

**Barriers and facilitators to providing CBT for people living with
dementia: perceptions of IAPT clinicians**

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Thesis declaration form

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

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Overview

Psychological symptoms of dementia like depression and anxiety are associated with lower quality of life, increased cognitive decline, and increased mortality rates. Psychosocial and therapeutic interventions are recommended. This thesis aims to understand the provision of these interventions, including the active mechanisms of interventions, and barriers and facilitators to providing them.

Part 1 of this thesis is a meta-synthesis which explores potential mechanisms underpinning a diverse range of psychosocial interventions. The quality of included studies varied, especially regarding reporting of qualitative methodology. Five potential mechanisms were identified: maintaining narratives of preferred identities, social inclusion, promoting an active and engaged lifestyle, and the role of implicit memory and emotional processing. The study provides hypothesised mechanisms which may be further explored through quantitative methods.

Part 2 is a qualitative study investigating the barriers and facilitators of providing cognitive behavioural interventions to people living with dementia or mild cognitive impairment, from the perspective of clinicians. 14 clinicians participated in semi-structured interviews and transcripts were analysed with thematic analysis. Themes identified relevant factors of high pressures on staff with a low level of support, attitudes towards dementia held by staff, referring professionals and society, and the competing demands of offering a service to people with extra needs in a context of limited resources.

Part 3 is a critical appraisal of the research process. It reflects on epistemological assumptions of the methods used, limiting bias during qualitative research, the role of service users in research, and practical challenges that arose during the process.

Impact statement

This thesis offers information that has value in both academic and clinical contexts in terms of mental health care for people living with dementia, and the wider NHS context.

Generating hypotheses about active mechanisms which may underpin interventions for people living with dementia provides a basis for empirical research which may test these mechanisms, furthering understanding of these interventions. When active mechanisms can be isolated, interventions can be developed and evaluated for efficiency as well as effectiveness, leading to the provision of the most effective interventions and the best patient outcomes, and increased NHS efficiency.

Understanding the barriers and facilitators to providing national mental health services for people living with dementia is critical when people living with disabilities like dementia are not getting the support with their mental health that they are entitled to. A greater understanding of the challenges staff and services face in providing equitable services enables us to problem solve barriers, and share examples of best practice which are also identified in the thesis. The thesis contributes information which allows NHS services and providers to have a better understanding of the challenges faced, with more tools to enable decision making which better addresses the balance between NHS resources allocation, staff wellbeing and effective patient care.

To begin disseminating this information, the thesis will be presented in a poster at the Alzheimer's Society conference and the upcoming BABCP symposium in 2019.

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And to Tom, for all that you have taught me.

Part 1: Literature Review

Exploring active mechanisms of psychosocial interventions for dementia: a qualitative meta-synthesis

Abstract

Background: Psychosocial interventions are recommended by the National Institute for Health and Care Excellence (NICE) to promote cognition and wellbeing for people living with dementia (PWD), but little is known about the mechanisms which underpin these interventions. This review aimed to investigate what qualitative research papers reveal about potential mechanisms of psychosocial interventions for people living with dementia.

Method: This qualitative meta-synthesis identified 468 qualitative studies during a systematic search. 16 articles which met the inclusion criteria were reviewed and a thematic synthesis method was used to analyse the data to generate themes.

Results: Twelve group and four individual interventions were found, with nine being delivered to PWD only, and six delivered to PWD-carer dyads. Four were exercise based interventions, six were cognitive based, three were psychological based and 2 were other methods. Four themes and two sub-themes were found which described five mechanisms underpinning a wide range of psychosocial intervention methods. Potential mechanisms included maintaining the identity of people living with dementia, facilitating social inclusion, promoting an active and engaged lifestyle, facilitating processing by supporting implicit memory, and emotional processing through reminiscence and group support.

Conclusions: Mechanisms appear similar across a diverse range of interventions and are supported through triangulation with previous reviews. Implications for clinical practice include the potential for the generation of a wider range of psychosocial interventions offering greater patient choice in treatment, and the opportunity for health and social care professionals to incorporate these mechanisms into their clinical practice.

Introduction

Dementia is defined by the World Health Organisation (WHO) as a progressive deterioration in cognitive functioning, often accompanied by deterioration in emotional, social and behavioural function (WHO, 2017). Deterioration is chronic and more severe than typical decline expected in ageing. Prevalence rates in England for April 2017 were 4.33% of over 65 year olds (Public Health England, 2018) and over one million individuals are estimated to have dementia by 2025 (Prince et al., 2014).

People living with dementia (PWD) experience poorer quality of life, lower physical health status and increased functional dependency compared with older adults without dementia (Martín-García, Rodríguez-Blázquez, Martínez-López, Martínez-Martín & Forjaz, 2013). People living with dementia experience higher rates of depression than older adults without dementia (Snowden et al., 2015), with prevalence rates estimated at 25% and rates of anxiety in people living with dementia are around 14% (Kuring, Mathias & Ward, 2018).

Dementia and mental health

PWD and poor mental health are more likely to have more severe dementia symptoms (van der Mussele et al., 2013) and earlier nursing home admission (Seignourel, Kunik, Snow, Wilson & Stanley, 2008), and the experience of depression, anxiety and low quality of life are associated with a lower perceived quality of relationship between the person with dementia and family carer (Spector, Orrell, Charlesworth & Marston, 2016). Increased functional impairment, increased behavioural and psychological symptoms of dementia, and increased caregiver burden are all associated with an increased risk of long-term admission for PWD (Cepoiu-Martin, Tam-Tham, Patten, Maxwell & Hogan, 2016). Factors associated

with living well with dementia include self-esteem, optimism and self-efficacy (Lamont et al., 2019) and increased social engagement and increased functional ability (Martyr et al., 2018).

Psychosocial interventions

Psychosocial interventions are recommended as a first line approach to managing psychological and behavioural symptoms of dementia (Azermai et al., 2012). These include dementia support groups, cognitive stimulation therapy, structured reminiscence, cognitive training, life story work, music therapy, creative art therapies, cognitive training and counselling or psychotherapy (British Psychological Society, 2014). Psychosocial interventions can be provided by external facilitators, paid carers or family carers, and can target both PWD and their carers, either together or as separate groups. Psychosocial interventions such as multi-component exercise and cognitive stimulation therapy can have good outcomes for physical and cognitive function, social interaction and quality of life (McDermott et al., 2019), however evidence supporting outcomes for mood and behaviour change is limited due in part to the heterogeneity between studies which creates a challenge for quantitative synthesis (McDermott et al., 2019). The National Institute for Health and Care Excellence (NICE) recommends cognitive stimulation therapy and suggests group reminiscence therapy or cognitive rehabilitation should also be considered (NICE, 2018). Qualitative syntheses can allow for a systematic review of interventions across wide variety of interventions, and highlight benefits perceived by participants which are not sensitive to quantitative measures; Dugmore, Orrell and Spector (2015) found benefits for participants across 16 studies including improvements in mood, communication, self-confidence and cognitive ability in participants with dementia.

Intervention mechanisms

While systematic reviews highlight data related to outcomes, less is known about the active mechanisms which enable change in psychosocial interventions. Qualitative studies and qualitative reviews are key sources of information to generate hypotheses about mechanisms which can then be empirically tested in quantitative work (Moore et al., 2015). Lawrence, Fossey, Ballard, Moinz-Cook and Murray (2012) found in a qualitative systematic review and meta-synthesis across 39 studies in care homes that key mechanisms for change included enabling PWD to connect with others and be included, make a meaningful contribution through activity and sharing of experience, and the opportunity for structured or spontaneous reminiscence.

Dugmore et al. (2015) found themes relating to potential active mechanisms of interventions in various settings as perceived by participants: ‘story-telling’ as a means to reinforce participants’ social identity and integrate and resolve difficult life events into a coherent narrative, and strengthen social belonging; ‘gaining new information about the person with dementia’, which was thought to enable carers to ‘rehumanise’ the person with dementia by learning about the person’s history, and demonstrating to carers and the person with dementia the person’s strengths and capacity to learn; ‘enabling openness and acceptance’ of the dementia diagnosis and adjustment; ‘continuity of identity,’ through familiar activities and life story work, assimilating past and present identities; and ‘peer identification, support and membership,’ encouraging social interaction and mutual understanding through shared experience.

Van’t Leven, de Lange, van der Ploeg and Pot (2018) in a qualitative research study of home based interventions found a core mechanism of ‘empowerment’

thought to be underpinned by enabling participation in activities, personalised approaches to meeting PWD and carer needs, and solution focused approaches to change.

Changing political priorities in dementia care have resulted in the increased awareness of the need for holistic support for PWD and a national aim for a reduction in the inappropriate use of some pharmacological treatments for symptoms of dementia (Department of Health, 2015). The continued development and evaluation of psychosocial interventions is key to achieving these recommendations, and understanding the mechanisms of change underpinning these interventions is important for developing effective and efficient interventions for individuals with a variety of needs (Moore et al., 2015).

Current review aims

This review offers a recent review of psychosocial interventions for dementia aiming to capture qualitative information from published articles regarding potential mechanisms underpinning interventions with diverse methods.

Dugmore et al. (2015) was used as a basis for the method. This article was selected as part of the review question related to mechanisms of interventions within similar types of study of interest, the search criteria were narrow enough to be suitable for the scope of this review, sufficient detail was included in the report to allow replication and a thematic synthesis method of analysis was appropriate for the aims of this review. The decision was made to select studies after the end date of the search by Dugmore et al. with the aim of creating separate data to allow for triangulation of findings across reviews in line with guidelines about increasing the rigour of qualitative research (Elliott, Fischer & Rennie, 1999). Replicating methods used by Dugmore et al. further facilitated this triangulation.

Method

Search strategy

Databases Embase and PsychInfo were searched using the initial search terms precisely replicating those used by Dugmore et al. (2015): ‘treatment’, ‘treatment effectiveness evaluation’, ‘intervention’, ‘therap*’ and ‘dement*’. Qualitative studies and peer-reviewed article limits were applied to the search, as well as maximising specificity of the search to limit returns to items which relate well to the search items. The search period was 1st August 2011 – 31st November 2018. This initial search retrieved 6316 studies which was too high to manually review and so the search exclusion ‘NOT pharmaco* or antipsychot*’ was applied in addition to the search criteria above. Abstracts and titles were reviewed to remove articles outside the inclusion criteria.

Inclusion criteria

- Empirical studies using qualitative methodology
- Published between August 2011 and November 2018
- Evaluating a non-pharmacological, clinical, psychosocial intervention for PWD
- Published in English

Exclusion criteria

- Intervention directly for carers of PWD
- A service model or environmental intervention
- Pharmacological interventions

Qualitative methodology was defined as a paper which included entirely or partly qualitative aims and procedures. Studies which used mixed methods designs were included to expand the search base, as it was apparent that a mixed methods approach for process evaluation and other purposes which appear in our search results was common. The definition of psychosocial intervention defined by the Dugmore et al. (2015) review was used: a purposeful, facilitated activity for PWD, which aimed to bring about positive behavioural, cognitive and/or emotional change in PWD. Where a professional who is paid to care for a person with dementia is referred to, the term 'staff carer' is used. Where a family or relative is acting as a carer for a person with dementia the term 'family carer' is used.

Quality evaluation

The selected articles were subject to a quality evaluation and this report replicated criteria from Dugmore et al. (2015), which were adapted from Mays and Pope (2000) and the Critical Appraisal Skills Programme (2006) (Table 1.) Each study was credited a score of 1 for each criterion that was met, with a possible total score of 12. Studies that obtained a score above the mean for the review were considered to be of good quality. Judging the attainment of each criteria was based on data present in the report. It was recognised that methodological procedures may be not be reported fully in the text of each article even if a rigorous procedure was followed during implementation of the study, but reviewers are able to make evaluation judgements solely on the information reported (Crowe, Inder & Porter, 2015).

Following the protocol from Dugmore et al. (2015), the first criterion was used as a basis for exclusion if not met: studies where the methodological reporting or rigour was extremely poor. In this review, all studies met this criterion and

therefore none were excluded from the analysis. All studies were included in the review even when scoring poorly on the remaining criteria. Excluding studies from qualitative systematic reviews even when the methodology is poorly reported is thought to be unhelpful in terms of generalisability of results; Carroll and Booth (2015) report that while excluding these studies has been shown to have no impact on the content of the results, it could however affect generalisability of the review findings if excluded reviews related to novel participants or settings, and so including these studies in the review has greater benefits than risk of harm to the rigour of the review.

Analysis

The method of analysis chosen was thematic synthesis (Thomas & Harden, 2008). This was based on the thematic analysis approach adopted by the initial review (Dugmore et al., 2015) and allows for recognition of patterns and themes across the entire data set in a flexible manner, in this case from a realist perspective. Crowe et al. (2015) reported that this structure offers the flexibility required to allow for an inductive, descriptive analysis of data, which is appropriate for application to this heterogeneous selection of studies. The articles were reviewed by Samantha Baker (SB) and initial ideas about codes and themes were noted during this process. Data were extracted from the data set and entered verbatim into a spreadsheet. Data items were selected based on a definition from Dugmore et al. (2015): any information which is reasonably considered to form a finding or conclusion from the paper, and which is relevant to the research question. Each data item was coded at a semantic level before being grouped into initial themes by SB.

