… and adapted for Minnie as an individual”. Mo also thanked me for understanding Minnie and them as a family. I try to hold on to this nugget of information during times of uncertainty in myself and to defuse from self-doubting thoughts.

5.5.2 Development of research & clinical skills

Prior to the DClinPsy, I had had some experience of academic research, but not to the extent and rigour required for this level of training. This meant that at each stage of the process, I was confronted with tasks that were new to me and needed to find a balance between seeking guidance from my supervisors and finding solutions independently. I found the process of ethical approval for the study and submission of amendments complex and time consuming, possibly more so due to the recruitment of clients from the NHS and from the population concerned. Time management between this study and other clinical and academic commitments was a challenge, but my organisational skills and methodical approach served me well. This interventional research has been a steep learning curve that has provided invaluable knowledge and experience of both research skills and clinical practice (formulation, client engagement and reflection, to name a few). My understanding of therapy process, therapy effectiveness, research design and implementation and critical thinking have vastly improved, and I hope that the study intervention offered some help to those clients who most needed it.

Extended Paper References

Alzheimer’s Research UK. (2015). *Women and dementia: A marginalised majority.* Retrieved from https://www.alzheimersresearchuk.org/about-us/our-influence/policy-work/reports/women-dementia/

Alzheimer’s Society. (2021). *Treatments for dementia.* Retrieved from https://www.alzheimers.org.uk/about-dementia/types-dementia/treatments-dementia#content-start

Åkerblom, S., Perrin, S., Fischer, M. R., & McCracken, L. M. (2015). The mediating role of acceptance in multidisciplinary cognitive behavioral therapy for chronic pain. *The Journal of Pain, 16*(7), 606-615. https://doi.org/10.1016/j.jpain.2015.03.007

American Psychiatric Association. (2013). *Diagnostic and statistical manual of mental disorders* (5th ed.). Arlington, VA, US: American Psychiatric Publishing, Inc. https://doi.org/10.1176/appi.books.9780890425596

Bacon, T., Farhall, J., & Fossey, E. (2014). The active therapeutic processes of acceptance and commitment therapy for persistent symptoms of psychosis: Clients’ perspectives. *Behavioural and Cognitive Psychotherapy, 42*(4), 402- 420. https://doi.org/10.1017/S1352465813000209

Badrakalimuthu, V. R., & Tarbuck, A. F. (2012). Anxiety: A hidden element in dementia. *Advanced Psychiatric Treatment, 18*(2), 119-128. https://doi.org/10.1192/apt.bp.110.008458

Bandelow, B., & Michaelis, S. (2015). Epidemiology of anxiety disorders in the 21st century. *Dialogues in Clinical Neuroscience, 17*(3), 327-335. https://doi.org/10.31887/DCNS.2015.17.3/bbandelo

Banerjee, S., Hellier, J., Dewey, M., Romeo, R., Ballard, C., & Baldwin, R. (2010). Study of the use of antidepressants for depression in dementia: The HTA-SADD Trial - a multicentre randomised double-blind, placebo-controlled trial of the clinical effectiveness of sertraline and mirtazapine. *Lancet, 378,* 403-411. https://doi.org/10.3310/hta17070

Barmish, A. J., & Kendall, P. C. (2005). Should parents be co-clients in cognitive–behavioral therapy for anxious youth? *Journal of Clinical Child & Adolescent Psychology, 34,* 569–581. https://doi.org/10.1207/s15374424jccp3403_12

Beck, A. T., Rush, A. J., Shaw, B. F., & Emery G. (1979). *Cognitive therapy of depression*. New York: Guilford Press.

Benelli, E., De Carlo, A., Biffi, D., & McLeod, J. (2015). Hermeneutic single case efficacy design: A systematic review of published research and current standards. *TPM-Testing, Psychometrics, Methodology in Applied Psychology, 22*(1), 97-133. https://doi.org/10.4473/TPM22.1.7

Bennett, R. & Oliver, J. (2019). *Acceptance and commitment therapy: 100 key points and techniques.* Abingdon, UK: Routledge.

Beutler, L. E., Blatt, S. J., Alimohamed, S., Levy, K. N., & Angtuaco, L. (2006). Participant factors in treatment conditions with dysphoria. In L. Castonguay & E. Beutler (Eds.), *Principles of therapeutic change that works* (pp. 13-63). New York, New York: Oxford University Press.

Bond, F. W., Hayes, S. C., Baer, R. A., Carpenter, K. M., Guenole, N., Orcutt, H. K., et al. (2011). Preliminary psychometric properties of the Acceptance and Action Questionnaire-II: A revised measure of Psychological Inflexibility and Experiential Avoidance. *Behavior Therapy, 42*(4), 676-688. https://doi.org/10.1016/j.beth.2011.03.007

Borkovec, T., Alcaine, O., & Behar, E. (2004). Avoidance theory of worry and generalized anxiety disorder. In R. Heimberg, C. Turk, & D. Mennin (Eds.), *Generalized anxiety disorder: Advances in research and practice* (pp. 77-108). New York, NY, US: Guilford Press.

Brassington, L., Ferreira, N. B., Yates, S., Fearn, J., Lanza, P., & Kemp, K. (2016). Better living with illness: A transdiagnostic acceptance and commitment therapy group intervention for chronic physical illness. *Journal of Contextual Behavioral Science, 5*(4), 208-214. https://doi.org/10.1016/j.jcbs.2016.09.001

Brewer, J., & Hunter, A. (1989). *Multimethod research: A synthesis of styles.* Newbury Park, CA: Sage Publications, Inc.

Brock, M. J., Batten, S. V., Walser, R. D., & Robb, H. B. (2015). Recognizing common clinical mistakes in ACT: A quick analysis and call to awareness. *Journal of Contextual Behavioral Science, 4*(3), 139-143. https://doi.org/10.1016/j.jcbs.2014.11.003

Burns, D. D., & Spangler, D. L. (2001). Do changes in dysfunctional attitudes mediate changes in depression and anxiety in cognitive behavioral therapy? *Behavior Therapy, 32*(2), 337-369. https://doi.org/10.1016/S0005-7894(01)80008-3

Carey, T. A., & Stiles, W. B. (2016). Some problems with randomized controlled trials and some viable alternatives. *Clinical Psychology & Psychotherapy*, *23*(1), 87-95. https://doi.org/10.1002/cpp.1942

Carr, A. (2001). *Abnormal psychology.* East Sussex: Psychology Press.

Centers for Disease Control and Prevention. (2019). What is dementia? Retrieved from https://www.cdc.gov/aging/dementia/index.html

Christie, C. A., & Fleischer, D. (2009). Social inquiry paradigms as a frame for the debate on credible evidence. In S. I. Donaldson, C. Christie, & M. M. Mark (Eds.), *What counts as credible evidence in applied research and evaluation practice?* (pp. 19-30). Thousand Oaks, CA: Sage Publications, Inc. https://doi.org/10.4135/9781412995634.d7

Coplan, J. D. (2015). Treating comorbid anxiety and depression: Psychosocial and pharmacological approaches. *World Journal of Psychiatry, 5*(4), 366. https://doi.org/10.5498/wjp.v5.i4.366

Craddock, N., & Mynors-Wallis, L. (2014). Psychiatric diagnosis: Impersonal, imperfect and important. *British Journal of Psychiatry, 204(2),* 93-95. https://doi.org/10.1192/bjp.bp.113.133090

Dawson, D., & Golijani Moghaddam, N. (2015). *Formulation in action: Applying psychological research to clinical practice.* De Gruyter: Warsaw/Berlin. https://doi.org/10.1515/9783110471014

Drapeau, A., Marchand, A., & Beaulieu Prevost, D. (2012). Epidemiology of psychological distress. In L. LAbate (Ed.), *Mental Illnesses: Understanding, Prediction and Control* (pp. 105-124). Rijeka: InTech. https://doi.org/10.5772/30872

Dugas, M. J., Gagnon, F., Ladouceur, R., & Freeston, M. H. (1998). Generalized anxiety disorder: A preliminary test of a conceptual model. *Behaviour Research and Therapy, 36*(2), 215-226. https://doi.org/10.1016/S0005-7967(97)00070-3

Duncan, B. L., Miller, S. D., Sparks, J., Claud, D., Reynolds, L., & Brown, J. (2003). The session rating scale: Preliminary psychometric properties of a “working” alliance measure. *Journal of Brief Therapy, 3,* 3-12. Retrieved from https://www.scottdmiller.com/wp-content/uploads/documents/SessionRatingScale-JBTv3n1.pdf

Elliott, R. (2002). Hermeneutic single-case efficacy design. *Psychotherapy Research*, *12*(1), 1–21. https://doi.org/10.1016/j.buildenv.2006.10.027

Elliott, R. (2015). Hermeneutic single-case efficacy design. In J. F. Pierson & J. F. T. Bugental (Eds.), *The handbook of humanistic psychology* (2nd ed., pp. 351-360). Thousand Oaks, California: Sage Publications. https://doi.org/10.1080/713869614

Elliott, R., Mack, C., & Shapiro, D. (1999). *The simplified personal questionnaire procedure*. University of Toledo: Toledo.

Elliott, R., Stephen, S., Robinson, A. (2021). Extending the boundaries of systematic case study research: Conceptual and methodological issues. *Pragmatic Case Studies in Psychotherapy, 17*(2), 235-254. https://doi.org/10.14713/pcsp.v17i2.2097

Ferster, C. B. (1966). Animal behavior and mental illness. *The Psychological Record, 16,* 345-356. https://doi.org/10.1007/BF03393678

Francis, A., Dawson, D., & Moghaddam, N. (2016). The development and validation of the comprehensive assessment of acceptance and commitment therapy processes (CompACT). *Journal of Contextual Behavioral Science*, *5*(3), 134-135.

Garcia, A., & Benjumea, S. (2001). Ontogenetic prerequirements for the emergence of symmetrical relationships. *International Journal of Psychology and Psychological Therapy, 1,* 115-135.

Gaudiano, B. A. (2011). A review of acceptance and commitment therapy (ACT) and recommendations for continued scientific advancement. *The Scientific Review of Mental Health Practice, 8*(2), 6-22.

Gifford, E., & Hayes, S. (1999). Functional contextualism: A pragmatic philosophy for behavioral science. In W.O'donohue & R. Kitchener (Eds.), *Handbook of Behaviorism* (pp. 285-327). San Diego: Academic Press.

Gillanders, D., & Laidlaw, K. (2014). ACT and CBT in older age: Towards a wise synthesis. In N. Pachana and K. Laidlaw (Eds.) *The Oxford handbook of clinical geropsychology*. Oxford: OUP.

Gloster, A. T., Sonntag, R., Hoyer, J., Meyer, A. H., Heinze, S., & Ströhle, A. (2015). Treating treatment-resistant patients with panic disorder and agoraphobia using psychotherapy: A randomized controlled act for anxiety self-help 457 switching trial. *Psychotherapy and Psychosomatics, 84,* 100-109. https://doi.org/10.1159/000370162

Gould, R. L., Wetherell, J. L., Kimona, K., Serfaty, M. A., Jones, R., Graham, C. D., et al. (2021). Acceptance and commitment therapy for late-life treatment-resistant generalised anxiety disorder: A feasibility study. *Age and Ageing, 50*(5), 1751-1761. https://doi.org/10.1093/ageing/afab059

Grant, R. W., & Casey, D. A. (1995). Adapting cognitive behavioural therapy for the frail elderly. *International Psychogeriatrics, 7*(4), 561-571. https://doi.org/10.1017/s1041610295002298

Green, M. F., Kern, R. S., & Heaton, R. K. (2004). Longitudinal studies of cognition and functional outcome in schizophrenia: Implications for MATRICS. *Schizophrenia Research, 72*(1), 41-51. https://doi.org/10.1016/j.schres.2004.09.009

Hacker, T., Stone, P., & Macbeth, A. (2016). Acceptance and commitment therapy - Do we know enough? Cumulative and sequential meta-analyses of randomized controlled trials. *Journal of Affective Disorders, 190,* 551-565. https://doi.org/10.1016/j.jad.2015.10.053

Hann, K. E. ., & McCreacken, L. (2014). A systematic review of randomized controlled trials of acceptance and commitment therapy for adults with chronic pain: Outcome domains, design quality, and efficacy. *Journal of Contextual Behavioral Science, 3*(4), 217-227. https://doi.org/10.1016/j.jcbs.2014.10.001

Hansen, N. B., Lambert, M. J., & Forman, E. M. (2002). The psychotherapy dose-response effect and its implications for treatment delivery services. *Clinical Psychology: Science and Practice, 9,* 329-343. https://doi.org/10.1093/clipsy.9.3.329

Harris, R. (2006). Embracing your demons: An overview of acceptance and commitment therapy. *Psychotherapy in Australia, 12,* 2-8. Retrieved from https://www.actmindfully.com.au/upimages/Dr_Russ_Harris_-_A_Non-technical_Overview_of_ACT.pdf

Haver, A., Akerjordet, K., Caputi, P., Furunes, T., & Magee, C. (2015). Measuring mental well-being: A validation of the short warwick-edinburgh mental well-being scale in Norwegian and Swedish. *Scandinavian Journal of Public Health*, *43*(7), 721-727. https://doi.org/10.1177/1403494815588862

Hayes, S. C. (2008). Climbing our hills: A beginning conversation on the comparison of acceptance and commitment therapy and traditional cognitive behavioral therapy. *Clinical Psychology: Science and Practice, 15,* 286-295. https://doi.org/10.1111/j.1468-2850.2008.00139.x

Hayes, S. C., Levin, M. E., Plumb-Vilardaga, J., Villatte, J. L., & Pistorello, J. (2013). Acceptance and commitment therapy and contextual behavioral science: Examining the progress of a distinctive model of behavioral and cognitive therapy. *Behavior Therapy, 44,* 180-198. https://doi.org/10.1016/j.beth.2009.08.002

Hayes, S. C., Luoma, J. B., Bond, F. W., Masuda, A., & Lillis, J. (2006). Acceptance and commitment therapy: Model, processes and outcomes. *Behaviour Research and Therapy*, *44*(1), 1-25. https://doi.org/10.1016/j.brat.2005.06.006

Hayes, S. C., Pistorello, J., & Levin, M. E. (2012). Acceptance and commitment therapy as a unified model of behavior change. *The Counseling Psychologist, 40*(7), 976-1002. https://doi.org/10.1177/0011000012460836

Hayes, S. C., Strosahl, K., & Wilson, K. G. (1999). *Acceptance and commitment therapy: An experiential approach to behavior change*. New York: Guilford Press.

Hayes, S. C., Villatte, M., Levin, M., & Hildenbrandt, M. (2011). Open, aware and active: Contextual approaches as an emerging trend in the behavioural and cognitive therapies. *Annual Review of Clinical Psychology, 7,* 141-168. https://doi.org/10.1146/annurev-clinpsy-032210-104449

Hayes, S. C., Wilson, K. G., Gifford, E. V., Follette, V. M., & Strosahl, K. (1996). Experiential avoidance and behavioral disorders: A functional dimensional approach to diagnosis and treatment. *Journal of Consulting and Clinical Psychology, 64*(6), 1152-1168. https://doi.org/10.1037/0022-006X.64.6.1152

Herbert, M. S., Afari, N., Liu, L., Heppner, P., Rutledge, T., Williams, K., et al. (2017). Telehealth versus in-person acceptance and commitment therapy for chronic pain: A randomized noninferiority trial. *The Journal of Pain: Official Journal of the American Pain Society, 18*(2), 200-211. https://doi.org/10.1016/j.jpain.2016.10.014

Hofer, P. D., Waadt, M., Aschwanden, R., Milidou, M., Acker, J., & Meyer, A. H. (2018). Self-help for stress and burnout without therapist contact: An online randomised controlled trial. *Work & Stress, 32,* 189-208. https://doi.org/10.1080/02678373.2017.1402389

Hofmann, S. G., & Hayes, S. C. (2019). The future of intervention science: Process based therapy. *Clinical Psychological Science, 7*(1), 37-50. https://doi.org/10.1177/2167702618772296

Hubble, M., Duncan, B., & Miller, S. (1999*). The heart & soul of change: What works in therapy.* Washington, DC, US: American Psychological Association. https://doi.org/10.1037/11132-000

Isaacowitz, D. M., & Seligman, M. E. P. (2002). Cognitive style predictors of affect change in older adults. *The International Journal of Aging and Human Development, 54*(3), 233-253. https://doi.org/10.2190/J6E5-NP5K-2UC4-2F8B

Johnstone, L. (2014). *A straight-talking introduction to psychiatric diagnosis.* Ross-on-Wye, England: PCCS Books.

Karlin, B. E., Walser, R. D., Yesavage, J., Zhang, A., Trockel, M., & Taylor, C. B. (2013). Effectiveness of acceptance and commitment therapy for depression: Comparison among older and younger veterans. *Aging & Mental Health, 17*(5), 555-563. https://doi.org/10.1080/13607863.2013.789002

Kennerley, H., Kirk, J., & Westbrook, D. (2017). *An introduction to cognitive behaviour therapy: Skills and applications* (3rd ed.). London: Sage.

Kishita, N., & Laidlaw, K. (2017). Cognitive behaviour therapy for generalized anxiety disorder: Is CBT equally efficacious in adults of working age and older adults? *Clinical Psychology Review, 52,* 124-136. https://doi.org/10.1016/j.cpr.2017.01.003

Kroenke, K., Spitzer, R. L., & Williams, J. B. W. (2001). The PHQ-9: Validity of a brief depression severity measure. *Journal of General Internal Medicine*, *16*(9), 606-613. https://doi.org/10.1046/j.1525-1497.2001.016009606.x

Kuhn, T. (1970). *The structure of scientific revolutions*. Chicago, IL: University of Chicago Press.

Leung, D., Chan, W. C., Spector, A., & Wong, G. (2021). Prevalence of depression, anxiety, and apathy symptoms across dementia stages: A systematic review and meta-analysis. *International Journal of Geriatric Psychiatry*, *36*(9), 1330-1344. https://doi.org/10.1002/gps.5556

Lewinsohn, P. M. (1975). Clinical and theoretical aspects of depression. In K. S. Calhoun, H. E. Adams, & K. M. Mitchell (Eds.), *Innovative treatment methods of psychopathology* (pp. 63-120). New York, NY: Wiley.

Llewelyn, S. P., Elliott, R., Shapiro, D. A., Firth, J., & Hardy, G. (1988). Client perceptions of significant events in prescriptive and exploratory periods of individual therapy. *British Journal of Clinical Psychology, 27,* 105-114. https://doi.org/10.1111/j.2044-8260.1988.tb00758.x

Manassis, K., Lee, T. C., Bennett, K., Zhao, X. Y., Mendlowitz, S., Duda, S., et al. (2014). Types of parental involvement in CBT with anxious youth: A preliminary meta-analysis. *Journal of Consulting and Clinical Psychology, 82,* 1163–1172. https://doi.org/10.1037/a0036969

Martin, B. (2021, Jun 1). What are the risk factors for depression? *Psych Central*. Retrieved from https://www.psychcentral.com/lib/what-are-the-risk-factors-for-depression/

Masuda, A., Hayes, S., Sackett, C., & Twohig, M. (2004). Cognitive defusion and self-relevant negative thoughts: Examining the impact of a ninety year old technique*. Behaviour Research and Therapy, 42*(4), 477-485. https://doi.org/10.1016/j.brat.2003.10.008

Mccracken, L. M., & Gutiérrez-martínez, O. (2011). Behaviour research and therapy processes of change in psychological flexibility in an interdisciplinary group-based treatment for chronic pain based on acceptance and commitment therapy. *Behaviour Research and Therapy*, *49*(4), 267-274. https://doi.org/10.1016/j.brat.2011.02.004

McLaughlin, J. E. (2006). The pros and cons of viewing formal diagnosis from a social constructionist perspective. *The Journal of Humanistic Counseling, 45*(2), 165-172. https://doi.org/10.1002/j.2161-1939.2006.tb00015.x

McManus, S., Meltzer, H., Brugha, T., Bebbington, P., & Jenkins, R. (2009). *Adult psychiatric morbidity in England 2007: Results of a household survey. NHS information centre for health and social care.* Retrieved from https://www.digital.nhs.uk/data-and-information/publications/statistical/adult-psychiatric-morbidity-survey/adult-psychiatric-morbidity-in-england-2007-results-of-a-household-survey

Mental Health Statistics (2020, October 15). *Depression.* Retrieved from https://www.mhfaengland.org/mhfa-centre/research-and-evaluation/mental-health-statistics/#depression

Miller, W. R., C'de Baca, J., Matthews, D. B., & Wilbourne, P. (2011). Personal values card sort. Albuquerque, NM: University of New Mexico.

Morris, N. (2018). *Acceptance and Commitment Therapy for adults with head and neck cancer experiencing psychological distress: A hermeneutic single case efficacy design (HSCED) series* (Unpublished doctoral dissertation). University of Nottingham, Nottingham.

Morris, J. (2019). *Development and validation of a short form of the comprehensive assessment of acceptance and commitment therapy processes (CompACT-SF)* (Doctoral dissertation). University of Nottingham, Nottingham.

Mulder, R., Murray, G., & Rucklidge, J. (2017). Common versus specific factors in psychotherapy: Opening the black box. *The Lancet Psychiatry, 4*(12), 953-962. https://doi.org/10.1016/S2215-0366(17)30100-1

Muliyala K. P., & Varghese, M. (2010). The complex relationship between depression and dementia. Annals of Indian Academy of Neurology 13(2), 69-73. https://doi.org/10.4103/0972-2327.74248

National Institute for Health and Clinical Excellence. (2009). *Depression in adults: Recognition and management.* Retrieved from https://www.nice.org.uk/guidance/cg90/chapter/1-Guidance#care-of-all-people-with-depression

National Institute for Health and Care Excellence. (2011). *Generalised anxiety disorder and panic disorder in adults: Management.* Retrieved from https://www.nice.org.uk/guidance/cg113/chapter/1-Guidance#stepped-care-for-people-with-gad

National Institute for Health and Care Excellence. (2018)*. Dementia: assessment, management and support for people living with dementia and their carers.* Retrieved from https://www.nice.org.uk/guidance/ng97

National Health Service (NHS) Digital. (2018). *More than half of patients who finished psychological therapy recovered in 2017-18*. Retrieved from https://digital.nhs.uk/data-and-information/publications/statistical/psychological-therapies-annual-reports-on-the-use-of-iapt-services

National Health Service. (2020). *About dementia: Dementia guide.* Retrieved from https://www.nhs.uk/conditions/dementia/about/

O’Keeffe, J. R., Golijani-Moghaddam, N., Burrell, R., & De Boos, D. (2021). *Acceptance and Commitment Therapy for older adult clients experiencing psychological distress: A hermeneutic single case efficacy design (HSCED) series* (Unpublished doctoral dissertation). University of Nottingham, Nottingham.

O'Neill, L., Latchford, G., McCracken, L. M., & Graham, C. D. (2019). The development of the acceptance and commitment therapy fidelity measure (ACT-FM): A delphi study and field test. *Journal of Contextual Behavioral Science, 14,* 111-118. https://doi.org/10.1016/j.jcbs.2019.08.008

Orgeta, V., Qazi, A., Spector, A. E., & Orrell, M. (2014). Psychological treatments for depression and anxiety in dementia and mild cognitive impairment. *The Cochrane database of systematic reviews*, *2014*(1), CD009125.https://doi.org/10.1002/14651858.CD009125.pub2

Öst, L. G. (2008). Efficacy of the third wave of behavioral therapies: A systematic review and meta-analysis. *Behaviour Research and Therapy, 46*(3), 296-321. https://doi.org/10.1016/j.brat.2007.12.005

Öst, L.G. (2014). The efficacy of acceptance and commitment therapy: An updated systematic review and meta-analysis. *Behaviour Research and Therapy*, *61*, 105-121. https://doi.org/10.1016/j.brat.2014.07.018

Petkus, A. J., & Wetherell, J. L. (2013). Acceptance and commitment therapy with older adults: Rationale and considerations. *Cognitive and Behavioral Practice, 20*(1), 47-56. https://doi.org/10.1016/j.cbpra.2011.07.004

Piet, J., Würtzen, H., & Zachariae, R. (2012). The effect of mindfulness-based therapy on symptoms of anxiety and depression in adult cancer patients and survivors: A systematic review and meta-analysis. *Journal of Consulting and Clinical Psychology, 80*(6), 1007-1020. https://doi.org/10.1037/a0028329

Plumb, J. C., & Vilardaga, R. (2010). Assessing treatment integrity in acceptance and commitment therapy: Strategies and suggestions. *International Journal of Behavioral Consultation and Therapy*, *6*(3), 263-278. https://doi.org/10.1037/h0100912

Pots, W., Fledderus, M., Meulenbeek, P., Ten Klooster, P., Schreurs, K., & Bohlmeijer, E. (2016). Acceptance and commitment therapy as a web-based intervention for depressive symptoms: Randomised controlled trial. *British Journal of Psychiatry, 208*(1), 69-77. https://doi.org/10.1192/bjp.bp.114.146068

Prince, M., Knapp, M., Guerchet, M., McCrone, P., Prina, M., Comas-Herrera, M., …Salimkumar, D. (2014). *Dementia UK: Update.* King's College, London: Alzheimer's Society. Retrieved from https://kclpure.kcl.ac.uk/portal/files/35828472/P326_AS_Dementia_Report_WEB2.pdf

Ranganathan, P., Pramesh, C. S., & Buyse, M. (2015). Common pitfalls in statistical analysis: Clinical versus statistical significance. *Perspectives in Clinical Research, 6*(3), 169-170. https://doi.org/10.4103/2229-3485.159943

Read, K. (2013). *Instructor's manual for acceptance and commitment therapy: Facing the struggle with Steven Hayes, PhD.* Mill Valley, CA: Psychotherapy.net.

Ren, Z., Zhao, C., Bian, C., Zhu, W., Jiang, G., & Zhu, Z. (2019). Mechanisms of the acceptance and commitment therapy: A meta-analytic structural equation model. *Acta Psychologica Sinica, 51*(6), 662-676. https://doi.org/10.3724/SP.J.1041.2019.00662

Robie, K. J. (1999). An exploration of psychologists' perceptions of the process of psychotherapy for the treatment of psychological concerns and mental disorders in elders who have concomitant dementia. *Dissertation Abstracts International, 59,* 5108.

Robinson, A., & Moghaddam, N. (2022). Psychological treatments and therapy adaptations for psychological distress in dementia and mild cognitive impairment: A systematic review and meta-analysis. *Mental Health Review Journal.* Advanced online publication. https://doi.org/10.1108/MHRJ-05-2021-0043

Roche, B., Barnes-Holmes, Y., Barnes-Holmes, D., Stewart, I., & O'Hora, D. (2002). Relational frame theory: A new paradigm for the analysis of social behavior. *The Behavior Analyst, 25*(1), 75-91. https://doi.org/10.1007/BF03392046

Rosness, T. A., Strand, B. H., Bergem, A. L. M., Nafstad, P., Langballe, E. M., & Engedal, K. (2016). Association of psychological distress late in life and dementia-related mortality. *Aging & Mental Health, 20*(6), 603-610. https://doi.org/10.1080/13607863.2015.1031639

Ruiz, F. J. (2010). A review of acceptance and commitment therapy (ACT) empirical evidence: Correlational, experimental psychopathology, component and outcome studies. *International Journal of Psychology and Psychological Therapy 10,* 125-162.

Skinner, B. F. (1953). *Science and human behavior.* Oxford, England: Macmillan.

Smith, A. J. (2017). *Acceptance and commitment therapy for depression and anxiety: An interpretative phenomenological analysis of clients' experiences in a group context* (Unpublished doctoral thesis). London Metropolitan University, London.

Sowislo, J. F., Lange, C., Euler, S., Hachtel, H., Walter, M., Borgwardt, S., et al. (2017). Stigmatization of psychiatric symptoms and psychiatric service use: A vignette-based representative population survey. *European Archives of Psychiatry and Clinical Neuroscience, 267(4),* 351-357. https://doi.org/10.1007/s00406-016-0729-y

Spector, A., Charlesworth, G., King, M., Lattimer, M., Sadek, S., Marston, L., et al. (2015). Cognitive–behavioural therapy for anxiety in dementia: Pilot randomised controlled trial. *The British Journal of Psychiatry, 206,* 509-516. https://doi.org/10.1192/bjp.bp.113.140087

Spector, A, Orrell, M, Lattimer, M, Hoe, J, King, M, & Harwood, K. (2012). Cognitive behavioural therapy (CBT) for anxiety in people with dementia: Study protocol for a randomised controlled trial. *Trials, 13,* 197. https://doi.org/10.1186/1745-6215-13-197

Spitzer, R. L., Kroenke, K., & Williams, J. B. (1999). Patient health questionnaire primary care study group, validation and utility of a self-report version of PRIME-MD: The PHQ primary care study. *JAMA, 28*(2), 1737-1744. https://doi.org/10.1001/jama.282.18.1737

Spitzer, R. L., Kroenke, K., Williams, J. B. W., & Löwe, B. (2006). A brief measure for assessing generalized anxiety disorder. *Archives of Internal Medicine*, *166*(10), 1092. https://doi.org/10.1001/archinte.166.10.1092

Suveg, C., Morelen, D., Brewer, G. A., & Thomassin, K. (2010). The emotion dysregulationmodel of anxiety: A preliminary path analytic examination. *Journal of Anxiety Disorders, 24*(8), 924-930. https://doi.org/10.1016/j.janxdis.2010.06.018.

Tashakkori, A., & Teddlie, C. (1998). *Mixed methodology: Combining qualitative and quantitative approaches. Thousand Oaks, CA:* Sage.

Tennant, R., Hiller, L., Fishwick, R., Platt, S., Joseph, S., & Weich, S. (2007). The warwick-edinburgh mental well-being scale (WEMWBS): Development and UK validation. *Health and Quality of Life Outcomes 5,* 63. https://doi.org/10.1186/1477-7525-5-63

Tsao, J. C. I., Mystkowski, J. L., Zucker, B. G., & Craske, M. G. (2005). Impact of cognitive-behavioral therapy for panic disorder on comorbidity: A controlled investigation. *Behaviour Research and Therapy, 43*(7), 959-970. https://doi.org/10.1016/j.brat.2004.11.013

Twohig, M. P., Hayes, S. C., Plumb, J. C., Pruitt, L. D., Collins, A. B., Hazlett-Stevens, H., et al. (2010). A randomized clinical trial of acceptance and commitment therapy versus progressive relaxation training for obsessive-compulsive disorder. *Journal of Consulting and Clinical Psychology*, *78*(5), 705-716. https://doi.org/10.1037/a0020508

Vilardaga, R., Hayes, S. C., & Schelin, L. (2007). Philosophical, theoretical and empirical foundations of acceptance and commitment therapy. *Anuario de Psicología, 38*(1), 117-128.