An independent reviewer coded a selection of the data (four papers) as a reliability check, to encourage discussion around differences and similarities of

Table 1. *Quality criteria*

From Dugmore et al. (2015) adapted from Mays and Pope (2000)

Worth or relevance

(1) Was this piece of work worth doing at all? Has it contributed usefully to knowledge?

Clarity of research question

(2) If not at the outset of the study, by the end of the research process was the research question clear?

Appropriateness of the design to the question

(3) Would a different method have been more appropriate? For example, if a causal hypothesis was being tested, was a qualitative approach really appropriate?

Context

(4) Is the context or setting adequately described so that the reader could relate the findings to other settings?

Sampling

(5) Did the researcher explain how the participants were selected, and why the participants they selected were the most appropriate to provide access to the type of knowledge sought by the study?

Data collection and analysis

(6) Were the data collection and analysis procedures systematic?

(7) Was an 'audit trail' provided such that someone else could repeat each stage, including the analysis?

(8) Did the researcher search for and/or discuss disconfirming cases?

(9) Were sufficient data included in the reports of the study to provide sufficient evidence for readers to assess whether analytical criteria had been met?

(10) Were findings triangulated with results from other data collection methods/sources?

(11) Were findings/interpretations validated via respondent validation or 'member checking'?

Reflexivity of the account

(12) Did the researcher self-consciously assess the likely impact of the researcher (e.g. personal biases and characteristics) and research process on the data and interpretation?

each reviewer's coding strategy. Each reviewer extracted largely the same data items for each paper, only variations in the names of codes were found. In total the independent reviewer generated 32 codes and SB generated 50. This was understood to be a difference in the coding strategy whereby SB coded verbatim and the second coder used higher order coding strategies. Discussion around these differences led to the agreement on 45 codes from this sample. The learning from this reliability check was applied to the remaining twelve papers to be coded. Initial themes were then reviewed in conjunction with Joshua Stott (JS) and themes were merged and discarded, as well as codes being moved to more appropriate themes. Efforts were made to include all of the codes in the themes. The entire data set was again reviewed for any further data items that were missed. The data within each theme were reviewed to check for a consistent narrative appropriate to the theme, and adjustments were made with the aim of achieving a good level of internal homogeneity and external heterogeneity across themes.

Results

The search retrieved 468 results. These results were filtered to remove duplications and conference abstracts. The title and abstract of each result were reviewed and 92 articles were excluded (Figure 1. summarises the exclusion process). The remaining 53 papers were read in full and 37 were excluded, with 16 articles included in the review. 'Not intervention' includes studies investigating individuals' experiences of a phenomenon or conceptualisation of a phenomenon or process. Non-psychosocial interventions included, for example, medical or physical health based interventions or outcomes. Two studies were excluded because they

were of a mixed sample design including participants without a dementia diagnosis. One paper was excluded because it was unavailable to access. 16 articles remained to be included in the review.

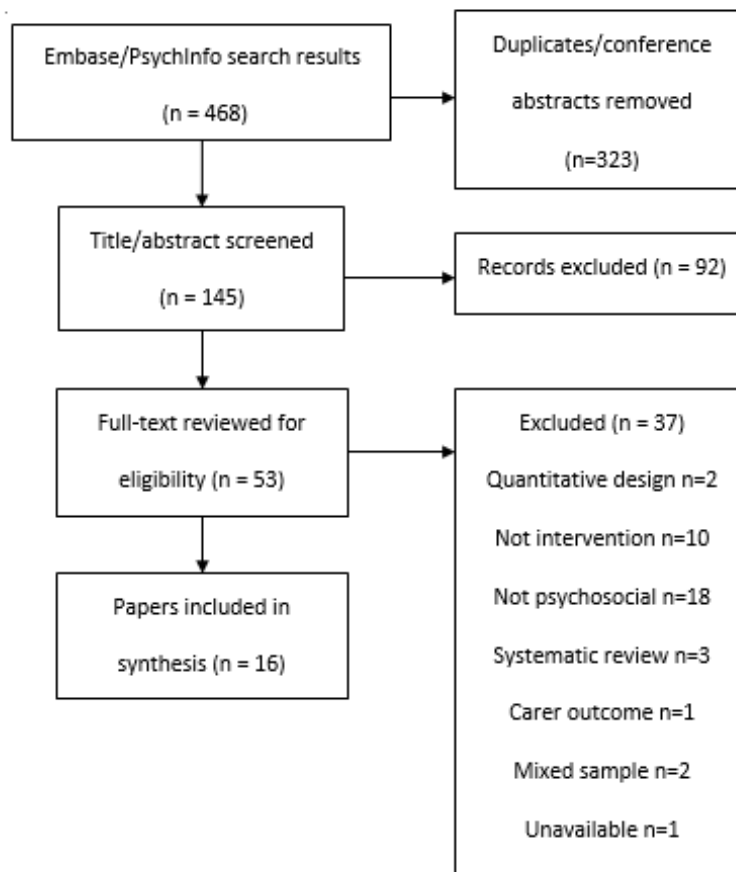


Figure 1. *Systematic search procedure*

Overview of studies

Table 2 summarises the main findings.

Design

Nine of the studies used a mixed methods approach, evaluating statistical change in outcome measures alongside interviews about the experience of the intervention (Camic, Tischler & Pearman, 2014; Cheston & Howells, 2016; George, 2011; Jaaniste, Linnell, Ollerton & Slewa-Younan, 2015; Kelly et al., 2017; Loizeau,

Kündig & Oppikofer, 2015; Prick, de Lange, van't Leven & Pot, 2014; Travers, 2017; Yates, Orgeta, Leung, Spector & Orrell, 2016). The remaining seven studies used a pure qualitative approach (Carone, Tischler & Dening, 2016; Guzman-Garcia, Mukaetova-Ladinska & James, 2012; Martin et al., 2015; Osman, Tischler & Schneider, 2016; Spector, Gardner & Orrell, 2011; Tuckett, Hodgkinson, Rouillon, Balil-Lozoya & Parker, 2015; Wu et al., 2015). All but one of the studies used interview as the primary source of information, with one study (Jaaniste et al., 2015) using a purely observational approach. Participants were a combination of PWD living at home and PWD living in residential settings.

Interventions

Twelve studies were group interventions, six interventions included PWD-carer dyads and nine were for PWD groups only. Four studies were individual interventions or interventions undertaken by a PWD-carer dyad. The style of intervention varied; six studies were cognitive based interventions, which were cognitive stimulation therapy (n=3; Kelly et al., 2017; Spector et al., 2011; Yates et al., 2016), singing group (Osman et al., 2016), a storytelling group (Loizeau et al., 2015) and an art group (Camic et al., 2014); four studies were exercise based interventions which were structured increase in pleasurable activity (Travers, 2017), a football group (Carone et al., 2016), strength based exercises (Wu et al., 2015), and a dance class (Guzman-Garcia et al., 2012); three were psychoeducational and psychological based which were drama therapy (Jaaniste et al., 2015), music therapy (Tuckett et al., 2015), and two psychoeducational and support groups (Cheston & Howells, 2015; Martin et al., 2015); one intervention was a multicomponent

Table 2. *Reviewed studies and main findings*

Author/Year/Country of study	Participants	Intervention	Qualitative methodology	Analysis method	Main mechanisms implicated
Participants living in community					
Camic, Tischler & Pearman (2014) UK	PWD-carer dyads (n=11 pairs) PWD: Mean age 78.5 years (range 58-94). Carers: demographics unknown	Art viewing, discussion, and creation group, with facilitator. PWD-carer dyads attend together (n=26). Eight weekly two-hour sessions	Semi-structured interview	Thematic analysis	Promote personhood, social inclusion, accepting, non-clinical environment, participate in community, meaningful activity, emotional engagement through non-verbal expression
Carone, Tischler & Dening (2014) UK	PWD (n=5): mean age 61 years (59-64), 5 male. Family carers (n=5): mean age 62.8 years (57-69), 5 female. Staff (n=10). Coaching staff (n=5): mean age 22.4 (17-39), 1 female. External specialist staff	Football group for men with early onset dementia (n=5). Social space for family to converse during session. Facilitated by staff. Weekly 90 min sessions, unknown number of weeks attending	Semi-structured interview, PWD interviewed individually or with chaperone, Interviewed family and staff in focus groups.	Thematic analysis	Maintaining narratives of identity, non-clinical, accepting environment, participating in community, social opportunity and shared experiences, meaningful activity and exercise promoting active lifestyle

Author/Year/Country of study	Participants	Intervention	Qualitative methodology	Analysis method	Main mechanisms implicated
Cheston & Howells (2015) UK	(n=5): demographics unknown PWD-carer dyads (n=3 pairs) PWD: mean age 81 years (79-84) Carers: mean age 65.7 years (50-85) Facilitators (unknown details)	“Living Well With Dementia” psychoeducation, skills training and emotional support group. PWD- carer dyads participate. Delivered by facilitator. Ten week course, duration of session unknown	Interview with participants Focus group with facilitators	Not specified	Reducing stigma, opportunity for peer support and sharing experience, supporting adjustment to diagnosis
Jaaniste, Linnell, Ollerton & Slewa- Younan (2015) Australia	PWD (n=17, 13 completed intervention) Mean age 74.8 (61- 88)	Drama therapy group with therapist for PWD (n=13) repeated measures comparison group. 16 week intervention in two eight-week blocks, plus pre and	Observation	Phenomenological, ethnographic, narrative	Emotion processing through non-verbal expression and reminiscence, maintenance of identity, strengths focus, social inclusion, physical contact, accepting environment, exercise

Author/Year/Country of study	Participants	Intervention	Qualitative methodology	Analysis method	Main mechanisms implicated
Kelly et al. (2017) Ireland	PWD (n=4), carers (n=6), group facilitators (n=4) Demographics unknown	post sessions. 90 min session duration Cognitive stimulation therapy group intervention for PWD (n=28). 90 minutes weekly for 14 weeks, following the manual	Semi-structured interviews	Not specified	Promoting active and engaged lifestyle, increasing self-confidence
Loizeau, Kündig & Oppikofer (2015) Switzerland	PWD- carer dyads (n=4 pairs) PWD: Mean age 75.8 (71-84), 3 female. Carers: Mean age 64.5 (46-72). Volunteers (n=4): no details	One hour improvised storytelling group, one hour social gathering with refreshments, participate in dyad (n=8). Weekly two-hour session over nine weeks.	Semi structured interviews, observation	Thematic analysis	Social inclusion, participated in community, positive and accepting atmosphere, reduce stigma, opportunity to be social and communicate, revealed skills still present, meaningful activity
Martin et al. (2013) UK	PWD (n=6), mean age 68.9 years, 3 female	Self management group intervention including relaxation, goal setting, problem solving, identifying	PWD semi-structured focus group	Thematic analysis	Maintaining narratives of identity through strengths focus, social inclusion, peer support, feeling part of a group, promoted active and

Author/Year/Country of study	Participants	Intervention	Qualitative methodology	Analysis method	Main mechanisms implicated
	Course facilitators (n=2) demographics unknown	strengths, facilitated, PWD only (n=6). Weekly 2.5 hour session for six weeks			engaged lifestyle through exercise, goal setting, meaningful activity
Osman, Tischler & Schneider (2014) UK	PWD-carer dyads (n=10 pairs) 13 female	“Singing for the Brain” group intervention, PWD and carers (n=20) singing familiar songs. Duration and dose not stated	Semi-structured interviews of PWD and carers	Thematic analysis	Promotes personhood, opportunity for social interaction, social inclusion, peer support through shared experience, stimulate memory, supported adjustment to diagnosis
Prick, de Lange, van’t Leven & Pot (2014) Netherlands	PWD-carer dyads (n=11 pairs) Demographics unknown	Multicomponent exercise and support intervention for PWD-carer dyads. Weekly or bi-monthly one hour home visits for 12 weeks.	Semi-structured interviews, carer daily reflection logs, interviewed separately	Not specified	Physical exercise, promoting engaged lifestyle, focus on pleasant activities
Spector, Gardner & Orrell (2011) UK	PWD (n=17): mean age 82 years, 12 female Carers (n=14)	Cognitive stimulation therapy group for PWD.	Focus groups and semi-structured interviews with	Framework analysis	Promoted personhood, increased confidence, provided opportunities for communication and shared

Author/Year/Country of study	Participants	Intervention	Qualitative methodology	Analysis method	Main mechanisms implicated
Wu et al. (2015) USA	Group facilitators (n=7) (demographics unknown) PWD (n=12): mean age 84 years (78-96), 9 female	14 sessions, dose not stated, sample taken from independent CST groups in community. "PLIÉ" 45 minute group exercise intervention for PWD only (n=11) repeated measures design with control activity. Delivered by facilitator. Three times a week for 18 weeks, 45 min session.	PWD, carers and staff Observation, home visit discussion	Constant comparison	experience through peer support, accepting environment Maintaining narratives of identity, opportunity for social contact, peer support and shared experience, promote active and engaged lifestyle through increased physical awareness, increased exercise, meaningful activity, activated implicit memory
Yates, Orgeta, Leung, Spector & Orrell (2016) UK	PWD-carer dyads (n=22 pairs) PWD: mean age 81.2 years, 11 female. Paid carers (n=6): mean age 42.6 years, 5 female	Individual cognitive stimulation therapy, delivered by carer at home, for PWD-carer dyads (n=44). Up to three sessions weekly up to 30 min duration,	Interview, telephone support, questionnaires	Thematic analysis	Enhancing maintenance of identity, informal sessions, improve carer knowledge of skills of person with dementia, opportunity for communication, enjoyment

Author/Year/Country of study	Participants	Intervention	Qualitative methodology	Analysis method	Main mechanisms implicated
	Family carers (n=16): mean age 65 years, 14 female	average of 12 sessions complete.			
Participants living in residential care homes					
George (2011) USA	PWD (n=15): Mean age 85.7, 7 female Carers Family Institution staff Demographics unknown	Volunteering visits to child classroom supporting singing, reading and writing activities, and life history sessions, with control group. For PWD (n=15). Weekly hour long sessions for five months	Observation of PWD, structured and unstructured third party interviews (carers, family and staff)	Grounded theory	Maintenance of identity, social inclusion, non-clinical, accepting environment, opportunity for social contact and physical contact, participate in community, opportunity for reminiscence
Guzman-Garcia, Mukaetova-Ladinska & James (2012) UK	PWD (n=7): Mean age 82.4 years, 5 female Care staff (n=9): 7 female	Danzón ballroom dance classes for PWD (n=13). Twice weekly 35 min sessions over 6 weeks	Interview with PWD and staff	Grounded theory	Social inclusion, physical contact, belonging to a group, shared experience and social contact, promote active lifestyle by promoting exercise, music enhanced arousal
Travers (2015) Australia	Facility staff and volunteers (n=14)	“BE-ACTIV” intervention (n=10)	Interviews with staff and	Not specified	Promoting active and engaged lifestyle,

Author/Year/Country of study	Participants	Intervention	Qualitative methodology	Analysis method	Main mechanisms implicated
	Demographics unknown	(encouraging meaningful activity, 45 minute contact with facilitator, supported by staff) vs 'walking and talking' control (n=8), PWD only. Weekly 45 min sessions, eight weeks.	residence volunteers		increasing pleasant activities, activity as a distraction
Tuckett, Hodgkinson, Rouillon, Balil-Lozoya & Parker (2015) Australia	Care staff: n=23, 21 female Family members: n=7, 4 female	Group music therapy for PWD, family may participate (57% had). Between three and nine participants in each group. Twice weekly, up to one hour sessions for 12 weeks.	Focus groups with care staff and family members	Content analysis	Promoted active and engaged lifestyle, promote exercise, stimulating environment, music enhances physical arousal, opportunity to be social, physical touch, distraction

Note: People living with dementia (PWD)

intervention (exercise and emotional support; Prick et al., 2014) and one was a volunteering intervention providing learning support in schools (George, 2011).

Participants

Descriptions of qualitative participants varied, and two studies did not describe the sample sufficiently to report the total number of participants interviewed: Cheston and Howells (2015) reported three person with dementia-carer dyad participants, along with an unknown number of intervention facilitators, George (2011) reported 15 PWD participated, along with an unknown number of family members, paid carers and other institution staff. Including the known numbers within all studies (including Cheston & Howells, 2015 and George, 2011), there were a total of 317 participants including PWD (n=144), family carers (n=87), paid carers and other clinical staff (n=38), non-clinical staff and volunteers (n=42) and intervention facilitators (n=13). The mean age of PWD where a mean was provided (n=11), was 77.8 years. No further demographic information can be usefully summarised due to the varied inclusion of demographics in different papers.

Quality evaluation

The mean score on quality evaluation across the studies was 8.6 out of 12. The highest score was 11 (Carone et al., 2016; Tuckett et al., 2015; Wu et al., 2015) and the lowest was 5 (Cheston & Howells, 2016; Travers, 2017). Nine studies scored above average in quality (over 8.6/12). These were Camic et al., 2014; Carone et al., 2016; George, 2011; Guzman-Garcia et al., 2012; Loizeau et al., 2015; Martin et al., 2015; Spector et al., 2011; Tuckett et al., 2015; Wu et al., 2015). Evaluation criteria common to both qualitative and quantitative methods such as clarifying the research question and describing the setting (Items 1-4 in Table 1) were demonstrated by all of the studies in the review; criteria specific to qualitative approaches had more

variance. A common criticism of qualitative research is the subjectivity of the analysis procedure and the resulting lack of replicability; providing a detailed description of the collection and analysis of data is a useful way of offering transparency about the method and increasing confidence in validity of the results. Only 9 out of 16 studies included a satisfactory audit trail in the reporting of their method such that the steps of the analysis were clear enough to repeat (Carone et al., 2016; George, 2011; Guzman-Garcia et al., 2012; Loizeau et al., 2015; Martin et al., 2015; Prick et al., 2014; Spector et al., 2011; Tuckett et al., 2015; Wu et al., 2015). A further method of enhancing quality in qualitative methodology is to report disconfirmatory data and only seven of the studies present data which contradict a theme in their reports (Camic et al., 2014; George, 2011; Loizeau et al., 2015; Martin et al., 2015; Spector et al., 2011; Tuckett et al., 2015; Wu et al., 2015). Many of the studies presented a good selection of verbatim extracts in support of the reported themes (n=12), and all of the studies use methods of triangulation in their design, which is a useful approach to increasing confidence in the conclusions drawn by the authors. This was achieved through using mixed methods designs to support qualitative data (Camic et al., 2014; Cheston & Howells, 2016; George, 2011; Jaaniste et al., 2015; Kelly et al., 2017; Loizeau et al., 2015; Prick et al., 2014; Travers, 2017; Yates et al., 2016), interviewing multiple stakeholders (all except Jaaniste et al., 2015 and Travers, 2017) and using multiple sources of data i.e. interviews as well as observation (Loizeau et al., 2015). In acknowledgement of the inherent subjectivity of qualitative analysis, participant validation checks and reflexivity are methods which can enhance the rigour of qualitative approaches. Only two studies explicitly report using validation checks (Carone et al., 2016; Guzman-Garcia et al., 2012), and only three include a reflexive piece about the perspectives

and expectations of the researcher, to assist the reader in evaluating any potential for bias in the analysis (Carone et al., 2016; Camic et al., 2014; Spector et al., 2011).

Themes

Four themes and five sub-themes relating to potential mechanisms underlying the interventions were developed (Table 3). Illustrative quotes are outlined in Table 4.

Table 3. *Themes and sub-themes*

Theme	Subtheme
Maintaining narratives of preferred identities	-
Social inclusion	Increase peer support Reduce isolation Acceptance
Promoting an active and engaged lifestyle	-
Facilitating processing	Memory Emotion and reminiscence

Maintaining narratives of preferred identities

The term ‘identity’ can have multiple definitions (Brubaker & Cooper, 2000). Here it is used to describe the sense of self constructed by social stories, interactions and language, as in narrative therapy, described by Kropf and Tandy (1998). As adults grow physically older, the social expectations of them also change, which Kropf and Tandy state can deny them of meaning and stories they previously identified with. This theme refers to interventions which provide opportunities for PWD to access and thicken preferred identities of themselves, rather than those placed upon them as a person with dementia or a person with a disability, by society. This theme was endorsed by findings from 14 studies. This refers to drawing attention to the preferred identities of PWD, rather than focusing on identity relating

Table 4. *Illustrative quotes for themes and subthemes*

Themes	Quotations	
Maintaining narratives of preferred identities	[The participants] described that being around other people with early dementia emphasized to them that they all remained individuals with strengths (Martin et al., 2013)	Program offers non-judgemental respect for personhood while engaging in meaningful and interactive physical exercises, may help to prevent cognitive decline...through its combination of mindful movement and respect for participants' moment-to-moment experience (Wu et al., 2015)
Social inclusion	An empowering and special environment that helped to support the participants to feel like active members of the society, who were socially included and valued as individuals (Camic, Tischler & Pearman, 2014)	Benefits that accrued when participants left their isolated institutional setting and regained access to a community-based social network...a meaningful relation context is imperative for achieving QOL benefits (George, 2011)
Promoting an active and engaged lifestyle	Additionally, it may be tapping into cognitive skills which are present but under-rehearsed (Spector, Gardner & Orrell, 2011)	It may be that it is the increased activity is key, rather than the specific activity itself (Travers, 2015)
Facilitating processing Subtheme: Memory	Focus on bodily sensation...might be a way of accessing 'implicitly known' emotions related to past experience	The benefit of the sessions is somewhat short-lived as the activity is forgotten in some cases; therefore, the intrinsic

Themes	Quotations	
	through sensory awareness of movements and associated feelings (Wu et al., 2015)	value of the sessions becomes most important (Osman, Tischler & Schneider, 2014)
Facilitating processing Subtheme: Emotion and reminiscence	The group seems to have been important in helping them to understand and empathise more with each other and to adjust to difficulties they were facing (Cheston & Howells, 2015)	The development of ways to cope with the diagnosis on the part of the person with dementia and the carer is crucial to finding a sense of well-being and minimising excess disability (Osman et al., 2014)

to increasing impairment and sick-roles in a medical context. It was concluded that promoting personhood was a key factor in supporting PWD, and many studies (Camic et al., 2014; Loizeau et al., 2015; Osman et al., 2016; Martin et al., 2015; Spector et al., 2011; Wu et al., 2015) drew on theory by Kitwood (1997) to explain this mechanism. Factors that seem to support the maintenance of identity were a non-clinical, informal environment (Carone et al., 2016; George, 2011; Guzman-Garcia et al., 2012; Osman et al., 2016; Tuckett et al., 2015; Yates et al., 2016) where PWD could be free from the expectations of others (Camic et al., 2014; George, 2011; Jaaniste et al., 2015), with a strong strengths-focus (George, 2011; Jaaniste et al., 2015; Martin et al., 2015). Sharing stories, social interactions, and enhancing meaningful roles and sense of purpose were methods that were thought to enhance preferred identities. It was found that these methods were validating and empowering, increasing confidence in the person with dementia; in drawing conclusions, some studies highlighted evidence that increased confidence was a potential mechanism for increasing cognitive function. In contrast, two studies found a small number of participants felt the intervention highlighted negative changes and limitations that they were unaware of previously (Guzman-Garcia et al., 2012; Prick et al., 2014).

Social inclusion

Social exclusion has been defined as the denial of or inability to participate in economic, social, cultural or political activities open to the majority of society (Levitas et al., 2007). Social inclusion was a potential mechanism of change in 14 studies. Particularly for interventions involving group treatment, social inclusion was thought to offer peer support, reduce isolation, and increase acceptance.

Increase peer support

Peer support was found to have an important role in allowing participants to share their experiences (Carone et al., 2016; Cheston & Howells, 2016; Jaaniste et al., 2015; Loizeau et al., 2015; Martin et al., 2015; Osman et al., 2016; Spector et al., 2011; Wu et al., 2015), and benefits were found for peer support for carers as well as PWD (Camic et al., 2014; Carone et al., 2016; Cheston & Howells, 2016; Loizeau et al., 2015; Osman et al., 2016). One study hypothesised that increased peer support may reduce burden on health and social services for information giving, through the ability to share information between peers (Osman et al., 2016). Where a facilitator was used, the facilitator was thought to have a key role in fostering a sense of inclusion by being open and engaging (Martin et al., 2015; Tuckett et al., 2015).

Reduce isolation

Interventions which increased opportunities for meaningful social interaction and communication were felt to reduce feelings of isolation for PWD (Camic et al., 2014; Carone et al., 2016; George, 2011; Jaaniste et al., 2015; Loizeau et al., 2015; Martin et al., 2015; Osman et al., 2016; Spector et al., 2011; Tuckett et al., 2015), which was felt to have a role in improving quality of life for PWD (George, 2011; Jaaniste et al., 2015), facilitate remembering (Spector et al., 2011), and stimulate social and language skills which may be underused (Spector et al., 2011).

Acceptance

The facilitation of a safe environment where dementia and its associated impairments were accepted was considered a key factor in social inclusion (Camic et al., 2014; Carone et al., 2016; Cheston & Howells, 2016; George, 2011; Jaaniste et al., 2015; Loizeau et al., 2015; Osman et al., 2016; Spector et al., 2011), and was thought to facilitate a positive atmosphere and improve mood (Carone et al., 2016;

Loizeau et al., 2015). Group settings were thought to facilitate a sense of belonging (Carone et al., 2016; Guzman-Garcia et al., 2012; Martin et al., 2015; Osman et al., 2016; Spector et al., 2011) and feeling part of a community (Camic et al., 2014; Carone et al., 2016; George, 2011; Loizeau et al., 2015; Martin et al., 2015).

Interventions held in non-clinical community settings i.e. art galleries allowed PWD to feel part of the community, rather than isolated to their homes (Camic et al., 2014; Carone et al., 2016; Loizeau et al., 2015). One study supported PWD to provide mentorships in a school, and concluded that active participation in community in this way was a key factor in the effectiveness of the intervention (George, 2011). Five studies found that physical contact was a useful aspect of their intervention, which can be a symbol of social inclusion and acceptance, although this method was not the primary aim of any of the included interventions (George, 2011; Guzman-Garcia et al., 2012; Jaaniste et al., 2015; Tuckett et al., 2015; Wu et al., 2015). This method was relevant for participants with more severe dementia or those in a palliative stage where other signs of social inclusion are less appropriate (Tuckett et al., 2015), as well as participants of higher functional ability who participated in social activities like dancing (Guzman-Garcia et al., 2012).