Wall, J. M., Kwee, J. L., Hu, M., & McDonald, M. J. (2017). Enhancing the hermeneutic single-case efficacy design: Bridging the research-practice gap. *Psychotherapy Research*, *27*(5), 539-548. https://doi.org/10.1080/10503307.2015.1136441

Wampold, B. E. (2013). The good, the bad, and the ugly: A 50-year perspective on the outcome problem. *Psychotherapy, 50*(1), 16-24. https://doi.org/10.1037/a0030570

Wampold, B. E. (2015). How important are the common factors in psychotherapy? An update. *World Psychiatry*, *14*(3), 270-277. https://doi.org/10.1002/wps.20238

Wells, A. (1999). A cognitive model of generalized anxiety disorder. *Behavior Modification, 23*(4), 526-555. https://doi.org/10.1177/0145445599234002

Wheaton, B. (2007). The twain meet: Distress, disorder and the continuing conundrum of categories (comment on Horwitz). *Health*, *11*(3), 303-319. https://doi.org/10.1177/1363459307077545

World Health Organization. (2017). *Depression and other common mental disorders: global health estimates.* Retrieved from https://apps.who.int/iris/bitstream/handle/10665/254610/WHO-MSD-MER-2017.2-eng.pdf?sequence=1&isAllowed=y

World Health Organization. (2018). *International statistical classification of diseases and related health problems 11th revision (ICD-11).* Retrieved from https://icd.who.int/browse11/l-m/en

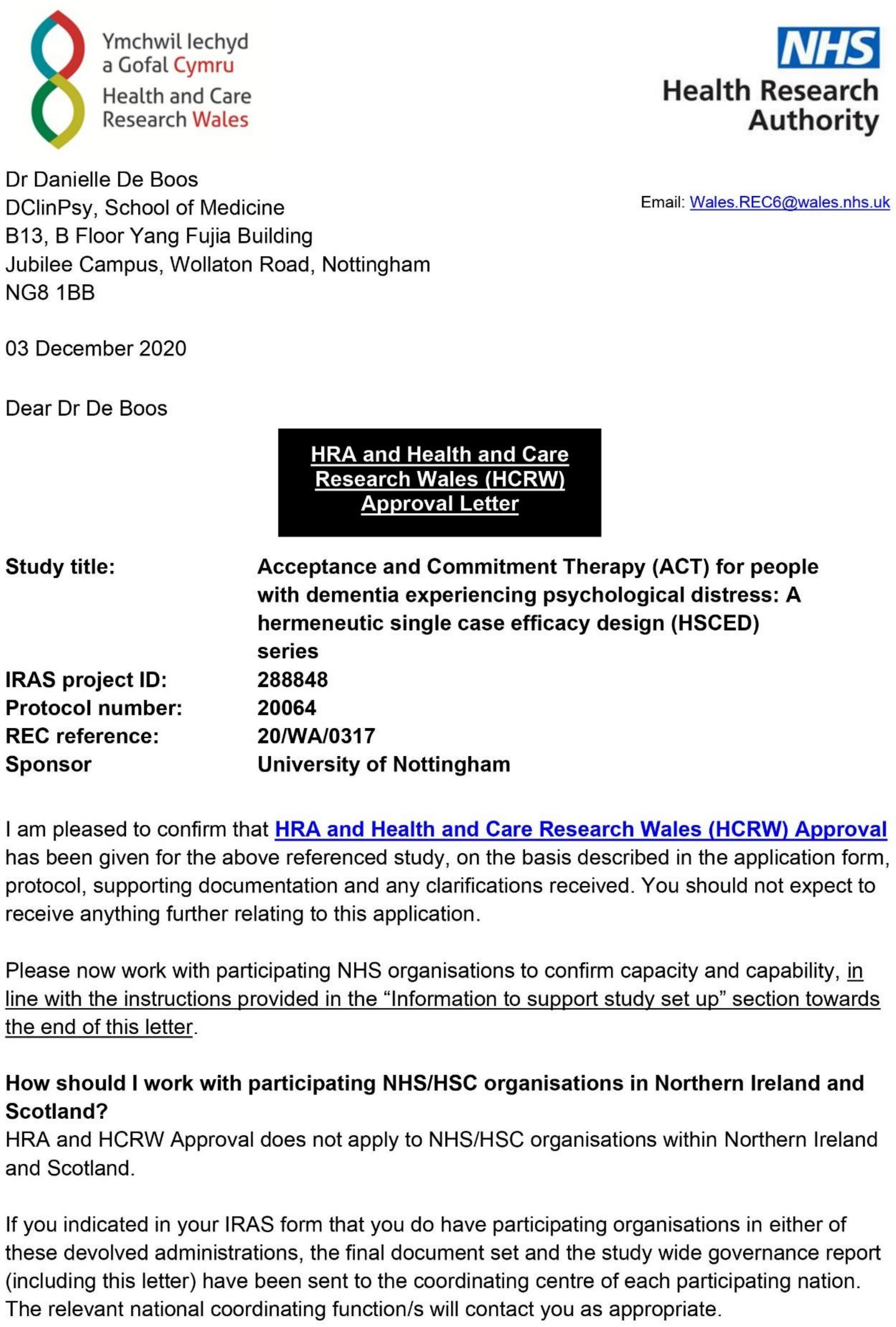
World Health Organization. (2021a). *Dementia.* Retrieved from https://www.who.int/news-room/fact-sheets/detail/dementia

World Health Organization. (2021b, September 13). *Depression.* Retrieved from https://www.who.int/news-room/fact-sheets/detail/depression

Zarafonitis-Müller, S., Kuhr, K. & Bechdolf, A. (2014). The relationship between therapist's competence and adherence to outcome in cognitive-behavioural therapy – Results of a metaanalysis. *Fortschritte der Neurologie-Psychiatrie, 82*(9), 502-510. https://doi.org/10.1055/s-0034-1366798

Thesis Appendices

Appendix A. Ethical Approval of Project



Ymchwil Iechyd a Gofal Cymru
Health and Care Research Wales

NHS
Health Research Authority

Dr Danielle De Boos
DClinPsy, School of Medicine
B13, B Floor Yang Fujia Building
Jubilee Campus, Wollaton Road, Nottingham
NG8 1BB

Email: Wales.REC6@wales.nhs.uk

03 December 2020

Dear Dr De Boos

HRA and Health and Care Research Wales (HCRW) Approval Letter

Study title: **Acceptance and Commitment Therapy (ACT) for people with dementia experiencing psychological distress: A hermeneutic single case efficacy design (HSCED) series**
IRAS project ID: **288848**
Protocol number: **20064**
REC reference: **20/WA/0317**
Sponsor **University of Nottingham**

I am pleased to confirm that **HRA and Health and Care Research Wales (HCRW) Approval** has been given for the above referenced study, on the basis described in the application form, protocol, supporting documentation and any clarifications received. You should not expect to receive anything further relating to this application.

Please now work with participating NHS organisations to confirm capacity and capability, in line with the instructions provided in the “Information to support study set up” section towards the end of this letter.

How should I work with participating NHS/HSC organisations in Northern Ireland and Scotland?
HRA and HCRW Approval does not apply to NHS/HSC organisations within Northern Ireland and Scotland.

If you indicated in your IRAS form that you do have participating organisations in either of these devolved administrations, the final document set and the study wide governance report (including this letter) have been sent to the coordinating centre of each participating nation. The relevant national coordinating function/s will contact you as appropriate.

Please see IRAS Help for information on working with NHS/HSC organisations in Northern Ireland and Scotland.

How should I work with participating non-NHS organisations?
HRA and HCRW Approval does not apply to non-NHS organisations. You should work with your non-NHS organisations to obtain local agreement in accordance with their procedures.

What are my notification responsibilities during the study?

The standard conditions document "*After Ethical Review – guidance for sponsors and investigators*", issued with your REC favourable opinion, gives detailed guidance on reporting expectations for studies, including:

- Registration of research
- Notifying amendments
- Notifying the end of the study

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

Who should I contact for further information?
Please do not hesitate to contact me for assistance with this application. My contact details are below.

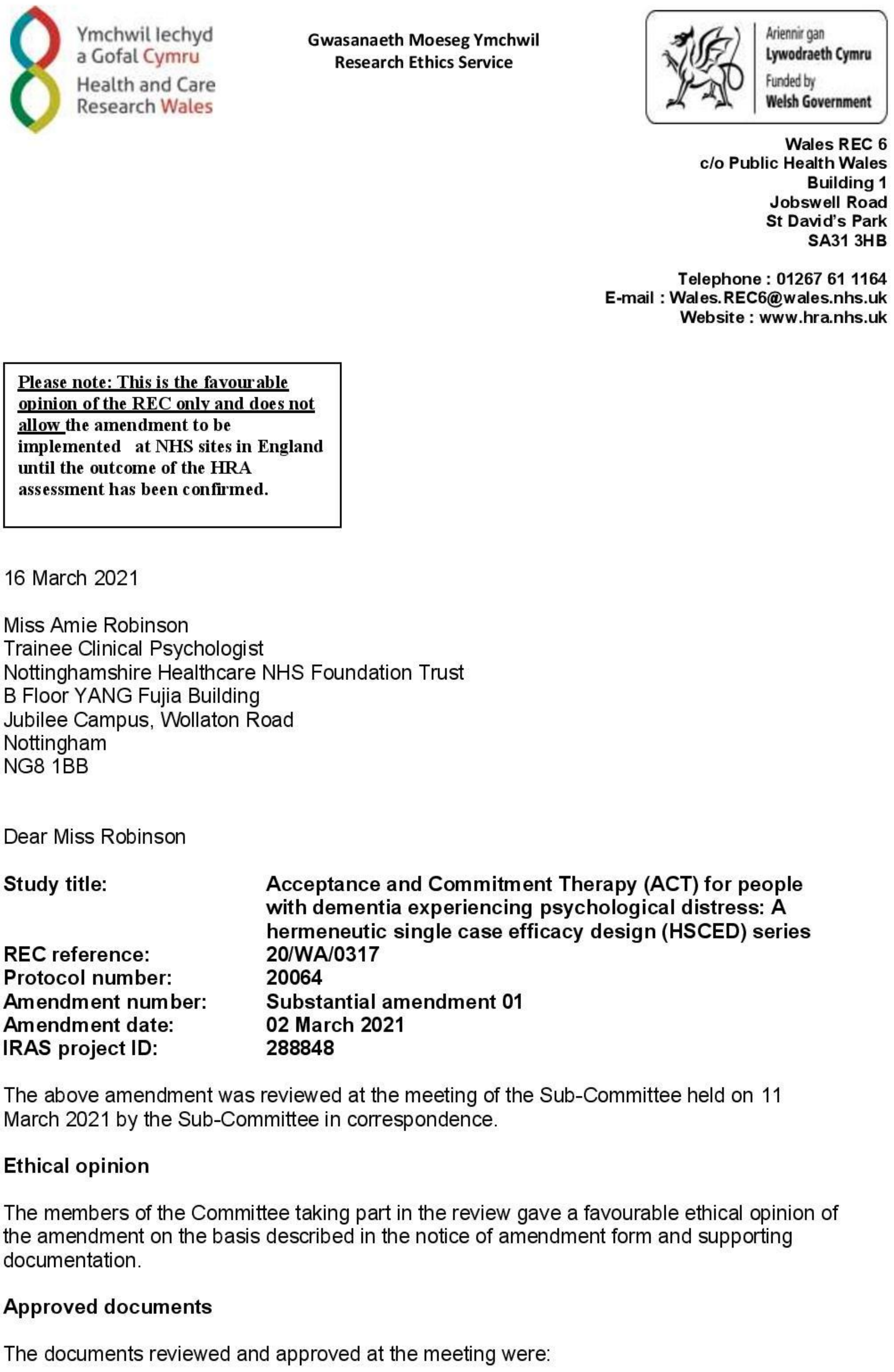
Your IRAS project ID is **288848**. Please quote this on all correspondence.

Yours sincerely,
Ann Parry

Email: Wales.REC6@wales.nhs.uk

Copy to: *Ms Angela Shone*

Appendix B. Ethical Approval of Substantial Amendment



Ymchwil Iechyd a Gofal Cymru
Health and Care Research Wales

Gwasanaeth Moeseg Ymchwil
Research Ethics Service

Ariennir gan Llywodraeth Cymru
Funded by Welsh Government

Wales REC 6
c/o Public Health Wales
Building 1
Jobswell Road
St David's Park
SA31 3HB

Telephone : 01267 61 1164
E-mail : Wales.REC6@wales.nhs.uk
Website : www.hra.nhs.uk

Please note: This is the favourable opinion of the REC only and does not allow the amendment to be implemented at NHS sites in England until the outcome of the HRA assessment has been confirmed.

16 March 2021

Miss Amie Robinson
Trainee Clinical Psychologist
Nottinghamshire Healthcare NHS Foundation Trust
B Floor YANG Fujia Building
Jubilee Campus, Wollaton Road
Nottingham
NG8 1BB

Dear Miss Robinson

Study title:	**Acceptance and Commitment Therapy (ACT) for people with dementia experiencing psychological distress: A hermeneutic single case efficacy design (HSCED) series**
REC reference:	**20/WA/0317**
Protocol number:	**20064**
Amendment number:	**Substantial amendment 01**
Amendment date:	**02 March 2021**
IRAS project ID:	**288848**

The above amendment was reviewed at the meeting of the Sub-Committee held on 11 March 2021 by the Sub-Committee in correspondence.

Ethical opinion

The members of the Committee taking part in the review gave a favourable ethical opinion of the amendment on the basis described in the notice of amendment form and supporting documentation.

Approved documents

The documents reviewed and approved at the meeting were:

Document	*Version*	*Date*
Completed Amendment Tool [288848_Substantial amendment 01]	1.0	02 March 2021
Copies of advertisement materials for research participants [PARTICIPANT RECRUITMENT POSTER (Tracked)]	2.0	01 March 2021
Copies of advertisement materials for research participants [CAREGIVER RECRUITMENT POSTER (Tracked)]	2.0	01 March 2021
Copies of materials calling attention of potential participants to the research [PARTICIPANT RECRUITMENT POSTER ACTforpeoplewithdementiaexperiencingpsychologicaldistress final v2.0 date 01.03.21]	2.0	01 March 2021
Copies of materials calling attention of potential participants to the research [CAREGIVER RECRUITMENT POSTER ACTforpeoplewithdementiaexperiencingpsychologicaldistress final v2.0 date 01.03.21]	2.0	01 March 2021
Participant information sheet (PIS) [PARTICIPANT INFORMATION SHEET FOR CLINICAL PSYCHOLOGIST ACTforpeoplewithdementiaexperiencingpsychologicaldistress final v2.0 date 01.03.21]	2.0	01 March 2021
Participant information sheet (PIS) [PARTICIPANT INFORMATION SHEET ACTforpeoplewithdementiaexperiencingpsychologicaldistress final v3.0 date 01.03.21]	3.0	01 March 2021
Participant information sheet (PIS) [CAREGIVER INFORMATION SHEET ACTforpeoplewithdementiaexperiencingpsychologicaldistress final v3.0 date 01.03.21]	3.0	01 March 2021
Participant information sheet (PIS) [CLINICAL PSYCHOLOGIST (Tracked)]	2.0	01 March 2021
Participant information sheet (PIS) [Tracked]	3.0	01 March 2021
Participant information sheet (PIS) [CAREGIVER INFORMATION SHEET (Tracked)]	3.0	01 March 2021
Research protocol or project proposal [PROTOCOL ACTforpeoplewithdementiaexperiencingpsychologicaldistress final v3.0 date 01.03.21]	3.0	01 March 2021
Research protocol or project proposal [Tracked]	3.0	01 March 2021

Membership of the Committee

The members of the Committee who took part in the review are listed on the attached sheet.

Working with NHS Care Organisations

Sponsors should ensure that they notify the R&D office for the relevant NHS care organisation of this amendment in line with the terms detailed in the categorisation email issued by the lead nation for the study.

Amendments related to COVID-19

We will update your research summary for the above study on the research summaries section of our website. During this public health emergency, it is vital that everyone can promptly identify all relevant research related to COVID-19 that is taking place globally. If you have not already done so, please register your study on a public registry as soon as possible and provide the HRA with the registration detail, which will be posted alongside other information relating to your project.

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.

HRA Learning

We are pleased to welcome researchers and research staff to our HRA Learning Events and online learning opportunities– see details at: https://www.hra.nhs.uk/planning-and-improving-research/learning/

IRAS Project ID - 288848:	**Please quote this number on all correspondence**

Yours sincerely

KLHoley

PP: Matthew Lawrence
Chair

E-mail: Wales.REC6@wales.nhs.uk

Enclosures:	*List of names and professions of members who took part in the review*
Copy to:	*Miss Amie Robinson, Nottinghamshire Healthcare NHS Foundation Trust*

Appendix C. Memory Assessment Service (MAS) Gatekeeper Crib Sheet

Administer GAD-7 and PHQ-9.

If score is below 8 on the GAD-7 and/or below 10 on the PHQ-9, please file in patient notes.

However, if score is 8 or above on the GAD-7 and/or 10 or above on the PHQ-9, please inform the patient (and their carer):

- There is currently some research being conducted in our department by Amie who is a Trainee Clinical Psychologist, and she has asked if I can help to recruit some participants from the Memory Assessment Service.

- I've seen from your notes/scores on these mood measures and from what you've told me today that there are times when you understandably feel low in mood and/or anxious.

- In Amie's research, she will be offering a 1:1 talking therapy with people like yourself with memory difficulties/a diagnosis of dementia who also experience low mood and/or anxiety.

- It may be that you are eligible to participate in her study.
  Would you be interested in having therapy?
  Would it be OK if I shared your contact details with Amie, who can contact you (both) to tell you more about her study?
  There is no pressure or obligation to agree to the study at this stage, but she could tell you more about it and then you could make up your mind about whether to participate?
  This wouldn't affect any other treatment/medications you are currently having or would be entitled to in the future.

If they require more information:

- The therapy is called Acceptance and Commitment Therapy or ACT, which can reduce anxiety or depression. Although Amie cannot guarantee that this will happen for you, at the very least, the information she will get from the study might help to explain how ACT may help in the future. There are no likely risks of taking part in the study.

Appendix D. Participant Information Sheet

University of Nottingham
UK | CHINA | MALAYSIA

NHS
Nottinghamshire Healthcare
NHS Foundation Trust

Participant Information Sheet
(Final Version 2.0: 23/11/20)

IRAS Project ID: 288848

Title of Study: Acceptance and Commitment Therapy (ACT) for people with dementia experiencing psychological distress

Name of Chief Investigator: Danielle De Boos
Local Researcher(s): Amie Robinson & Nima Moghaddam

We would like to invite you to take part in our research study. Before you decide we would like you to understand why the research is being done and what it would involve for you. One of our team will go through the information sheet with you and answer any questions you have. Talk to others about the study if you wish. Ask us if there is anything that is not clear.

What is the purpose of the study?

We would like a better understanding of if and how Acceptance and Commitment Therapy (ACT) may reduce anxiety and depression in people with dementia. ACT is a talking therapy with one therapist which can help to increase psychological flexibility. Psychological flexibility means that a person is able to lead a meaningful life, despite feelings of anxiety and depression. We know that this therapy is effective for reducing anxiety and depression but there is lots we need to know about how it might work for people with dementia.

Why have I been invited?

You are being invited to take part because you have a diagnosis of dementia and have said you would like therapy. We are inviting three participants like you to take part.

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 and without giving a reason. This would not affect your legal rights.

What will happen to me if I take part?

Part 1

Once you have consented to take part, you will be contacted by Amie Robinson (Trainee Clinical Psychologist and lead researcher) to arrange to meet with her for 12 weeks of therapy. It might be that you and Amie decide to meet face-to-face at a convenient location, or due to the Coronavirus, it may be that you decide to do therapy remotely, either by phone or by videocall. If it is helpful, we could ring you on the morning of each therapy session to remind you of when and where we are due to meet.

Each session may last up to 90 minutes, although we can decide how long is best for you. With your consent, we can also involve your caregiver in the study (e.g. family member, friend, carer), so they can support you in therapy sessions if you wish.

Therapy sessions will be recorded and stored electronically using an encrypted laptop so that they can be checked by the research team to make sure that the therapy is being delivered by Amie correctly. The recordings may also be helpful for Amie to listen back to when she transcribes recordings and writes up the study. We will seek your consent in the event we include what you say (direct quotations) in the study write-up. Recordings will be kept **strictly confidential** on an NHS shared drive for up to one year. Once recordings have been transcribed and possibly included in the study write-up, they will be confidentially destroyed (deleted from the laptop). Any information about you (e.g. via therapy recordings, transcripts) which leaves the NHS site will have your name, address and any identifiers removed, and a pseudonym will be used so that you cannot be recognised from it.

During the 12 weekly sessions, you will be asked to complete several short questionnaires. At session 1, session 6 and session 12, Amie will go through two questionnaires with you about your mood, one questionnaire which measures psychological flexibility, one questionnaire about your wellbeing, one about your goals for therapy and one about your relationship with the therapist (Amie). Every week, Amie will go through with you the questionnaires which will measure any changes in your psychological flexibility and your relationship with her over time. During sessions, we may also use pictures and written information to remind you to complete any tasks between sessions.

Part 2

Approximately one week after the final therapy session, an independent researcher will meet with you and your caregiver at a time that suits both of you to discuss your opinions of the therapy and any changes in your anxiety or low mood. This discussion will be recorded and kept **strictly confidential** at the University of Nottingham.

Lastly, two brief questionnaires will be sent to you (1 and 3 months after the therapy has ended) with a stamped addressed envelope for you to return them to Amie.

Expenses and payments

Participants will not be paid to participate in the study. Travel expenses such as parking and petrol costs will be offered if participants attend for face-to-face therapy appointments and provide evidence of costs (e.g. receipts). Mileage will be reimbursed at 24p per mile.

What are the possible disadvantages and risks of taking part?

There are no likely risks of taking part in this study. However, there are possible disadvantages. For example, therapy is often time-consuming and requires some emotional investment and commitment to regularly attend. You will also be required to fill out some questionnaires on a regular basis so that we can see if and how your mood and anxiety changes over time. If this proves to be too demanding or burdensome for you, a fallback option might be observer ratings (which can be completed either in session or another time outside of session, with your consent).

What are the possible benefits of taking part?

We cannot promise the study will help you but the information we get from this study may help explain how it may help in the future. Acceptance and Commitment Therapy (ACT) is a talking therapy that can reduce anxiety and depression, but we cannot guarantee this will happen. If you still require therapy after the study, you can opt for ‘usual care’ from your GP or Memory Assessment Service.

What happens when the research study stops?

When the study ends, we will use the data collected about you in the study write-up. This study is part of a Doctoral Thesis at the University of Nottingham and may be read by other students, but you will not be identified from the study. It is hoped that findings from the study will be published and presented in the future. In 2022, an information sheet with a summary of the study’s main findings will be made available and posted to you at your request, therefore we require your consent to hold your contact details until then.

What if there is a problem?

If you have a concern about any aspect of this study, you should ask to speak to the researchers who will do their best to answer your questions. The researchers’ contact details are given at the end of this information sheet. If you remain unhappy and wish to complain formally, you can do this by contacting the Patient Advice and Liaison Service (PALS) by telephone on **0115 993 4542**, email **PALSandComplaints@nottshc.nhs.uk** or postal address **PALS and Complaints, Highbury Hospital, Highbury Road, Nottingham NG6 9DR.**

In the event that something does go wrong and you are harmed during the research and this is due to someone's negligence then you may have grounds for a legal action for compensation against the University of Nottingham but you may have to pay your legal costs. The normal National Health Service complaints mechanisms will still be available to you.

Will my taking part in the study be kept confidential?

We will follow ethical and legal practice and all information about you will be handled in confidence.

If you join the study, we will use information collected from you during the course of the research. This information will be kept **strictly confidential**, stored in a secure and locked office, and on a password protected database at the University of Nottingham. Under UK Data Protection laws the University is the Data Controller (legally responsible for the data security) and the Chief Investigator of this study (named above) is the Data Custodian (manages access to the data). This means we are responsible for looking after your information and using it properly. Your rights to access, change or move your information are limited as we need to manage your information in specific ways to comply with certain laws and for the research to be reliable and accurate. To safeguard your rights we will use the minimum personally-identifiable information possible.

You can find out more about how we use your information and to read our privacy notice at:

https://www.nottingham.ac.uk/utilities/privacy.aspx.

The data collected for the study will be looked at and stored by authorised persons from the University of Nottingham who are organising the research. They may also be looked at by authorised people from regulatory organisations to check that the study is being carried out correctly. All will have a duty of confidentiality to you as a research participant and we will do our best to meet this duty.

Where possible information about you which leaves the NHS site will have your name and address removed and a pseudonym will be used so that you cannot be recognised from it, however sometimes we need to ensure that we can recognise you to link the research data with your medical records so in these instances we will need to know your name and date of birth. We will also need this information if we need to follow up your medical records as part of the research, where we may need to ask the Government services that hold medical information about you (such as NHS Digital, the Office for National Statistics, among others) to provide this information to us. By signing the consent form you agree to the above.

Your contact information will be kept by the University of Nottingham for up to 12 months after the end of the study so that we are able to contact you about the findings of the study and possible follow-up studies (unless you advise us that you do not wish to be contacted). This information will be kept separately from the research data collected and only those who need to will have access to it. All other data (research data) will be kept securely for 7 years. After this time your data will be disposed of securely. During this time all precautions will be taken by all those involved to maintain your confidentiality, only members of the research team given permission by the data custodian will have access to your personal data.

In accordance with the University of Nottingham's, the Government's and our funders' policies we may share our research data with researchers in other Universities and organisations, including those in other countries, for research in health and social care. Sharing research data is important to allow peer scrutiny, re-use (and therefore avoiding duplication of research) and to understand the bigger picture in particular areas of research. Data sharing in this way is usually anonymised (so that you could not be identified) but if we need to share identifiable information we will seek your consent for this and ensure it is secure. You will be made aware then if the data is to be shared with countries whose data protection laws differ to those of the UK and how we will protect your confidentiality.

Although what you say during therapy is confidential, if you said anything to us which we felt put you or anyone else at risk, we may feel it necessary to report this to the appropriate persons, like your caregiver or GP.

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

Your participation is voluntary and you are free to withdraw at any time, without giving any reason, and without your legal rights being affected. If you withdraw we will no longer collect any information about you or from you but we will keep the information about you that we have already obtained as we are not allowed to tamper with study records and this information may have already been used in some analyses and may still be used in the final study analyses. To safeguard your rights, we will use the minimum personally-identifiable information possible. Please note that your participation in therapy may also be stopped by the researcher (Amie) if you do not attend regularly or if there are concerns about your safety, but this would be discussed with you beforehand.

What will happen to the results of the research study?

This study is part of a Doctoral Thesis at the University of Nottingham and may be read by other students, but you will not be identified from the study. It is hoped that findings from the study will be published and presented in the future. In 2022, an information sheet with a summary of the study’s main findings will be made available and posted to you at your request.

Who is organising and funding the research?

This research is being organised and funded by the University of Nottingham. The study is being undertaken as part of an educational project as a requirement of the Trent Doctorate in Clinical Psychology (DClinPsy).

Who has reviewed the study?

All research in healthcare is looked at by independent group of people, called a Research Ethics Committee, to protect your interests. This study has been reviewed and given favourable opinion by University of Nottingham Research Governance Team.

Further information and contact details

Amie Robinson (Trainee Clinical Psychologist)
Email: amie.robinson@nottingham.ac.uk
Department of Psychiatry and Applied Psychology, Yang Fujia Building, Jubilee Campus, University of Nottingham, Wollaton Road, NG8 1BB

Dr Danielle De Boos (Associate Professor & Deputy Programme Director)
Email: danielle.deboos@nottingham.ac.uk
Phone: 0115 846 6696
Department of Psychiatry and Applied Psychology, B13 Yang Fujia Building, Jubilee Campus, University of Nottingham, Wollaton Road, Nottingham, NG8 1BB

Dr Nima Golijani Moghaddam (Research Clinical Psychologist/Senior Lecturer)
Email: nmoghaddam@lincoln.ac.uk
Phone: 01522 837733
Trent Doctorate in Clinical Psychology, Sarah Swift Building, University of Lincoln, Lincoln, LN6 7TS

Appendix E. Participant Demographic Sheet

University of Nottingham
UK | CHINA | MALAYSIA

NHS
Nottinghamshire Healthcare
NHS Foundation Trust

Participant Demographic Sheet

(Final Version 1.0: 23/10/20)

Participant Identifier (pseudonym) ……………………………………………………….

Title of Study: Acceptance and Commitment Therapy (ACT) for people with dementia experiencing psychological distress

If you consent to this study, we would like to collect some demographic information from you to use in the study write-up. The sharing of this information with any third parties is strictly prohibited.

Please provide the following information by circling your answer where appropriate:

Gender	Male
	Female
	Prefer not to say
Age	65-69
	70-79
	80-89
	90+
Race	**White**
	English / Welsh / Scottish / Northern Irish / British Irish
	Gypsy or Irish Traveller
	Any other White background
	Mixed / Multiple ethnic groups
	White and Black Caribbean
	White and Black African

	White and Asian Any other Mixed / Multiple ethnic background
	Asian / Asian British Indian Pakistani Bangladeshi Chinese Any other Asian background
	Black / African / Caribbean / Black British African Caribbean Any other Black / African / Caribbean background
	Other ethnic group Arab Any other ethnic group
Marital Status	Single Married Widowed Divorced Separated
Education	Employment Secondary school College / further education Bachelor’s degree Master’s degree Doctorate/PHD

Employment status

Employed, working 1-39 hours per week
Employed, working 40 or more hours per week
Not employed
Retired
Disabled, not able to work

Previous employment: Please state ………………………………………………………..

Your contact details:

Address ………………………………………………………………………..
………………………………………………………………………..
………………………………………………………………………..
………………………………………………………………………..

Telephone no. (Home) ……………………………………………………………………….
(Mobile) ……………………………………………………………………….

Email address ……………………………………………………………………….

Thank you

Appendix F. Participant Consent Form

University of Nottingham
UK | CHINA | MALAYSIA

NHS
Nottinghamshire Healthcare
NHS Foundation Trust

PARTICIPANT CONSENT FORM

(Final Version 2.0: 23/11/20)

Title of Study: Acceptance and Commitment Therapy (ACT) for people with dementia experiencing psychological distress

IRAS Project ID: 288848

Name of Researcher: Amie Robinson

Participant's pseudonym: **Please initial box:**

1. I confirm that I have read and understand the information sheet Final Version 2.0 dated 23/11/20 for the study and have had the opportunity to ask questions. ☐

2. I understand that my participation is voluntary and that I am free to withdraw at any time, without giving any reason, and without my medical care or legal rights being affected. I understand that should I withdraw then the information collected so far cannot be erased and that this information may still be used in the study. My participation may also be stopped at the discretion of the researcher if there is regular non-attendance or concerns about my safety due to my dementia, anxiety or low mood. ☐

3. I understand that data collected in the study may be looked at by authorised people from the University of Nottingham, the research group and regulatory authorities. I give permission for these individuals to have access to these records and to collect, store, analyse and publish information from my participation in this study. I understand that my personal details will be kept confidential. ☐

4. I consent to being recorded throughout the study (during therapy sessions and interview). ☐

5. I consent to what I say in the study (direct quotations) being included in the study write-up. ☐

6. I consent to my caregiver being involved in the study (supporting me in therapy sessions and at interview). ☐

7. In 2022 when the study has been written up, I would like to receive an information sheet with a summary of the study's main findings. Therefore, I consent to my contact details being retained until then. ☐

8. I agree to take part in the above study. ☐

Name of Participant	**Date**	**Signature**
Name of Person taking consent	Date	Signature

3 copies: 1 for participant, 1 for the project notes, 1 for medical records

Appendix G. Caregiver Information Sheet

Caregiver Information Sheet
(Final Version 2.0: 23/11/20)

IRAS Project ID: 288848

Title of Study: Acceptance and Commitment Therapy (ACT) for people with dementia experiencing psychological distress

Name of Chief Investigator: Danielle De Boos
Local Researcher(s): Amie Robinson & Nima Moghaddam

We would like to invite you to take part in our research study, alongside the person you care for. Before you decide we would like you to understand why the research is being done and what it would involve for you. One of our team will go through the information sheet with you and answer any questions you have. Talk to others about the study if you wish. Ask us if there is anything that is not clear.

What is the purpose of the study?

We would like to gain a better understanding of if and how Acceptance and Commitment Therapy (ACT) may reduce anxiety and depression in people with dementia. ACT is a talking therapy with one therapist which can help to increase psychological flexibility. Psychological flexibility can enable people to lead meaningful lives, despite feelings of anxiety and depression that may be associated with their condition. We are aware that ACT is effective for reducing anxiety and depression generally, but there is lots we need to know about how it might work for people with dementia.

Why have I been invited?

You are being invited to take part because you support somebody with a diagnosis of dementia and they have told us that they would like you to be involved throughout their therapy. We are inviting three participants like you (caregivers) to take part.

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 and without giving a reason. This would not affect your legal rights. However, the person you care for can continue to take part in the study without your involvement, if they wish and if it is feasible or appropriate to do so.

What will happen to me if I take part?

<u>Part 1</u>

Part 1 of the study involves the person you support participating in therapy with Amie. Therapy sessions may last up to 90 minutes and will be conducted weekly for 12 weeks but will be reviewed at 6 weeks. It might be that therapy is conducted face-to-face at a location convenient to you and the person you support, or due to the Coronavirus, it may be that it is conducted remotely, either by phone or videocall. You and the person you support will discuss with Amie which you think is best for you.