Connected to acceptance, the reduction of stigma was associated with the power of a group to allow individuals to ‘feel normal’ in an accepting environment where experiences could be shared (Carone et al., 2016; Jaaniste et al., 2015; Loizeau et al., 2015). One study found that association with recognised brands (i.e. a local football team, Alzheimer’s charities) supported engagement in the intervention, and it was thought that having a well-known organisation attached to the intervention reduced stigma associated with dementia (Carone et al., 2016).

Promoting an active and engaged lifestyle

This theme refers to the way in which each intervention was found to encourage PWD to practice underused skills and learn new ones, and apply them to their lives (Carone et al., 2016; George, 2011; Jaaniste et al., 2015; Loizeau et al., 2015; Osman et al., 2016; Spector et al., 2011). Interventions promoted activity and exercise, which was thought to increase pleasure through targeting enjoyable activities, address boredom associated with residential culture, and distract PWD from potentially negative thoughts and feelings (Carone et al., 2016; Guzman-Garcia et al., 2012; Jaaniste et al., 2015; Prick et al., 2014; Travers, 2017; Wu et al., 2015). Increased physical exercise was thought to increase functional skill (Guzman-Garcia et al., 2012; Spector et al., 2011; Wu et al., 2015), as well as provide enjoyment and increase confidence, with one study concluding that increased confidence may lead to increased quality of life for PWD (Kelly et al., 2017). Interventions were also found to promote agency and independence (Jaaniste et al., 2015; Loizeau et al., 2015; Martin et al., 2015; Osman et al., 2016; Wu et al., 2015) which may facilitate engagement in an active lifestyle. The provision of a stimulating environment (Guzman-Garcia et al., 2012; Loizeau et al., 2015) was reported to be a key factor in exercising the mind (Tuckett et al., 2015), making people think (George, 2011; Tuckett et al., 2015), and keeping people occupied (Tuckett et al., 2015), and enabling meaningful activity was further thought to be relevant to the mechanism of change (Camic et al., 2014; Carone et al., 2016; Loizeau et al., 2015; Martin et al., 2015; Tuckett et al., 2015; Wu et al., 2015). One study, however, considered whether any activity would suffice, and that the activity served mainly as a distraction from boredom (Travers, 2017). Three studies which used music in their intervention found that music enhances physical arousal in the person with dementia (Guzman-Garcia et

al., 2012; Osman et al., 2016; Tuckett et al., 2015) suggesting that music facilitates activity and engagement.

Facilitating Processing: Memory

Tailoring delivery to the person with dementia's level of memory functioning is considered here as an important mechanism of achieving greater intervention engagement and therefore outcomes for participants. Some carers, PWD and facilitators were doubtful that a psychosocial intervention would be useful for a population with significant memory problems (Kelly et al., 2017; Martin et al., 2015; Wu et al., 2015), but outcomes from all studies indicated various benefits for PWD. Post-intervention, some participants commented that content was remembered despite memory problems, and memory problems were not a barrier to participation (Martin et al., 2015; Spector et al., 2011; Wu et al., 2015); learning and change appears to happen regardless. Three studies commented that participants felt the intervention had a non-specific, intrinsic value despite a lack of recall of the content or an understanding of how the intervention worked (Osman et al., 2016; Spector et al., 2011; Tuckett et al., 2015). Wu et al. (2015) found benefits for PWD despite the lack of recall of the session and the authors suggested that the intervention activated implicit memory systems through exercise and increased body awareness, so the content was forgotten but the learning remained.

Music and physical stimulation may be methods of activating implicit memory systems: music was thought to enable engagement by stimulating physical arousal and activating intact autobiographical memories for PWD (Osman et al., 2016), and physical stimulation was thought to access implicit memory systems by enhancing procedural memory through repeated exercise (Wu et al., 2015). Four studies (Guzman-Garcia et al., 2012; Martin et al., 2015; Spector et al., 2011; Wu et

al., 2015) noted that when the structure and pace of interventions were adapted to the needs of an individual with cognitive impairment, this increased engagement and motivation of participants by enabling adequate processing and retention of information. This theme was endorsed by fewer studies than other themes, however many these studies are of higher quality than the average

Facilitating Processing: Emotion and reminiscence

The interventions were thought to facilitate the sharing and processing of emotions as a mechanism of improving the emotional wellbeing of participants. This was considered to be achieved through reminiscence, which allowed participants to share stories and memories in a safe structured space. One study (Wu et al., 2015) reported that this facilitated the processing of unresolved, distressing emotions and allowed for the improvement of participants' wellbeing. Reminiscence was facilitated by methods such as sport, making and observing art, music and singing, dance and drama and featured in eight interventions (Carone et al., 2016; George, 2011; Guzman-Garcia et al., 2012; Jaaniste et al., 2015; Martin et al., 2015; Osman et al., 2016; Tuckett et al., 2015; Wu et al., 2015). These non-verbal methods of expression were considered to be useful for PWD who may struggle with the demands of verbal expression that is normally expected of them (Camic et al., 2014; Jaaniste et al., 2015). Sharing emotions in a group context was also found to facilitate the adjustment and acceptance of the dementia diagnosis (Cheston & Howells, 2016; Osman et al., 2016), which was considered important for the wellbeing of participants (Martin et al., 2015; Osman et al., 2016). Martin et al. (2015) found that participants who could not remember the content of the session could remember the emotional experience of having enjoyed the session, and concluded that the retention of the emotional experience could positively impact their quality of life.

Discussion

This review of 16 qualitative research papers has found four themes and five sub-themes relating to potential mechanisms of change underpinning psychosocial interventions for PWD. Maintaining preferred identities of PWD, social inclusion, promoting an active and engaged lifestyle and memory and emotion processing are the potential mechanisms identified from this review.

There appears to be considerable overlap between the findings of this review and the review by Dugmore et al. (2015) as well as similar reviews by Lawrence et al. (2012) and van't Leven et al. (2018). The themes of this paper appear within the results of these related papers, for example 'Peer identification and membership' (Dugmore et al. 2015) and 'Connecting with others' (Lawrence et al., 2012) could be related to the theme here of 'Social inclusion'. Other similarities appear relating to the themes 'Maintaining preferred narratives of identity', 'Promoting an active and engaged lifestyle', and the subtheme 'Emotion processing and reminiscence'. Triangulation increases the rigour of qualitative research findings (Elliot, Fischer & Rennie, 1999), and so the similarities found here add weight to the conclusions of each review.

There are two themes which do not appear to overlap between studies, which are the subtheme 'Memory' from this paper, and that of 'Empowerment' described by van't Leven et al. It is worth noting that only one paper in this review considered memory processing directly, with other papers referencing the role of memory, and perhaps more research is needed to expand on this hypothesis. Elements of empowerment are found within the potential mechanisms described above, for example personhood involves enriching preferred identities rather than subjugated ones, and increasing personal choice, potentially related to empowerment.

Differences between the findings of these papers could be explained by differences in the interventions reviewed; all papers reviewed psychosocial interventions for PWD however the Lawrence et al. review included papers which reviewed service models and environmental interventions, whereas this paper and Dugmore et al. reviewed intervention-based papers only. There were also differences in the sample of reviewed papers; Lawrence et al. largely reviewed papers which used samples consisting of paid and family carers, whereas Dugmore et al. reviewed papers with mainly PWD as participants (n=11) and this paper mostly consisted of a mix of participants (PWD as well as carers and/or staff, n=12). The setting of reviewed papers also differed substantially, with papers reviewed by Lawrence et al. conducted in residential care homes, whereas Dugmore et al. reviewed papers mostly set in the community (n=10) along with this review (n=12).

Maintaining narratives of preferred identities

Kitwood's (1997) malignant social psychology is a longstanding theory of disability in dementia, and this review supports evidence which suggests enhancing and respecting individuals' preferred identities despite cognitive impairment is a key method of supporting PWD, which can enhance the person's wellbeing (Willemse et al., 2015). The Living Well with Dementia report highlights the role of person-centred care for PWD in the UK (Department of Health, 2009) and stems from the concept of personhood as described by Kitwood and Bredin (1992). Personhood refers to the recognition of an individual's right to autonomy, individualism and respect, and good dementia care acknowledges and nurtures personhood (Milte et al., 2016). This can be achieved by offering opportunities for PWD to share their 'legacy' similar to some reminiscence opportunities, facilitating meaningful

engagement of PWD, and acknowledging the person behind the patient (Johnston & Narayanasamy, 2016), all of which feature within the findings of this review.

Social inclusion

Isolation and loss of dignity are common experiences of PWD (Patterson, Clarke, Wolverson & Moniz-Cook, 2018) and social inclusion can be a powerful tool, offering peer support, validation, and reducing stigma through participation in community. Social interactions characterised by stigma and ‘other-ing’ where a person with dementia is treated as different or lesser than a person without dementia, are thought to contribute to PWD feeling devalued by society (Patterson et al., 2018). PWD seek out positive social interactions; it is the response that is received that shapes the identity of the person with dementia, rather than disability itself (Patterson et al., 2018). Therefore, interventions which facilitate positive social interactions and social inclusion are likely to increase the frequency of receiving a positive response from others in social circumstances, increase positive relating and self-confidence, and create meaning and a sense of personal value in social interactions for PWD.

Promoting an active and engaged lifestyle

Increased social engagement and increased functional ability are associated with better quality of life for PWD (Martyr et al., 2018), therefore activities which promote increased functional skill are likely to be beneficial. The ability of some PWD to use dormant skills and learn new skills was found in this review to challenge the perception of some PWD and carers that PWD are unable to learn, and remind PWD of aspects of their identity that they had forgotten, linking with maintaining narratives of preferred identities and enhancing personhood. Previous research suggests exercise and cognitive stimulation can improve the physical and cognitive impairment associated with dementia and that interventions with strong social

components are most beneficial (McDermott et al., 2019). Promoting an active and engaged lifestyle was a potential mechanism endorsed by all of the included reports, and for some was thought to improve mood and cognitive engagement, however the nature of this mechanism is very broad, including activities like physical exercise, cognitive stimulation, music and singing, goal setting and social engagement. More research is needed to tease these concepts apart to gain a comprehensive understanding of these as mechanisms.

Facilitating processing

The role of memory in information processing during psychosocial interventions was only explicitly considered as a mechanism by one of the reviewed studies (Wu et al., 2015) but several studies commented on the role of memory in the engagement of PWD in psychosocial interventions, as the deterioration of memory function in dementia is a considerable barrier to daily functioning. PWD commonly have apparent difficulties with explicit and semantic memory, whereas some studies indicate implicit memory remains functional for longer (Zwijsen, van der Ploeg & Hertogh, 2016). More research is needed to explore how engaging implicit and supporting explicit memory might facilitate psychosocial interventions further.

Processing emotions through reminiscence and group support was thought to be a mechanism for supporting the adjustment to a dementia diagnosis and resolving distress and reminiscence was considered to be an opportunity to facilitate this. A Cochrane review of structured reminiscence interventions found some benefits for cognition and mood for PWD as well as some indication of functional improvement (Woods, Spector, Jones, Orrell & Davies, 2005), although the authors concluded that the evidence was limited. In the current review, reminiscence was not necessarily a

structured or explicit part of the intervention, but was still considered useful in multiple papers.

It is important to be cautious in implying that these potential mechanisms underpin all of the reviewed interventions. There are differences between the reviewed papers, in that while ‘Maintaining narratives of preferred identities’, ‘Social inclusion’, and ‘Promoting an active and engaged lifestyle’ were themes endorsed by almost all of the papers, there are some exceptions. For example, no data supporting the theme of ‘Maintaining narratives of preferred identities’ or ‘Social inclusion’ were found within the papers by Prick et al. (2014) or Travers (2017), and no data for ‘Promoting an active and engaged lifestyle’ was found within Cheston and Howells (2016). The theme ‘Facilitating processing’ was collectively endorsed by 12 of the reviewed papers, but separately the subthemes were supported by six papers (‘Memory’) and eleven papers (‘Emotion and reminiscence’) respectively. The differences highlighted here suggest that there may be variation in the way in which the different interventions affect change, as much as there appear to be similarities.

Limitations

The systematic selection process was conducted largely by one author, and so the identification of suitable papers for review somewhat subjective. Further, the definition of a psychosocial intervention was the same as that used by Dugmore et al. (2015) however this definition is also subjective and differs to that used by Lawrence et al. (2012) in their review and likely across other papers. The search criteria did not make use of grey literature or reference lists, due to pragmatic limitations of the review. As a result, it is likely that some relevant papers have been missed from the search. In particular it appears that the search criteria were not sensitive to

psychotherapeutic interventions such as individual or group therapy. As a result, it is not possible to say whether the potential mechanisms identified by the themes here are applicable to therapy interventions.

Evaluating published papers to assess their quality is an inherently subjective process, and while a systematic procedure was adopted, opinions differ on how to most effectively establish rigour within qualitative methodology (CASP, 2006, Mays & Pope, 2000). The papers in the review were rated of mixed quality according to the criteria used, which raises questions about the rigour of the conclusions drawn. Despite this, the findings have been triangulated with earlier reviews with similar aims and the consistency of the findings appears high.

Describing the participants included in the review was challenging as the papers included a range of demographic data about their sample, and some very little data at all. It is therefore difficult to infer much context about the source of the data included in the review.

Some consider the lack of philosophical foundations of a thematic synthesis analysis to limit the validity of the outcomes presented, and this review synthesises data from researchers who have used a range of analyses methods with different epistemological positions, however Braun and Clarke (2006) argue that the flexibility with which thematic methods can be applied enhance its' utility across diverse data sets, providing the position of the researcher and the methods used are explicitly stated.

The analysis aimed to find themes which are distinct from each other, however the way in which they differ or relate to one another is unclear, and it is important to note some overlap between themes which future research may be able to begin to clarify. For example, it seems likely that experiences of social inclusion

would impact the formation of narratives of identity, and vice versa; increasing engagement in the community would likely create opportunities for highlighting preferred identities as well as reducing feelings of isolation. Further, sharing experiences with other people living with challenges of dementia is likely to enhance social inclusion through social contact, and also provide opportunities for processing emotions related to the experience of dementia.

Implications for future research

The role of qualitative research in evidence-based practice is of exploring complex or poorly understood areas of interest and where appropriate generating hypotheses for explaining the phenomena (Barker, Pistrang & Elliott, 2016). Future research should be concerned with testing the role of narratives of identity, social inclusion, activity, memory and emotion processing in psychosocial interventions and the relationships between them. It would be useful to know more about whether these mechanisms are necessary or incidental, and in what forms they can occur, to enhance the provision of psychosocial interventions for this client group. It would also be interesting to learn whether these mechanisms are relevant to some groups of PWD more than others, or different contexts. Mediators and moderating factors could be explored using process evaluation methods (Moore et al., 2015) and dismantling trials could begin to isolate active factors within interventions. It would be important to establish whether identified mechanisms are more strongly related to outcomes, and which relate directly to NICE recommended interventions (CST, reminiscence therapy and cognitive rehabilitation) so that the most effective interventions are being offered as a priority.

Implications for clinical practice

A better understanding of the mechanisms underlying psychosocial interventions for PWD is an important step to offering health services that are clinically effective and financially efficient. Interventions which are considered to have strong outcomes include cognitive stimulation therapy and multicomponent exercise (McDermott et al., 2019); potential mechanisms found in the papers reviewed here using these interventions (Kelly et al., 2017; Prick et al., 2014; Spector et al., 2011; Yates et al., 2016) may be particularly interesting in developing our understanding of how active mechanisms may relate to outcomes, and which types of interventions should be routinely offered, when so many varieties of method are available.

The mechanisms described above may be relevant within a wide range of health and social care contexts for PWD, even outside of structured psychosocial interventions. There may be a wealth of opportunities for professionals to adapt their practice to include opportunities to enhance independence and autonomy of PWD, to increase meaningful activity within a care setting, to learn more about the person with dementia's preferences and strengths, or to enhance opportunities for social inclusion. This could be in the form of adapting care procedures in a residential care home, or educating and supporting family carers to increase these opportunities where possible. Dementia Care Mapping, for example, is a staff training intervention in care homes which demonstrates outcomes for both PWD and care staff (Barbosa, Lord, Blighe & Mountain, 2017). Supervision and training could be offered to all professionals who come into contact with PWD and their carers regarding these principles and the possibility of increasing the person's functional ability and general wellbeing.

The diversity of methods within the reviewed papers suggests that some different interventions may have common underlying mechanisms, which has implications for the selection of psychosocial interventions offered to PWD and their families nationally. The NICE guidance recommends group cognitive stimulation therapy to promote cognition, independence and wellbeing, and suggests group reminiscence therapy or cognitive rehabilitation should also be considered (NICE, 2018). The guidance also suggests a range of activities should be offered according to the individual's preferences. Research suggests that there are multiple barriers and facilitators to offering psychosocial interventions in various health and social contexts (Dugmore et al., 2015; Lawrence et al., 2012), and a better understanding of the mechanisms of available options could ensure that each health and social care service has a range of interventions to select from according to the needs of the particular context and preferences of individuals under their care.

Conclusions

Potential mechanisms which underpin psychosocial interventions for dementia include maintaining the person's identity, facilitating social inclusion, promoting an active and engaged lifestyle, and facilitating the processing of emotions through reminiscence and group support. The role of memory in processing information is also considered. These mechanisms apply to a diverse range of interventions, and developing an understanding of these mechanisms could offer PWD greater choice of intervention, and services a wider range of options for treating PWD according to the care context.

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Part 2: Empirical Paper

**Barriers and facilitators to providing CBT for people living with dementia:
perceptions of IAPT clinicians**

Abstract

Background: People living with dementia and mild cognitive impairment (MCI) commonly experience anxiety and depression, and cognitive behavioural therapy (CBT) is a recommended treatment for adults, commonly provided through national Improving Access to Psychological Therapies (IAPT) services. This study explored the barriers and facilitators to providing CBT interventions in IAPT for people living with dementia or MCI, as perceived by IAPT clinicians.

Method: An interview topic guide was developed based on implementation theory and a consultation process. 14 participants were recruited through IAPT services and interviewed about their experience of working with individuals with dementia or MCI, and their ideas about factors that enhance or hinder offering CBT in IAPT to this group. Interview recordings were transcribed and results analysed using thematic analysis. Credibility checks were incorporated throughout the process.

Results: Three main themes were identified: attitudes towards dementia, competing demands of offering a service to people with dementia/MCI, and pressure without support. Barriers included high pressures on staff with a low level of support, negative attitudes towards dementia and older adults, and a restrictive service model perceived to be at odds with offering a service adapted to peoples' needs. Perceived facilitators were positive engagement and outcomes for people with dementia and MCI, positive attitudes of IAPT clinicians and the ability of some services to be flexible.

Conclusions: Multiple perceived barriers and facilitators were identified, and there are implications for commissioning practices within the NHS relating to the tension between minimal resources and adequate care, as well as supporting clinicians working within this context.

Introduction

Dementia

Dementia is a common and debilitating syndrome, defined by the World Health Organisation (WHO) as a progressive or chronic deterioration in cognitive functioning beyond that expected of normal ageing, commonly accompanied by deterioration in emotional control, social behaviour and motivation (WHO, 2017). Prevalence rates stand at 1.3 per cent of the UK population (Prince et al., 2014) and are increasing, largely due to increased life expectancy, with estimates that over one million people will be diagnosed with dementia by 2030 (Ahmadi-Abhari et al., 2017). Dementia was estimated to have cost the NHS £4.3 billion in 2012/2013, with social care costs of £10.3 billion (Prince et al., 2014). Living with dementia comes with challenges and providing good quality care for people living with dementia has not been a consistent priority for UK government policy. Alzheimer's Society produced a report highlighting that people affected by dementia carry a large financial burden in paying for essential social care which is detrimental to the quality of life of people living with dementia and their families (Alzheimer's Society, 2018). The National Dementia Strategy was introduced in 2009 (Department of Health, 2009a) and highlights the need to improve the quality of life of people living with dementia.

Dementia and mental health

Rates of depression in people living with dementia are estimated at around 25 per cent, with rates of anxiety estimated at 14 per cent (Kuring, Mathias & Ward, 2018). Depression comorbid with dementia is associated with increased mortality rates (Perna et al., 2019), while anxiety is associated with increased cognitive decline (Wolitzky-Taylor, Castriotta, Lenze, Stanley & Grasse, 2010), although this

association is not consistently found (Breitve et al., 2016). Depression and anxiety are negatively associated with quality of life in people living with dementia (Jing, Willis & Feng, 2016), and positively associated with increased disability including more severe dementia symptoms (van der Mussele et al., 2013) and earlier nursing home admissions (Lyketsos & Olin, 2002; Seignourel, Kunik, Snow, Wilson & Stanley, 2008).

Mild cognitive impairment

Mild cognitive impairment (MCI) has been defined as memory problems beyond that expected in normal ageing, with otherwise normal cognitive and daily functioning, and an absence of dementia (Peterson et al., 1997). Prevalence rates are uncertain, highlighting the challenge in research for this population, with worldwide estimates in one review of between 3-42 per cent, due to various definitions and methods of assessing MCI in a research context (Ward, Arrighi, Michels & Cedarbaum, 2012). More recent work (Sachdev et al., 2015) has used more precise criteria to estimate prevalence rates and found rates of 5.9 per cent, which increased with age. Given the human and economic costs of dementia, MCI is an important condition diagnosed in health services due to the increased risk of developing dementia in people with MCI, with annual conversion rates from MCI to dementia estimated at 9.6 per cent in clinical populations (Mitchell & Shiri-Feshki, 2009).

Mild cognitive impairment and mental health

Anxiety rates are estimated at 14.3 per cent in community samples and 31.2 per cent in clinic based samples of people living with MCI (Chen, Hu, Jiang & Zhou, 2018). Depression rate estimates vary, with one systematic review concluding an overall rate of 32 per cent (Ismail et al., 2017). Furthermore, anxiety is associated with increased risk of developing dementia in people with MCI (Li & Li, 2018).

Forrester, Gallo, Smith and Leoutsakos (2016) found that individuals with anxiety or depression and MCI had 1.5 times greater risk of developing dementia than participants with MCI and no neuropsychiatric symptoms. Individuals with MCI and depression are estimated to be at more than twice the risk of developing dementia than those without depression (Mondrego & Ferrández, 2004) and have poorer cognitive function than people with MCI without depression, which can improve if depression improves (Yoon, Shin & Han, 2017). Effectively treating common mental health problems could reduce excess disability for individuals diagnosed with dementia or MCI.

Accessing Treatment

Evidence suggests that people living with dementia can benefit from psychological treatment for depression and anxiety (Orgeta, Qazi, Spector & Orrell, 2015) but that more trials of high standard are needed in this area and for people with MCI, for which no trial data could be found by Orgeta et al. (2015) or a scoping review conducted for the current work. Availability of services and access to appropriate therapy is lacking: 21.6 per cent of people living with dementia in one study report psychological distress as an unmet need (Miranda-Castillo, Woods & Orrell, 2013). The National Institute for Health and Care Excellence (NICE, 2018) recommends psychological therapy should be considered for people with dementia and anxiety or depression and the care quality standard for dementia independence and wellbeing recommends people living with dementia should be supported to access services which support their physical and mental health needs (NICE, 2013). There appears to be a lack of standardised guidance for managing and treating mild cognitive impairment, which is not included in NICE guidelines.

Older adults in general are consistently under-represented in talking therapy services (Chaplin, Farquharson, Clapp & Crawford, 2015), diagnosing depression in people living with dementia is challenging due to substantial overlap of symptoms (Gutzmann & Qazi, 2015): it is highly likely that people with dementia are also underrepresented in talking therapy services.

IAPT services

The Improving Access to Psychological Therapy (IAPT) initiative was intended to increase the national availability of primary care therapy services with the aim of reducing the economic burden in the employment and health sectors relating to mental ill health. IAPT services are now one of the biggest providers of primary care CBT interventions. The accessibility of IAPT services has come under scrutiny and initiatives are now focused around increasing access to ‘hard to reach’ community groups such as older adults, and, recently, people living with long term health conditions. To support IAPT clinicians in working with these populations, guidelines have been developed to enhance clinicians’ skills and confidence (How to make IAPT accessible to Older People, Department of Health, 2013) as well as a manualised treatment for people with dementia (Charlesworth, Sadek, Schepers & Spector, 2015). However, accessibility of IAPT services to people with dementia continues to be less of a focus: performance and accessibility data are routinely collected for all IAPT services and while the number of patients over aged 65 forms part of this data set, the number of dementia patients is not, leaving the provision of these service to this particular client group ambiguous.

Accessibility

Barriers to accessing talking therapy services for older adults include social factors such as social isolation and reduced independence, individual factors such as

beliefs and attitudes in older adult communities about the shame and stigma associated with mental health problems, and service and professional factors such as discriminatory beliefs amongst GPs and other health professionals that mental health problems are a normal part of ageing and psychological treatments are not effective for older people (Department of Health, 2009b). To the author's knowledge there is no research directly investigating the barriers to accessing talking therapy services for people with dementia and MCI, but as people with dementia and MCI are commonly older, it is likely that these barriers may apply to this group as well as older adults more broadly.

It is possible that perceptions and beliefs about dementia and MCI more specifically could be additional barriers to accessing services. Given that people with MCI and dementia have cognitive impairments, and these have been shown to be barriers to accessing CBT in other groups with cognitive impairment (Marwood, Chinn, Gannon & Scior, 2017), it is possible that provision of services is limited due to a perception that the cognitive aspects of CBT are not appropriate for people with dementia and MCI. Collins and Corna (2018) found data that GP beliefs about the appropriateness of IAPT services for people with extra cognitive needs such as dementia leads some GPs to withhold referrals of people with cognitive impairment and instead manage the person's needs in the GP practice. Given that CBT for people with learning disabilities, who also have cognitive impairment is being routinely offered by services, the rationale for CBT being withheld for individuals with dementia or MCI is unclear. Also, the effectiveness of a behavioural CBT intervention has been demonstrated in people with dementia (Teri, Logsdon, Uomoto & McCurry, 1997) suggesting that even if a cognitive component is not appropriate

for a person's cognitive ability a behavioural component such as behavioural activation routinely offered in IAPT could still be clinically useful.