Therapy sessions will be recorded and stored electronically using an encrypted laptop so that they can be checked by the research team to make sure that the therapy is being delivered by Amie correctly. The recordings may also be helpful for Amie to listen back to when she transcribes recordings and writes up the study. We will seek your consent in the event we include what you say (direct quotations) in the study write-up. Recordings will be kept **strictly confidential** on an NHS shared drive for up to one year. Once recordings have been transcribed and possibly included in the study write-up, they will be confidentially destroyed (deleted from the laptop). Any information about you (e.g. via therapy recordings, transcripts) which leaves the NHS site will have your name, address and any identifiers removed, and a pseudonym will be used so that you cannot be recognised from it.

Your involvement in Part 1 will be in a supporting capacity for the person with dementia. It would be extremely helpful if you could offer reminders and prompts about therapy attendance to the person you support and encourage with any between-session tasks. If therapy is conducted in person, support with transportation to and from therapy would be greatly appreciated. Alternatively, if therapy is conducted remotely, any support you could provide with technology (e.g. telephone, accepting videocall invitations) would be valuable.

At the beginning of each therapy session, Amie will offer introductions, provide reminders about the purpose of the study, confidentiality and its limits and gain verbal consent to proceed. Reported changes will also be captured at the beginning of each session, for example, ‘checking-in’ with the person you support by inviting them to share any reflections on therapy or changes they have noticed between sessions. However, it would also be incredibly helpful for you to share your thoughts on the effectiveness or value of therapy and any changes you may or may not have noticed in the person you support. Therefore, there is the potential to capture any changes that the person you support may not report (if you have agreed with them beforehand that it would be OK to share with Amie). It may be that you keep brief written notes that you can share with Amie.

Part 2

Approximately one week after the final therapy session, an independent researcher will meet with you and the person you support at a time that suits both of you to discuss your opinions of the therapy and any changes in low mood or anxiety in the person you support. This discussion will be recorded and kept **strictly confidential** at the University of Nottingham.

Lastly, two brief questionnaires will be sent to the person you support (1 and 3 months after the therapy has ended) with a stamped addressed envelope for them to return to Amie. Any support you could offer the person with dementia with completing these questionnaires would be greatly appreciated.

Expenses and payments

Participants will not be paid to participate in the study. Travel expenses such as parking and petrol costs will be offered if participants attend for face-to-face therapy appointments and provide evidence of costs (e.g. receipts). Mileage will be reimbursed at 24p per mile.

What are the possible disadvantages and risks of taking part?

There are no likely risks of taking part in this study. However, there are possible disadvantages. For example, participation in research can often be time-consuming and therapy will require commitment to regularly attend. Therefore, there may be pressures on your time in transporting the person you support to therapy appointments, being present throughout them, the time taken to support with any between-session tasks and supporting the person with dementia to complete regular questionnaires in session so that we can see if and how their mood and anxiety changes over time. If this proves to be too demanding or burdensome for the person you support, a fallback option might be observer ratings (which can be completed either in session or another time outside of session, with their consent).

What are the possible benefits of taking part?

We cannot promise the study will help the person you support but the information we get from this study may help explain how it may help in the future. Acceptance and Commitment Therapy (ACT) is a talking therapy that can reduce anxiety and depression, but we cannot guarantee this will happen. If the person you support still requires therapy after the study, they can opt for ‘usual care’ from your GP or Memory Assessment Service.

What happens when the research study stops?

When the study ends, the data collected about you and the person you support will be used in the study write-up. This study is part of a Doctoral Thesis at the University of Nottingham and may be read by other students, but you will not be identified from the study. It is hoped that findings from the study will be published and presented in the future. In 2022, an information sheet with a summary of the study’s main findings will be made available and posted to you at your request, therefore we require your consent to hold your contact details until then.

What if there is a problem?

If you have a concern about any aspect of this study, you should ask to speak to the researchers who will do their best to answer your questions. The researchers’ contact details are given at the end of this information sheet. If you remain unhappy and wish to complain formally, you can do this by contacting the Patient Advice and Liaison Service (PALS) by telephone on **0115 993 4542**, email **PALSandComplaints@nottshc.nhs.uk** or postal address **PALS and Complaints, Highbury Hospital, Highbury Road, Nottingham NG6 9DR.**

In the event that something does go wrong and you are harmed during the research and this is due to someone's negligence then you may have grounds for a legal action for compensation against the University of Nottingham but you may have to pay your legal costs. The normal National Health Service complaints mechanisms will still be available to you.

Will my taking part in the study be kept confidential?

We will follow ethical and legal practice and all information about you will be handled in confidence.

If you join the study, we will use information collected from you [and your medical records] during the course of the research. This information will be kept **strictly confidential**, stored in a secure and locked office, and on a password protected database at the University of Nottingham. Under UK Data Protection laws the University is the Data Controller (legally responsible for the data security) and the Chief Investigator of this study (named above) is the Data Custodian (manages access to the data). This means we are responsible for looking after your information and using it properly. Your rights to access, change or move your information are limited as we need to manage your information in specific ways to comply with certain laws and for the research to be reliable and accurate. To safeguard your rights we will use the minimum personally-identifiable information possible.

You can find out more about how we use your information and to read our privacy notice at:

https://www.nottingham.ac.uk/utilities/privacy.aspx.

The data collected for the study will be looked at and stored by authorised persons from the University of Nottingham who are organising the research. They may also be looked at by authorised people from regulatory organisations to check that the study is being carried out correctly. All will have a duty of confidentiality to you as a research participant and we will do our best to meet this duty.

Where possible information about you which leaves the NHS site will have your name and address removed and a pseudonym will be used so that you cannot be recognised from it, however sometimes we need to ensure that we can recognise you to link the research data with your medical records so in these instances we will need to know your name and date of birth. We will also need this information if we need to follow up your medical records as part of the research, where we may need to ask the Government services that hold medical information about you (such as NHS Digital, the Office for National Statistics, among others) to provide this information to us. By signing the consent form you agree to the above.

Your contact information will be kept by the University of Nottingham for up to 12 months after the end of the study so that we are able to contact you about the findings of the study and possible follow-up studies (unless you advise us that you do not wish to be contacted). This information will be kept separately from the research data collected and only those who need to will have access to it. All other data (research data) will be kept securely for 7 years. After this time your data will be disposed of securely. During this time all precautions will be taken by all those involved to maintain your confidentiality, only members of the research team given permission by the data custodian will have access to your personal data.

In accordance with the University of Nottingham's, the Government's and our funders' policies we may share our research data with researchers in other Universities and organisations, including those in other countries, for research in health and social care. Sharing research data is important to allow peer scrutiny, re-use (and therefore avoiding duplication of research) and to understand the bigger picture in particular areas of research. Data sharing in this way is usually anonymised (so that you could not be identified) but if we need to share identifiable information we will seek your consent for this and ensure it is secure. You will be made aware then if the data is to be shared with countries whose data protection laws differ to those of the UK and how we will protect your confidentiality.

Although what you say during therapy is confidential, if you said anything to us which we felt put you or anyone else at risk, we may feel it necessary to report this to the appropriate persons, like your GP.

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

Your participation is voluntary and you are free to withdraw at any time, without giving any reason, and without your legal rights being affected. If you withdraw we will no longer collect any information about you or from you but we will keep the information about you that we have already obtained as we are not allowed to tamper with study records and this information may have already been used in some analyses and may still be used in the final study analyses. To safeguard your rights, we will use the minimum personally-identifiable information possible. Please note that your participation in therapy may also be stopped by the researcher (Amie) if you or the person you support do not attend regularly or if there are concerns about your safety, but this would be discussed with you beforehand.

What will happen to the results of the research study?

This study is part of a Doctoral Thesis at the University of Nottingham and may be read by other students, but you will not be identified from the study. It is hoped that findings from the study will be published and presented in the future. In 2022, an information sheet with a summary of the study’s main findings will be made available and posted to you at your request.

Who is organising and funding the research?

This research is being organised and funded by the University of Nottingham. The study is being undertaken as part of an educational project as a requirement of the Trent Doctorate in Clinical Psychology (DClinPsy).

Who has reviewed the study?

All research in healthcare is looked at by independent group of people, called a Research Ethics Committee, to protect your interests. This study has been reviewed and given favourable opinion by University of Nottingham Research Governance Team.

Further information and contact details

Amie Robinson (Trainee Clinical Psychologist)
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Dr Danielle De Boos (Associate Professor & Deputy Programme Director)
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Phone: 0115 846 6696
Department of Psychiatry and Applied Psychology, B13 Yang Fujia Building, Jubilee Campus, University of Nottingham, Wollaton Road, Nottingham, NG8 1BB

Dr Nima Golijani Moghaddam (Research Clinical Psychologist/Senior Lecturer)
Email: nmoghaddam@lincoln.ac.uk

Phone: 01522 837733
Trent Doctorate in Clinical Psychology, Sarah Swift Building, University of Lincoln, Lincoln, LN6 7TS

Appendix H. Caregiver Demographic Sheet

Caregiver Demographic Sheet

(Final Version 1.0: 23/10/20)

Caregiver Identifier (pseudonym) ………………………………………………………

Title of Study: Acceptance and Commitment Therapy (ACT) for people with dementia experiencing psychological distress

If you consent to this study, we would like to collect some demographic information from you to use in the study write-up. The sharing of this information with any third parties is strictly prohibited.

Please provide the following information by circling your answer where appropriate:

Gender	Male
	Female
	Prefer not to say
Age	18-19
	20-29
	30-39
	40-49
	50-59
	60-69
	70-79
	80-89
	90+
Race	**White**
	English / Welsh / Scottish / Northern Irish / British Irish
	Gypsy or Irish Traveller

	Any other White background
	Mixed / Multiple ethnic groups
	White and Black Caribbean
	White and Black African
	White and Asian
	Any other Mixed / Multiple ethnic background
	Asian / Asian British
	Indian
	Pakistani
	Bangladeshi
	Chinese
	Any other Asian background
	Black / African / Caribbean / Black British
	African
	Caribbean
	Any other Black / African / Caribbean background
	Other ethnic group
	Arab
	Any other ethnic group
Marital Status	Single
	Married
	Widowed
	Divorced
	Separated
Education	Employment
	Secondary school
	College / further education

	Bachelor’s degree
	Master’s degree
	Doctorate/PHD
Employment status	Employed, working 1-39 hours per week
	Employed, working 40 or more hours per week
	Not employed
	Retired
	Disabled, not able to work

Please state current/previous employment: ………………………………………………

Name of and relation to person you support ……………………………………………

Your contact details:

Address ……………………………………………………………………………..
……………………………………………………………………………..
……………………………………………………………………………..
……………………………………………………………………………..

Telephone no. (Home) ………………………………………………………………………
(Mobile) ………………………………………………………………………

Email address …………………………………………………………………………

Thank you

Appendix I. Caregiver Consent Form

University of Nottingham
UK | CHINA | MALAYSIA

NHS
Nottinghamshire Healthcare
NHS Foundation Trust

CARGIVER CONSENT FORM

(Final Version 2.0: 23/11/20)

Title of Study: Acceptance and Commitment Therapy (ACT) for people with dementia experiencing psychological distress

IRAS Project ID: 288848

Name of Researcher: Amie Robinson

Caregiver's Pseudonym: **Please initial box:**

1. I confirm that I have read and understand the information sheet Final Version 2.0 dated 23/11/20 for the above study and have had the opportunity to ask questions. ☐
2. I understand that my participation is voluntary and that I am free to withdraw at any time, without giving any reason, and without my legal rights being affected. I understand that should I withdraw then the information collected so far cannot be erased and that this information may still be used in the project analysis. My participation may also be terminated at the discretion of the researcher if there is regular non-attendance or concerns about mine or others' safety. ☐
3. I understand that data collected in the study may be looked at by authorised individuals from the University of Nottingham, the research group and regulatory authorities where it is relevant to my taking part in this study. I give permission for these individuals to have access to these records and to collect, store, analyse and publish information obtained from my participation in this study. I understand that my personal details will be kept confidential. ☐
4. I consent to being recorded throughout the study (during therapy sessions and interview). ☐
5. I consent to what I say in the study (direct quotations) being included in the study write-up. ☐
6. In 2022 when the study has been written up, I would like to receive an information sheet with a summary of the study's main findings. Therefore, I consent to my contact details being retained until then. ☐
7. I agree to take part in the above study. ☐

______________________	____________	________________
Name of Participant	**Date**	**Signature**
______________________	____________	________________
Name of Person taking consent	Date	Signature

2 copies: 1 for participant, 1 for the project notes

Appendix J. Clinical Psychologist Information Sheet

Participant Information Sheet for Clinical Psychologists
(Final Version 1.0: 23/11/20)

IRAS Project ID: 288848

Title of Study: Acceptance and Commitment Therapy (ACT) for people with dementia experiencing psychological distress

Name of Chief Investigator: Danielle De Boos
Local Researcher(s): Amie Robinson & Nima Moghaddam

We would like to invite you to take part in our research study. Before you decide we would like you to understand why the research is being done and what it would involve for you. One of our team will go through the information sheet with you and answer any questions you have. Talk to others about the study if you wish. Ask us if there is anything that is not clear.

What is the purpose of the study?

We would like a better understanding of if and how Acceptance and Commitment Therapy (ACT) may reduce anxiety and depression in people with dementia. ACT is a talking therapy with one therapist which can help to increase psychological flexibility. Psychological flexibility means that a person is able to lead a meaningful life, despite feelings of anxiety and depression. We know that this therapy is effective for reducing anxiety and depression but there is lots we need to know about how it might work for people with dementia.

Why have I been invited?

You are being invited to take part because you are a Clinical Psychologist who has prominent clinical research experience, has an interest in assessing psychotherapy effectiveness and has a theoretical orientation which may be valuable in analysing the efficacy of this study. We are inviting three participants like you to take part, who may vary in their theoretical orientation.

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 and without giving a reason. This would not affect your legal rights.

What will happen to me if I take part?

You will be asked to critically examine the effectiveness of a study, which involves a 12-week 1:1 ACT intervention for three people with dementia. During the ACT sessions, the therapist and lead researcher (Amie Robinson) will have taken notes, made audio recordings, and administered questionnaires to participants on a regular basis to measure their mood, psychological flexibility, wellbeing, goals for therapy and relationship with the therapist. After the 12-week intervention, an independent researcher will meet with the participants and their caregivers to conduct a Change Interview to discuss their opinions of the therapy and any changes in the participants' anxiety or depression. Lastly, two brief questionnaires will be sent to participants (1 and 3 months after the therapy ended). All of this data will be collated into participant briefs by Amie for analysis (or 'adjudication') by a review panel of three independent Clinical Psychologists (yourself included).

You will be provided with each client's case record and Change Interview transcripts. You will be asked to critically cross-examine each case record and corresponding affirmative and sceptic briefs. You will then use an Adjudication Interview Schedule to respond to a series of semi-structured questions regarding the extent and type of client change, and conclusions made about the effectiveness of the intervention.

Expenses and payments

Participants will not be paid to participate in the study. Travel expenses such as parking and petrol costs will be offered if participants attend for face-to-face adjudication panel and provide evidence of costs (e.g. receipts). Mileage will be reimbursed at 24p per mile.

What are the possible disadvantages and risks of taking part?

There are no likely risks or disadvantages of taking part in the study.

What are the possible benefits of taking part?

The information we get from this study may help explain how ACT may help people with dementia in the future.

What happens when the research study stops?

When the study ends, we will use your analysis of the ACT intervention in the study write-up. This study is part of a Doctoral Thesis at the University of Nottingham and may be read by other students, but you will not be identified from the study. It is hoped that findings from the study will be published and presented in the future.

What if there is a problem?

If you have a concern about any aspect of this study, you should ask to speak to the researchers who will do their best to answer your questions. The researchers' contact details are given at the end of this information sheet. If you remain unhappy and wish to complain formally, you can do this by contacting the Patient Advice and Liaison Service (PALS) by telephone on **0115 993 4542**, email **PALSandComplaints@nottshc.nhs.uk** or postal address **PALS and Complaints, Highbury Hospital, Highbury Road, Nottingham NG6 9DR.**

In the event that something does go wrong and you are harmed during the research and this is due to someone's negligence then you may have grounds for a legal action for compensation against the University of Nottingham but you may have to pay your legal costs. The normal National Health Service complaints mechanisms will still be available to you.

Will my taking part in the study be kept confidential?

We will follow ethical and legal practice and all information about you will be handled in confidence.

If you join the study, any information collected from you during the course of the research will be kept **strictly confidential**, stored in a secure and locked office, and on a password protected database at the University of Nottingham. Under UK Data Protection laws the University is the Data Controller (legally responsible for the data security) and the Chief Investigator of this study (named above) is the Data Custodian (manages access to the data). This means we are responsible for looking after your information and using it properly. Your rights to access, change or move your information are limited as we need to manage your information in specific ways to comply with certain laws and for the research to be reliable and accurate. To safeguard your rights we will use the minimum personally-identifiable information possible.

You can find out more about how we use your information and to read our privacy notice at:

https://www.nottingham.ac.uk/utilities/privacy.aspx.

The data collected for the study will be looked at and stored by authorised persons from the University of Nottingham who are organising the research. They may also be looked at by authorised people from regulatory organisations to check that the study is being carried out correctly. All will have a duty of confidentiality to you as a research participant and we will do our best to meet this duty.

Where possible information about you which leaves the NHS site will have your name and address removed and a pseudonym will be used so that you cannot be recognised from it, however sometimes we need to ensure that we can recognise you to link the research data with your medical records so in these instances we will need to know your name and date of birth. We will also need this information if we need to follow up your medical records as part of the research, where we may need to ask the Government services that hold medical information about you (such as NHS Digital, the Office for National Statistics, among others) to provide this information to us. By signing the consent form you agree to the above.

Your contact information will be kept by the University of Nottingham for up to 12 months after the end of the study so that we are able to contact you about the findings of the study and possible follow-up studies (unless you advise us that you do not wish to be contacted). This information will be kept separately from the research data collected and only those who need to will have access to it. All other data (research data) will be kept securely for 7 years. After this time your data will be disposed of securely. During this time all precautions will be taken by all those involved to maintain your confidentiality, only members of the research team given permission by the data custodian will have access to your personal data.

In accordance with the University of Nottingham's, the Government's and our funders' policies we may share our research data with researchers in other Universities and organisations, including those in other countries, for research in health and social care. Sharing research data is important to allow peer scrutiny, re-use (and therefore avoiding duplication of research) and to understand the bigger picture in particular areas of research. Data sharing in this way is usually anonymised (so that you could not be identified) but if we need to share identifiable information we will seek your consent for this and ensure it is secure. You will be made aware then if the data is to be shared with countries whose data protection laws differ to those of the UK and how we will protect your confidentiality.

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

Your participation is voluntary and you are free to withdraw at any time, without giving any reason, and without your legal rights being affected. If you withdraw we will no longer collect any information about you or from you but we will keep the information about you that we have already obtained as we are not allowed to tamper with study records and this information may have already been used in some analyses and may still be used in the final study analyses. To safeguard your rights, we will use the minimum personally-identifiable information possible.

What will happen to the results of the research study?

This study is part of a Doctoral Thesis at the University of Nottingham and may be read by other students, but you will not be identified from the study. It is hoped that findings from the study will be published and presented in the future. In 2022, an information sheet with a summary of the study's main findings will be made available and posted to you at your request.

Who is organising and funding the research?

This research is being organised and funded by the University of Nottingham. The study is being undertaken as part of an educational project as a requirement of the Trent Doctorate in Clinical Psychology (DClinPsy).

Who has reviewed the study?

All research in healthcare is looked at by independent group of people, called a Research Ethics Committee, to protect your interests. This study has been reviewed and given favourable opinion by University of Nottingham Research Governance Team.

Further information and contact details

Amie Robinson (Trainee Clinical Psychologist)
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Department of Psychiatry and Applied Psychology, Yang Fujia Building, Jubilee Campus, University of Nottingham, Wollaton Road, NG8 1BB

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Email: danielle.deboos@nottingham.ac.uk
Phone: 0115 846 6696
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Dr Nima Golijani Moghaddam (Research Clinical Psychologist/Senior Lecturer)
Email: nmoghaddam@lincoln.ac.uk
Phone: 01522 837733
Trent Doctorate in Clinical Psychology, Sarah Swift Building, University of Lincoln, Lincoln, LN6 7TS

Appendix K. Clinical Psychologist Consent Form

University of Nottingham
UK | CHINA | MALAYSIA

NHS
Nottinghamshire Healthcare
NHS Foundation Trust

PARTICIPANT CONSENT FORM FOR CLINICAL PSYCHOLOGIST

(Final Version 1.0: 23/11/20)

Title of Study: Acceptance and Commitment Therapy (ACT) for people with dementia experiencing psychological distress

IRAS Project ID: 288848

Name of Researcher: Amie Robinson

Psychologist's pseudonym/Judge no.: **Please initial box:**

1. I confirm that I have read and understand the information sheet Final Version 1.0 dated 23/11/20 for the study and have had the opportunity to ask questions. ☐
2. I understand that my participation is voluntary and that I am free to withdraw at any time, without giving any reason, and without my legal rights being affected. I understand that should I withdraw then the information collected so far cannot be erased and that this information may still be used in the study. ☐
3. I understand that data collected in the study may be looked at by authorised people from the University of Nottingham, the research group and regulatory authorities. I give permission for these individuals to have access to these records and to collect, store, analyse and publish information from my participation in this study. I understand that my personal details will be kept confidential. ☐
4. I agree to take part in the above study. ☐

______________________	______________	____________________
Name of Participant	**Date**	**Signature**
______________________	______________	____________________
Name of Person taking consent	Date	Signature

2 copies: 1 for participant, 1 for the project notes

Appendix L. Generalised Anxiety Disorder Questionnaire (GAD-7; Spitzer, Kroenke, Williams, & Lowe, 2006)

Name:

Date:

This self-administered patient questionnaire is used as a screening tool and severity measure for generalised anxiety disorder.

Over the last 2 weeks, how often have you been bothered by any of the following problems?

	Not at all	Several days	More than half the days	Nearly every day
1. Feeling nervous, anxious or on edge?	0	1	2	3
2. Not being able to stop or control worrying?	0	1	2	3
3. Worrying too much about different things?	0	1	2	3
4. Trouble relaxing?	0	1	2	3
5. Being so restless that it is hard to sit still?	0	1	2	3
6. Becoming easily annoyed or irritable?	0	1	2	3
7. Feeling afraid as if something awful might happen?	0	1	2	3
TOTAL out of 21=				

Scores of 5, 10, and 15 are taken as the cut-off points for mild, moderate and severe anxiety, respectively.

Appendix M. Patient Health Questionnaire (PHQ-9; Spitzer, Kroenke, & Williams, 1999)

Name:

Date:

This self-administered patient questionnaire is used as a screening tool and severity measure for depression.

Over the last 2 weeks, how often have you been bothered by any of the following problems?

	Not at all	Several days	More than half the days	Nearly every day
1. Little interest or pleasure in doing things?	0	1	2	3
2. Feeling down, depressed, or hopeless?	0	1	2	3
3. Trouble falling or staying asleep, or sleeping too much?	0	1	2	3
4. Feeling tired or having little energy?	0	1	2	3
5. Poor appetite or overeating?	0	1	2	3
6. Feeling bad about yourself - or that you are a failure or have let yourself or your family down?	0	1	2	3
7. Trouble concentrating on things, such as reading the newspaper or watching television?	0	1	2	3
8. Moving or speaking so slowly that other people could have noticed? Or the opposite - being so fidgety or restless that you have been moving around a lot more than usual?	0	1	2	3
9. Thoughts that you would be better off dead, or of hurting yourself in some way?	0	1	2	3
TOTAL out of 27=				

Scores of 0-4, 5-9, 10-14, 15-19 and 20-27 are taken as the cut-off points for none, mild, moderate, moderately severe and severe depression, respectively.

Appendix N. Comprehensive assessment of Acceptance & Commitment Therapy- short form (CompACT-SF; Morris, 2019)

Name:	**Date:**

Please rate the following 8 statements using the scale below:

0	**1**	**2**	**3**	**4**	**5**	**6**
Strongly disagree	Moderately disagree	Slightly disagree	Neither agree nor disagree	Slightly agree	Moderately agree	Strongly agree

1.	I act in ways that are consistent with how I wish to live my life	0	1	2	3	4	5	6
2.	I get so caught up in my thoughts that I am unable to do the things that I most want to do	0	1	2	3	4	5	6
3.	I rush through meaningful activities without being really attentive to them	0	1	2	3	4	5	6
4.	I go out of my way to avoid situations that might bring difficult thoughts, feelings, or sensations	0	1	2	3	4	5	6
5.	I undertake things that are meaningful to me, even when I find it hard to do so	0	1	2	3	4	5	6
6.	Even when doing the things that matter to me, I find myself doing them without paying attention	0	1	2	3	4	5	6
7.	I work hard to keep out upsetting feelings	0	1	2	3	4	5	6
8.	I can keep going with something when it’s important to me	0	1	2	3	4	5	6

Scoring instructions (administrative use only) **REMOVE FOR CLIENTS**

- Scores are derived by summing responses for each of the three subscales (Openness to Experience; Behavioural Awareness; Valued Action) or the scale as a whole (CompACT Total score).
- Five items are reverse-scored before summation (items 2, 3, 4, 6, and 7).

Openness to Experience (OE) subscale

Calculated as the sum of scores for items: 2 (reversed), 4 (reversed), and 7 (reversed).

Subscale scores range from 0-18, with higher scores indicating greater openness to experience (willingness to experience internal events [thoughts, feelings, sensations, etc.] without trying to control or avoid them

Behavioural Awareness (BA) subscale

Calculated as the sum of scores for items: 3 (reversed) and 6 (reversed).

Subscale scores range from 0–12 with higher scores indicating greater behavioural awareness (mindful attention to current actions)

Valued Action (VA) subscale

Calculated as the sum of scores for items: 1, 5, and 8.

Subscale scores range from 0–18 with higher scores indicating greater engagement in valued actions (meaningful activity)

CompACT Total

Calculated as the sum of the three subscale scores, the full-scale CompACT Total score ranges from 0–48, with higher scores indicating greater psychological flexibility: The ability to attend and adapt to situational demands in the pursuit of personally-meaningful longer-term goals.

Appendix O. Short Warwick-Edinburgh Mental Wellbeing Scale (SWEMWBS; Tennant et al., 2007)

Below are some statements about feelings and thoughts.
Please tick the box that best describes your experience of each over the last 2 weeks

STATEMENTS	None of the time	Rarely	Some of the time	Often	All of the time
I've been feeling optimistic about the future	1	2	3	4	5
I've been feeling useful	1	2	3	4	5
I've been feeling relaxed	1	2	3	4	5
I've been dealing with problems well	1	2	3	4	5
I've been thinking clearly	1	2	3	4	5
I've been feeling close to other people	1	2	3	4	5
I've been able to make up my own mind about things	1	2	3	4	5

Appendix P. Personal Questionnaire (PQ; Elliott, Mack & Shapiro, 1999)

The Personal Questionnaire (PQ) is an expanded target complaint measure which is individualized for each client. It is generated from the PQ Problem Description Form, completed by the client during the screening process. It is intended to be a list of problems that the client wishes to work on in therapy, stated in the client's own words.

Client ID: Today's date:

Problem Description Form: Do this one first!

1. Please describe the main problems you are having right now that led you to seek treatment.

2. If you are seeking psychotherapy, please list the specific problems or difficulties that you would like assistance with. Please feel free to add to your list as you fill out other forms.

Client ID _______________ Today's date:______________________

Instructions: Please rate each of the following problems according to how much it has bothered you during the **past seven days, including today.**

	Not At All	Very Little	Little	Moderately	Considerably	Very Considerably	Maximum Possible
1.	1	2	3	4	5	6	7
2.	1	2	3	4	5	6	7
3.	1	2	3	4	5	6	7

Additional Problems:

4.	1	2	3	4	5	6	7
5.	1	2	3	4	5	6	7
6.	1	2	3	4	5	6	7
7.	1	2	3	4	5	6	7
8.	1	2	3	4	5	6	7
9.	1	2	3	4	5	6	7
10.	1	2	3	4	5	6	7

Appendix Q. Session Rating Scale (SRS; Duncan et al., 2003)

Name ………………………………………………………………

Age ……………………………….. Sex M/F Session no. ……

Date ………………………………

Please rate today's session by placing a mark on the line nearest to the description that best fits your experience

Relationship

I did not feel heard,
understood,
and respected.

I felt heard,
understood,
and respected.

Goals and Topics

We did not work on or
about what I wanted
and talk about.

We worked on and talk
talked about what I to work on
wanted to work on
and talk about.

Approach or Method

The therapist's approach
is not a good fit for me.

The therapist's approach
is a good fit for me.

Overall

There was something
missing in the session
today.

Overall, today's session
was right for me.

Appendix R. Therapy Adaptations

Pre-adaptational work to ACT Protocol

The ‘Better Living with Illness’ (Brassington et al., 2016) protocol was chosen as most suitable to guide the intervention, however, this was initially developed for use in a group setting of people with chronic physical health conditions, comprising of six weekly sessions lasting up to 2.5 hours. Hence, the protocol had to be somewhat adapted for use in:

(i) Individual therapy by creating a familiar structure to each session, beginning with a present-moment awareness exercise and completion of measures at the beginning and end of each session.

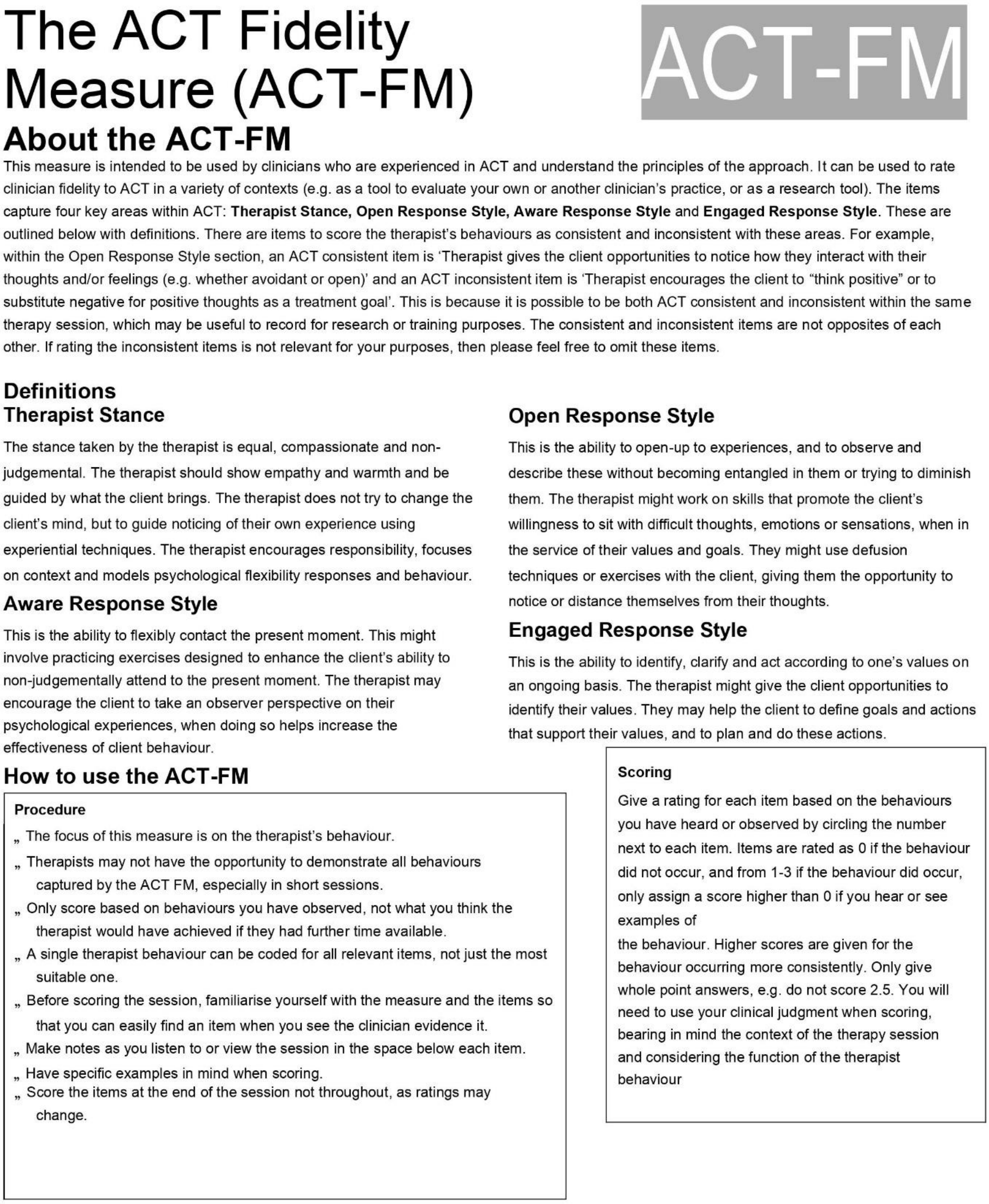
(ii) People with dementia by extending therapy over 12 weeks, planning regular breaks, recapping previous sessions, checking understanding, and adapting terminology from chronic physical health difficulties to dementia. For example, within discussions about the impact of dementia on clients’ lives and in between-sessions tasks (e.g., ‘Write down one or two activities that are important to you that you can do even with your condition, such as, “If I plan reminders well enough, I can go for a coffee with a friend, even with the forgetting”’).