It is possible that the likely lack of provision could be because of the lack of strength of the evidence base. The main pilot RCTs in the area both conclude that larger RCTs are required to demonstrate effectiveness of these interventions. However, there are other possibilities too. The evidence base for the use of CBT in people with learning disabilities is at a comparable stage to that of people with MCI and dementia. A systematic review by Jennings and Hewitt (2015) concludes that this evidence base is promising but small, and larger RCTs are required to develop the evidence base further. Despite this similar evidence base to dementia, IAPT services are obliged to be inclusive of people with learning disabilities in accordance with NICE guidance for care for this client group (NICE, 2016) and the Equality Act (2010). The question is raised then, why provision for people with dementia or MCI is not similarly provided, when the Equality Act also states people should not be prevented access to mental health services due to age or disability.

Study aims

The main aim of this study is to examine the perceived barriers and facilitators to accessing CBT interventions in people with dementia and MCI, according to IAPT clinicians.

This aim presupposes that people living with dementia are under-represented in IAPT. While it is highly unlikely that people with dementia are well represented in IAPT services, this is not something that has been studied, thus a preliminary aim of the current study is to survey IAPT services in England for data about access rates and eligibility of people living with dementia or MCI for each service.

Dementia and MCI

There were several reasons for inclusion of people with MCI. As much of the research into psychological therapy for people with dementia focuses on mild to moderate stages of dementia (Tay, Subramaniam & Oei, 2018), findings as to MCI will be useful for dementia research. It is also important to investigate access to therapy of people with MCI in and of itself as due to the higher functioning level of people with MCI, they may be more likely than people with dementia to present in therapy services, and, like those with dementia, will have particular needs associated with cognitive impairment. This is of particular importance because depression and anxiety are also associated with MCI.

Implementation of guidelines in services

The implementation of best practice guidance can be challenging in health services, even when the culture of a service is motivated towards improving health care for patients. Health care research suggests that there is a gap between guidance for evidence based practice and actual clinical care in health settings, resulting in poorer health outcomes (Haines & Donald, 1998.) Implementation research aims to understand the barriers to implementing the evidence base in health services and to develop strategies to facilitate behaviour change in services, to achieve the best possible health outcomes. Grol and Wensing (2004) reviewed the healthcare implementation literature and created a framework of six levels of healthcare provision with the potential for different barriers and facilitators for change at each level: the innovating practice itself, the individual professionals involved, the patient, the social context, the organisational context and the economic/political context. This framework will therefore form the basis of the topic guide for interviews aimed at understanding factors which may support or hinder the delivery of IAPT services for people with dementia and MCI. The wide range of levels identified in this

framework highlights the need to sample staff at different levels of the system as some barriers may be more or less relevant according to a clinician's specific role in the service.

Method

Ethics

The study received ethical approval from University College London Ethics Committee number CEHP/2015/531. NHS Health Research Authority was consulted about NHS Ethical Approval requirements and advised that NHS ethical approval was not required for the survey or interview arms of the study (see Appendix A).

Quantitative study: Survey

Services

All IAPT services listed in the Psychological Therapies: Annual report on the use of IAPT services (Health and Social Care Information Centre, 2016) in 2015-2016 were invited to participate in a survey gathering data about access rates of people with dementia or MCI in each service (n=185). One service explicitly declined to participate when contacted. Eight services were unable to be contacted by telephone or email, resulting in 176 services who received the invitation.

Procedure

IAPT services were invited to participate by email (Appendix B). The email outlined the study, presented an information sheet (Appendix C), and directed consenting service managers to a Qualtrics online survey.

The survey (Appendix D) was developed in consultation with experts in CBT for dementia and IAPT services. Two consultants, one within the research team and one external, reviewed a draft of the survey and provided feedback on whether the

questions addressed the research question appropriately, and questions were amended accordingly, for example by adding specific dates for access rate data. The questions aimed to gather data on overall access rates of the service, access rates of older adults and access rates of people with dementia, for the financial year 2017-18. The survey also enquired about whether the service has nominated specialist interest roles for older adults or dementia, whether the service has a policy addressing the suitability of their service for people with dementia or MCI, whether referrals would be accepted or declined on this basis and whether the service records information about dementia or MCI diagnoses.

Services with no public email were contacted by telephone to request details of a responsible person to send the survey to. Due to low response rates, services were sent two further emails reminding them of the closing date of the survey.

Results

176 services were contacted out of 185 total IAPT services in England. Only six services responded to the survey (3% response rate). All six services provided access data for their service. Five services provided data about the access rates of older adults within their service. Three of five services stated that they have a nominated clinician working in an older adult special interest role within service. No services had a nominated clinician specialising in dementia or MCI.

Only one service explicitly excluded people with dementia and MCI in their eligibility criteria; the remaining five services stated that dementia is not addressed by their referral criteria, and a referral of a person with dementia or MCI would be considered and a service offered if appropriate. A different service reported that they record data about MCI diagnoses in their service but provided no data for this. No other service reported recording data for dementia or MCI.

Qualitative study: Interviews

Researcher perspective

Declaring the researcher perspective is considered an important factor in increasing the credibility of qualitative research (Mays & Pope, 2000). The first author who led the interviews and analysis is a white British woman studying a doctoral level clinical psychology with a clinical background working in IAPT services and no clinical or personal experience of dementia. The author believes IAPT services have both positive and negative aspects within the service context and in their contribution to mental health care and a strongly positive view of providing CBT to people with anxiety and depression who also have dementia in general, with a curious perspective of how this might work in the IAPT context.

Procedure

Recruitment

The study was advertised by emailing a recruitment poster to IAPT services to be circulated within clinical teams (Appendices E and F). Purposive and snowball sampling methods were also used; purposive, to allow the interviewer to select volunteers based on their qualifications and experience to allow for a range of participants with and without experience working with the client group at different levels of the service (PWP, CBT therapist etc.); snowball, to increase recruitment via participating clinicians promoting the study with interested colleagues through word of mouth. Senior clinical psychologists working in IAPT were recruited through personal contacts in the research team.

Interview

Interested clinicians contacted the researcher by email and an information sheet was sent to each potential participant outlining the details of the study

(Appendix G). Clinicians who chose to participate were then asked to confirm that they met the eligibility criteria and an interview appointment was arranged at the participant's convenience; interviews were conducted at UCL, the participant's workplace with permission from their service manager, or the participant's home. Participants signed a consent form and received £20 shopping vouchers in appreciation of their involvement. Interviews were recorded with a voice recorder for transcription and lasted between 30-50 minutes.

The interview was structured around a topic guide (Appendix H) which was informed by Grol and Wensing (2004). The framework for potential barriers and facilitators for change in healthcare provision outlined by Grol and Wensing formed the framework of the interview: questions were developed to prompt for information from participants regarding each level of healthcare provision, relating to the individual clinician, the client group, the organisational context, the wider social context and the economic and political context. A draft of the interview was reviewed by IAPT and implementation experts as well as experts in psychological and psychosocial approaches for people living with dementia and MCI, to ensure it had meaningful scope, with positive feedback. After completing a consent form (Appendix I), the interview began with a definition of dementia and MCI and common symptoms. Participants were then invited to describe their experience of working with older adults including the positives and challenges of this work, as well as their awareness of the evidence base. Due to the older age of people with dementia/MCI it was thought that beliefs, assumptions and barriers to working with older adults would be raised by participants in relation to people living with dementia or MCI.

The interviewer then asked participants to describe their experiences of working with people with dementia or MCI. Participants who had no clinical experience with this client group were asked to give their perspectives based on their current knowledge and experience in IAPT. Participants were asked about their confidence working with the client group, what they knew about the evidence base, and how they perceived dementia or MCI might impact the work. The interviewer then explored the participant's view of barriers, challenges and positives in providing CBT interventions with the client group in the IAPT context. Prompt questions were used to elicit information about the participant's personal views, service factors and societal or political factors that might be relevant in providing this service. Participants were asked whether they consented to being contacted at the end of the project to review the final thematic framework as part of the credibility checking process (Elliott, Fischer & Rennie, 1999).

Analysis

Interview data were transcribed verbatim and the interviews were anonymised, removing potentially identifying information about the participant and the service or borough they worked in. Thematic analysis was used to analyse the data. This approach is consistent with an inductive design and allows theory to be generated from the data, while the flexibility of the approach allows for a contextual analysis of the data as appropriate (Braun & Clarke, 2006). The researcher held a realist/essentialist position: data provided by the participants were considered to be an account of their true experience. The implementation framework outlined by Grol and Wensing (2004) was held in mind during the procedure and analysis but data were not interpreted according to the framework; the researcher was concerned with the entirety of the participants' experience not limited to the framework.

The analysis procedure followed Braun and Clarke's (2006) method of thematic analysis due to their emphasis on the balance of scientific rigour with flexibility to respond to the data gathered. As the interviews were conducted, the researcher kept a log of points of interest that occurred in the interviews, and initial ideas about potential themes and areas to explore during analysis. The reports were read thoroughly and repeatedly along with the logs, and codes were generated through this process, using NVivo for administrative support (Appendix J). After all transcripts were coded, an independent trainee psychologist reviewed a selection of transcripts and coded data items according to the research question, and these were then reviewed together with the original coding by the author, and similarities and differences in coded items were discussed. This enabled the researcher to reconsider the data from another perspective and attempt to increase credibility in the process (Elliott, Fischer & Rennie, 1999). The researcher then returned to the entire transcript collection and recoded the data with the new ideas and perspectives, and to ensure previous codes were comprehensively collected from the data. The codes were reviewed for relevance to the research question and refined as appropriate. Codes were then clustered into themes, and the data relating to each code was reviewed separately to ensure there was a consistent narrative within each theme and subtheme. Attempts were made to include all codes within the themes to ensure the richness of data was included and very few codes which had no relevance to other codes were removed as they could not be considered themes in isolation (n=3). The themes were then reviewed with a second member of the research team and some themes were combined to ensure clarity within and between themes. The final themes were sent to participants who consented to take part in credibility checks for a participant perspective (see results).

Results

Participants

14 participants were recruited from London IAPT services (see Table 1). Participants were seven Psychological Wellbeing Practitioners (PWPs), five CBT therapists and two clinical psychologists. Ten were female, seven were of White British ethnicity, two of Black British, two Asian British, and three of other ethnic origin. The mean age of the sample was 29.6 (26-37) and the mean number of years qualified was 3.1 (1-15). Seven had worked with people living with dementia or MCI in the IAPT context, and two had received specific training on working with dementia or MCI (clinical psychologists only).

Qualitative data

Three themes and seven subthemes were found (Table 2). All clinicians had clinical experience working with older adults, seven clinicians had experience working with people with dementia or MCI in IAPT. Those without direct experience of dementia or MCI were asked to share their ideas on working with this client group based on their current knowledge and experience. Two participants gave feedback on the findings, and stated that the findings represented their views as discussed in the interview, and broadly represented experiences working in IAPT.

Attitudes towards dementia

Both positive and negative attitudes towards dementia were evident within the data.

Positive participant attitudes

The attitudes of participants towards offering CBT to this client group were overwhelmingly positive. 11 participants felt that CBT had the potential to be useful,

Table 1. *Overview of participant clinical experience*

Professional role	No. years qualified	Worked with older adults?	Aware of dementia/ CBT research?	Worked with PWD?	Had dementia training?
CBT therapist	1	Yes	Yes	No	No
CBT therapist	1	Yes	No	Yes	No
PWP	3	Yes	Yes	No	No
PWP	2	Yes	No	Yes	No
PWP	1	Yes	No	No	No
PWP	2.5	Yes	No	No	No
CBT therapist	1	Yes	No	Yes	No
PWP	3	Yes	No	No	No
CBT Therapist	3	Yes	No	Yes	No
CBT Therapist	1	Yes	Yes	No	No
Clinical Psychologist	4	Yes	Yes	Yes	Yes
PWP	3	Yes	Yes	No	No
PWP	3	Yes	No	Yes	No
Clinical Psychologist	15	Yes	Yes	Yes	Yes

Note: Psychological Wellbeing Practitioner (PWP), Cognitive Behaviour Therapy (CBT), People living with dementia (PWD)

Table 2. *Themes and sub-themes*

Theme	Sub-theme
Attitudes towards dementia	Positive participant attitudes
	Older adult attitudes
	Negative referrer attitudes
	Societal attitudes and service provision
Competing demands of offering a service to people with dementia/MCI	Adapting therapy
	Service (in)flexibility
	Commissioning and funding
Pressure without support	-

particularly for individuals with milder impairment, and six felt that ethically this service should be offered, particularly considering the emerging evidence base. Ten participants commented on work with older adults as extremely positive, that older adults are appreciative and this makes working with them highly enjoyable, and two participants said working with people living with dementia or MCI could also be rewarding. Three participants commented on the resilience and dedication of NHS staff to keep providing good work in a changing and challenging context, and two felt that working in new client groups adds interest and excitement to their role by learning new skills.

“That’s really nice as a therapist though, to feel, like, appreciated in the work that you do.” P1

“Personally I do it [CBT with dementia] because I love it. So its, er, it can be challenging sometimes but it’s also very rewarding.” P14

“I’d say we’d definitely be wrong to not offer it because we think that someone – that it might not work for them.” P5

Older adult attitudes

Negative attitudes and stigma were perceived by most participants to be held by others, with regards to living with dementia and offering appropriate care. Nine participants felt that older adult stigma about mental health problems and mental health services due to cohort factors and previous experience might be a significant barrier to their ability to access mental health services.

“You were supposed to get on with it and that stiff upper lip thing and just, push through, keep calm and carry on, that sort of attitude.” P1

“There might not have been a culture in the past that you would access help or talk to somebody.” P9

Negative referrer attitudes

Nine participants felt that attitudes held by referrers might present a barrier, that some professionals might prioritise physical health treatment over mental health treatment, or make assumptions about a person’s ability to engage in therapy, perhaps confounded by a lack of understanding of therapy itself, and withhold a referral to therapy services.

“It’s more likely that they might be misdiagnosed so the GP might not pick up that actually they are depressed because they kind of see it more as like a physical health problem.” P6

“Maybe that there was just like this underlying type of “well it’s not going to be successful anyway because people need these skills to be able to engage in therapy and they don’t have those skills.” P7

Societal attitudes and service provision

Ten participants felt that the perception of older adults and dementia in society contributes to a lack of service provision, as care for older adults and people with dementia was not felt to be a priority for policy makers due to a widely held view that poor mental health is to be expected in old age or dementia, and discrimination against people with disabilities might influence policy decision making about services, or the ability of affected individuals to access services easily. Two participants commented on a widely held fear of dementia and stereotypical views of the needs of a person with dementia as a potential barrier to accessing or providing a service, as decisions about service provision might be based on these stereotypes.

“People are still very fearful of dementia and have a bad outlook or image of what having dementia might be like.” P14

“I remember her saying that it’s almost as if people are waiting for her to die.” P3

In contrast, two participants commented that the increased focus on the importance of mental health and awareness of mental health problems in the media has contributed to an increased ability for individuals to access mental health services. They felt that there was an increased awareness of the needs of people with dementia in society as well, which could enable engagement in and provision of services.

“People are maybe a bit more aware of dementia and the effect it has and how it can have an effect on mental health problems means that people are more likely to actually think about psychology.” P1

“Mental health is getting a push within the press and the sort of common media that it hasn’t had for quite some time.” P11

Competing demands of offering a service to people with dementia/MCI

Most participants discussed that services need to be flexible in order to meet the needs of people living with dementia, many of whom will be older adults, and the challenges of doing so. Participants felt that there were two opposing priorities of good quality patient care and offering a cost-effective service within the context of an under-resourced NHS.

Adapting therapy

Participants described perceptions and experiences of the challenges of working with people living with dementia within the IAPT context. 11 participants expressed concern about the impact of memory problems or other impairments on the ability of the person to benefit from CBT, and as a result queried whether CBT could be helpful for this client group. Two participants with direct clinical experience of dementia or MCI said the individual was confused throughout the session and struggled to engage due to their memory problems. Other perceived barriers to CBT included the high number of appointments a person with dementia is likely to have, side effects of medication, concern about implementing outcome measures, and concern about working with family and carers in a CBT context. One participant expressed uncertainty about effectively implementing risk management policies in the context of memory problems, and another was concerned that an individual might wait a long time for therapy to start by which time disease progression could mean that they waited for a therapy that is no longer appropriate.

“The person I was working with was coming back every week not remembering what we talked about the week before. So it’s quite hard to continue working with that.” P13

“I don’t know how they’d be able to retain the information and use it.” P2

Eleven participants mentioned barriers related to the older adult context more broadly, such as practical concerns about accessing the building, cultural differences with regard to age differences and the low average age of IAPT clinicians as a barrier to engagement, and isolation as a barrier to therapy. Seven clinicians felt that isolation leads older adults to struggle to maintain the structure of therapy. Low referral numbers was another barrier mentioned by three participants. On the other hand, some participants highlighted positive experiences of working with people with dementia and older adults in IAPT, which appeared to balance the challenges of working with a client group with extra needs.

“Trying to get them to work rigidly on a model kind of feels sometimes erm challenging...it appears to be a lot of a talking element in the sessions.” P10

“The age range I suppose in the service as well everyone’s very young, really, erm so whether that would be a barrier as well.” P12

Seven participants commented that older adults seem to engage well in therapy, which was perceived as a facilitator for offering work. Some felt that older adults have more time to dedicate to the work, and that they are more keen to learn than younger client groups, however most participants (n=10) felt that individual differences have a significant effect on engagement for older adults both with and without cognitive impairment, and therefore their comments on engagement were generalisations. Three participants commented that older adults approach mental health services and professionals with an attitude that the professional is an expert and an expectation that therapy will be helpful, which is perceived to be due to cohort related norms of medical professionals being of high standing in the community.

“Generally older adults have kind of like respect for professionals and kind of what they say goes really.” P1

“They tend to come to their sessions, do the homework, take the treatment quite seriously.” P2

Few participants had worked with people living with dementia or MCI in treatment so many could not comment on outcomes; three participants who had worked with individuals with cognitive impairment commented that the impairment had little impact on the work, that the person engaged well, and had a positive outcome from therapy. In general, participants (n=6) felt older adult clients more broadly had good outcomes from therapy.

“I can’t remember [the MCI] really affecting the work so much.” P9

“I suppose he was positive about therapy and what it could do.” P1

“So they seem to engage with the therapy...complete treatment and then, good treatment outcomes for most of them, at recovery.” P14

12 participants identified factors specific to CBT that could facilitate the provision of services to people with dementia or MCI. These included the collaborative philosophy of CBT, the empathy and person-centred approach to therapy, and the fundamental structure of CBT and protocolised interventions, which participants felt could be containing for people with cognitive impairment who might benefit from the time-limited nature. Incorporating acceptance methods was felt to be useful by two participants, as well as structured and simplified formulations which one participant had found useful in a piece of work with a client with MCI.

“The structure of it actually might be useful... keeping them on track and focused.” P12

“A lot of the resources that we use and the interventions are they are very you know clear, understandable, step by step interventions and I imagine that that could be yeah pretty transferable and useful.” P8

All participants commented that adapting therapy to meet the needs of individuals is an important facilitator for both older adults and people with dementia or MCI, and seven participants felt this would be no different to adapting therapy to meet the needs of other individuals who use the service. Suggestions included using the network of community, family and carers to support the intervention, incorporating a narrative approach to the work, spending time validating clients’ life experiences as opposed to rigidly adhering to an agenda, and using memory aids to support the work.

“I would take steps to try and ensure that memory and coding retrieval was going to be supported... put a reminder in your phone, things on the back of the door, erm and that seemed to work pretty well most of the time.” P11

“You get training for that about how to adapt things because those people who have learning disabilities so I don’t see why it would be much different from doing that.” P13

Service (in)flexibility

12 participants highlighted features of their service which support provision of CBT for people with dementia. Service facilities including accessible buildings, specialist and shared knowledge in teams through group supervision and trained supervisors, and older adult leads were seen to support staff to offer this work. Four participants had prior experience of their service being flexible for the needs of individuals and felt it would be possible that their service could be flexible in this context. Eight participants felt that multiagency work would be important to facilitate

delivery, and four had previous experience of working alongside GP and memory services in a positive way. Six participants referenced the recent long term health conditions (LTC) expansion, indicating that previous experience of expansions of service provision can support new areas of expansion. Specifics about what worked well within this expansion were incorporated into all themes when participants suggested these features are replicated to support this work.

“On a really practical level we have a building, it’s in a really easy to access place, erm, most of our clinicians work there most of the time, we co-locate to GPs.” P8

“I think [the service] does genuinely erm want to make the service accessible and be erm inclusive and be flexible with how we deliver sort of the treatments that we have.” P9

All participants reflected that the IAPT model of high volume caseloads resulted in extremely limited ability of clinicians to offer a flexible service to meet the needs of clients who need adaptations to a service in order to engage. Participants felt that these restrictions impact work with older adults (n=8) and people living with dementia or MCI (n=11) as they believed these clients need a longer intervention to benefit from therapy, and eight participants said flexibility to offer this was limited within the IAPT context. Six participants said offering longer or greater number of sessions would be difficult within the service model, and four participants felt lack of room availability would further impact this. Of note, four participants felt some flexibility within service provision is possible, highlighting a discrepancy about what is possible across different services. Ten participants commented on the lack of time available to make service delivery adaptations by clinicians and administration staff, such as adapting letters, methods of contacting patients, time to research the evidence

base and recommended adaptations for particular client needs, and time to attend necessary training, which participants felt is not always prioritised. Five participants felt that providing this service would require a reduction in clinician targets which was perceived as unlikely. Four participants expressed concern about the impact on the quality of their work with other clients as a result of coping with the extra demands of providing this work.

“I think in an ideal world as well we’d just have a lot more time for anyone that we see, but in IAPT it doesn’t kind of work so well like that does it. Its kind of back to back, and no time to think about anyone.” P6

“There’s just so much constraints in terms of trying to be flexible and trying to adapt.” P7

“Resources are quite limited and that sometimes I think with this group you do have to have a little bit more time.” P9

Commissioning and funding

All participants described the service commissioning context, and how this poses a challenge in offering the flexible service they strive to provide. These concerns related to how services are commissioned based on outcomes, how commissioning impacts the remit of IAPT services and the consequences of this for clients with extra needs, and the relationship between service provision and evidence-based practice. Participants also described the challenges of working within what they saw as an under-resourced NHS, and the impact of this on their work.

12 participants expressed concern about implementing outcome measures in this client group, due to memory problems influencing the validity of measures, and perceptions that IAPT outcome measures are not valid for older adults more generally. Participants were concerned about the impact of this inconsistency on the

overall recovery rates of the service, with the perception that overall recovery rates are a crucial part of the service because of their influence on commissioning decisions. Four participants reported previous experience of older adults having lower recovery rates than working age adults, and one participant with experience working with a client with MCI reported a lower recovery rate than expected. It is important to note that this contradicts some other participants views that recovery rates for older adults and people with dementia or MCI are generally good.

“If we have more people who are less sensitive to measures that we ...that might impact how well the service looks like we’re doing. And then that affects things like funding and stuff.” P13

“We’d be seeing patients that we can’t count towards recovery ...would reduce our recovery rates, which would therefore forward impact how effective our service looks to commissioners, which would impact the funding we get.” P3

Nine participants commented on the service remit with regards to dementia. Two participants said referrals of people with dementia are very low. Seven participants said their service does not work with this client group but refers on to specialist services, some referred to boundaries between primary and secondary care services being exclusive with one participant stating their service is not commissioned to work with people with dementia in any capacity. One participant said clients open to memory services are not eligible for primary care mental health services, but are unlikely to have mental health needs met at a memory service either.

“As soon as someone has a diagnosis of dementia, the, any CBT work should not be done by the IAPT services, it should be done by the secondary care team. So that’s the commissioning arrangement.” P11

“Once they see they are open to a secondary care team, they said no, you’re not suitable for a primary care mental health service.” P14

Seven participants commented on the need for evidence to influence commissioning decisions, and one said that as the evidence base for CBT for people with dementia is very new, perhaps the service is not offered because commissioners are unaware of it. Some participants felt that more research needs to be done in service to support the evidence base and offer meaningful evidence to commissioners for decision making, but due to the lack of flexibility and time in service it can be difficult to prioritise this. One participant felt that a lack of access to up to date research in clinical services was a barrier to offering the latest evidence based interventions. Three participants expressed concern about bias in the research or the need for clinical research to support initial lab-based findings. One participant commented that low referrals of people with dementia as well as an inability in service to track people with cognitive impairment further impacted the ability to collect data for audit and research in this area.

“We can make the case of, okay, if we do this piece of work, although we will have to offer them longer sessions this is going to save X amount of money in the future for.... And then if the CCG see that they might say OK you can do that.” P14

“The whole premise of IAPT is supposed to be that’s its completely you know evidence based.” P4

Nine participants commented that perceived cuts to NHS mental health budgets affects care provision, and has resulted in a negative effect on the quality of care or tight constraints within which services function. Five participants commented that IAPT services appear to have consistently increased targets without the

necessary funding to meet the increased demand. Two participants commented on the inequity of funding between mental and physical health services, and the lack of integration between these types of services, despite increasing need for mental health resources. Four participants felt that while IAPT continues to be funded, other specialist services are increasingly limited as a result of insufficient funding; four participants felt that IAPT services become catch-all services for complex needs as a result. In contrast, one participant felt that offering a CBT service to people with dementia could result in NHS savings in other areas, as it could reduce NHS spending on long term consequences of poor mental health.

“It’s a lot to do with money. Erm, or I guess the NHS mental health budget being cut but also the demand is to still see as many people as you can... they’re trying to do what they can do with limited time and limited resources.” P7

“I suppose funding as well, of course, erm, so a lot of it goes the physical way, and not the mental health way.” P12

Pressure without support

All participants described how working within a high-volume service model increases pressure on clinician staff, and a lack of resources and training results in staff feeling unsupported.