(iii) Remote delivery by developing resources, including audio recorded exercises that could be emailed to clients and carers and visual aids that could be screen shared. For example, the values circle, goals worksheets and pictures to support the introduction of new ACT metaphors/concepts. Also, offering flexibility with the start time to support with any technical issues and ensuring the videocall was ended for all at session completion.

Adaptations during therapy delivery

(i) Slowing the pace of therapy by increasing the number and frequency of sessions (Robie, 1999) and offering regular breaks.
(ii) Using straightforward language to simplify communications (Robie), with communication adapted to the clients’ cognitive ability.
(iii) Checking understanding throughout (“Is this familiar?”)
(iv) Emphasising behavioural strategies, as suggested by Grant and Casey (1995), with use of procedural learning and modelling during intervention delivery.
(v) Using learning strategies, such as increased repetition (Grant & Casey).
(vi) Use of compensatory strategies and memory aids, such as visual (e.g., screen sharing), written, and verbal information, and offer of guidance, reminders, and prompts (Robinson & Moghaddam, 2022).
(vii) Making environmental adaptations, for example, delivering the intervention in clients’ homes, protecting from distractions, and using headphones to reduce any background noise (Robinson & Moghaddam).
(viii) Involving family members or carers to support in-session and with between-session tasks, according to client preference, using written and audio recorded exercises (Robinson & Moghaddam).
(ix) A supportive therapist style using non-verbal gestures, verbal encouragers, and paraphrasing, and allowing sufficient time for clients to respond (Robinson & Moghaddam).

Appendix S. ACT Fidelity Measure (ACT-FM; O’Neill et al., 2019)



The ACT Fidelity Measure (ACT-FM)

ACT-FM

About the ACT-FM

This measure is intended to be used by clinicians who are experienced in ACT and understand the principles of the approach. It can be used to rate clinician fidelity to ACT in a variety of contexts (e.g. as a tool to evaluate your own or another clinician’s practice, or as a research tool). The items capture four key areas within ACT: **Therapist Stance, Open Response Style, Aware Response Style** and **Engaged Response Style**. These are outlined below with definitions. There are items to score the therapist’s behaviours as consistent and inconsistent with these areas. For example, within the Open Response Style section, an ACT consistent item is ‘Therapist gives the client opportunities to notice how they interact with their thoughts and/or feelings (e.g. whether avoidant or open)’ and an ACT inconsistent item is ‘Therapist encourages the client to “think positive” or to substitute negative for positive thoughts as a treatment goal’. This is because it is possible to be both ACT consistent and inconsistent within the same therapy session, which may be useful to record for research or training purposes. The consistent and inconsistent items are not opposites of each other. If rating the inconsistent items is not relevant for your purposes, then please feel free to omit these items.

Definitions

Therapist Stance

The stance taken by the therapist is equal, compassionate and non-judgemental. The therapist should show empathy and warmth and be guided by what the client brings. The therapist does not try to change the client’s mind, but to guide noticing of their own experience using experiential techniques. The therapist encourages responsibility, focuses on context and models psychological flexibility responses and behaviour.

Aware Response Style

This is the ability to flexibly contact the present moment. This might involve practicing exercises designed to enhance the client’s ability to non-judgementally attend to the present moment. The therapist may encourage the client to take an observer perspective on their psychological experiences, when doing so helps increase the effectiveness of client behaviour.

Open Response Style

This is the ability to open-up to experiences, and to observe and describe these without becoming entangled in them or trying to diminish them. The therapist might work on skills that promote the client’s willingness to sit with difficult thoughts, emotions or sensations, when in the service of their values and goals. They might use defusion techniques or exercises with the client, giving them the opportunity to notice or distance themselves from their thoughts.

Engaged Response Style

This is the ability to identify, clarify and act according to one’s values on an ongoing basis. The therapist might give the client opportunities to identify their values. They may help the client to define goals and actions that support their values, and to plan and do these actions.

How to use the ACT-FM

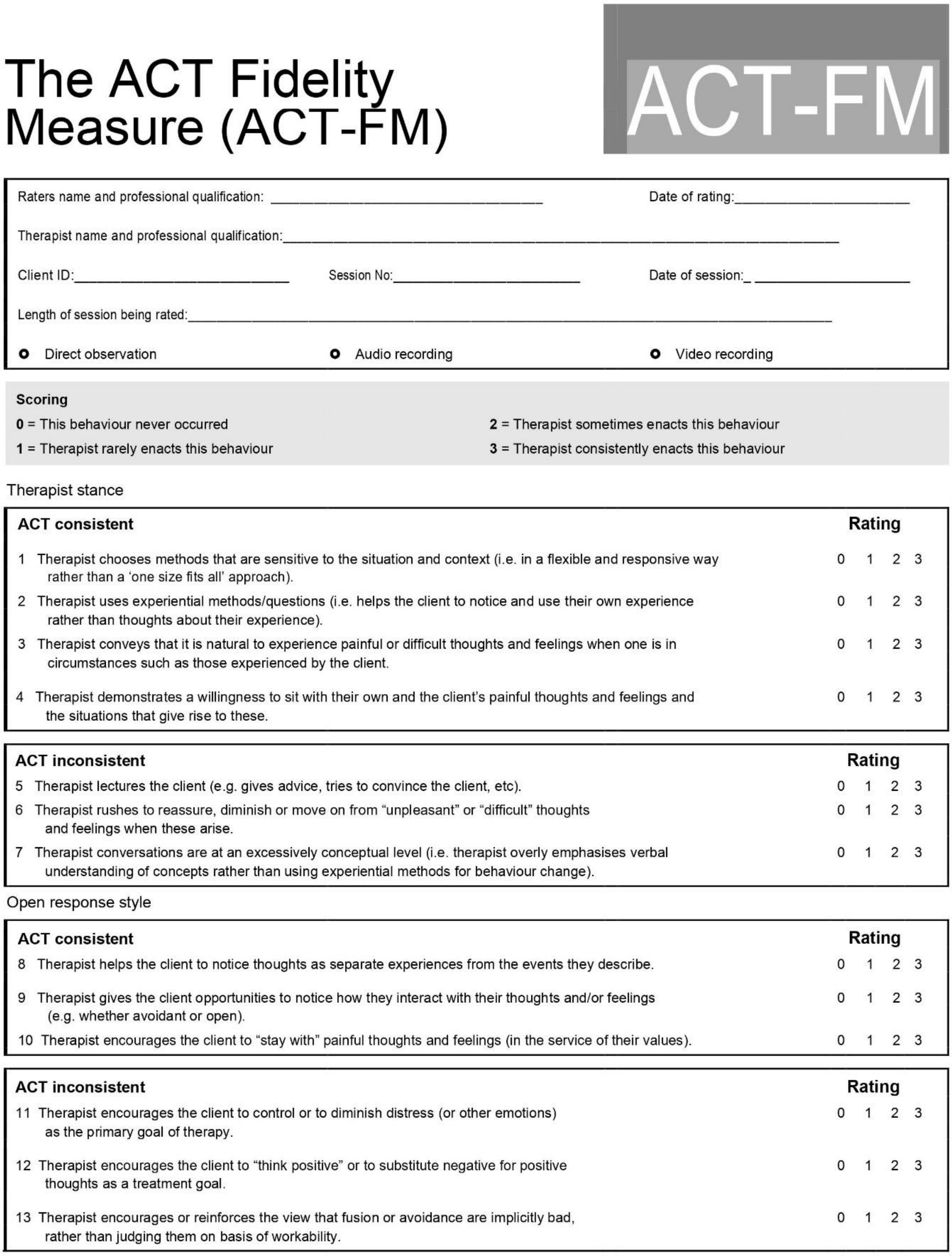
Procedure

- The focus of this measure is on the therapist’s behaviour.
- Therapists may not have the opportunity to demonstrate all behaviours captured by the ACT FM, especially in short sessions.
- Only score based on behaviours you have observed, not what you think the therapist would have achieved if they had further time available.
- A single therapist behaviour can be coded for all relevant items, not just the most suitable one.
- Before scoring the session, familiarise yourself with the measure and the items so that you can easily find an item when you see the clinician evidence it.
- Make notes as you listen to or view the session in the space below each item.
- Have specific examples in mind when scoring.
- Score the items at the end of the session not throughout, as ratings may change.

Scoring

Give a rating for each item based on the behaviours you have heard or observed by circling the number next to each item. Items are rated as 0 if the behaviour did not occur, and from 1-3 if the behaviour did occur, only assign a score higher than 0 if you hear or see examples of

the behaviour. Higher scores are given for the behaviour occurring more consistently. Only give whole point answers, e.g. do not score 2.5. You will need to use your clinical judgment when scoring, bearing in mind the context of the therapy session and considering the function of the therapist behaviour



The ACT Fidelity Measure (ACT-FM)

ACT-FM

Raters name and professional qualification: ______________________ Date of rating: ______________

Therapist name and professional qualification: ____

Client ID: ________________ Session No: ________________ Date of session: _ ______________

Length of session being rated: ____

○ Direct observation ○ Audio recording ○ Video recording

Scoring

0 = This behaviour never occurred

1 = Therapist rarely enacts this behaviour

2 = Therapist sometimes enacts this behaviour

3 = Therapist consistently enacts this behaviour

Therapist stance

ACT consistent	**Rating**
1 Therapist chooses methods that are sensitive to the situation and context (i.e. in a flexible and responsive way rather than a 'one size fits all' approach).	0 1 2 3
2 Therapist uses experiential methods/questions (i.e. helps the client to notice and use their own experience rather than thoughts about their experience).	0 1 2 3
3 Therapist conveys that it is natural to experience painful or difficult thoughts and feelings when one is in circumstances such as those experienced by the client.	0 1 2 3
4 Therapist demonstrates a willingness to sit with their own and the client's painful thoughts and feelings and the situations that give rise to these.	0 1 2 3

ACT inconsistent	**Rating**
5 Therapist lectures the client (e.g. gives advice, tries to convince the client, etc).	0 1 2 3
6 Therapist rushes to reassure, diminish or move on from "unpleasant" or "difficult" thoughts and feelings when these arise.	0 1 2 3
7 Therapist conversations are at an excessively conceptual level (i.e. therapist overly emphasises verbal understanding of concepts rather than using experiential methods for behaviour change).	0 1 2 3

Open response style

ACT consistent	**Rating**
8 Therapist helps the client to notice thoughts as separate experiences from the events they describe.	0 1 2 3
9 Therapist gives the client opportunities to notice how they interact with their thoughts and/or feelings (e.g. whether avoidant or open).	0 1 2 3
10 Therapist encourages the client to "stay with" painful thoughts and feelings (in the service of their values).	0 1 2 3

ACT inconsistent	**Rating**
11 Therapist encourages the client to control or to diminish distress (or other emotions) as the primary goal of therapy.	0 1 2 3
12 Therapist encourages the client to "think positive" or to substitute negative for positive thoughts as a treatment goal.	0 1 2 3
13 Therapist encourages or reinforces the view that fusion or avoidance are implicitly bad, rather than judging them on basis of workability.	0 1 2 3

The ACT Fidelity Measure (ACT-FM)

ACT-FM

Scoring

0 = This behaviour never occurred	**2** = Therapist sometimes enacts this behaviour
1 = Therapist rarely enacts this behaviour	**3** = Therapist consistently enacts this behaviour

Aware response style

	ACT consistent	**Rating**
14	Therapist uses present moment focus methods (e.g. mindfulness tasks, tracking, noticing, etc) to increase awareness of the moment, including thoughts and feelings.	0 1 2 3
15	Therapist helps the client to notice the stimuli (thoughts, feelings, situations, etc) that hook them away from the present moment.	0 1 2 3
16	Therapist helps the client to experience that they are bigger than and/or separate from their psychological experiences.	0 1 2 3

	ACT inconsistent	**Rating**
17	Therapist introduces or uses mindfulness and/or self-as-context methods as means to control or diminish or distract from unwanted thoughts, emotions and bodily sensations	0 1 2 3
18	Therapist introduces or uses mindfulness and/or self-as-context methods to challenge the accuracy of beliefs or thoughts.	0 1 2 3
19	Therapist introduces mindfulness and/or self-as-context methods as formulaic exercises.	0 1 2 3

Engaged response style

	ACT consistent	**Rating**
20	Therapist gives the client opportunities to notice workable and unworkable responses (e.g. whether their actions move them towards or away from their values).	0 1 2 3
21	Therapist gives the client opportunities to clarify their own values (overarching life goals and qualities of action).	0 1 2 3
22	Therapist helps the client to make plans and set goals likely to meet reinforcing consequences (i.e. shapes action that is consistent with their values).	0 1 2 3

	ACT inconsistent	**Rating**
23	Therapist imposes their own, other's or society's values upon the client (i.e. suggests what the client should or should not value or what valuing something should look like).	0 1 2 3
24	Therapist encourages action without first hearing, exploring or showing curiosity regarding the client's psychological experiences (e.g. painful thoughts, feelings and emotions).	0 1 2 3
25	Therapist encourages the client's proposed plans even when the client has noticed clear impracticalities.	0 1 2 3

Scoring

A total score for each subscale can be calculated by adding the 3 items together. The Therapist stance – ACT consistent section has 4 items, so please convert this to give a total out of 9 in line with the other sections by adding the 4 items, dividing by 4 and multiplying by 3. The ACT consistent items can be added to give a total ACT consistency score and the ACT inconsistent items can be added to give a total ACT inconsistency score.

ACT Consistent Therapist Stance (0-9) =
ACT Consistent Open Response Style (0-9) =
ACT Consistent Aware Response Style (0-9) =
ACT Consistent Engaged Response Style (0-9) =
Total ACT Consistency Score (0-36) =

ACT Inconsistent Therapist Stance (0-9) =
ACT Inconsistent Open Response Style (0-9) =
ACT Inconsistent Aware Response Style (0-9) =
ACT Inconsistent Engaged Response Style (0-9) =
Total ACT Inconsistency Score (0-36) =

Appendix T. Change Interview Schedule (Elliott et al., 1999; based on The Helpful Aspects of Therapy framework by Llewelyn et al., Hardy, 1988)

Change Interview Schedule

(Final Version 1.0: 23/10/20)

Participant ………………………………………………….. Date ……………………

1. General questions (5 mins)

1a. How are you doing now in general?

1b. What has therapy been like for you? How has it felt to be in therapy?

1c. What medications are you currently on? (dose, how long, last adjustment, herbal remedies).

2. Changes (10 mins)

2a. What changes, if any, have you noticed in yourself since therapy started? (Interviewer: reflect back change to client and write down brief versions of the changes one per change sheet. Optional follow-up questions: "Are you doing, feeling or thinking differently from the way you did before?", "What specific ideas, if any, have you got from therapy, including ideas about yourself or other people?", "Have any changes been brought to your attention by other people?"

2b. Has anything changed for the worse since therapy started?

2c. Is there anything that you wanted to change that hasn't since therapy started?

3. Change ratings (10 mins) (*see separate change sheet with rating scales a, b and c*).

4. Helpful aspects (10 mins)

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

5. Attributions (5 minutes)

In general, what do you think has caused the various changes you described? What do you think might have brought them about, including things both outside of therapy and in therapy?

6. Resources (5 minutes)

6a. What personal strengths do you think have helped you make use of therapy to deal with your problems (what you're good at; personal qualities)?

6b. What things in your current life situation have helped you make use of therapy to deal with your problems (family, relationships, living arrangements)?

7. Problematic aspects (5 minutes)

7a. What kinds of things about the therapy have been hindering, unhelpful, negative, or disappointing for you (general aspects or specific events)?

7b. Were there things in therapy which were difficult or painful but still OK or perhaps helpful? What were they?

7c. Has anything been missing from treatment? What would have made therapy more effective or helpful?

8. Limitations (5 minutes)
8a. Are there things about you that you think have made it harder for you to use therapy to deal with your problems? If so, what?

8b. Are there things in your life situation that have made it harder for you to use therapy to deal with your problems (family, relationships, living arrangements etc.)?

9. Suggestions (5 minutes)
Do you have any suggestions for us, regarding the research or the therapy?
Do you have anything else that you want to tell me?

10. Reflecting on changes shown on measures
We have put together the scores from all of the questionnaires you filled in during therapy. I would like to talk through them, and as I do, get your view on the results, for example, whether you think they are in line with your expectations or not.

The GAD-7 & PHQ-9: These are the Generalised Anxiety Disorder Questionnaire and Patient Health Questionnaire. They measure anxiety and low mood. You completed them at your first, sixth and last therapy session. The GAD-7 indicates *. The PHQ-9 indicates *.

The SWEMWBS: This is the Short Warwick-Edinburgh Mental Wellbeing Scale that you completed just before, mid and after therapy. The * indicates clinically significant change. A higher score shows greater wellbeing.

Personal Questionnaire: This is the measure that you used to label problems you wanted to work on, and you rated how much they bothered you. A lower score suggests the problem bothers you less. The dark line shows before you started therapy; the lighter line shows your scores on your last session. Where there is an * this is considered clinically significant change, which is good.

CompACT-SF: This is the 8-question measure of what we call psychological flexibility. A higher score indicates better psychological health. These are your scores from the start to the end of therapy.

The CompACT-SF breaks down into three sections (other side of the sheet): behavioural awareness, openness to experience, and valued action, i.e., what you do that is in line with how you want to live. These graphs show your scores from the start to the end of therapy on the three scales. Higher scores indicate better psychological health.

The Session Rating Scale: This is the measure you completed at the end of each session, about your experience of the session. A higher score indicates better working alliance with the therapist.

Change/s ratings sheet:

(Complete one sheet per identified change)

What was the change? ……………………………………………………………………..

a. Please rate how much you expected it vs. were surprised by it:

1	2	3	4	5
Very much expected it	Somewhat expected it	Neither expected nor surprised by it	Somewhat surprised by it	Very much surprised by it

b. Please rate how likely you think it would have been if you had not had therapy?

1	2	3	4	5
Very unlikely without therapy (clearly would not have happened)	Somewhat unlikely without therapy (probably would not have happened)	Neither likely nor unlikely (no way of telling)	Somewhat likely without therapy (probably would have happened)	Very likely without therapy (would have happened anyway)

c. How important or significant to you personally do you consider this change to be?

1	2	3	4	5
Not at all important	Slightly important	Moderately important	Very important	Extremely important

Appendix U. Minnie’s Rich Case Record (for demonstration purposes)

Acceptance and Commitment Therapy (ACT) for People with Dementia Experiencing Psychological Distress: A Hermeneutic Single Case Efficacy Design (HSCED) Series

Rich Case Record
Minnie

A. The Client

Minnie was a Caucasian British female in her early 70s, who was referred to a Memory Assessment Service (MAS) in Nottinghamshire and diagnosed with Alzheimer’s Disease in September 2020. She was a retired farmer’s wife and widowed two years ago.

Minnie had three adult children; two daughters who lived locally and one son who lived with her. Minnie’s daughter, Mo was in her 50s and married, and was a full-time carer for Minnie. Despite a complex family relationship, all of Minnie’s children offered daily support and supervision to Minnie. It seemed Minnie used to be a very independent and strong-willed person, but her insight into her capabilities could now fluctuate. For example, she once stated that she was grateful to her family and that she could not cope without them but had also said that though it was nice to have them around, she did not need them as she was capable of looking after herself. Minnie said she felt very comfortable in her own environment after many years of living on the farm.

Minnie experienced the bereavement of her husband, sister and mother-in-law in close succession in 2019. Her husband’s death was particularly difficult as she had been his primary carer for many years during the progression of his Parkinson’s Disease. Minnie continued to experience feelings of guilt about not being able to ‘split myself three ways’ and believed she had neglected her sister who had dementia.

Minnie was prescribed Sertraline for depression following the bereavements. She also took Galantamine for dementia. She had not previously had psychological therapy.

Minnie’s family believed Minnie’s memory difficulties pre-dated the bereavements. Mo had noticed problems with Minnie’s memory over the past 2-3 years, which had started with her forgetting birthdays. Others who knew Minnie had also noticed she was much quieter nowadays, for example, during parish church meetings. Mo said Minnie had understandably felt angry when she had become aware of her memory difficulties and reduced functional abilities, for example, when making crafts, but now seemed to be accepting of her dementia.

Minnie reported she did not think about having dementia and that it had not stopped her from doing what she wanted, though admitted she was less active now, for example, in researching archaeology, which she had previously enjoyed. With some prompting from Mo, Minnie acknowledged the dementia had impacted her independence, for example, in relinquishing her driving licence and ability to take holidays abroad. Due to Coronavirus (COVID-19) restrictions, Minnie said she also felt scared and unsafe about going out, as well as concerns about slipping, which had reduced her confidence outside of her home.

Minnie reported a great deal of fatigue much of the time. Mo said that Minnie often had opportunities to socialise with others but that she did not take them up due to her fatigue and lack of motivation. Minnie stated, “I can’t face being in a group of people,” and shared thoughts that she did not wish to be a burden. Mo had also noticed Minnie could become easily overwhelmed, for example, in noisy environments, and tended to escape the situation to cope.

Minnie continued to have a keen interest in archaeology and geology and advocated for where she lived, having written books, and taught in summer school on the subject. She also had an interest in politics and a passion for books, spinning (wheel) and gardening, which were hobbies she had used to get through difficult times in life. Her interests had been therapeutic and offered comfort, enjoyment, and a sense of satisfaction for many years. Minnie stated she always had a project, was ‘never idle’ and seemed to enjoy her own company.

Mo informed that Minnie had been raised in a family with a ‘British stiff upper lip’, where due to generational and cohort beliefs, did not openly discuss emotions or difficulties. Mo felt that Minnie found it hard to deal with her emotions, especially in front of her. It seemed Minnie had used internal control strategies for many years, with attempts to ignore difficult thoughts and feelings by changing her focus of attention onto something else, though said she was not aware of suppressing them. Minnie stated she did not indulge difficult thoughts and feelings and was ‘in charge’ of them, otherwise fearing that her emotions would become overpowering.

A family informant, separate to the research, described Minnie as a ‘very complex character’ and that they believed Minnie had an undiagnosed mental health condition such as bipolar disorder, dating back her whole life. The informant described how Minnie’s mood had ‘always been very up and down’ which made family life difficult, and that Minnie and her family continued to have a fractious relationship.

B. Adaptations to the ACT protocol

To promote positive client-change, ACT aims to increase psychological flexibility through six model-specific processes; acceptance, cognitive defusion, present moment awareness, self-as-context, values, and committed action (please see Appendix V for more information).

Minnie attended a 12-week ACT intervention with the therapist via Microsoft Teams, supported in person by Mo. The ‘Better Living with Illness’ (Brassington et al., 2016) protocol was used to guide the intervention (please see Appendix W for more information). The protocol provided structure and familiarity to sessions, for example, each week, Minnie completed the Comprehensive Assessment of Acceptance and Commitment Therapy Processes- Short form (CompACT-SF), Session Rating Scale (SRS), a present moment awareness exercise and reviewed any between-session practice. However, the intervention was also conducted flexibly according to client need. For example, with Minnie’s theme of controlling thoughts, the ‘white rabbit’ and ‘pushing away paper’ exercises were introduced as metaphors for acceptance. Mindful breathing was also offered because, at times, Minnie could become tearful about her bereavements and associated feelings of guilt, with the aim of increasing her openness to experience before offering her a break. Less relevant exercises were removed, sometimes due to time constraints. For example, some exercises regarding thought defusion were not introduced since Minnie seemed to have difficulty in identifying particular thoughts to work with.

Other adaptations included:

- Offer of regular breaks.
- Sharing the screen so Minnie and Mo could see the measures as Minnie completed them and the sharing of materials from previous sessions as a prompt.
- Providing prompting, scaffolding and concrete examples to Minnie when completing the CompACT-SF, for example, “It sounds like *x,* is that slightly, moderately or strongly agree?” Whilst it was recognised this risked asking loaded questions and may have been ACT-inconsistent, this was balanced with a need to give additional support and direction to help (re)orient Minnie to the questions.
- At Minnie and Mo’s request, the therapist recorded a reading of a mindfulness script and emailed this to Mo so she could support Minnie with between-session practice.
- Following the therapy review at session 6, it was agreed that session time would be reduced from 90 to 60 minutes.
- Negotiating and protecting time for both Minnie and Mo to share their perspectives and feelings (the therapist debriefed with Mo a couple of days after the first session).

ACT-adherence was ensured in monthly clinical supervision discussions and fidelity ratings for one session recording were completed by an independent rater using the ACT Fidelity Measure (ACT-FM). In Minnie’s case, the recording of session 6 was chosen at random, which focused on recapping from the previous session (openness and awareness), and values clarification. Average ACT consistency was rated as 31 out of 36 with a median of 3 (maximum possible), indicating the therapist enacted ACT-congruent behaviours. ACT inconsistency was rated as 0.3 out of 36 with extremely rare occasions of ACT-inconsistent behaviours.

In therapy, it is also worth commenting on the working relationship between Minnie and Mo, since Mo’s support to Minnie was deemed extremely beneficial to the intervention, as shown in the following ways:

- Offering reassurance where necessary, as Minnie would often look to Mo to answer.
- Prompting during completion of measures and reorienting Minnie to the question.
- Offering additional information and support to help Minnie to understand and engage with ACT metaphors and exercises where necessary.
- Supporting with between-session practice such as playing or reading a mindfulness script to Minnie in the morning as part of her daily routine to ‘set her for the day’.

- Both Mo and her sister helped to support Minnie to achieve her goals towards committed action, including contacting archaeologists and finding maps and photos for Minnie to look at. Mo stated that Minnie would not have done these things without her support.

In therapy, the therapist's impression was that Minnie could become distractible, tangential in speech and repetitive at points, for example, often reverted to speaking about her hobbies such as archaeology, which may have been used as a strategy to mask or distract from her memory difficulties. In a similar way, Minnie's insight into her difficulties also appeared to vary, as she sometimes stated that she was not forgetful but just required reassurance. Minnie could also struggle to switch her attention between conversations, such as picking up with the session content after a break. Furthermore, during the completion of the CompACT-SF, on most weeks, Minnie could perseverate on a particular question which needed reframing to aid her understanding and her overall ability to complete the measures and her responses appeared to fluctuate each week. Minnie seemed to struggle with some of the longer ACT metaphors and exercises, such as the '80th birthday party', which may have been too cognitively-taxing. With the 'Passengers on a Bus' metaphor, Minnie appeared to have difficulty in engaging with this due to the possible rigidity of her thinking, stating, "I don't see where this is going… it'd be dangerous… they wouldn't let me drive a bus". She did, however, engage well with the beach ball metaphor, body scan and mindfulness exercises which may have been more immediate and not relied as much on her short-term memory.

C. Client and therapy goals

Using the Personal Questionnaire (PQ), Minnie generated personal goals for therapy which were as follows:

(i) To improve low mood (due to feelings of isolation, bereavements, and fleeting thoughts that life is not worth living).
(ii) To decrease worry about long-term coping.

As well as Minnie's personal goals, the goals for the intervention were to improve Minnie's psychological flexibility, re-engagement with a life of valued activities and improved functional wellbeing, with a secondary aim of symptom reduction. Tables 2-4 present data for and against each of these goals being met throughout the intervention, with regards to the following research questions:

(1) Do (meaningful) changes occur for client-participants over the course of the ACT intervention?;
(2) Are observed changes broadly attributable to the ACT intervention?;
(3) What specific factors (within ACT or outside of it) contribute to observed changes?

The changes of interest will be specific to the personal concerns and goals of each client-participant.

D. Minnie's quantitative outcome measures

At each session, Minnie completed a self-report measure of psychology flexibility (CompACT-SF) and relational process (SRS) to provide data on the quality of the therapeutic alliance as a rival hypothesis for interventional change. At the initial screening, baseline (session 1), mid-point (session 6), last session (session 12) and at 1 and 3-month follow-ups, Minnie also completed measures of anxiety (Generalised Anxiety Disorder Questionnaire; GAD-7) and depression (Patient Health Questionnaire; PHQ-9), where lower scores indicate reduced levels of anxiety and depression, a measure of wellbeing (Short Warwick-Edinburgh Mental Wellbeing Scale; SWEMWBS), where higher scores indicate increased wellbeing, personal problems (PQ), where lower scores indicate less bothersome problems, and the CompACT-SF, where higher scores indicate increased psychological flexibility. These scores are shown in Table 33 and visually represented in Figures 7-10.

Using the PQ, Minnie reported specific difficulties and quantified how much each of these problems had been bothering her over the past week. Pre-therapy (session 1), Minnie rated low mood caused by feeling isolated as bothering her 'considerably' and low mood due to memories of bereavements as bothering her the 'maximum possible'. She also rated worry as 'considerably' bothersome. At the end of therapy (session 12), Minnie rated her low mood due to both factors as 'not at all' bothersome and worries as bothering her 'very little', indicating improvement towards her goals.

Table 33. Minnie's therapy measures

Measure	Timepoint														
	Screening	Session 1	Session 2	Session 3	Session 4	Session 5	Session 6	Session 7	Session 8	Session 9	Session 10	Session 11	Session 12	1-month follow-up	3-month follow-up
GAD-7 (clinical cut-off 8)	0	3					4						1	3	0
PHQ-9 (clinical cut-off 10)	14	9					9						6	7	0
SWEMWBS		23					26						29	28	35
PQ (out of 42)		22					11						7	11	6
CompACT-SF		27	38	37	45	37	36	45	43	32	37	39	43	38	46
SRS		x	36	36	36	36	36	36	36	36	32	36	40		

Figure 7. Minnie's GAD-7 & PHQ-9 scores

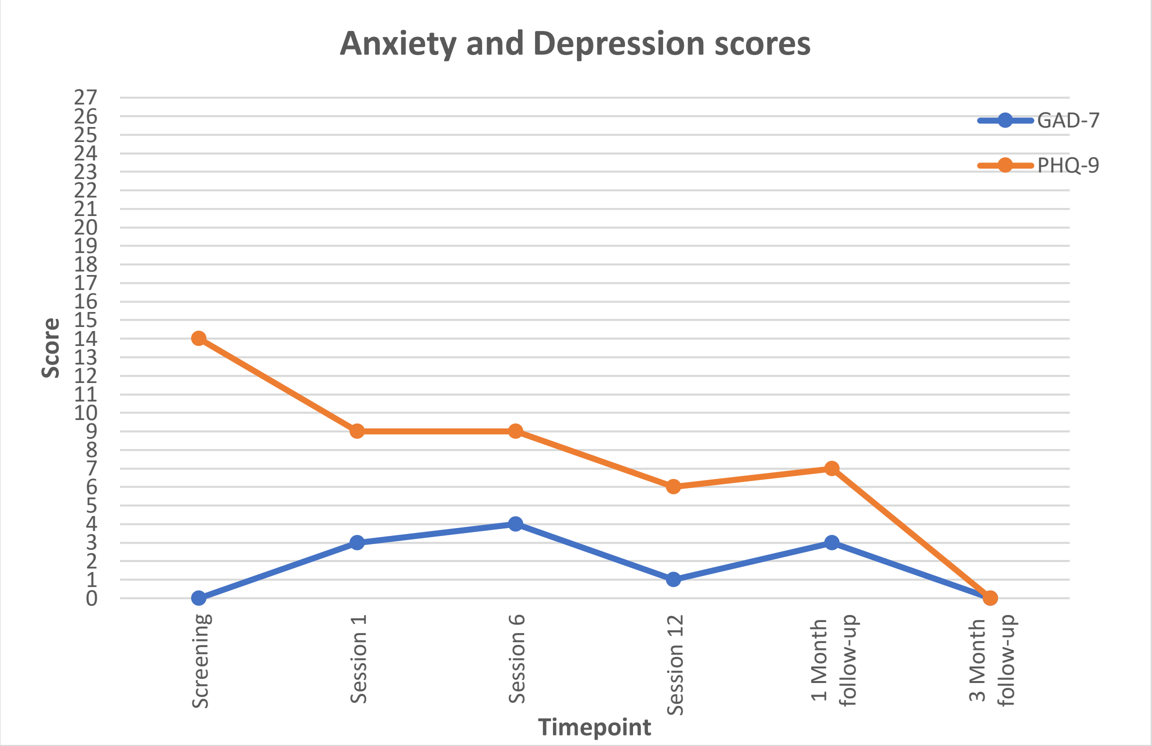


Figure 8. Minnie's SWEMWBS scores

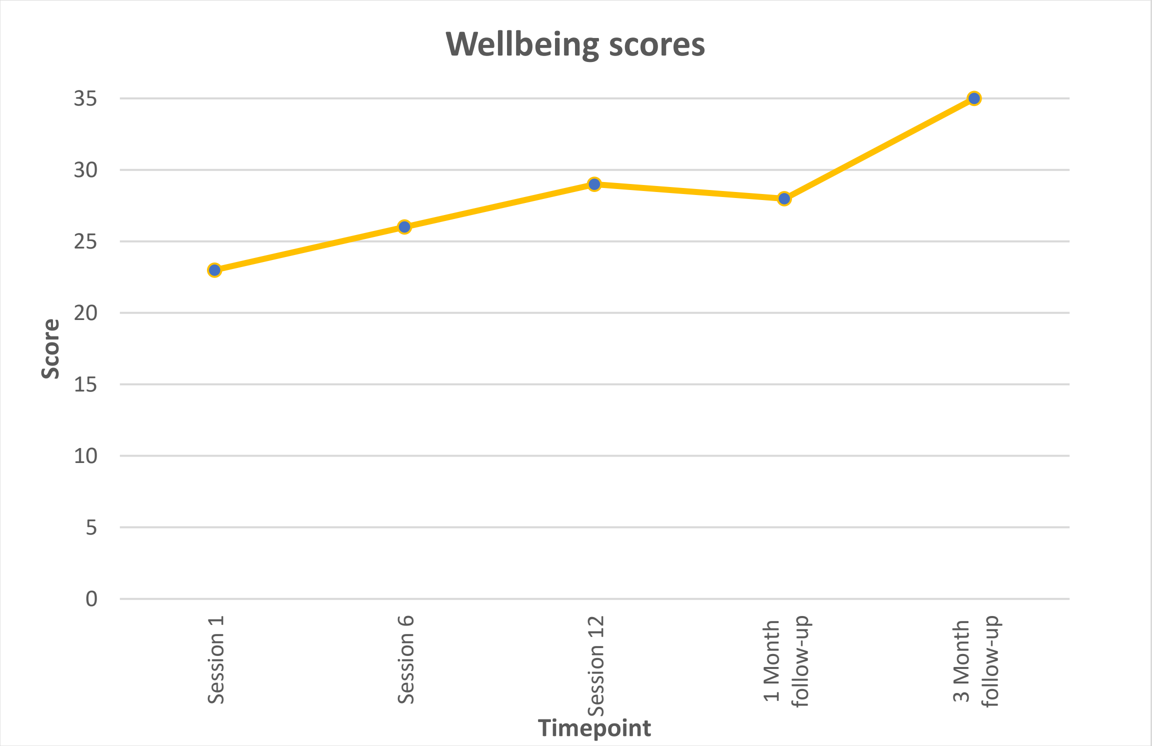


Figure 9. Minnie's PQ scores

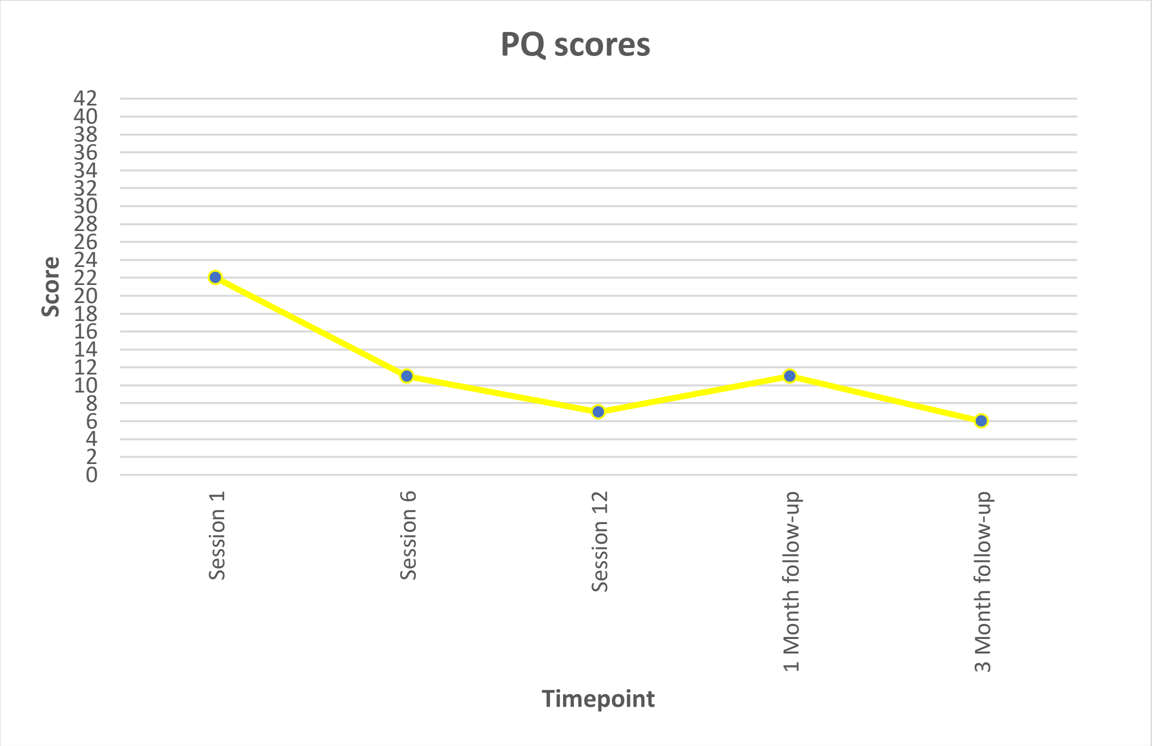


Figure 10. Minnie's CompACT-SF scores

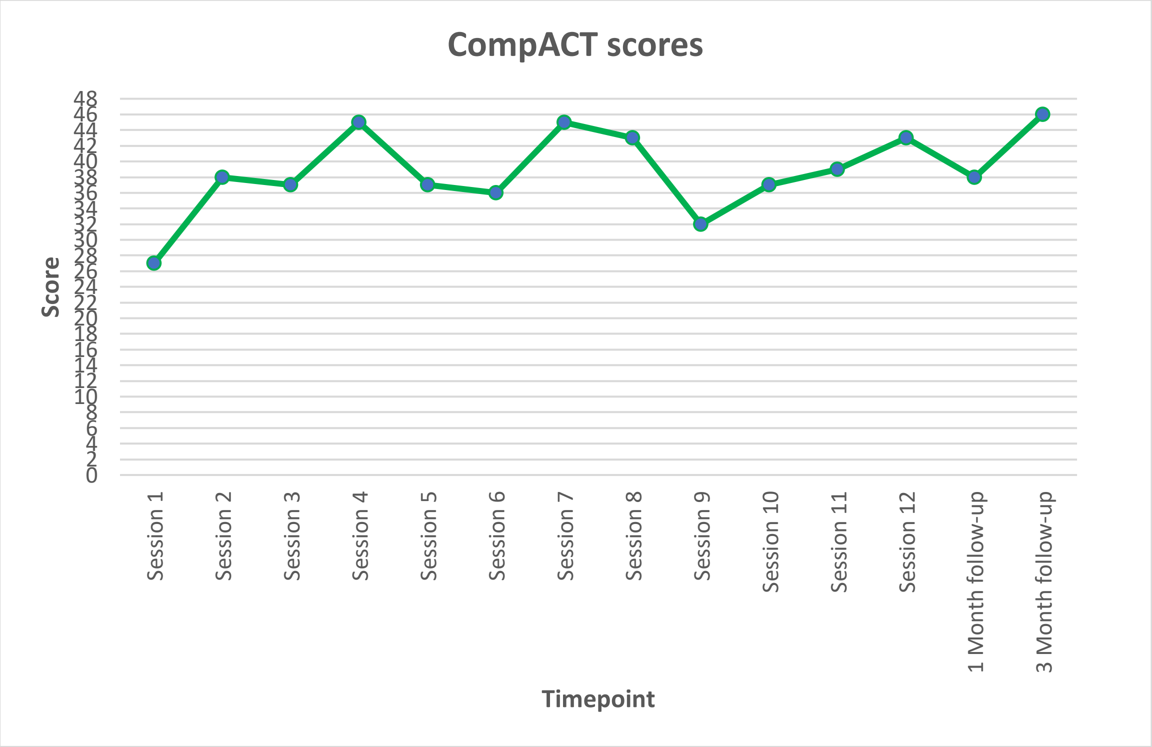
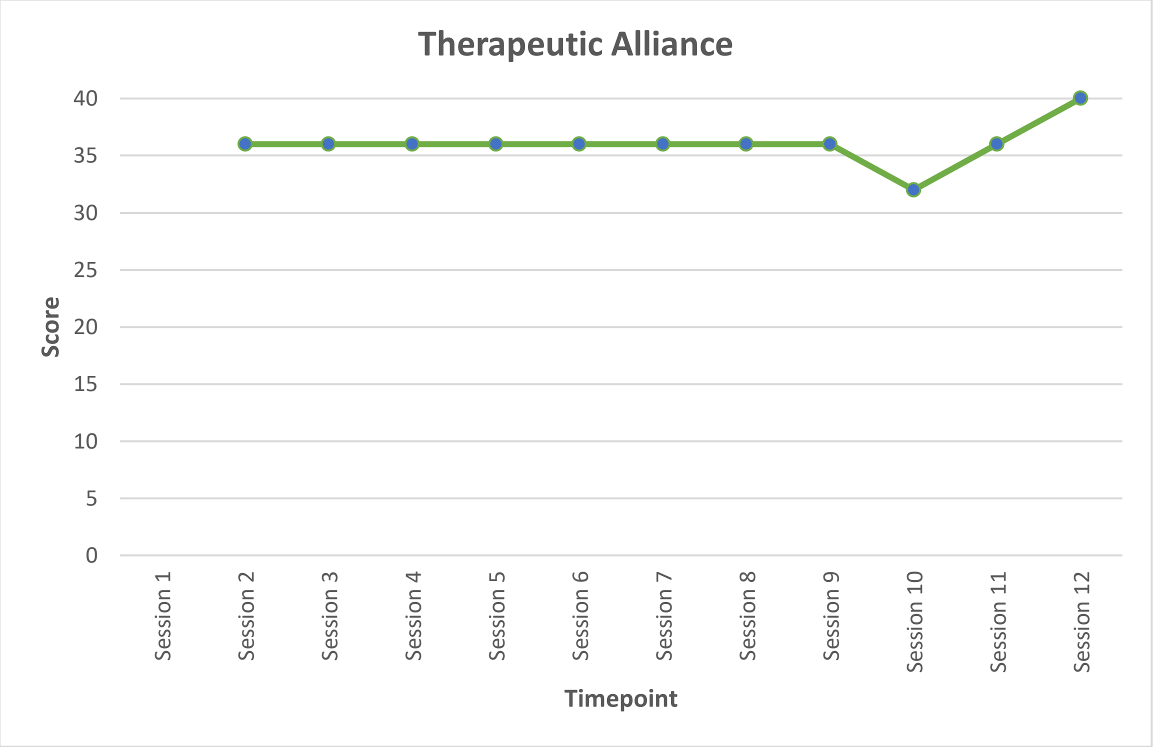


Figure 11. Minnie's SRS scores



Over the course of the intervention, scores appeared to remain stable. At 1- and 3-month follow-up, scores remained similar or improved, for example, PHQ-9 scores appeared to reduce and SWEMWBS scores seemed to increase.

E. Evidence for and against ACT-specific processes

In response to the research questions, Tables 34-36 present evidence for and against meaningful changes occurring for Minnie during and following the intervention, if changes were broadly attributable to the ACT intervention and the specific factors that contributed to the observed changes. Attributions have been suggested by the first author where appropriate in the tables to assist with understanding and context.

3.1.4 Minnie’s Rich Case Summary

Do (meaningful) changes occur for Minnie over the course of (and after) the ACT intervention?

Table 34. Evidence For and Against Meaningful Change- Minnie

Therapeutic goals	**Supporting evidence** *(meaningful change did occur)*	**Refutational evidence** *(meaningful change did not occur)*
Change generally	**Change interview** “I think not being frightened to admit that, yes, I have got problems, you know, and accept that because I am who I am, I can always divert my thoughts and needs to a hobby, a sort, whether it's just researching history…”. “Well, I suppose since then I've lost my mother [in law], sister and husband, so you learn to actually cope with this and yeah, you accept that it's happened, you can't change it, so you’ve got to learn to live with the losses you’ve got. But that shouldn't overcome the other interests in life and ways of moving forward… I don't feel guilty about moving forward now”. **Change rating sheet** When asked, ‘What was the change?’ Minnie identified she was giving herself more time and understanding. She rated this change as neither expected nor surprising but that it was personally ‘very important’ to her.	**Change interview** “Have I [noticed any changes], Mo? I don't know” “I don't think I can tell you very much, no not really” **Therapist notes** Minnie often stated that she could not recall last week’s session or discussions. Minnie did not appear to understand some metaphors and exercises, therefore, required re-explaining or reframing; “I don’t get that Amie, it’s going over my head” (session 9). Minnie reported feeling guilty and that her confidence had reduced due to fears of falling and feeling scared and unsafe about going out due to COVID-19 (sessions 4, 7, 8). It seemed internal control strategies were generally working well for Minnie. She stated, “I get on with life, I always have done, I don’t sit and brood or feel sorry for myself as then you’re not in control of your emotions and I’d have to claw back control… I have to shut them out or push them away and do something

	Minnie also identified feeling more relaxed, which she said she was somewhat surprised by and was an ‘extremely important’ change for her. Finally, Minnie identified a positive change of recognising her goals and living in line with them which she rated as being ‘somewhat surprised’ by and ‘extremely important’. **Therapist notes** Minnie reported therapy had offered a reminder of techniques to use and that she had found it helpful “just talking and listening to your ideas that aren’t far from mine”. Minnie said she had learned to take time out and evaluate what we had been talking about. She reported feeling more confident. Mo said Minnie was more relaxed (session 12).	else. I don’t indulge them” (sessions 2, 3). Minnie identified no costs to this. Minnie reported difficulties in planning steps towards committed action during COVID-19, for example, said she wanted to go on holiday or to the garden centre but could not (session 2).
To improve low mood	**Therapist notes** When reminded that, at session 1, Minnie had identified thoughts of not wanting to be here anymore, she appeared surprised and in disbelief that she had said this (session 12). Minnie stated, “Dementia doesn’t stop me from doing things although I’m less active now [in researching archaeology and sharing knowledge with others]” (session 2). Both Minnie and Mo seemed to use and responded well to humour in session.	**Therapist notes** Minnie continued to become tearful when thinking about or discussing the people she had lost (sessions 3, 9 and 10). Mo and a family informant reported Minnie’s moods had ‘always been up and down’. Mo stated she had noticed that some weeks Minnie was in a good mood and relaxed following the session, but at other weeks, she could find it very hard and was mentally exhausted. Mo reported Minnie was, in general, ‘constantly tired’ (session 6).

	PQ scores Reduction in PQ ratings of this problem. Pre-therapy: score of 5 (feeling isolated), 7 (memories of bereavements) End of therapy: both a score of 0 **PHQ-9 scores** Overall reduction across intervention. Pre-therapy: score of 14 Session 1: score of 9 Session 6: score of 9 Session 12: score of 6 1 month follow-up: score of 7 3 month follow-up: score of 0 **Change interview** Mo stated, “‘Cause there was a point you would sit in your chair and just zone out with the telly but you are doing a lot more things even though the collecting the pebbles winds me up, but yeah, you like collecting your pebbles”.	Mo said Minnie had opportunities to engage with others and activities but did not take them up due to tiredness and lack of motivation (session 7).
To decrease worry	**Therapist notes** When practising the mindful breathing both in session and between sessions, Minnie and Mo described this as helping Minnie to feel relaxed and she could notice the changes in her body.	**GAD-7 scores** Appeared to remain stable across the intervention. Pre-therapy: score of 0 Session 1: score of 3 Session 6: score of 4 Session 12: score of 1 1 month follow-up: 3 3 month follow-up: 0

	Minnie appeared to engage well with mindfulness, which she said helped her feel more relaxed. Minnie commented, “I’m remarkedly content” (session 6). Minnie said a bonfire had reignited in her garden and she had telephoned Mo, despite noticing thoughts about ‘not being very good’ on the phone (session 12). **PQ scores** Reduction in PQ ratings of this problem. Pre-therapy: score of 5 Session 12: score of 1	**Therapist notes** Minnie reported concerns about slipping outside (sessions 4, 7, 8). Mo anticipated Minnie would be ‘stuck to my side’ when they went to the supermarket once COVID-19 restrictions were lifted (session 5). When discussing thoughts that may act as a barrier to valued living (to advocate), Minnie stated, “I can’t face being in a group of people [archaeologists], I don’t want to be a burden… they’re awfully busy” (session 9). Mo said Minnie did not want others to perceive her as pestering. Minnie seemed to have difficulty keeping in mind what her experience told her; “I love *[archaeologist],* he’s interested in the project, he agreed with me” (session 11).

Are observed changes broadly attributable to the ACT intervention?

Table 35. Evidence For and Against Changes attributable to therapy- Minnie

Supporting evidence *(change is due to therapy)*	**Refutational evidence** *(change is due to external factors)*
Change interview/rating sheet Giving herself more time and understanding was a change Minnie seemed to attribute to therapy, rating this as ‘very unlikely without therapy (clearly would not have happened)’. The change of feeling more relaxed and the change of recognising her goals and living in line with them were both rated as ‘somewhat unlikely without therapy (probably would not have happened)’. Mo stated, “Amie’s helped you to realise your goals… you've been obviously contacting the archaeologists about the stones and the pebbles you keep collecting and stuff like that. So, Amie’s sort of, which we wouldn’t have done, if we'd not been seeing Amie, I don't think we would have gone down that route”. Minnie said, “… it's [therapy’s] not something that I would have thought was necessary, but I can see the positive in it”. “I think the therapy reminded me of methods that I could use to get to a stable place where I was alright”. “I think having therapy it sort of nudged me into a position that I realised I could take control of what was happening to me and to understand the reasoning and what was happening to me”.	**Change interview** Minnie reported, “I'm a creature of the 60s so, you know, some of the exercises are quite transferable from the 60s… I always say I was a creature of the 60s and the breathing and all those exercises were all very reminiscent of a 60s lifestyle”. *Attribution- personal attributes/established coping skills.* “I think I realised that I’d got to move on, that it's no good sat there brooding about what you've lost. So, I grow things. I have done in the past. When I lost [mother-in-law], [husband]’s mum, that put me into a terrible depression. But by growing things, by keeping things moving, you claw back, you get at least some peace… And it's technique I've had to use two or three times in my life”. *Attribution- established coping skills.* **PQ scores** Minnie stated that she used to practise breathing as a teenager as a ‘hippy’. Mo said Minnie could do this quite automatically (session 12). *Attribution- established coping skills.* When asked why they thought Minnie’s PQ scores had changed over time, Minnie attributed this to the season and improved weather in enabling her to engage in her hobbies; “…When stuff starts growing and I’m gardening, being busy and occupied”. Mo also said, “Winter

“I think the therapist certainly reminded me of ways forward and what I needed to do”. “I think in actual fact, I did recognise that therapy could be a good thing because it does make you order your thoughts, it does make you understand”. Mo stated, “In your first few sessions you were really low and like I say, the therapy steered you into something you wanted to do so that gave you the positivity and that there is life with the Alzheimer’s, about taking control and doing what you want to do”. “… but the therapy has gave us some techniques, even down to the carer, I can use some of them techniques to zone out a bit. It was that ‘river’ one, I loved that river one”. **Therapist notes** Mo said, “It’s [therapy’s] highlighted we’re in a fortunate place” (session 12). She added that the questions and techniques used had been “pure genius, bloody brilliant” and had been adapted for Minnie as an individual; “I totally commend you for how you’ve dealt with us, we’re not the easiest of families. Thank you for trying to understand us” (session 12).	months have always been hard for Mum, she becomes more positive when the weather improves” (session 12). *Attribution- time of year.*

What specific factors (within ACT or outside of it) contribute to observed changes?

Table 36. Evidence For and Against Therapy as a Mechanism of Change- Minnie

Supporting evidence *(contributing internal factors)*	**Refutational evidence** *(contributing external factors)*
Therapeutic Alliance **Therapist notes** Mo stated, "You've said more to Amie than you have to me", Minnie replied, "You've never wanted me to" (session 12). "It was good to have given opportunities for a break and reading the situation at the time, you were fast thinking" (session 12). Minnie stated, "Just talking and listening to your ideas that aren't far from mine [was helpful]… I'm grateful for what you've done, it's been good" (session 12). **SRS scores** Most weeks, Minnie provided a score of 36 out of 40 on the SRS, apart from session 10 when she reported it had been hard (becoming tearful when thinking of bereavements) and rated the session at 32 out of 40. Minnie rated session 12 as 40 out of 40, indicating satisfaction with her relationship with the therapist, therapist approach and the goals and topics covered. ACT Techniques **Therapist notes** When mindful breathing both in session and between sessions, Minnie and Mo described this as helping her to	Family support **Therapist notes** Mo reported she was worried that there was a genetic link with developing dementia and the reason for agreeing to participate in therapy was to help their family and others in the future to see if this therapy was effective (session 1). When reviewing between-session tasks on committed action (contacting archaeologists), Mo stated, "She [Minnie] wouldn't have done it without me" (session 9). **Change interview** Mo said, "…I'm having to support you [Minnie] more and more and my brain capacity's obviously trying to understand what you want to say and do, so yeah it's a hard process…". Time of year **Therapist notes** Mo said, "Winter months have always been hard for Mum, she becomes more positive when the weather improves" (session 12). Minnie said, "But then it got warmer, and I could start and grow things and… nature's wonderful". Personal attributes/established coping strategies **Therapist notes**

feel relaxed and that she could notice the changes in her body. Mo reported, “You’ve adapted it for Minnie as an individual” (session 12). **Change interview** Mo said, “But she [therapist] was spot on, she’d go away after each session and then come back the following session and I used to think, yeah, you're spot on here. That’s what I think”. “…the therapy has made me my mum realise that she’s still got things she wants to do in life”. “Amie, like I’ve told her, she's been spot on, she's understood my mum and she’s made it quite individual to you and that was just spot on”.	Minnie stated that she used to practise breathing as a teenager as a ‘hippy’. Mo said Minnie could do this quite automatically (session 12). Mo reflected that ladies in the family were ‘tough cookies’ and that Minnie had been brought up not to show any feelings (session 12). **Change interview** Minnie referred to established, helpful coping strategies; “So I grow things. I have done in the past… And it's technique I've had to use two or three times in my life”. “It’s hard work! It really is hard work. I usually go from these sessions home… exhausted”.

3.1.5 Minnie’s Briefs

3.1.5.2 Minnie’s Affirmative Case

The affirmative case proposes that there are clear links between therapy process and outcome, and requires at least two of the following pieces of evidence, as outlined by Elliott (2002):

1) change in stable client problems (client experiences changes in longstanding or chronic difficulties)
2) retrospective attribution
3) outcome-process mapping (content of the CI plausibly matches specific events, aspects, or processes within therapy)
4) event-shift sequences (significant therapy events are followed forward in time for evidence of their later effects e.g., stable shifts in client distress).

<u>Changes across therapy</u>

Minnie’s scores changed on the PHQ-9, PQ, and CompACT-SF. Though not the primary aim of ACT, this indicates symptoms reduced over the course of the intervention. This may be attributed to Minnie’s increased PF in enabling her to become more open to the experience of difficult thoughts and feelings, increased behavioural awareness and improvements in functional ability through re-engaging in meaningful, value-led activity. Though distraction and keeping busy appeared to be a pervasive coping strategy, arguably in the guise of experiential avoidance, Minnie chose to engage in valued action such as gardening (in line with her value of enjoyment) and liaising with ex-colleagues about archaeology projects (value of advocating) which may have resulted in improvements in her mood and problems as indicated in the PQ. Minnie always appeared to engage well in mindfulness and the weekly three-minute present moment awareness exercise, reflecting that she was able to stay with it, found it calming and did not notice any thoughts or feelings crop up. Though this may have been the case, she was given regular opportunity to notice and experience thoughts and feelings rather than to distract from them. Over the course of therapy, it was acknowledged that Minnie’s ability to discuss her experiences and feelings openly was a huge improvement. Therefore, ACT could have been a vehicle for therapeutic change for Minnie.

Retrospective attribution

Retrospective attribution requires Minnie to attribute any changes she noticed to therapy, which is highlighted in the CI and change rating sheets when asked how likely she thought the identified changes would have been without therapy. Minnie reported in the CI that she had noticed positive changes which would have been 'extremely' or 'somewhat' unlikely without therapy.

Therapist attributed these changes to the therapy

It may be helpful to consider whether the therapist attributed any changes to the therapy using knowledge of Minnie, her presentation and through discussion within sessions. With Mo's support, Minnie was observed to engage in planned committed action exercises as between-session practice and her reactions of sadness to any intrusive thoughts about her bereavements seemed to become less evident over time. Understandably, it is recognised that Minnie may have had difficulty in reflecting upon therapy and identifying changes without support, as mentioned in the CI. GAD-7 scores pre-therapy to session one worsened, which may indicate that improvements were not made prior to therapy.

Process-outcome mapping

Process-outcome mapping refers to Minnie's CI information about significant events corresponding with aspects or processes within therapy. In the CI, Minnie stated that therapy had helped her to recognise her goals and live in line with them and this was demonstrated in therapy with between-session practice of committed action tasks (session eight onwards). Therefore, it would be expected that Minnie's scores on the valued action subscale of the CompACT-SF, for example, may have improved after session eight. However, scores remained somewhat stable at 16-18, which may query the reliability or sensitivity of self-report measures in the context of memory difficulties.

Change in stable problems

Information from the MAS gatekeeper highlighted that Minnie's life was 'chaotic' and that she had 'good and bad days'. This was corroborated by Mo and the family informant. It may be assumed that the therapeutic intervention is responsible for change when this occurs in chronic, pervasive difficulties. Minnie described experiencing a change in giving herself more time and understanding and feeling more relaxed. Minnie's PQ scores regarding low mood due to feeling isolated and her bereavements appeared to change considerably.

Changes not due to relational artefacts

It did not appear that changes were due to relational artefacts (the client emphasising change to please the therapist) as the first author and therapeutic relationship was mentioned more by Mo during the CI. It felt as though the therapeutic relationship could fluctuate (e.g., "I don't get that Amie"), especially if Minnie interpreted questions as testing or exposing. However, SRS scores suggest that the therapeutic relationship remained strong throughout therapy. Scores remained stable and were not shown to increase steadily over time. Furthermore, there may have been some internal consistency in Minnie and Mo's relationship as Mo tended to 'chip in' to discussion as she would in day-to-day life and helped to prompt Minnie's recall. Moreover, it is unknown whether the therapeutic relationship and Minnie's engagement in therapy may have increased if therapy had taken place in person rather than online. Therefore, relational factors between the first author and Minnie and Mo and Minnie cannot fully account for the improvements identified over the course of the therapy.

Changes not due to expectancy artefacts

This pertains to whether changes occurred due to Minnie's expectations or hopes for change. Minnie identified two changes that she was surprised by (feeling more relaxed and living in line with her goals). She also said that therapy was not something she thought necessary but could see the positive in it, indicating she did not have particular expectations or hopes for therapy. Therefore, changes are unlikely due to expectancy artefacts.

Statistical artefacts

All clinical cut-off scores are approximate and have been calculated using existing means for clinical and/or non-clinical populations. Therefore, the affirmative case suggests that Type II errors could be responsible for lack of significant change in measures. Furthermore, due to Minnie's attention and memory difficulties, she could find some of the wording in the questionnaires confusing and at times, required a lot of scaffolding and examples to aid her understanding, which may explain why significant change was absent in some measures. The sensitivity of the measures may also be questionable when used with older adults with memory difficulties.

Conclusion

This affirmative case stipulates that:

- Minnie demonstrated substantial change in her problems.
- Minnie attributed these changes to therapy, even if her psychometric scores did not correspond with sessions.
- The therapist attributed most of these changes to therapy.
- This evidence contradicts sceptic non-therapy reasons for change and/or lack of change.

This evidence provides a basis for you to support the case that Minnie changed substantially during the period of therapy and infer that this change was caused by her participation in the ACT intervention.

3.1.5.2 Minnie’s Sceptic Case

This sceptic brief describes a good attempt to counter the argument that Minnie changed substantially during therapy and that this change was due to the intervention. As suggested by Elliott (2002), the sceptic case will examine Minnie’s case record for evidence of alternative explanations.

The following explanations suggest that any observed changes do not represent clinical improvement due to:

1) trivial or negative changes on measurement
2) statistical artefacts
3) relational artefacts
4) expectancy artefacts

Trivial or negative changes on measurement

Minnie’s problems were not stable since her screening scores and pre-therapy scores (session one) were dissimilar. Therefore, it is difficult to establish whether the distress she experienced would have remained stable over time or naturally improved without therapy. Though some measures showed improvement, others did not, which may suggest that ACT processes were less transferrable to older adults with dementia and hence did not result in symptom reduction.

Statistical artefacts

Statistical errors cannot be ruled out and relies on primary analysis being accurate. Therefore, the presence of a change in PQ, PHQ-9 and CompACT-SF scores could be due to statistical inaccuracy. Furthermore, Minnie may have misinterpreted or misunderstood the questions. At times, there also seemed to be a negotiation in given answers on measures with Mo, which therefore questions the extent to which Mo's presence was helpful or hindering. If the intervention had been truly effective, it would be expected that stable changes would have occurred as indicated on the measures.

Furthermore, the reliability and validity of the measures was queried as it was felt that the stability or consistency of Minnie's answers were possibly state-dependent due to her difficulties in recalling or reflecting upon the past week. Though measures were used to assess change, they must also be conceptualised, thus questions were raised regarding the usefulness of self-report measures in the context of memory difficulties. For example, at session eight, Minnie disagreed with the CompACT-SF statement, 'I go out of my way to avoid situations that might bring difficult thoughts, feelings, or sensations' but later in the session said, "I'm keen to avoid situations that would cause upset, I'd distract from or ignore them", indicating agreement with the statement. Without confidence in self-report measures, it is hard to detect clinically significant improvement. A family informant reported Minnie's difficulties were not likely reflected in the measures, nor changes sustained after therapy, which again, queries the accurateness of self-report measures in this case.

Relational artefacts

Elliott (2002) suggests this can be evaluated by careful assessment of specific changes in Minnie's experiences and whether changes were identified due to a desire to impress or reassure the first author. Not only should Minnie's relationship with the first author be considered (which was seemingly strong according to SRS scores), but also her working alliance and relationship with Mo since ACT was used systemically in the triad between therapist, client, and carer. Mo's involvement was deemed helpful since the management of Minnie's distress became shared, similar to real life clinical practice and the context in which Minnie was living (becoming more reliant upon Mo). Moreover, there were likely between-session processes with facilitative conversations about therapy outside of sessions and with Mo prompting and supporting Minnie with between-session tasks. Thus, relational factors may have resulted in the identified improvements.

Expectancy artefacts

Though not particularly verbalised by Minnie, Mo appeared to have expectations about therapy in helping their family to see if ACT was effective for people with dementia. Mo shared upsetting memories of caring for family members with dementia, prior to caring for her mother, and tangible fears about developing dementia herself in the future. Since Mo was involved in the intervention and spoke of her motivations for participating in therapy in Minnie's presence, this may have influenced Minnie's expectations or hopes for therapy.

The following explanations, as suggested by Elliott (2002), stipulate that change has occurred but not due to therapy and is therefore as a result of the following factors:

5) self-correction
6) life events
7) psychobiological factors
8) reactive effects of research participation

Self-correction and other factors

This potential reason for change suggests that any improvement is caused by self-help outside of therapy. As previously discussed, consideration should be given to between-session processes and facilitative conversations about therapy between Minnie and Mo, with Mo supporting Minnie with between-session tasks. Furthermore, Minnie referred to mindfulness exercises, especially mindful breathing, as reminiscent of practices in the 1960s, indicating that this skillset was already established and that prompting and opportunity alone enabled Minnie to re-engage with and develop her skills in mindfulness. Over the course of therapy, Minnie also increased her engagement in established hobbies and interests.

Life events

Minnie did not experience any major life events over the three months of therapy; however, it is recognised that her abilities may have reduced according to the progressive nature of her dementia. Minnie's certainty in whether or not things had changed as a result of therapy varied since she had difficulty in reflecting upon and recalling previous sessions, and therefore required support from Mo to do this. Hence, Minnie's level of impairment likely acted as a barrier to getting the most from therapy.

Furthermore, changes to one's life during COVID-19 restrictions likely brought additional challenges which could understandably affect mood and wellbeing, rendering the intervention less effective. Alternatively, some improvements in mood may have been as a result of lighter nights and better weather, enabling Minnie to re-engage in interests that may have been harder to do in winter months. This was reported by both Minnie and Mo in the CI and in therapy.

Psychobiological factors

Although not reported by Minnie, changes in hormones, such as melatonin, may have improved Minnie's circadian rhythm and contributed to fluctuations in her mood or distress. Minnie did report fluctuations in physical discomfort and chronic fatigue which may have accounted for variation in her scores, particularly as fluctuations indicating improvement were not statistically significant week-to-week. Minnie's dementia medication may have also affected her mood or sense of wellbeing.

Reactive effects of research participation

Mo reported that Minnie had spoken more to the first author about her feelings than she had to her her whole life. She also said that Minnie had enjoyed the first author's attention and in talking about her interests. The overall positive experience of therapy may therefore explain the positive changes identified.

Lack of event-shift sequences

Any changes were not sustained as Minnie's scores across all measures appeared to fluctuate throughout the intervention. It would be expected that significant therapy events would result in significant shifts in difficulties, yet only weak evidence exists for event-shift sequences because reliable shifts did not occur when coinciding with helpful events as per Minnie's CI.

Conclusion

This sceptic case stipulates that:

- Minnie did not make significant changes
- Minnie did not attribute changes to therapy
- Any minor changes made were due to extra-therapeutic factors
- This evidence contradicts evidence presented by the affirmative case

This evidence provides a basis for you to reject the case that Minnie changed substantially during therapy and infer that any change was caused by extra-therapeutic factors.

Appendices for Minnie's Rich Case Record

Appendix V. ACT Processes of psychological flexibility

Extracted from the Association for Contextual and Behavioral Science (ACBS) website: https://contextualscience.org/the_six_core_processes_of_act

The Psychological Flexibility Model

The general goal of ACT is to increase psychological flexibility – the ability to contact the present moment more fully as a conscious human being, and to change or persist in behaviour when doing so serves valued ends. Psychological flexibility is established through six core ACT processes. Each of these areas is conceptualised as a positive psychological skill, not merely a method of avoiding psychopathology.

Acceptance

Acceptance is an alternative to experiential avoidance. Acceptance involves the active and aware embrace of those private events (i.e. feelings, physical sensations, memories) occasioned by one's history without unnecessary attempts to change their frequency or form, especially when doing so would cause psychological harm. For example, anxiety patients are taught to feel anxiety, as a feeling, fully and without defense; pain patients are given methods that encourage them to let go of a struggle with pain, and so on. Acceptance (and defusion) in ACT is not an end in itself. Rather acceptance is fostered as a method of increasing values-based action.

Cognitive Defusion

Cognitive defusion techniques attempt to alter the undesirable functions of thoughts rather than trying to alter their form, frequency or situational sensitivity. ACT attempts to change the way one interacts with or relates to thoughts by creating contexts in which their unhelpful functions are diminished. For example, a negative thought could be watched dispassionately, repeated out loud until only its sound remains, or treated as an externally observed event by giving it a shape, size, colour, speed, or form. A person could thank their mind for such an interesting thought, label the process of thinking ("I am having the thought that I am no good"), or examine the historical thoughts, feelings, and memories that occur while they experience that thought. Such procedures attempt to reduce the literal quality of the thought, weakening the tendency to treat the thought as what it refers to ("I am no good") rather than what it is directly experienced to be (e.g., the thought "I am no good"). The result of defusion is usually a decrease in believability of, or attachment to, private events rather than an immediate change in their frequency.

Being Present

ACT promotes ongoing non-judgmental contact with psychological and environmental events as they occur. The goal is to have clients experience the world more directly so that their behaviour is more flexible and thus their actions more consistent with the values that they hold. This is accomplished by allowing workability to exert more control over behaviour; and by using language more as a tool to note and describe events, not simply to predict and judge them. A sense of self called "self as process" is actively encouraged: the defused, non-judgmental ongoing description of thoughts, feelings, and other private events.

Self as Context

As a result of relational frames such as me versus You, Now versus Then, and Here versus There, human language leads to a sense of self as a locus or perspective, and provides a transcendent, spiritual side to normal verbal humans. This idea was one of the seeds from which both ACT and RFT grew and there is now growing evidence of its importance to language functions such as empathy, theory of mind, sense of self, and the like. In brief the idea is that “I” emerges over large sets of exemplars of perspective-taking relations (what are termed in RFT “deictic relations”), but since this sense of self is a context for verbal knowing, not the content of that knowing, its limits cannot be consciously known. Self as context is important in part because from this standpoint, one can be aware of one’s own flow of experiences without attachment to them or an investment in which particular experiences occur: thus defusion and acceptance is fostered. Self as context is a perspective fostered in ACT by mindfulness exercises, metaphors, and experiential processes.

Values

Values are chosen qualities of purposive action that can never be obtained as an object but can be instantiated moment by moment. ACT uses a variety of exercises to help a client choose life directions in various domains (e.g. family, career, spirituality) while undermining verbal processes that might lead to choices based on avoidance, social compliance, or fusion (e.g. “I should value X” or “A good person would value Y” or “My mother wants me to value Z”). In ACT, acceptance, defusion, being present, and so on are not ends in themselves; rather they clear the path for a more vital, values consistent life.

Committed Action

ACT encourages the development of larger and larger patterns of effective action linked to chosen values. Almost any behaviourally coherent behaviour change method can be fitted into an ACT protocol, including exposure, skills acquisition, shaping methods, goal setting, and the like. Unlike values, which are constantly instantiated but never achieved as an object, concrete goals that are values consistent can be achieved and ACT protocols almost always involve therapy work and homework linked to short, medium, and long-term behaviour change goals. Behaviour change efforts in turn lead to contact with psychological barriers that are addressed through other ACT processes (acceptance, defusion, and so on).

Taken as a whole, each of these processes supports the other and all target psychological flexibility: the process of contacting the present moment fully as a conscious human being and persisting or changing behaviour in the service of chosen values. The six processes can be chunked into two groupings. Mindfulness and acceptance processes involve acceptance, defusion, contact with the present moment, and self as context. Indeed, these four processes provide a workable behavioural definition of mindfulness (see the Fletcher & Hayes, in press in the publications section). Commitment and behaviour change processes involve contact with the present moment, self as context, values, and committed action. Contact with the present moment and self as context occur in both groupings because all psychological activity of conscious human beings involves the now as known.

Appendix W. Intervention details

Client-participants were invited to attend a 12-week ACT intervention with the therapist via Microsoft Teams (MST), supported by their carer, with a review at week 6. Sessions lasted up to 90 minutes. The ‘Better Living with Illness’ (Brassington et al., 2016) protocol was used flexibly to guide the intervention. This included specific ACT techniques and resources tailored to those with chronic physical health conditions. The ‘Better Living with Illness’ (Brassington et al.) protocol was initially a 6-week intervention, however, in consideration of using with clients with cognitive impairment, the pace of the intervention was slowed and offered over 12 weeks. Whilst the protocol provided structure and familiarity to sessions, the therapist took an active and responsive role, targeting inflexible processes in flight.

Intervention fidelity using session audio recordings was assessed by an independent rater via the ACT Fidelity Measure (ACT-FM). ACT fidelity was achieved in all sessions.

Table 37. General Protocol Structure

Session number	Session objectives
1, 2	• Exploring the client’s experiences of dementia and coping strategies (distinguishing between control and non-control strategies) • Distinguishing between primary and secondary suffering
3, 4	• Learning about thoughts, emotions, behaviour and physiology • Understanding how strategies like suppression can be unhelpful • Introducing concept of values • Learning about mindfulness as an awareness technique
5, 6	• Understanding what values are and begin to identify them • Practising mindful awareness
7, 8	• Learning about and practising defusion from thoughts • Practising mindful awareness and introducing self-as-context perspective
9, 10	• Discussing valued action and setting goals • Reviewing and consolidating previous sessions
11, 12	• Learning about pacing • Preparing for setbacks

Appendix X. Minnie’s Change Interview Transcript

Interviewer: There we go, has that popped up on your screen Minnie? Does it say it's recording OK?

Mo: ‘Someone started recording’.

Interviewer: Yeah lovely, OK. So as Amie said, we've got quite a few questions to go through today. So, if you need a break or anything Minnie just let me know, but I'll probably kind of stop halfway through and see if you need kind of five or 10 minutes. And if you don't understand anything, just let me know and I'll try and kind of explain in a better way if that's alright. Is that OK? So, are you happy to kind of start then, is that is that alright?

Minnie: Yes.

Interviewer: Alright then, Minnie, so I guess, first of all how are you feeling now in general?

Minnie: A bit weary, a bit tired. Life's pretty hectic at the moment

Interviewer: Right.

Minnie: We’re decorating the farmhouse, I’ve got gardening to do, I keep busy. I don't sit and feel sorry for myself.

Interviewer: No…

Minnie: I'm collecting stones. Sounds daft, but it's a project I've wanted to do for a lot of years.

Interviewer: Yeah…

Minnie: And the nice thing is that we're sort of in a glacial valley, so you've got stones and the wear on stones, and you can pick up different things from them. So that's been keeping me quite busy. I've always had a passion for stones.

Interviewer: It sounds really interesting Minnie, it sounds like you've got a lot going on with the decorating and the gardening, at least the weather's picking up a little bit now for gardening.

Minnie: A little bit of sunshine makes all the difference, it really does.

Interviewer: It does, it does. OK, but it sounds like you still kind of, a little bit tired and you said weary didn’t you, as well.

Minnie: I'm always weary at the moment but then life's buzzing around me… and the girls are good and *[son].*

Interviewer: Good, it sounds like you've got some good support around you, which is really…

Minnie: I'm very lucky, I really am, not that the kids always realise that I am grateful.
Interviewer: Well, I guess Mo's heard you!

Mo: It's just getting her out of bed, but we've done rather well this morning. She would sleep for Britain if we let her.

Minnie: I'm not so bad now.

Mo: You're not. You're on your medication, so I think that's made a slight difference to you getting up.

Minnie: Probably.

Mo: And yeah, taking not so long to get you out of bed, basically.

Interviewer: Well, that was kind of one of the other questions I wanted to ask was are you on any medication at the moment Minnie?

Mo: Yes, she's on, 800mg of Glucosamine, the second lot of dementia tablets they've tried her on. It's a weird name.

Interviewer: No, the names are a little bit strange aren't they?

Mo: Hang on *[goes to look in handbag].*

Minnie: I just take what they give me.

Mo: We have got a review meeting with *[Memory Assessment Nurse]* on Wednesday next week. Yeah, is it… It's spelt GALZE, yeah, Galzemic XL *[galantamine]* 8 micrograms.

Interviewer: Ok, and is that a recent medication change then or…?

Mo: Yeah. My mum had another medication which they tried. Again, it was only a small dose, but it was causing a lot of acid and stomach cramps and causing you a lot of problems so we stopped that at Christmas and I think this one's been being taken from about January. I think *[MAS Nurse]* sorted it out after Christmas, but we have got a review next week on Wednesday with *[MAS Nurse]* from *[MAS]*.

Interviewer: OK right, that's helpful information, thank you. So, I guess how has therapy been for you, Minnie? What's it been like?

Minnie: It's been a help I'm sure. Nobody likes to think they'd come to this sort of thing, but at the end of the day, I'm quite prepared to do what's necessary. I am quite used to being on my own a lot of the time and that doesn't worry me in the slightest. We're in a bit of a mess at the moment., we're decorating, we've got decorators in.

Mo: No, it’s the electrician.

Minnie: The electrician.

Mo: My mum lives in a farmhouse and it was built 1798 so we are trying to get it up to the 21st century. It's just 4 rooms have been, well, they’ve had the first fix of electrics, 'cause one particular room was quite scary *[inaudible]* pop light bulbs out.

Interviewer: Gosh, it sounds like a lot of work.

Minnie: Well, it’s not to us, we *[inaudible]…* there is a lot of mess. But that won’t take long to sort.

Interviewer: That's good. So, you feel like therapy’s been helpful?

Minnie: I'm sure it has.

Interviewer: Yeah ok. So in terms of any changes you might have noticed, is there anything that you've noticed since therapy started? Any changes in yourself?

Minnie: I suppose to give myself a little bit more time and understanding. I get quite frustrated at times, you know. Life moves at a pace around me, but yeah, it's, I'm sure it's a help. I'm a creature of the 60s so, you know, some of the exercises are quite transferable from the 60s.

Mo: Well they made you quite relaxed.

Minnie: Yeah.

Mo: You're a lot more…

Minnie: Yeah, I’m a lot more zoned.

Interviewer: OK, so kind of thing, so giving yourself more time but also feeling more relaxed?

Minnie: Yes.

Interviewer: OK. And have you kind of noticed any sort of changes in your kind of thinking differently or doing things differently to before?

Minnie: Have I, Mo? I don't know.

Mo: Amie’s helped you to realise your goals, what you’ve got to…

Minnie: Positive.

Mo: Yeah, and you've been obviously contacting the archaeologists about the stones and the pebbles you keep collecting and stuff like that. So Amie’s sort of, which we wouldn’t have done, if we'd not been seeing Amie, I don't think we would have gone down that route.

Minnie: I don’t think I’d have had the energy.

Mo: It gave you some sort of…

Minnie: Purpose?

Mo: Yeah, purpose, so it has helped you, it’s steered you in a direction you wanted to go anyway, but with it, it's helped you to do that.

Interviewer: OK, that's good, so kind of the main things then Minnie are kind of giving yourself more time feeling more relaxed but also kind of recognising your goals and sort of behaving in line with those goals, so kind of doing things like contacting the archaeologist, to pursue and give yourself some purpose in something that's important to you.

Minnie: That's right, yeah. Well, I always have, I’ve always pursued hobbies of time, you know, and trying to understand the landscape that we live in. I’m in a fantastically fortunate position. The house looks down onto the forest and, you know, the whole setup is quite brilliant really, and of course I've lived in the house a long while now. I lived there with my husband until he died and it's my cocoon. I'm quite safe there.

Mo: A little world.

Minnie: Yes, my world.

Interviewer: It sounds like you're in a in a really kind of good environment that's really kind of suited to you and your interests and kind of feels quite safe.

Minnie: it is.

Interviewer: That's really good to hear. OK, so we've got kind of a few positive changes. So, has anything changed for the worse since starting therapy, Minnie?

Minnie: I don't think so, really. I'm on a level, you know, I'm on a level playing field. There is nothing in that property that worries me or annoys me, or, you know, I am so at home there, I am part of the bricks and mortar, I shall never leave it, I'll haunt it even if I'm not in a physical position! I really am comfortable.

Mo: If I can just butt in, the only thing, at the beginning, obviously the grief, we lost my dad, my grandma, my mum's mum, and my mum’s sister my Auntie within months of each other in 2019. So, the only bit you did find really hard, was obviously anything, you are grieving still. You've managed to sort of…

Minnie: I’ve moved on.

Mo: Yeah, you've moved on, but at the beginning of this therapy, it was very raw.

Minnie: It… you just feel guilty. *[Husband]* had got Parkinson's and life was quite tough, particularly for me.

Mo: So, you’ve had to… My mum's had to deal with obviously the grief of losing people and obviously the diagnosis of Alzheimer’s and, so yeah, it's been rough in places, but that's why, you're a lot better, you can deal with, if we mention my Dad and whatever you're not getting ‘upset upset’, but that has triggered a bit in therapy hasn't it?

Minnie: Yeah, yeah.

Interviewer: I think that's you know that's understandable, and it sounds like that was a really kind of difficult, really difficult time for you, and I'm glad, I mean, I guess I'll speak a bit later about things that perhaps were difficult, but then still helpful through therapy. I know therapy can be a difficult process, but it sounds like you had a lot to manage as well. But yeah, that sounds a really tough time for you, that you and your family have been through.

Minnie: Yes, it was my world, it was my children.

Mo: But then in some ways, would we have coped if they'd been still alive in this year without… yeah precisely.

Minnie: I was having to leave one to be with the other, and then it was sort of four of them that needed looking after.

Interviewer: Gosh, that’s a lot to manage, a real lot to manage, and then this year on top of that as well last year it's not been a great time.

Minnie: A year of COVID’s not been good, has it?

Mo: No, but then you've been very lucky where you live, which, it's made you realise talking about the farm and everything, how lucky you actually are.

Minnie: Oh Mo, I’ve always appreciated how lucky I was and how much I want I want to remain there. Not that I wouldn't like a holiday! But we'll get there.

Interviewer: And is there anything that perhaps you might have wanted to kind of change that hasn't since starting therapy?

Minnie: I don't think so. I think not being frightened to admit that, yes, I have got problems, you know, and accept that because I am who I am, I can always divert my thoughts and needs to a hobby, a sort, whether it's just researching history… I live in a part of England that, well, I own *[landmark]* and the land in which it sits, and at the moment I'm neglecting it, but it's in safe hands. The archaeologists are looking after that so... Yeah, I haven’t had much inclination to sort of go chasing about, go down there just at the moment, I just don't feel like I can cope with that. So it’s a little bit too much and I don't want to go down there and be a burden so it'll come back and the interest, the research, doesn't stop. You know, I'm still up on that. I can always divert my thoughts to a project.

Interviewer: So, it sounds like it's kind of on the whole been a positive experience for you and it's helped you focus your attention on those things that are really important to you?

Minnie: I think it has. You know, it's not something that I would have thought was necessary, but I can see the positive in it. So yeah, yeah.

Interviewer: Good, ok. So, in terms of those, so we kind of briefly touched on a few key changes that you that you'd noticed Minnie. So, I have kind of a separate sort of questionnaire that we can kind of work through for each of those changes. Is that OK?

Minnie: That's fine.

Mo: You'll need your glasses on, Mum.

Minnie: Do I need my glasses?

Interviewer: Well, I'm not going to put it on screen. I can what I can do is I can kind of read you the response options to the different questions, and then if you kind of tell me which one fits the most.

Minnie: OK.

Interviewer: OK, so if we start with the first change then, so giving yourself more time you talked about. I'd like you to rate how much you expected that change versus were surprised by it. So, if I tell you the options that might make that make a bit more sense. So, the first option is you very much expected to kind of be able to give yourself more time, somewhat expected it, neither expected or was not surprised by it, somewhat surprised by it, or very much surprised by it.

Minnie: I think, I think it wasn't a surprise that I did that. I've done it in the past at the time where lost my mother in law and all sorts of things *and [husband]*'s Parkinson's. It was quite a difficult time that was. I mean, this was the man I was married to and had my children by and very much part of my life. But then he became violent and aggressive.

Mo: Yeah, but it was his Parkinson's.

Minnie: Yeah, it was his Parkinson's, I know it was. But I got through that.

Mo: We got diverted with the question.

Minnie: I'm sorry.

Interviewer: No, it's fine, you know, sometimes these things come up and it's fine to talk about what comes into your head sometimes, so don't worry, we can kind of redirect back if we need to so don't worry about. So the question was around how much you expected versus were surprised by being able to give yourself more time.

Minnie: I think I realised that I’d got to move on, that it's no good sat there brooding about what you've lost. So I grow things. I have done in the past. When I lost *[mother in law], [husband]*’s mum, that put me into a terrible depression. But by growing things, by keeping things moving, you claw back, you get at least some peace.

Interviewer: Sure, so in terms of that, the question then Minnie so about kind of being expected versus being surprised by being able to give yourself more time. Would you say that you very much expected it somewhat expected it?

Minnie: I think because I’d got an opening to go elsewhere, I can move my interests to the stones or the plants or the growing, all those sorts of techniques that grab you and hold you and keep you there because if you don't continue doing those sorts of things, things die. You lose your plants, so you get on and you move forward and they become an anchor. And it's technique I've had to use two or three times in my life. I always say I was a creature of the 60s and the breathing and all those exercises were all very reminiscent of a 60s lifestyle.

Interviewer: OK, so in terms of that change as well then Minnie around just giving yourself that more time, how likely do you think that would have been if you had not had therapy? So, kind of very unlikely, somewhat likely, neither likely nor unlikely, somewhat likely, or very likely?

Minnie: I think the therapy reminded me of methods that I could use to get to a stable place where I was alright. All the time there is that, ‘I don't want to be a burden to the children’. Sometimes they’re a bit bullish but they have, they’ve looked after me brilliantly. And, of course, the farm there and they’re more involved now so *[daughter]* and Mo and *[son],* my three children, they've all been busy doing things to make the farm a nice place to live and safe.

Interviewer: Oh good. I think what I'm going to do Minnie is pop this questionnaire on the screen so it's easy for you to see the options. Would that be helpful?

Mo: Yeah, it would so that I can help her a bit.

Interviewer: Yeah, of course you can. Right, if you just give me one moment and I'll try and find the questionnaire that Amie sent me. Let's have a look. Where are you? OK. Alright, so let's see if I can share this. OK, so are you able to see?

Mo: Yep, yeah.

Interviewer: So, it's this bit here. So, what we're going to do is just kind of go through each of these so there's only cost of three questions for each change that you described Minnie. So, the first one was that you feel like you're able to give yourself more time. So, if you look at Question A. Can you rate how much you expected it versus were surprised by it?

Mo: Because with your condition now, are you taking longer to do things? Have you noticed is it the same or has it changed or… 'cause it says very much expected, somewhat expected it, neither expected nor surprised by it, somewhat surprised by it and very much surprised by it.

Minnie: Well because I've been in this position before, I wasn't very much… I didn’t… I knew what was useful, I really did, and the first thing you’ve got to do is to ditch the feeling sorry for yourself.

Interviewer: So perhaps in the middle then? Neither expected nor surprised?

Minnie: Yeah.

Mo: Yeah.

Interviewer: OK? So, in terms of the second one, then so again we're kind of thinking about that change of being able to give yourself more time. How likely do you think that would have been if you'd not had therapy?

Minnie: I think having therapy it sort of nudged me into a position that I realised I could take control of what was happening to me and to understand the reasoning and what was happening to me. It’s not what I would have liked to expect, but this is where I was and I'd got to find a way to move through it and to accept the changes about what’d happened.

Interviewer: So perhaps therapy helped you recognise that…

Minnie: I think it reminded me that there are ways of doing this.

Interviewer: OK, so perhaps would you perhaps a kind of somewhat unlikely then without therapy? Number 2 or…?

Minnie: So, what was the question? I think without therapy I wouldn't have been as structured than I would have been about getting out of this.

Interviewer: OK, so perhaps we're looking at either one or two, options one or two. Which one do you think?

Mo: Yeah, which one do you think?

Minnie: I think it was unlikely that, without therapy. I wouldn’t have latched on to where I'm going and what I've got to do to control my life because of these things, because I’ve moved forward and was beginning to look for projects and things I wanted to do, that I could direct my thoughts to these areas and find some satisfaction and, you know, find some pleasure in being able to work my way through it.

Interviewer: Sure. Ok so, would you say that would have been somewhat unlikely or very unlikely without therapy?

Minnie: I think the therapist certainly reminded me of ways forward and what I needed to do.

Mo: Which number would you pick, one or two?

Minnie: I suppose ‘very unlikely without therapy’, clearly. I'm certain that moving forward…

Mo: Would you say number 1 then?

Minnie: Probably.

Interviewer: Number 1. Thank you, Minnie. And I guess again, just thinking about being able to give yourself more time, how important or significant to you personally do you consider this change to be? So, we're looking at those ones.

Minnie: I think probably very important.

Interviewer: Very important, excellent, thank you Minnie. So, if we go through the same questions again but with the other two changes that you described, so feeling more relaxed was something else you identified. So, how much did you expect versus were surprised by being able to feel more relaxed? Which one of those numbers fits best?

Minnie: Yeah, yeah... I wasn’t surprised.

Mo: You wasn’t?

Minnie: No.

Mo: I was.

Minnie: You was but you weren’t me, you weren’t in my head. I suppose to a degree I was somewhat surprised by it, but I was in a position where I was beginning to pull myself together and to work on things that I was interested in.

Interviewer: So, I guess somewhat surprised, but it was also helpful that you were in a place where you were ready for those changes?

Minnie: I think that's probably, yes, I was in a position that I wasn't fighting my corner at that point.

Interviewer: OK. So, in terms of feeling more relaxed, Minnie, can you rate how likely you think it would have been if you'd not had therapy? So, it's those options there.

Minnie: I suppose if I hadn't have had therapy then I might have rushed through everything that was sort of on this first agenda and not realise that I've actually got the answer to what... a way forward to get out of this position, you know.

Interviewer: OK.

Mo: What number would you say? One or two?

Minnie: Likely without therapy, so probably yes, number 2.

Interviewer: ‘Somewhat unlikely without therapy’, thank you Minnie and thank you for your help Mo as well.

Mo: Well, I’m hoping it’s right, I feel like I’m in an exam!

Interviewer: No, it’s really tricky, isn't it? And it's a really strange situation online. We're managing as best we can. So how important or significant to you personally do you consider feeling more relaxed to be?

Minnie: Extremely actually, yeah.

Interviewer: Yeah, excellent, OK. And then we've got the last change that you identified, Minnie, which was essentially being able to recognise your goals and behave in line with those goals. So being able to behave in a way that brings you closer to what's important to you. So how much did you expect that versus were surprised by it?

Minnie: I think because I have been, in the past, when I lost *[husband]*’s mother, that I understand what grief can do and that really was quite rough, it really was. So I've got the experience of that and once it all kicks in and you start to realise that you've got to change your thought patterns a little bit and you can't actually change what's gone and it's no good being haunted by what is gone.

Interviewer: Of course, so being able to recognise those goals moving forward,

Minnie, and being able to do things that are in line with those goals, how much did you expect versus was surprised by it? Which one of those options would you pick?

Minnie: Think maybe 4.

Interviewer: Number 4? Excellent thank you, Minnie. So, in terms of that same change, again, being able to recognise your goals and what's important and be able to do what's important, how likely would that have been if you'd not had therapy?

Minnie: Erm, I probably wouldn’t have realised how structured it could be, I mean when you start and think, I realised how you work your way out of this.

Mo: Is it one or two? Because if you'd not had therapy, I wouldn’t have realised what your goals are and I don't think you would have done anything, would you? You would have done in the past ‘cause you’d just go out and do it, but it’s given you something of your old self.

Minnie: It’s reminded me of who I was and what I’ve done already and it gave me the confidence to move forward.

Mo: So, if you didn't have therapy…

Minnie: Then I wouldn’t have picked up on the order of things.

Mo: I think number 2.

Minnie: Number 2 do you think? Who’s doing this, me or you?

Interviewer: Yes, so we're thinking it was unlikely without therapy but do you think it would have been very unlikely or somewhat unlikely, Minnie?

Minnie: Without therapy, somewhat unlikely… There is a chance I could have missed this opportunity if I hadn't have done this, if I hadn’t have gone through these sorts of exercises, I wouldn't have put things in the same order I'm putting them now.

Mo: So, what number do you think? One or two?

Minnie: I think I would've realised at that point.

Mo: So, in the middle?

Minnie: Yeah, neither likely nor unlikely. I'm not negative and that's negative. But to somewhat unlikely without therapy probably would not have happened.

Interviewer: OK number 2. And lastly for this part, Minnie, how important or significant to you personally do you consider this change to be? So again, we're talking about recognising those goals and doing what's important.

Minnie: Well, I'm certainly doing that. I’ve got bedroom full of stones.

Mo: Yeah, we know.

Interviewer: Excellent, so how significant to you personally is that, Minnie?

Minnie: Extremely important. I've been trying to get my head around because the geology of the land is the way the history is portrayed and understanding that a lot of these stones are actually telling me where the glaciers have probably come from, how important they are in the movement and understanding of this landscape. It's a good project.

Interviewer: Good. I’ll stop sharing this screen now. Have I come back to you? Can you see alright?

Mo: Yep.

Interviewer: Excellent. So, I'm conscious we've been talking for 40 minutes, Minnie, and I'm wondering if you'd like a break?

Mo: I’m ok but…

Minnie: I’m ok.

Interviewer: You're OK, alright, we’ll carry on then. So, can you sum up what's been helpful about therapy, Minnie?

Minnie: It's reminded me, it's reminded me of how difficult it was when I lost *[husband]*’s mother and how her family hardly bothered at all and it was left to me to do all the looking after. So, you know that sort of comes back, quite strongly even now, and that I worked hard at not letting *[husband’s mother]* down. And, so you know, it's the grief that that does for you in the end.

Interviewer: Sure, so kind of how was therapy helped you with that?

Minnie: Well, I suppose since then I've lost my mother, sister and husband, so you learn to actually cope with this and yeah, you accept that it's happened, you can't change it, so you’ve got to learn to live with the losses you’ve got. But that shouldn't overcome the other interests in life and ways of moving forward.

Interviewer: OK, so it's perhaps helped you to take those steps and move forward and carry on doing those things that you're interested in and that you really value. OK?

Minnie: I don't feel guilty about moving forward now. I think that's important.

Interviewer: Absolutely, no, absolutely, that's really good to hear, Minnie. What do you think’s caused the kind of various changes you've described? What do you think might have brought them about, including things inside and outside of therapy?

Minnie: Taking hold of what I'm doing, giving myself an interest in what’s important to me, diverting the bad thoughts into querying thoughts about what I'm doing, you know, and what is the realisation of the results from collecting stones. I’ve had weird hobbies all my life.

Interviewer: OK, and what personal strengths have you got, Minnie, that have helped you make the best use of therapy?

Minnie: I think because of what I’ve gone through in the past. I say that it was two major times when grief really takes over and, but you know, you’ve still got to keep going. Farming, you know, that's what we had to.

Interviewer: So those past experiences and I guess it sounds like you've got a lot of strength within you to, Minnie.

Minnie: Yeah, I had to.

Interviewer: Yeah, and that's kind of helped you to make the best use of therapy and help to move forwards.

Minnie: Yes, I'm sure of that.

Interviewer: Ok. And what do you think's been helpful in your current life situation, so whether it's family relationships, living situation, how have those things helped you make use of therapy?

Minnie: I think the children being there and the children being supportive means an awful lot. They don't realise how much it means. They think I'm the bully and the boss.

Interviewer: You've talked a lot about the support from your family, but also where you live, and it sounds like that's been really helpful throughout your life and even during therapy.

Minnie: Yes, it's a wonderful place to live, it really is. I worked with archaeologists. I own the ruins of *[landmark]* and I own the field *[landmark]*. So, all these things mean a lot to me.

Interviewer: And is there been anything about therapy that's been hindering or unhelpful or disappointing for you?

Minnie: It's hard work! It really is hard work. I usually go from these sessions home…

Mo: Exhausted!

Minnie: Exhausted. But yes, I understand what you're saying.

Interviewer: Yeah, it is. It is very hard work, and it can be very exhausting, but you know, it's quite common for people to say that, that can be a difficulty in therapy. And, I guess, was there any things in therapy that, I think you touched on this earlier Minnie, but any things in therapy that were difficult or painful but still helpful for you?

Minnie: I suppose accepting the necessity of having to do this, instead of seeing it as an enemy, you tend to think, no, this can help guide me back to where I should be, you know.

Interviewer: OK, and is there anything missing from therapy, or anything that would have made therapy more helpful or more effective?

Minnie: I can't think of anything.

Mo: No. Amie did have to, sort of, tweak it for an individual like you which was good and that's what I said to Amie, she worked really hard to…

Minnie: Understand me.

Mo: Yeah, yeah, because you're not a normal character sometimes.

Minnie: I'm me, Mo.

Mo: Yeah, we know.

Interviewer: Well, I'm pleased to hear that you were able to do that with Amie and that you kind of found the right balance together and how to work best together, that sounds good.

Mo: But she was spot on, she'd go away after each session and then come back the following session and I used to think, yeah, you're spot on here. That's what I think. Whether you agree with me…?

Minnie: I don't think I thought…

Mo: Yeah, you were too busy concentrating on the questions.

Interviewer: No, that's really good to hear. Are there any things about you then, Minnie, that made it harder for you to use therapy or to deal with the problems that you had?

Minnie: I think in actual fact, I did recognise that therapy could be a good thing because it does make you order your thoughts, it does make you understand. I am in control, really, and what you're doing and saying and it all helps you put things in order. And I shall go home and I shall do some gardening and I shall look at my stones. I'll sink the farmhouse with stones.

Interviewer: And has there been anything in your life situation that's made it harder to use therapy or deal with problems, so anything within family, living arrangements or even COVID that's made it harder for you to use therapy?

Mo: Do you want me to answer?

Minnie: Yeah.

Mo: The COVID situation, like I said to Amie, the COVID situation has been something no one's ever dealt with, and that's sort of been a bit harder because…

Minnie: Not being able to go shopping and things like that, you know.

Mo: And we're having to do this, which, we've had to come to my sister's 'cause we've tried the Internet at the farm and it doesn't work, so it has put, not pressure on us, but we've done it. It's just that coming…

Minnie: You've done it.

Mo: Well, I've done it. You've not felt pressured.

Minnie: No.

Mo: But then if we didn't have COVID, I probably would have had to bring my mum to Newark. Yeah.

Interviewer: So, practicalities have been difficult and obviously the restrictions of not being able to do what we always want to do.

Mo: COVID has been totally a bit unusual 'cause the other thing is with my mum being on the farm, she's very relaxed on the farm but once I take her off the farm, you do need a lot more support.

Minnie: Well, let's face it, it's been a long time since I've been out in the real world.

Mo: So, it's going to be, after your second jab, you'll start going out so that'll be interesting to see how you cope, but then we've been given the techniques through therapy to hopefully bring you back into a safe space, yeah.

Interviewer: Brilliant, OK, alright, and do you have any suggestions for us regarding the research or the therapy?

Minnie: I don't think I can tell you very much, no not really. She's been quite… it's nothing to be frightened of.

Interviewer: I'm really pleased that you've found that and is there anything else that we haven't talked about, Minnie, that would be important for us to know in terms of your experience of therapy?

Minnie: No, I don't think so. It's been quite calming, it's not been pushy or intrusive. No, it's been quite nice, yeah.

Interviewer: Oh, good. Ok, so the last part of this session, Minnie, is to have a think about some of those, I think you've done lots of questionnaires throughout your time with Amie, so she's given me a summary of your scores on those questionnaires and I'd be interested to know if you have any views about those scores.

Minnie: Yeah.

Interviewer: Ok so, I think you filled most of them in the beginning, middle and end of therapy. So, the first two questionnaires, one was a Generalized Anxiety Disorder questionnaire and the other was a Patient Health Questionnaire, so they measure anxiety and low mood. You completed those at your first, sixth and last therapy sessions, and they indicate a reduction in anxiety over time and a reduction in depression, too. What are your thoughts on that?

Minnie: I think probably.

Mo: Yeah, in your first few sessions you were really low and like I say, the therapy steered you into something you wanted to do so that gave you the positivity and that there is life with the Alzheimer's, about taking control and doing what you want to do.

Minnie: I should think it's more uncomfortable for you than it is for me.

Mo: Yeah, I've seen the inner workings of your mind, mother.

Interviewer: So, you completed another questionnaire as well, Minnie, and this was called the Short Warwick Edinburgh Mental Wellbeing Scale, so it's a big, long name, and again, you completed that the first, sixth and last therapy session with Amie and it indicated that your wellbeing had improved over time. Do you have any views on that?

Minnie: Yeah, I suppose, if that's what I was saying at the time, yeah. There's no question I can cope with it and there's no question now that I've started gardening as well, ‘cause that is a wonderful healer, that's how I got out of the last period in my life when everybody around me was dying. So, I think…

Mo: You’re pottering more.

Minnie: Yeah, I’m doing a lot more.

Mo: You’re not sat in your chair.

Minnie: I’m gardening.

Mo: ‘Cause there was a point you would sit in your chair and just zone out with the telly but you are doing a lot more things even though the collecting the pebbles winds me up, but yeah, you like collecting your pebbles.

Minnie: I shall sink the farmhouse. It’ll be two foot lower and going down.

Mo: Yeah, I never thought I'd have to dust pebbles.

Minnie: I love my pebbles. Some are just… the brown ones that seem to...

Minnie: You're not looking hard enough.

Interviewer: It sounds like that improvement in your wellbeing, indicated by that questionnaire, is reflected in what you're able to do now. So, you also completed something called the Personal Questionnaire, so this is what we use to label problems and what you wanted to work on, and you rated how much it bothered you. A lower score suggests that the problem bothers you less. So, you completed, again, at the first, sixth and last therapy session with Amie and it shows that your problems have become less bothersome. Is that in line with what you'd expect?

Minnie: I think I'm getting better at building up resistance to where I am in life and also understanding that it's probably not all one thing. I'm hoping I'm not as much of a nuisance to the girls.

Mo: It’s not that you’re a nuisance, it’s that all we ask you to do is just potter, not asking you to do a normal life. It's just about helping yourself which you are, you make yourself drinks, you make yourself small meals and stuff, we do the big meals, and just get outside, which you are.

Minnie: Yeah, I've been painting walls.

Mo: Yes, slave labour.

Minnie: Who's slave labour? I'm the slave labour.

Mo: Yeah, I just give you the brush and the paint pot.

Interviewer: Sounds like you're busy, very busy.

Mo: Yeah, as a family, we do. I can't sit still, I'm a hyperactive person.

Minnie: *[daughter]*'s the same. She's hyper.

Mo: Yeah, she's worse than me. We just like to get on with things and you'd sort of lost your way to a point or, at the beginning, you would just sit in your chair, that's all you wanted to do and that's not you.

Minnie: But then it got warmer, and I could start and grow things and… nature's wonderful.

Mo: So it has been… therapy, for the for the time of year, 'cause my mum does have low moods over the winter months, she always has done, it's worked out spot on.

Interviewer: That's good, the timing seems to have been...

Mo: Yeah, it's been spot on.

Interviewer: Ok, so you also completed a couple more questionnaire, Minnie. You completed one, it was an 8-question measure, and you completed this every session, and it was to measure something called psychological flexibility, so that's something that's specific to the type of therapy you did with Amie, and a higher score indicates better psychological health. Your scores show an increase in behavioural awareness, openness to experience and valued action since the first week of therapy but have remained fairly stable over time. Is that in line with your expectations?

Minnie: Probably.

Interviewer: Probably? Ok. And the last one was a Session Rating Scale, so you did this at the end of every session with Amie, and a higher score indicates a better working alliance or working relationship with your therapist. So, overall, it seems you were satisfied with the session content and Amie's therapeutic style. Would you say that's what you'd expect?

Minnie: I think so, yes, definitely.

Interviewer: Ok, well that concludes all of my questions, Minnie, but is there anything else that you'd want to feed back about therapy before we go?

Minnie: It's not as painful as one might think, it's almost fun.

Mo: You've had some good therapy sessions, there's been one where it was a bit raw…

Minnie: Hard work.

Mo: Yeah, but like I said to Amie, Amie was a bit concerned 'cause obviously my mum's always tired, but even if we had it at 2 o'clock in the afternoon, we'd still… part of my mum's condition is that she seems to be tired all the time and they've checked for underactive thyroids and obviously deficiencies and stuff, and it is probably part of the illness she's got. But it doesn't matter what time of the day, and I used to say this to Amie, it doesn't matter what time we made this appointment, your biggest symptom has been the tiredness.

Minnie: I think a lot of that's been the grief, the worry and…

Mo: You were scared because we have sat and watched my mum's sister with Alzheimer's so we do know what's around the corner, which is a bit scary, but we deal with things day by day and that's all we can do at the minute so, and, as I say, the therapy has made me my mum realise that she's still got things she wants to do in life.

Minnie: It's made me more positive.

Interviewer: That's really brilliant, that's really good to hear that you know you can focus on all those things that you know are really important to you, like your stones and your archaeology.

Mo: The only thing I agree with with my mum is the gardening, I love my gardening, but the stone thing I have to sort of stand back, and yeah, it keeps you happy. And there is some very pretty pebbles, I agree, but as you say…

Interviewer: Well, it's been really lovely to meet you, Minnie, I know it's a one-off kind of session, and you Mo, it's been really nice to meet you. It's good to hear about your time working with Amie as well. It sounds like it's been positive.

Mo: Amie, like I've told her, she's been spot on, she's understood my mum and she's made it quite individual to you and that was just spot on 'cause…

Minnie: And you were able to judge that better than I could.

Mo: Even though occasionally Amie caught me zoning out a bit. I was like, she would ask me a question and then I'd come back into the room. Yeah, occasionally when Amie was in control with my mum, I'd switch off a bit, so as a carer, there is that side of it, I could just switch off and zone out a bit, which is quite unusual because I do find the whole process, I'm having to support you more and more and my brain capacity's obviously trying to understand what you want to say and do, so yeah it's a hard process, but the therapy has gave us some techniques, even down to the carer, I can use some of them techniques to zone out a bit. It was that 'river' one, I loved that river one.

Interviewer: Leaves on the stream.

Mo: Yeah, that was spot on, I was gone. When she spoke to me, I'm like, what's my name? I've totally gone on that one, so yeah.

Interviewer: It's a very nice exercise that one. But it sounds like it's been helpful, and I'm really pleased to hear that. So, that's everything for today. Like I say, it's been lovely to meet you both, and all the best and enjoy the rest of you day.

Minnie: Yeah.

Mo: Thank you *[interviewer].*

Interviewer: Take care, bye.

Mo: Bye bye.

Appendix Y. Minnie’s Change Interview Rating Sheets

Change/s ratings sheet

What was the change? Giving myself more time (positive change)

c. Please rate how much you expected it vs. were surprised by it:

1	2	[✓ 3]	4	5
Very much expected it	Somewhat expected it	Neither expected nor surprised by it	Somewhat surprised by it	Very much surprised by it

d. Please rate how likely you think it would have been if you had not had therapy?

[✓ 1]	2	3	4	5
Very unlikely without therapy (clearly would not have happened)	Somewhat unlikely without therapy (probably would not have happened).	Neither likely nor unlikely (no way of telling)	Somewhat likely without therapy (probably would have happened)	Very likely without therapy (would have happened anyway)

c. How important or significant to you personally do you consider this change to be?

1	2	3	[✓ 4]	5
Not at all important	Slightly important	Moderately important	Very important	Extremely important

Change/s ratings sheet

What was the change? Feeling more relaxed (positive change)

a. Please rate how much you expected it vs. were surprised by it:

1	2	3	[✓ 4]	5
Very much expected it	Somewhat expected it	Neither expected nor surprised by it	Somewhat surprised by it	Very much surprised by it

b. Please rate how likely you think it would have been if you had not had therapy?

1	[✓ 2]	3	4	5
Very unlikely without therapy (clearly would not have happened)	Somewhat unlikely without therapy (probably would not have happened).	Neither likely nor unlikely (no way of telling)	Somewhat likely without therapy (probably would have happened)	Very likely without therapy (would have happened anyway)

c. How important or significant to you personally do you consider this change to be?

1	2	3	4	[✓ 5]
Not at all important	Slightly important	Moderately important	Very important	Extremely important

Change/s ratings sheet

What was the change? Recognising my goals and living in line with them (positive change)

a. Please rate how much you expected it vs. were surprised by it:

1	2	3	[✓ 4]	5
Very much expected it	Somewhat expected it	Neither expected nor surprised by it	Somewhat surprised by it	Very much surprised by it

b. Please rate how likely you think it would have been if you had not had therapy?

1	[✓ 2]	3	4	5
Very unlikely without therapy (clearly would not have happened)	Somewhat unlikely without therapy (probably would not have happened).	Neither likely nor unlikely (no way of telling)	Somewhat likely without therapy (probably would have happened)	Very likely without therapy (would have happened anyway)

c. How important or significant to you personally do you consider this change to be?

1	2	3	4	[✓ 5]
Not at all important	Slightly important	Moderately important	Very important	Extremely important

Appendix Z. Author Guidelines for submission to Counselling and Psychotherapy Research

https://onlinelibrary.wiley.com/page/journal/17461405/homepage/forauthors.html

Thesis Poster

Acceptance and Commitment Therapy (ACT) for people with dementia experiencing psychological distress: A hermeneutic single case efficacy design (HSCED) series

Amie Robinson, Danielle De Boos, & Nima Moghaddam
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Introduction

People with dementia experience high psychological distress[1],[2] but have limited evidence-based psychological interventions[3].

ACT promotes psychological flexibility[4] (PF) so people can lead meaningful lives despite distress.

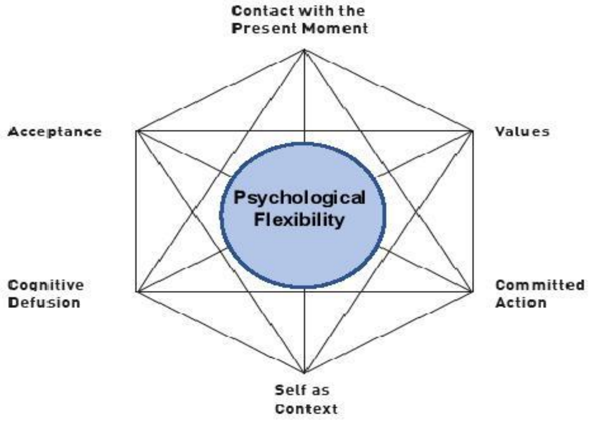


Figure 1. ACT hexaflex (Hayes et al., 2006[4])

ACT works with parallel populations[5] but we do not know if it is effective for people with dementia.

Study Aims

To investigate the effectiveness and acceptability of ACT for people with dementia.

Methods

Three clients with dementia, supported by their carers, attended up to 12 ACT sessions via Microsoft Teams.

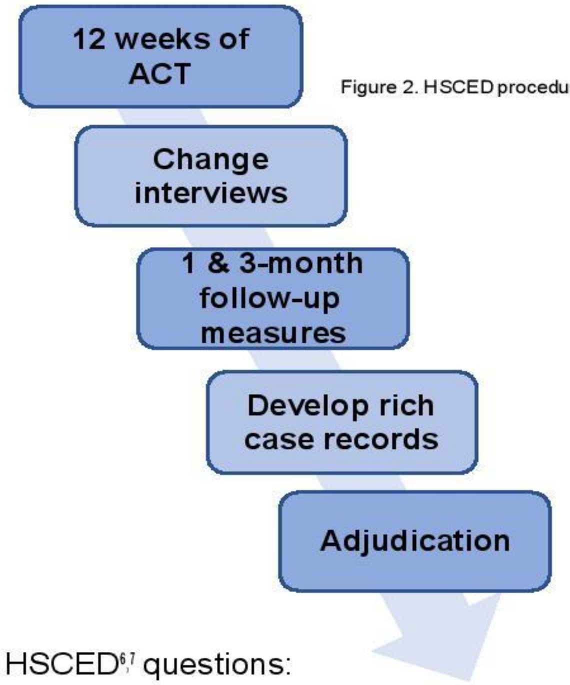


Figure 2. HSCED procedure

HSCED[6,7] questions:

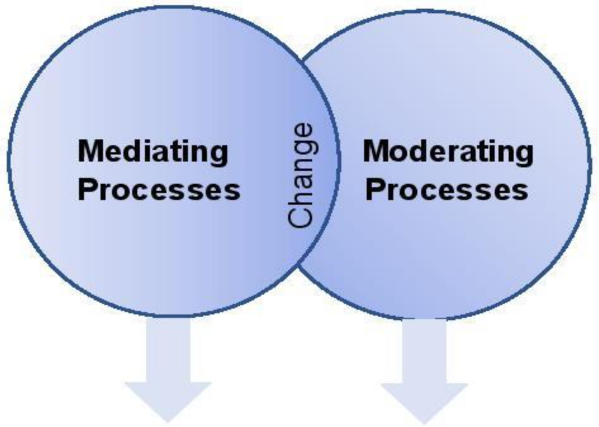
1) Did the client change over therapy?
2) Is therapy responsible?
3) What events or processes facilitated changes?

Rich case records for each client were examined by three expert judges who concluded on outcomes.

Results

One client changed due to ACT. Two clients remained unchanged.

Where change occurred, psychological distress was sensitive to increases in PF.



<u>ACT processes</u>:
- **Values**
- **Committed action**
- **Acceptance**

<u>Non-therapy factors:</u>
- **A strong client-carer relationship**

<u>Non-therapy factors</u>:
- Client openness
- Willingness
- Resilience
- Perseverance
- Therapeutic experience
- Established coping strategies
- Level of impairment

Discussion

ACT processes and a strong client-carer alliance provided the setting in which ACT can be a feasible, effective intervention, by helping carers to better meet the needs of their loved ones with dementia.

Figure 3. Client and carer quotes

Acceptability can be supported with:
- Visual prompts
- Repetition and examples
- Shorter, less abstract ACT metaphors

Recommendations for Research/Practice

- Assess carers' PF and the client-carer relationship.
- Use behavioural/process measures and/or post-therapy change interviews.
- Offer flexibility for therapy delivery (in-person or remote).

References

[1] Muliyala K. P., & Varghese, M. (2010). The complex relationship between depression and dementia. *Annals of Indian Academy of Neurology 13*(2), 69-73; [2] Badrakalimuthu, V. R., & Tarbuck, A. F. (2012). Anxiety: A hidden element in dementia. *Advanced Psychiatric Treatment, 18*(2), 119-128; [3] Laidlaw, K. (2013). ViewPoint: A deficit in psychotherapeutic care for older people with depression and anxiety. *Gerontology 59*(6), 549-556. https://doi:10.1159/000351439; [4]Hayes, S. C., Luoma, J. B., Bond, F. W., Masuda, A., & Lillis, J. (2006). Acceptance and commitment therapy: Model, processes and outcomes. *Behaviour Research and Therapy, 44*(1), 1-25. https://doi.org/10.1016/j.brat.2005.06.006; [5] Mccracken, L. M., & Gutiérrez-martínez, O. (2011). Behaviour research and therapy processes of change in psychological flexibility in an interdisciplinary group-based treatment for chronic pain based on acceptance and commitment therapy. *Behaviour Research and Therapy, 49*(4), 267-274. https://doi.org/10.1016/j.brat.2011.02.004; [6]Elliott, R. (2002). Hermeneutic single-case efficacy design. *Psychotherapy Research, 12*(1), 1–21. https://doi.org/10.1016/j.buildenv.2006.10.027; [7]Wall, J. M., Kwee, J. L., Hu, M., & McDonald, M. J. (2017). Enhancing the hermeneutic single-case efficacy design: Bridging the research-practice gap. *Psychotherapy Research, 27*(5), 539-548.

Small Scale Research Project (SSRP)

A Service Evaluation of the Assessment Process in a Step4 Psychological Therapies Service[30]

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[30] This journal paper has been prepared for submission to Mental Health Review Journal; Appendix DD shows Author Guidelines.

Background: With a high prevalence of poor mental health in the UK, mental health services are often overstretched, hence efforts must be made to identify and reduce unnecessary burden upon valuable service time and protect resources to effectively meet people’s needs. Purpose: To identify factors related to assessment non-attendance and inappropriate referrals to improve the efficiency of the assessment process within a local Step4 Psychological Therapies Service. Methodology: Referral and assessment information was accessed between October 2019–March 2020 from three areas; Step4 routine service data, electronic client records where necessary and Step4 staff self-report questionnaires. Findings: All clients offered an assessment during this time attended, thus, it was not possible to examine factors related to non-attendance. Findings indicated a combination of factors that could influence a client’s appropriateness for the service, including readiness to change, which was not necessarily identified at referral or prior to assessment. Though the necessity for assessment in clarifying client needs and treatment was indicated, assessment of an inappropriate referral could cost the service time, approximately, in excess of one working day, which is important to service activity when considering competing demands on service time and the opportunity cost to other clients awaiting assessment. Conclusions: Though assessments are a fundamental part of accessing Step4, recommendations are made for improving the efficiency of the assessment process.

Keywords: Service evaluation; referrals; psychological assessment; Step4; mental health

Background

Each year in the UK, approximately one in four people experience a mental health difficulty (McManus et al., 2009; Evans et al., 2015). The Department of Health estimates that mental health difficulties cost the UK economy between £70 billion and £100 billion per year (Davies, 2013). With a high prevalence of poor mental health in the UK, mental health services can often be overstretched and insufficiently funded (Dehghan et al., 2017). The associated level of work for practitioners can also mean that services are at risk of acquiring long waiting lists (Marzillier & Hall, 1999). Hence, resource allocation is vital to ensure care is provided in the most appropriate setting and that there are efficient pathways to specialist care for those who need it (Dehghan et al.).

In 2008, the Improving Access to Psychological Therapies (IAPT) programme was established with the aim of enabling access to a range of evidence-based psychological therapies recommended by the National Institute for Health and Care Excellence (NICE). IAPT uses a stepped-care approach to manage the provision of services for people with mental health difficulties, ‘stepping down’ when a less intensive treatment is more appropriate or ‘stepping up’ to more intensive treatments (NHS England, 2021). The stepped-care approach consists of Step 1 (all common mental health difficulties), Step 2 (persistent mild to moderate depression or anxiety) and Step 3 (mild to moderate depression or anxiety disorders that have not responded to lower-intensity interventions; NICE, 2011). Step 4 services offer specialist psychological assessment and intervention to people with a higher chronicity and severity of mental health difficulty or functional impairment which may include risk of self-neglect or harm, complex social factors, or multiple diagnoses. A reported advantage of the stepped care model is that it can maximise treatment effectiveness by improving resource allocation, making it an economically viable and useful treatment option (Ho et al., 2016). However, due to differences in the availability of resources across diverse settings, it can be difficult to standardise the stepped model nationally, thus it may be argued that flexibility within stepped care is needed to adequately respond to these differences (Ho et al.).

Step4 Psychological Therapies Service

This local Step4 Psychological Therapies Service, as part of Nottinghamshire Healthcare National Health Service (NHS) Trust (NHCT), covers four areas with a total population of approximately 476,900 people (Office for National Statistics, 2019). The service consists of one Consultant Clinical Psychologist/Service Lead, five Clinical Psychologists and Counselling Psychologists and two Trainee Clinical Psychologists on placement, supported by a small team of administrative staff. According to NICE (2011), there should be sufficient capacity within Step 4 services to increase the amount of people who are identified, assessed, and offered treatment. However, to date, there is no equivalent benchmark to compare against when considering staffing, referrals or assessments in Step 4 services in other localities. Within this service, annual reports for commissioners contain comparison data from primary care (General Practice) and IAPT services but there is acknowledgement that Step4 is a ‘higher’ level service with relatively fewer clients in comparison to Steps 2 and 3 (Mental Health Matters, 2018) and may therefore make for a poor comparison.

Psychological Assessment in Step4

According to NICE (2011), assessment in Step4 should be a fundamental part of the stepped-care pathway for mental health difficulties. This Step4 service, like many, uses an ‘opt-in’ model whereby, following a referral, the client is contacted to complete and return a battery of opt-in questionnaires within two weeks. Opt-ins are reportedly an effective way to manage inappropriate referrals, limit ‘Did Not Attends’ (DNAs) and effectively utilise staff time (NHS England, 2015). However, opt-ins may also act as a type of effort test based on an assumption that clients will complete them if distressed enough to do so. Thus, to support client engagement, it has been recommended that there should be no over-complicated referral process or opt-in system (The National Collaborating Centre for Mental Health, 2018). In this service, clients are asked to complete a personal history questionnaire to collect demographic information and a description of their difficulties in their own words, as well as the University of Rhode Island Change Assessment (URICA; McConnaughy, 1981) as a measure of readiness for change. This information is reviewed before the client is invited to assessment. Clients are then asked to complete the Clinical Outcomes in Routine Evaluation Outcome Measure- 34-item (CORE-34; Evans et al., 2000), as a measure of psychological distress, which is reviewed by the clinician at assessment.

Assessment would likely involve identifying the presenting problem, establishing service suitability and, in considering how therapy may be helpful (Sweeney et al., 2019), determining the most suitable NICE-recommended treatment (The National Collaborating Centre for Mental Health, 2018). Assessments conducted by a mental health professional are reported to lead to more accurate identification of problems and appropriate treatment in comparison to primary care but is likely to involve greater cost and longer waiting times for treatments, which can have a negative impact on care (NICE, 2011).

Not appropriate for service at referral

Step4 provides referral guidelines which outline service and exclusion criteria. For example, people who currently misuse substances, pose a forensic risk, experience psychosis or are participating in another therapy are not considered appropriate for Step4 (NHCT, 2019). Although there is suggestion that referral guidelines are helpful, they may not be consistently adhered to, though the reasons for this are ambiguous (Hartveit, et al., 2013; Rogers et al., 2013). The content and quality of referrals can also vary which can lead to delayed treatment and impact the efficacy of services (Allwood et al., 2019). A lack of necessary information in the referral may affect whether people reach the most appropriate destination first time and the service's ability to pre-empt appropriateness for therapy prior to assessment (Dehghan, 2017). Greater understanding of the referral process by clients and referrers is vital to the clients' overall healthcare experience, with rejected referrals and adjusted timescales a regular cause of client apprehension and uncertainty (Dehghan).

Not appropriate for service following assessment

Presumably, those who do not meet service criteria or meet any exclusion criteria would not be accepted for assessment. Step4 service criteria states that clients should be ready, willing, and able to engage in talking therapy (NHCT, 2019), therefore, assessment of a client's motivation for therapy is deemed important in influencing the likelihood of becoming meaningfully and actively involved in therapy (Ogrodniczuk et al., 2018). The URICA (McConnaughy, 1981), underpinned by the Transtheoretical Model of Behaviour Change using the stages of precontemplation, contemplation, preparation, action, maintenance, and termination (Prochaska & Velicer, 1997), has shown excellent reliability, prediction of treatment retention and attrition and modest utility for predicting treatment outcome (Dozois et al., 2004). However, it may be criticised for its arbitrary dividing lines between the stages which may, misleadingly, be perceived as time-specific and sequential (West, 2005). Hence, URICA scores may be used alongside clinical judgement to consider client suitability. Those who are deemed inappropriate for Step4 following assessment are referred back to the care of their General Practitioner (GP) or signposted to other services.

Non-attendance at assessment

Long waiting times between referral and first appointment can lead to poor therapeutic engagement and increased attrition (Grunebaum et al., 1996; Foreman & Hanna, 2000). DNAs can cause further delay for other individuals waiting to be seen (Phillips et al., 2017), thus services with high non-attendance often retain longer waiting lists (Trusler et al., 2006). Research has indicated major predictors of first appointment non-attendance can include clients with a lower non-risk score on the CORE-34 (Evans et al., 2000), regular thoughts of 'being better off dead' (as indicated on the CORE-34; Evans et al.), or recent onset of a mental health difficulty (one month or less) or long-term condition (more than two years; Di Bona et al., 2014). Conversely, clients found to most likely attend their first appointment included those who self-referred and those with fewer previous referrals (Davis et al., 2020).

Despite individual characteristics, there may be external factors that impact non-attendance. Though psychological difficulties may be viewed as located within the individual, the service sits in a context of a relationship between itself and the community it serves, hence, consideration must also be given to systemic facilitators and barriers and the service’s role in providing access, opportunity and reducing attrition. This may be further explained using the COM-B model of behaviour (Michie et al., 2011) which highlights a complex mix of internal and external influences on behaviour. The COM-B (Michie et al.) states that capability, motivation, and opportunity must be present and interact as part of a dynamic system to provide optimal conditions for behaviour change. Though important to consider in relation to service efficiencies, the COM-B may be criticised for missing the element of ‘wanting’, a possible motivational element in explaining why people do or do not do the things important for their wellbeing (Marks, 2020), in this case, attending healthcare appointments.

The Present Study

Though mental healthcare quality and delivery is at the forefront of the modernisation agenda of the NHS (Trusler et al., 2006), the NHS continues to operate within a context of organisational change, with increased demand for mental health services and minimal growth in funding. Hence, efforts must be made to identify and reduce unnecessary burden upon valuable service time and protect resources to effectively meet people’s needs. This is in line with NHCT’s commitment to targeting and reducing unwarranted variation in service efficiency to maximise productivity and ensure clients have a positive experience (NHCT, 2016). It is hoped that this service evaluation will help to identify factors related to assessment non-attendance and inappropriate referrals in this Step4 service to inform recommendations in improving the efficiency of the assessment process and subsequent quality and timeliness of care for the people who use the service.

Aims

The service evaluation aims to examine individual and service level outcomes between October 2019–March 2020 to address the following research questions:

1. Pre-assessment;
    a. how many opt-in referrals did not attend for assessment;
    b. could non-attendance have been predicted in any way and;
    c. how much service time is taken with non-attendance at assessment?
2. Post-assessment;
    a. how many people were discharged as ‘inappropriate’ for the service;
    b. could this have been identified at referral and;
    c. how much service time is taken to assess people who are then deemed inappropriate?

Methodology

Setting

The service evaluation was conducted in a local Step4 Psychological Therapies Service in Nottinghamshire and was approved under local NHS governance procedures in August 2020.

Materials

Referral and assessment information was accessed from routine service data (two CORE databases). Clients were informed via their invitation to assessment that their data may be used by the service to produce reports to enable service improvement. Returning their opt-in questionnaires confirmed that they consented to this. Though the databases contained identifiable information (date of birth and electronic record numbers), data was referred to as a collective, hence no identifiable information was used. Clients' electronic Rio records, referral letters, and previous contact and correspondence with services were reviewed where necessary. Data collected from staff self-report questionnaires were also reviewed (Appendices AA and BB).

Procedure

In response to questions 1a and 2a, referral and assessment data from the service's CORE databases were reviewed for numbers of assessment non-attenders and those discharged following assessment between the 6-month period of October 2019–March 2020. Data after March 2020 was excluded as it was deemed likely unrepresentative of routine service data due to the impact of the Coronavirus (COVID-19) on service procedures.

To address all remaining research questions regarding predictors of or related factors to non-attendance and service suitability, a combination of methods was used. This included reviewing CORE-34 (Evans et al., 2000) and URICA (McConnaughy, 1981) scores at assessment from the CORE databases where available, clients' electronic clinical notes, referral letters, previous contact with services and consulting the service's DNA policy. Furthermore, two electronic, self-report questionnaires were circulated to Step4 staff via NHS encrypted email to request an estimate of the time taken for assessment-related tasks. Completed questionnaires were returned via email to the first author. By completing the questionnaires, staff consented to taking part in the service evaluation.

Consideration of compromised data integrity due to missing data in the CORE databases was deemed inconsequential since the data set was small and did not undergo statistical analysis. With regards to questionnaire data, there may have been potential response bias, thus the first author selected permanent staff to complete the questionnaires (excluding Trainees and bank staff) who arguably had better knowledge, experience of and familiarity with the service to avoid inconclusive or incorrect insights and increase the reliability and validity of the results. Separate questionnaires were developed for clinicians and administrative staff to enable question context and clarity. Though questionnaires were anonymous, to address social desirability or self-presentational bias, in this case, staff possibly recording shortened activity times to convey competence, the first author reassured that data would be viewed collectively to help inform recommendations.

Findings

Appropriateness of referral

According to the CORE databases, the service received 185 referrals between October 2019–March 2020. Of these, 60 (32%) were not accepted to the service, with repeated instances of clients meeting exclusion criteria, such as those who required psychiatric assessment, deemed high risk to themselves or others or had recently engaged in therapy. There was also indication that some clients required a ‘lower step’ service for stabilisation work. Of the 185 referrals, 125 were sent opt-in questionnaires, however, over one quarter of people (34) did not return them and were discharged.

Attendance at assessment

Of the 91 who returned their opt-in questionnaires, 40 were invited to assessment and all 40 attended. As there were no assessment non-attenders during this review period, no conclusions could be made about possible predicting factors of non-attendance. However, questionnaire data from Step4 staff provided an estimate of service time taken when clients did not attend for assessment or cancelled less than 24 hours beforehand. For clinicians, this included the time taken for preparatory administration such as reviewing client referrals and notes and liaising with administrative staff regarding next steps to either discharge or rearrange the appointment. Between the five clinicians, this averaged at 89 minutes (1 hour 29 minutes) of clinician time per assessment non-attendance. For administrative staff, each assessment non-attendance could cost them approximately 139 minutes (2 hours 19 minutes) of service time, which included initial processing of the referral, attending referral meetings, accepting or rejecting the referral, processing returned opt-ins, sending assessment appointment letters and discharging or rearranging client appointments as requested by the clinician.

Appropriateness following assessment

Of the 40 people assessed, 36 were accepted to the service. An assessment audit form, completed by assessing clinicians (Appendix CC), was used to consider readiness for therapy. From the CORE databases, data was available for 38 of the 40, as shown in Tables 38-42.

Table 38. Clients’ Level of Appropriateness

Level of Appropriateness	Number of referrals
Very Appropriate	13 (34.2%)
Appropriate	21 (55.3%)
Less Appropriate	4 (10.5%)
Not Appropriate	0 (0%)

Table 39. Clients’ Psychological Insight

Psychological Insight	Number of Clients
Very Good	7 (18.4%)
Good	22 (57.9%)
Moderate	8 (21.1%)
Poor	1 (2.6%)

Table 40. Clients’ Readiness for Therapy

Readiness for Therapy	Number of Clients
Ready Now	13 (34.2%)
Moderately	19 (50%)
Somewhat	3 (7.9%)
Not Ready	3 (7.9%)

Table 41. Clients' Potential for Change

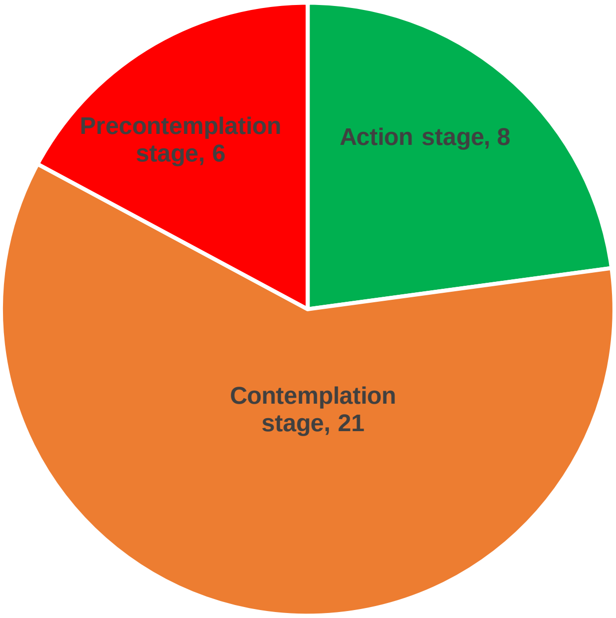
Potential for Change	Number of Clients
Considerable	9 (23.7%)
Somewhat	24 (63.2%)
A Little	5 (13.1%)
None at all	0 (0%)

Table 42. Clients' Motivation Level

Motivation Level	Number of Clients
Highly Motivated	10 (26.3%)
Motivated	24 (63.2%)
Moderate	4 (10.5%)
Poor	0 (%)

Data indicated that 34 clients (89.5%) were viewed by clinicians as very appropriate or appropriate for the service, with 29 clients (76.3%) having either good or very good psychological insight into their difficulties. Most clients (92.1%) were ready for therapy to some degree, and all were viewed as being motivated and having potential for improvement. In addition to the assessor-rated scores, URICA data (from the CORE databases, available for 35 of the 40 assessed) was used to further assess readiness to change, as shown in Figure 12.

Figure 12. Indication of readiness to change using URICA scores



Data showed that URICA scores from 21 clients (60%) fell within the 'Contemplation' stage, eight (22.9%) within the 'Action' stage and six (17.1%) clients within the 'Pre-Contemplation' stage. One client at the 'Action' stage and one client at the 'Contemplation' stage were discharged. Of the six people who were not deemed ready for change ('Pre-contemplation'), one was discharged, and one referred on. Thus, in total, four of the 40 clients (10%) were deemed unsuitable and therefore readiness appeared to be a major predictor of appropriateness for the service.

In consideration of whether these four clients could have been identified at referral, their referrals, URICA (McConnaughy, 1981) and CORE-34 (Evans et al., 2000) scores, and clinical notes were reviewed for any commonalities, including demographic information such as gender, age, socioeconomic status according to their postcode and employment status. More information is provided below.

Client 1
Client 1 was a White British, 54-year-old female who lived with her partner in a former mining village and had carer responsibilities. She was unemployed and receiving disability and sickness benefits. Client 1 was referred by her GP after presenting at A&E with low mood, self-harm and suicidal thoughts. There did not appear to be a cover letter from the GP. Instead, the GP had forwarded the letter, received from the A&E Mental Health Liaison Nurse, to Step4. At her assessment, Client 1's CORE score was 2.30 (above the cut-off of 1), which may have indicated a 'moderate-severe' (Mellor-Clark, 2006) clinically-significant level of psychological distress. Her URICA scores placed her within the Contemplation stage, however, the assessing clinician felt that she was not ready to make changes, owing to the client allegedly stating she wanted to change others and their actions, with less emphasis upon wanting to improve her own coping skills. She was discharged back to her GP.

Client 2
Client 2 was a White British, 33-year-old female who had separated from her partner and lived with her young children in a small village in Nottinghamshire. She was not in employment and received sickness and disability benefits. Client 2 had been referred by a psychiatrist from a local mental health inpatient unit for trauma work in the context of Emotionally Unstable Personality Disorder (EUPD). Client 2's CORE score was 2.41 which suggested a 'moderate-severe' (Mellor-Clark, 2006) level of psychological distress. Her URICA scores indicated she was at the Action stage of change, however at assessment, the clinician considered Client 2 was not ready for trauma work due to her ongoing dissociation and lack of adaptive coping strategies should therapy trigger overwhelming emotions. She was thus discharged.

Client 3
Client 3 was a single, White British, 29-year-old male who lived with his parents in a former mining village. He was unemployed and receiving sickness and disability benefits. Client 3 was referred for assessment by a council re-enablement service due to anxiety and depression in the context of childhood trauma and ongoing physical health difficulties. Though the opt-in battery was returned, no CORE data was available in the CORE databases or electronic records for Client 3. His URICA scores fell within the Precontemplation stage, which may have indicated his ineligibility for the service. Client 3 stated he was managing well and that the only change he wished to make was to regain his driving licence, with which Step4 could not support, and was therefore discharged.

Client 4
Client 4 was a single, White British, 31-year-old female who lived with her children in a market town in Nottinghamshire. She was employed and receiving sickness and disability benefits. Client 4 was referred by IAPT for trauma work as she had requested Eye Movement Desensitisation Reprocessing (EMDR) which was not

offered within local Step 3 services. Client 4's CORE scores were missing from the service data. Her URICA scores indicated that she was at the Precontemplation stage. She was referred onto a Step 3 therapist for Cognitive Behavioural Therapy (CBT) for depression, which was assessed as a priority over the trauma work, and according to client preference. Client 4 was also referred to the Local Mental Health Team (LMHT) for support with activity scheduling and self-care.

Questionnaire data offered an estimate of the average service time taken to assess clients who were then deemed unsuitable for the service. For clinicians, this was approximately 458 minutes (7 hours 38 minutes) per person, which included time spent on administration prior to assessment, two, up to 90-minute appointment slots with the client, administration following assessment including notes, care plans, risk assessments, service audit data and assessment letter with psychological formulation and care plan. There were also additional demands on clinician time between areas such as attending local referral meetings, liaising with colleagues within and outside of Step4 about client eligibility, sending resources to clients between assessment appointments and attending to any safeguarding or risk issues raised at assessment. This could add an additional, on average, 42 minutes onto clinician time. For administrative staff, each assessment that resulted in discharge could cost them approximately 33 minutes, including sending discharge letters and closing the client's referral to the service.

Discussion

The aim of the service evaluation was to identify any factors related to assessment non-attendance and inappropriate referrals in this Step4 service. Between October 2019–March 2020, the service received 185 referrals, 125 of which were sent opt-in questionnaires but over a quarter were not returned. Though the reasons for this are unknown, it could be argued that the opt-in model effectively managed inappropriate referrals (NHS England, 2015). Alternatively, it may be that the opt-in questionnaires served to impact client engagement and access. It would have been interesting to further investigate any pertinent demographic information of the 34 who did not return their opt-in battery to elucidate whether there was a disproportionate cut-off, for example, considering gender, age, socioeconomic status, or education and literacy abilities to ensure a larger number of people were identified, assessed, and offered treatment (NICE, 2011).

Though not anticipated, every client who was offered an assessment attended. Therefore, it was not possible to examine potential predictors of or factors related to non-attendance, such as those indicated by Di Bona et al. (2014). The total estimated service time for each assessment non-attendance equated to approximately 3 hours 48 minutes. If an average working day is 7.5 hours, one assessment non-attendance could take over half a day of service time. However, data in the 6-month review period was narrow and featured only a small slice of service activity. Hence, should the typical number of DNAs be deemed underrepresented in this data, it would be useful to review a larger period to calculate an average number of assessments not attended and provide more precise indication of the burden upon time.

The service evaluation revealed that 10% of clients were not suitable following assessment and discharged from Step4. It was estimated that each of these cases could cost the service, on average, 8 hours 11 minutes, in excess of one working day. This finding has relevance for service quality and efficiency, considering Step4 should preserve sufficient capacity for assessment and intervention (NICE, 2011). This figure (10%) provides a service level average, therefore, if some clinicians are discharging more than 10% of their clients following assessment, it would be worth further enquiry. Though it is recognised that the service needs strict criteria, reasons for determining clients as ineligible should be explored with curiosity and compassion, considering systemic factors in facilitating or hindering access and opportunity. Although client motivation is often deemed important in influencing the likelihood of becoming meaningfully involved in therapy (Ogrodniczuk et al., 2018), it seemed that URICA scores alone were not a predictor of service appropriateness. For example, Client 2’s scores fell within the ‘Action’ stage but was discharged following assessment. This may emphasise the importance of assessment by mental health professionals to judge suitability, supporting the notion that they lead to more accurate identification of problems and treatment (NICE, 2011). Alternatively, Client 2’s EUPD diagnosis, which Step4 is not commissioned to work with, may have acted as a barrier. Moreover, Client 1’s referral appeared to lack necessary information which may have impeded her reaching the most appropriate destination first time and hence reduced the service’s ability to pre-empt her appropriateness prior to assessment (Dehghan, 2017).

There were commonalities between Clients 1-4 including their nationality, ethnicity, receipt of government financial support, trauma and objective levels of psychological distress as measured using the CORE-34 (Evans et al., 2000). However, only tentative links can be made between individual traits, circumstance and service suitability which seems reductionistic, risks oversimplifying human complexities, and fails to recognise other factors such as variation between assessing clinicians. Larger scaled data would be needed to identify crude demographic factors and potential inequalities, hence the commonalities highlighted here are likely coincidental.

With regards to methodological shortcomings, though there was a strength in triangulating information from different sources, a weakness was in the completeness and accuracy of data. For example, when staff were asked to broadly quantify service time, it may have been that this did not correspond with actual time (Zakay, 2012) since individual retrospection can vary when compared with timestamped activity data and group consensus (Fine & Vajsbaher, 2013). Though questionnaire data was collectively combined to estimate average service time, timings provided by clinicians were highly variable which questions standards of uniformity, shared practice and consequent quality of experience for clients. Thus, uncertainty remains about whether clinician timings were heterogenous, reflective of assessing clients of differing complexities, variability in how clinicians recorded their activity timings or, due to small scale data, generated by chance distribution.

A further criticism is that the service evaluation involved only a single service with no comparison to other Step 4 services, hence, findings may be less applicable to other localities. Instead, via informal benchmarking, consideration was given to how data fits with other services. Though Step4 treats a relatively smaller minority of people in comparison to ‘lower’ level services (Mental Health Matters, 2018), the number of people discharged following assessment seemed comparable to the third-sector organisation Mind, for example, who found that one in 10 people following assessment were not offered therapy (Mind, 2013). Likewise, Step4 received a similar number of inappropriate referrals (32%) when compared with IAPT, where estimates suggested 31% of clients referred in 2019–2020 did not enter therapy (NHS Digital, 2020), including those who declined initial appointments and those determined unsuitable for IAPT (NHS Digital).

Recommendations
The implementation of the below recommendations may help to optimise this Step4 service's assessment process, however, may require further consideration due to likely changes in current working practices with COVID-19:

- Continued consideration of client engagement to maintain assessment attendance and comparable working with other mental healthcare providers.
- To better identify appropriateness at referral, though not strongly supported here, a standardised referral form may provide a reminder of exclusion criteria and request necessary information from referrers, if doing so would not further complicate the referral process (The National Collaborating Centre for Mental Health, 2018).
- Though they provide indication of distress, risk and motivation, psychometric scores and even referral information alone cannot predict service suitability. URICA (McConnaughy, 1981) scores were not consistently used in predicting appropriateness, with no apparent relationship between scores and invitation to assessment. Therefore, the service may wish to consider streamlining the opt-in battery.
- Clinical assessment is necessitated to clarify client treatment, especially since Step4 serves people with a high severity of mental health difficulty (Mental Health Matters, 2018). However, the cost of assessment to service time is important to consider alongside staff's competing demands and the opportunity cost for other clients awaiting assessment.
- Since group consensus is reportedly accurate (Fine & Vajsbaher, 2013), clinician idiosyncrasies and timings may be more precisely quantified via collective staff discussion and ongoing monitoring and evaluation to ensure standardised, shared practice, reduced variation, increased productivity and positive client experience (NHCT, 2016). For example, considering a 'crib sheet' to standardise the assessment appointment. Quality standards and adherence to a structured assessment could be further explored in a service audit.

Suggestions for future research include exploration of client attitudes towards the opt-in battery, specifically those who did not return them, to identify possible themes and recommendations to improve access. Moreover, further investigation may be warranted into clinicians' experiences of assessment, especially in relation to the impact of change in the NHS and during COVID-19, to consider and address any systemic factors affecting service processes and efficiencies.

SSRP References

Allwood, C., O'Brien. A., & Glue, P. (2019). Referrals from primary care to community mental health teams: What's missing? *Journal of Primary Health Care 11,* 334–341. https://doi.org/10.1071/HC19053

Davies, S. C. (2013). Chief Medical Officer's summary. In N. Metha (Ed.). *Annual report of the Chief Medical Officer 2013, public mental health priorities: Investing in the evidence* (pp. 11–19). London: Department of Health.

Davis, A., Smith, T., Talbot, J., Eldridge, C., & Betts, D. (2020). Predicting patient engagement in IAPT services: A statistical analysis of electronic health records. *Evidence-Based Mental Health, 23*(1)*,* 8-14. https://doi.org/10.1136/ebmental-2019-300133

Dehghan, A., Nowar, M., & Molodynski, A. (2017). Improving the referral process from primary care to an AMHT. *Progress in Neurology and Psychiatry, 21*(3), 22–25. https://doi.org/10.1002/pnp.476

Di Bona, L., Saxon, D., Barkham, M., Dent-Brown, K., & Parry, G. (2014). Predictors of patient non-attendance at Improving Access to Psychological Therapy services demonstration sites. *Journal of Affective Disorders, 169,* 157–164. https://doi.org/10.1016/j.jad.2014.08.005

Dozois, D. J., Westra, H. A., Collins, K. A., Fung, T. S., & Garry, J. K. (2004). Stages of change in anxiety: Psychometric properties of the University of Rhode Island Change Assessment (URICA) scale. *Behaviour Research and Therapy, 42*(6), 711–729. https://doi.org/10.1016/S0005-7967(03)00193-1

Evans, C., Mellor-Clark, J., Margison, F., Barkham, M., McGrath, G., Connell, J., et al. (2000). Clinical outcomes in routine evaluation: the CORE-OM. *Journal of Mental Health, 9,* 247–255. https://doi.org/10.1080/jmh.9.3.247.255

Evans, J., Macrory, I., & Randall, C. (2015). *Measuring national wellbeing: Life in the UK, 2015*. London: Office for National Statistics.

Fine, P., & Vajsbaher, T. (2013). How good are groups at estimating time? *International Symposium on Performance Science,* 741–746. Retrieved from https://www.researchgate.net/publication/311674463_How_good_are_groups_at_estimating_time

Foreman, D. M., & Hanna, M. (2000). How long can a waiting list be? The impact of waiting time on intention to attend child and adolescent psychiatry clinics. *Psychiatric Bulletin, 24*(6)*,* 211–213. https://doi.org/10.1192/pb.24.6.211

Grunebaum, M., Luber, P., Callahan, M., Leon, M. C., Olfson, M. & Portera, L. (1996). Predictors of missed appointments for psychiatric consultations in a primary care clinic. *Psychiatric Services, 47,* 848–852. https://doi.org/10.1176/ps.47.8.848

Hartveit, M., Thorsen, O., Biringer, E., Vanhaecht, K., Carlsen, B., & Aslaksen, A. (2013). Recommended content of referral letters from general practitioners to specialised mental health care: A qualitative multi-perspective study. *BMC Health Services Research, 13,* 329. https://doi.org/10.1186/1472-6963-13-329

Ho, F. Y., Yeung, W. F.., Ng, T. Y., & Chan, C. S. (2016). The efficacy and cost-effectiveness of stepped care prevention and treatment for depressive and/or anxiety disorders: A systematic review and meta-analysis*. Scientific Reports, 6*(1), 29281. https://doi.org/10.1038/srep29281

Marks, D. F. (2020). The COM-B system of behaviour change: Properties, problems and prospects. Qeios. https://doi.org/10.32388/U5MTTB.2

Marzillier, J, & Hall, J. (1999). (Eds.), What is clinical psychology? Oxford: Oxford University Press.

McConnaughy, E. A. (1981). Development of the University of Rhode Island Change Assessment (URICA) scale: A device for the measurement of stages of change. *Open Access Master's Theses,* Paper 1614. https://doi.org/10.23860/thesis-mcconnaughy-eileen-1981

McManus, S., Meltzer, H., Brugha T, Bebbington, P. E., & Jenkins, R. (2009). *Adult psychiatric morbidity in England: Results of a household survey.* Leeds, UK: Health and Social Care Information Centre.

Mental Health Matters. (2018, n.d.). *Stepped care.* Retrieved from https://www.mhm.org.uk/pages/faqs/category/stepped-care

Michie, S., van Stralen, M. M., & West, R. (2011). The behaviour change wheel: A new method for characterising and designing behaviour change interventions*. Implementation Science 6,* 42. https://doi.org/10.1186/1748-5908-6-42

Mind. (2013). *We still need to talk: A report on access to talking therapies.* Retrieved from https://www.mind.org.uk/media-a/4248/we-still-need-to-talk_report.pdf

National Institute for Health and Care Excellence, (2011). *Common mental health problems: Identification and pathways to care.* Retrieved from https://www.nice.org.uk/guidance/cg123/chapter/1-guidance

NHS Digital. (2020). *Psychological therapies, annual reports on the use of IAPT services.* Retrieved from https://digital.nhs.uk/data-and-information/publications/statistical/psychological-therapies-annual-reports-on-the-use-of-iapt-services

NHS England. (2015). *Improving Access to Psychological Therapies (IAPT) waiting times guidance and FAQ’s.* Retrieved from https://www.england.nhs.uk/wp-content/uploads/2015/02/iapt-wait-times-guid.pdf

NHS England. (2021). *Service standards.* Retrieved from https://www.england.nhs.uk/mental-health/adults/iapt/service-standards/

Nottinghamshire Healthcare NHS Foundation Trust. (2016). *Our strategy 2016-2021: Through partnerships, improve lives and the quality of care.* Retrieved from https://www.nottinghamshirehealthcare.nhs.uk/download.cfm?doc=docm93jijm4n3285.pdf&ver=3938

Nottinghamshire Healthcare NHS Foundation Trust (2019). *Step4 psychology (county) induction pack* [Brochure]. Nottinghamshire: N.p.

Office for National Statistics. (2019, n.d.). Mid-year population estimates. Retrieved from https://www.ons.gov.uk/peoplepopulationandcommunity/populationandmigration/populationestimates

Ogrodniczuk, J., Kealy, D., Laverdière, O., & Joyce, A. (2018). So, who wants to be here? A survey of patients' motives for seeking psychotherapy services and their expected un-involvement in therapy. *Archives of Psychiatry and Psychotherapy, 20*(3)*,* 26–30. https://doi.org/10.12740/APP/92165

Phillips, J. L., Jackson, B. E., Fagan, E. L., Arze, S. E., Major, B., Zenarosa, N. R., et al. (2017). Overcrowding and its association with patient outcomes in a median-low volume emergency department. *Journal of Clinical Medicine Research, 9*(11), 911– 916. https://doi.org/10.14740/jocmr3165w

Prochaska, J. O., & Velicer, W. F. (1997). The transtheoretical model of health behavior change. *American Journal of Health Promotion, 12*(1), 38–48. https://doi.org/10.4278/0890-1171-12.1.38

Rogers, C., Heatherington, S., Carroll, M., Leonard, M., Cullen, W., & Meagher, D. (2013). An analysis of 100 referrals for depression from primary care to an adult mental health service. *Irish Journal of Psychological Medicine, 30*(4), 237-244. https://doi.org/10.1017/ipm.2013.48

Sweeney, A., Clement, S., Gribble, K., Jackson, E., Carr, S., Catty, J., et al. (2019). A systematic review of qualitative studies of adults' experiences of being assessed for psychological therapies. *Health Expectations: An International Journal of Public Participation in Health Care and Health Policy, 22*(2), 133–148. https://doi.org/10.1111/hex.12844

The National Collaborating Centre for Mental Health. (2018). *The Improving Access to Psychological Therapies manual.* Retrieved from https://www.england.nhs.uk/wp-content/uploads/2020/05/iapt-manual-v4.pdf

Trusler, K., Doherty, C., Mullin, T., Grant, S., & McBride, J. (2006) Waiting times for primary care psychological therapy and counselling services. *Counselling and Psychotherapy Research, 6*(1), 23–32. https://doi.org/10.1080/14733140600581358

West, R. (2005). Time for a change: Putting the Transtheoretical (Stages of Change) Model to rest. *Addiction. 100*(8), 1036–1039. https://doi.org/10.1111/j.1360-0443.2005.01139.x

Zakay D. (2012). Experiencing time in daily life. *The Psychologist, 25*(8), 578–581.

SSRP Appendices

Appendix AA. Self-report questionnaire for Step4 Administrative Staff

We understand that calculating the time taken for individual tasks can be difficult when there are regular interruptions, for example, having to take phone calls. However, please do your best to give a rough estimate of the time taken for each of the below steps in the assessment process.

Procedure	**Task**	**Average time taken in minutes**
Step 1- Referral received	Scan referral onto Rio (if received by letter), open a referral to Step4 on Rio, print out the referral and make a front sheet for the Referrals meeting	
Step 2- Attend Referrals Meeting	Record actions	How many referrals are discussed per meeting?
Step 3- Process referral	If accepted, send client Opt-In questionnaire and URICA	
	If rejected, compose rejection letter to referrer, scan to Rio, print and post	
Step4- Questionnaires returned	Scan to Rio and print for second Referrals meeting	
Step 5- Attend second Referrals Meeting	Review returned Opt-In questionnaires Record actions	How many referrals are discussed per meeting?
Step 6- Invite to Assessment appointment	Compose appointment letter, scan to Rio, print and post. Enclose CORE-34.	
Then, if the client does not attend for Assessment appointment:		
Step 7- Discharge	Send DNA letter to client, referrer and GP, and scan to Rio. Discharge (close their referral on Rio).	
Or, if they do attend but are not appropriate for the service:		
Step 7- Discharge	Send clinician's Discharge letter to client, referrer and GP, and scan to Rio. Discharge (close their referral on Rio).	

Are there any other tasks you undertake as part of the assessment process that has not been mentioned above and that you think would be important to discuss here? If so, please state whereabouts in the process you believe this fits (i.e. which step), briefly describe the task and provide an estimate of the time taken to complete it in minutes:

…………………………………………………………………………………………………

…………………………………………………………………………………………………

…………………………………………………………………………………………………

Thank you for completing this questionnaire.

Appendix BB. Self-report questionnaire for Step4 Clinicians

Please give a rough estimate of the time taken for each of the below steps in the assessment process.

Procedure	**Task**	**Average time taken in minutes**
Step 1- Attend Referrals Meeting (*Consultant Clinical Psychologist only*)	Discuss appropriateness of referral and agree actions	How many referrals are discussed per meeting?
Step 2- Attend second Referrals meeting (*Consultant Clinical Psychologist only*)	Review returned Opt-In questionnaires, risk, alcohol/drug dependence, appropriateness etc.	How many referrals are discussed per meeting?
Step 3- Prepare for Assessment appointment	Read Rio notes, referral etc.	
Step4- First Assessment appointment	If client attends, conduct first assessment appointment	
	If client DNAs or cancels within 24hrs of appt, ask admin to discharge	
Step 5- Second Assessment appointment	If client attends, conduct second assessment appointment	
	If client cancels within 24 hrs of appt, ask admin to send second appt letter.	
	If client DNAs, ask admin to send DNA letter to request that client contacts to arrange another appt.	
	If client does not make contact, ask admin to send DNA letter and discharge.	
Step 6- Admin following Assessment appointments	If client is not appropriate, complete Rio notes, CORE assessment (with care plan and risk assessment), HONOS, CPA, CORE audit assessment form, and Assessment letter to inform that the client is being discharged back to GP/being referred on.	
Step 7- Discharge	If referring on, complete referral to another	

	service. Wait for referral to be accepted before closing to Step4 on Rio.	

Are there any other tasks you undertake as part of the assessment process that has not been mentioned above and that you think would be important to discuss here? If so, please state whereabouts in the process you believe this fits (i.e. which step), briefly describe the task and provide an estimate of the time taken to complete it in minutes (including any tasks specific to your area):

……………………………………………………………………………………………

……………………………………………………………………………………………

……………………………………………………………………………………………

Thank you for completing this questionnaire.

Appendix CC. CORE Assessment Audit Form

To be completed electronically and sent to the placement student

Therapist Name: Click or tap here to enter text.**Waiting List:** Choose an item.

Client ID: Click or tap here to enter text. **RiO Number:** Click or tap here to enter text.

Date of Assessment: Click or tap to enter a date.

Ethnic Origin of Client: Choose an item. **Employment:** Choose an item.

If other, please specify: Click or tap here to enter text.

Relationships/Support: Choose an item. **Caring:** Choose an item.

If other/combination, please specify: If other/combination, please specify:

Click or tap here to enter text. Click or tap here to enter text.

Current/Previous Use of Services

	Concurrent	**Less than 12 Months Ago**	**More than 12 Months Ago**
1. GP	☐	☐	☐
2. Community e.g. CPN – (specify):	☐	☐	☐
3. Psychiatrist	☐	☐	☐
4. Day Therapy	☐	☐	☐
5. Hospital Admission (less than 10 days)	☐	☐	☐
6. Hospital Admission (10 days or more)	☐	☐	☐
7. Therapist	☐	☐	☐
8. Counsellor	☐	☐	☐
9. IAPT	☐	☐	☐
10. Other	☐	☐	☐

Is the client currently prescribed medication to help with their psychological problems? Choose an item.

If yes please indicate type of medication:

Anti-psychotic ☐ Anti-depressant ☐ Anxiolytic/hypnotic ☐ Other ☐

Presenting Problems/Concerns

Please tick all presenting problems which are relevant and indicate the severity of the problems.
1 = causing minimal difficulty, not affecting day to day functioning
2 = causing mild difficulty in one area but not affecting overall day to day functioning
3 = causing moderate difficulty; significant difficulty in one or more areas of day to day functioning
4 = causing severe impairment in all areas of functioning

Leave item box empty if the difficulty is not being experienced.

1. Depression	Choose an item.	**19. Physical abuse**	Choose an item.
2. Anxiety/stress/panic	Choose an item.	**20. Emotional abuse**	Choose an item.
3. Phobias	Choose an item.	**21. Self-esteem/confidence**	Choose an item.
4. Obsessive-compulsive disorder	Choose an item.	**22. Interpersonal/relationship problems**	Choose an item.
5. Bereavement reactions	Choose an item.	**23. Social problems e.g. poverty, housing**	Choose an item.
6. Personality problems/disorder	Choose an item.	**24. Work/academic**	Choose an item.
7. Alcohol	Choose an item.	**25. Cognitive/learning difficulties**	Choose an item.
8. Drugs/substance misuse	Choose an item.	**26. Self-harm**	Choose an item.
9. Anorexia	Choose an item.	**27. Suicidal behaviour**	Choose an item.
10. Bulimia	Choose an item.	**28. Aggression/violence**	Choose an item.
11. Binge-easting	Choose an item.	**29. Perpetration of sexual abuse**	Choose an item.
12. Obesity	Choose an item.	**30. Legal/forensic**	Choose an item.
13. Physical problems incl. sexual, sleep	Choose an item.	**31.Other (specify):** ***Type below…***	Choose an item.
14. Trauma/PTSD	Choose an item.	**32. Asperger's**	Choose an item.
15. Dissociation	Choose an item.	**33. Anger**	Choose an item.
16. Sexual abuse	Choose an item.	**34. Non-epileptic seizures**	Choose an item.
17. Attachment difficulties	Choose an item.	**35. Medically unexplained symptoms**	Choose an item.
18. Physical health	Choose an item.		

Are the client's problems related to their service in the armed forces?
Yes ☐ No☐

Your view of…

Assessment outcome: Choose an item.

If 'other' please specify - ☐

* **If client is not entering therapy please give a brief reason why below**

Click or tap here to enter text.

Risk. **Tick the risk level for each item.** ***(Risk to be documented using CPA Level 1 Risk Assessment form and kept in file)***

Suicide	**None ☐**	**Mild ☐**	**Moderate ☐**	**Severe ☐**
Self-harm	**None ☐**	**Mild ☐**	**Moderate ☐**	**Severe ☐**
Harm to Others	**None ☐**	**Mild ☐**	**Moderate ☐**	**Severe ☐**
Harm from Others	**None ☐**	**Mild ☐**	**Moderate ☐**	**Severe ☐**

	1	**2**	**3**	**4**
Appropriateness of referral	**Not appropriate ☐**	**Less appropriate ☐**	**Appropriate ☐**	**Very appropriate ☐**
Psychological mindedness/insight	**Poor ☐**	**Moderate ☐**	**Good ☐**	**Very good ☐**
Readiness for Therapy	**Not ready ☐**	**Somewhat ☐**	**Moderately ☐**	**Ready now ☐**
Potential for Improvement	**Not at all ☐**	**A little ☐**	**Moderate ☐**	**Considerable ☐**
Motivation	**Poor ☐**	**Moderate ☐**	**Motivated ☐**	**Highly motivated ☐**

Child Protection	**None ☐**	**Mild ☐**	**Moderate ☐**	**Severe ☐**
Legal/Forensic	**None ☐**	**Mild ☐**	**Moderate ☐**	**Severe ☐**

Abuse History Question

"Have you ever experienced any physical, sexual or emotional abuse at any time in your life?"

None stated ☐

Yes ☐
(please tick all that apply)
Physical abuse ☐
Sexual abuse ☐
Emotional abuse ☐
Unknown ☐

Not asked ☐
(please state why)

Did not carry out full assessment
☐
Not yet had training to ask the question
☐
Has been assessed in psychology before and abuse history is well documented
☐
Client became upset and wanted to end assessment ☐
Other
☐ *(please specify)* Click or tap here to enter text.

CPA Status

Care pathway ☐ **CPA** ☐

Which therapeutic approach/intervention will be used?

(please tick all that apply)

1. CBT ☐
2. CAT ☐
3. Psychodynamic ☐
4. Attachment ☐
5. EMDR ☐
6. ACT ☐

7. CFT ☐
8. Sensori-motor/Body focussed ☐
9. Trauma focussed CBT ☐
10. Other (please state in box below) ☐
Click or tap here to enter text.

Assessor's signature: Click or tap here to enter text.

Position: Choose an item.

If 'other' please specify… Click or tap here to enter text.

Appendix DD. Author Guidelines for submission to Mental Health Review Journal

https://www.emeraldgrouppublishing.com/journal/mhrj#author-guidelines