13 participants felt that increased caseload pressures from adapting the service for clients with extra needs resulted in increased stress for clinicians. They also commented that working with impairment and older adults can be harder work in itself. Participants commented that there are very high expectations on staff to see more people and meet high targets, and that therapists are stretched, and linked caseload pressures to exhaustion and burnout. One participant commented that staff

felt undervalued as a result, and that people who made decisions about caseload and targets had a lack of understanding of the challenges of the job.

11 participants expressed a lack of confidence working with people with dementia or MCI, in particular due to a lack of knowledge and skills in the area. Only two participants received specialist training in this area (clinical psychologists), and many had no previous experience of dementia or cognitive impairment personally or professionally. Four participants expressed a concern about working with a person with a diagnosis or suspected diagnosis, and not having the skills to handle this sensitively or appropriately. Five felt that working with mental health problems that might closely cross over with dementia would be challenging without specialist training, as well as coping with realistic worry about the progression or impact of the disease, although this comment was also made about working with older adults who might worry about realistic problems (i.e. poor health, anxiety about dying). One participant with experience of working with a person with impairment said that if they had known about the diagnosis they would not have accepted the referral and instead referred on to a specialist service. Six participants felt that due to their lack of specialist knowledge and experience, a specialist service or pathway would be more appropriate in offering CBT for this client group. One participant highlighted that the idea of working with dementia could raise anxiety in therapists and make the work appear harder than it is, due to stereotypes and myths about dementia. Four participants commented that they are not confident that their supervisor would have the knowledge and skills to support them properly, and therefore felt specialist supervision would be required.

“How is that going to impact our recovery rates, how is that going to impact our session attendance and cancellations.” P8

“There’s high level of burnout because of kind of increased caseloads.” P10

“Also the lack of training, so altogether that means I don’t feel that confident working with it at all.” P1

Having personal or professional experience of dementia or MCI was thought to increase confidence or knowledge in providing this work. Six participants commented that their personal experience of dementia added to their confidence in working with the client group, or to their understanding of the need to offer psychological support to individuals with dementia or MCI. Participants who had had training in working with dementia or MCI (two participants) were confident in providing this work. Of those who had not had specific dementia training, five participants said that learning how to adapt their work during training for people with diverse needs (learning disabilities, minority cultures) would be useful transferable skills for this group. Eight participants said that training would be a key factor in supporting them to provide CBT to people with dementia or MCI.

“I have personal experience of dementia because my grandfather had dementia... I think I’ve got some of my own personal ideas of what might be helpful.” P8

“I think the general principles in the training would probably help, about sort of identifying barriers and thinking of creative adaptations.” P9

Discussion

The main barriers found by this study to providing CBT for people with dementia or MCI within IAPT as perceived by clinicians were high pressure on staff to perform with a lack of support to do so, negative attitudes and stigma towards older adults and dementia, and the restrictive nature of the IAPT model and

resources, perceived to reduce flexibility of practice and increase clinician stress as a result. The main facilitators found were positive engagement and outcomes for older adults within IAPT, positive attitudes of interviewed clinicians, and accessible features of services and therapy.

Many participants perceived IAPT services as fundamentally inflexible due to a lack of resources as well as a focus on targets and outcomes related to commissioning of services, despite the Equality Act (2010) mandating reasonable adjustments to public services for individuals with extra needs. The principles of the IAPT scheme of reducing symptomatology within the working population to decrease pressure on employment welfare systems and heavy focus on financial outcomes (Clark, 2011) leaves services at odds with pragmatic requirements needed to offer highly accessible services. Chinn and Abraham (2016) found similar results when they investigated barriers to provision of IAPT services for people with learning disabilities (PWLD). They found discourses regarding “tightly defined eligibility criteria, measurable and uniformly operationalised process and outcome variables, efficiency and value for money” (Chinn & Abraham, 2016, p. 576) were associated with decreased level of inclusivity of services for PWLD, and some IAPT staff felt unable to adapt their practice within these constraints. They also found some alternative experiences where some participants reported flexibility within their service to meet the needs of PWLD. Founded in positivist principles of scientific evidence and numerical outcomes (Williams, 2015), perhaps the philosophy of IAPT disregards alternative narratives of distress and recovery that could be more meaningful to more diverse client groups.

Increased clinician stress due to increased workload was perceived to be a consequence of adapting clinician practice within tight service limitations.

Organisational factors have been associated with high levels of burnout for PWP's and CBT therapists, and increased hours of overtime predict higher levels of burnout in PWP's (Westwood, Morison, Allt & Holmes, 2017). Further, increased levels of burnout in IAPT have been associated with reduced treatment outcomes (Delgadillo, Saxon & Barkham, 2018).

Findings in this study support research that older adults can have good outcomes from CBT, but that referrals to IAPT services are low (Chaplin, Farquharson, Clapp & Crawford, 2015), and attitudes of health professionals can impact referrals, with referrers sometimes prioritising physical over mental healthcare, in part due to assumptions that older adults are unable or unwilling to engage in mental health services, but also due to lack of time for GPs during consultations and perceived complexity of health needs of older people (Frost, Beattie, Bhanu, Walters & Ben-Shlomo, 2019). Negative attitudes and stigma about dementia can also be held by carers, people with dementia, and within society, negatively affecting help-seeking (Herman et al., 2018). People living with dementia or MCI are subject to an interacting stigma of both characteristics and may find access to mental health support particularly difficult, with consequences for both their physical and mental wellbeing.

A survey was developed to investigate the implicit assumption that people living with dementia are excluded from IAPT services however the survey did not generate enough data due to the low response rate. Research suggests that health professionals often find time to be a significant barrier to responding to surveys in health research (Cunningham et al., 2015) and more time and resources within the research team would be required to support staff to participate in a survey of this kind. Follow up telephone calls, personal visits and mandated data collection

programmes such as the National Audit of Psychological Therapies commissioned by the Healthcare Quality Improvement Partnership used by Chaplin et al. (2015) may all be ways of increasing the response rate, but were beyond the scope of this particular project. This would be a useful research study in future.

Limitations

Although all participants had experience of adapting therapy within the IAPT context for different client groups, some participants had not worked clinically with dementia, and their answers were based on their knowledge and assumptions about dementia and MCI, which means some of the data could be considered conjecture, and therefore the results of the study may represent perceived rather than true barriers to practice. However, the sample was intended to be representative of the IAPT workforce, with regards to gathering data from IAPT clinicians about the potential for work with this client group. The research question is interested in the perspectives of current clinicians, and the sample offers this. The perspectives of staff about potential service change is an important stage in preparing adequately for successful implementation (NICE, 2007), which is where this study is situated in the implementation process. The results should be interpreted within the context that the data were collected. Future research would investigate the perspectives of staff who provide therapy for people living with dementia or MCI more routinely, which may offer further insights to the barriers or facilitators of therapy, and investigate whether there are gaps in therapy provision within specialist services.

Separating out data relating to people living with dementia from data relating specifically to working with older adults is challenging due to the significant overlap between these contexts. Despite emphasising questions about older adults and people with dementia separately within the interview, some participants struggled to

separate these populations in their answers. This is to be expected, as many people with dementia are indeed older adults, however not all older adults have dementia, and research into the provision of care for people with dementia is important in its own right.

Recruiting solely within the London region increases the likelihood that many participants trained at the same institution, as training courses cover a 'catchment area' of local IAPT services. This has the potential to homogenise experiences within the sample due to exposure to the same information and training practices, and increase the level of agreement between participants about their experiences and therefore the themes, which may not be applicable nationally. IAPT training courses are curriculum based, (Health Education England, 2019) which is expected to maintain standards and similarity of training across all training sites and so there is potential for the current findings to be relevant in other areas of the country.

Implications for research

These findings suggest that flexibility and equality of access within IAPT services is an ongoing problem but that some services can offer flexibility; the experiences of staff within these services should be explored further to establish good practice and how this links with commissioning practices. Future research should also investigate the views of other IAPT stakeholders, such as commissioners, service managers or people living with dementia or MCI, who may have similar or different views to the findings here. The perspectives of staff and service users would offer information at different levels of healthcare provision, from the perspectives of those involved in funding, through to people who would be accessing the service. This extra information could provide useful insights to potential barriers or

facilitators that clinical staff may not recognise, and the assumptions made by participants in this study could be investigated further.

IAPT services essentially offer only NICE recommended interventions, therefore in order to influence commissioning and instigate change in services that meaningfully includes people with dementia or MCI, more research is needed to demonstrate the efficacy and effectiveness of CBT for this client group.

Implications for clinical practice

These findings highlight that more needs to be done to support IAPT clinicians to adapt their work in a range of contexts, as well as supporting older adults with cognitive impairment to access support they are entitled to. IAPT recently rolled out a change programme to support clinicians to work with long term health conditions which some participants referenced in this study; this programme could provide a guide to increasing knowledge and skills in working with people with dementia or MCI. Increasing knowledge and skills within the workforce appears an important step at a clinical level, but this study also indicates that commissioning of primary and secondary care mental health services is a complex process. Despite the empathic and ethical views of individual clinicians in this study, services must operate within a context of finite resources and economic priorities; changing this process is complex and reliant on multiple factors however changes may need to be made at a business or policy level for services to work together to provide effective interventions and equity of access while being adequately funded to do so.

The structural barriers to providing therapy to people living with dementia in IAPT services may present limitations to providing good quality care for the particular needs of this client group. For example, many adapted therapeutic interventions recruit a carer or family member to support the therapy (Cheston &

Ivanecka, 2017) which some IAPT services may struggle to accommodate. As such, providers need to carefully consider whether IAPT services should be routinely offering therapy services to people with complex needs like dementia or MCI at all. The results of this project also indicate areas of practice in which flexible services are being offered, which suggests that there is a potential for IAPT services meet the needs of some people living with dementia or MCI in IAPT services in some cases, and future research should be concerned with exploring the potential for this in more detail.

Conclusions

Clinician perceived barriers to providing CBT for people with dementia or MCI in IAPT services include high pressures on staff with a low level of support, negative attitudes towards older adults and dementia in society, and a restrictive model of care alongside limited resources, perceived to restrict services in offering a suitably flexible service for people with extra needs. The main facilitators were positive engagement and outcomes of people with dementia and MCI and older adults in IAPT, positive attitudes of IAPT clinicians, and opportunities for flexibility in the IAPT context. This presents implications for the commissioning of services within the NHS in a challenging political context and the support of clinicians working with limited resources, and future research should focus on increasing the evidence base for treating common mental health problems for people living with dementia and MCI.

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Part 3: Critical Appraisal

Introduction

This critical appraisal outlines my personal reflections on the procedure of planning and conducting the research project above. Firstly, this report outlines my reflections on the systematic review, beginning with my impressions regarding the epistemological assumptions of a qualitative meta-synthesis, followed by reflections on decisions that I made throughout the process.

The appraisal then describes the bracketing exercise conducted at the beginning and end of the research, and my reflections on what I learned and why, including my experience of identifying and developing my own attitudes which were potentially underpinned by implicit stigma prior to commencing the research.

The report then considers the role of service user involvement, and whether there were any missed opportunities for elevating the perspectives of people with dementia or MCI throughout the research project.

Finally, the appraisal reviews the challenges of implementing a national survey to IAPT services working within limited resources of time and staff to support research, while prioritising competing clinical and economic demands.

Reflections on the systematic review

The process of a qualitative meta-synthesis as an alternative to a traditional systematic review was one that appealed to my preference for finding meaning in experience, as opposed to generating meaning from statistical calculations. The result was a time consuming and subjective process of selecting qualitative data from qualitative papers. The epistemological foundations of a meta-synthesis versus a qualitative piece of research could be seen as inherently in opposition in that it might be seen to be finding positivist 'truth' about how interventions work from the subjective experiences of participants. Further, the subjective nature of this approach

poses a challenge, as a qualitative review of qualitative research adds layers of subjectivity during each stage of analysis, which may impact the perceived ‘truth’ of the findings. That being said, qualitative research is used to generate understanding of little known or complex phenomena and develop hypotheses about frameworks or mechanisms which can later be empirically tested, and so the ‘truth’ of the findings is not entirely the point. Using each of the reviewed papers for triangulation to identify subjectivity, the mechanisms which were found were common across most papers, and fit well with the literature. This suggests that people with dementia, their carers and professional staff are adept at describing what works for them in a way that contributes meaningfully to scientific understanding. My reflections on this are that including service users in research could be highly valuable in this way and it is important not to dismiss the contribution of service users to academic or professional ventures based on assumptions about their ability to understand.

I chose to model the meta-synthesis on a previous published review by Dugmore, Orrell and Spector (2015). This decision was taken for pragmatic reasons; as this review was also a doctorate project the scope of the review seemed appropriate and it was written clearly and the methodology was easy to follow. Having a review to model my own on was useful as a trainee conducting a systematic review for the first time and it being part of a doctoral thesis added a level of reassurance that the task was achievable. On writing my rationale for this decision in the paper, I struggled to justify the choice beyond practical reasons, and I am aware that a more scientific procedure could have been undertaken to choose a review on which to model my own. A review by Lawrence et al. (2012) is another example of a review whose methodology I may have chosen, and the search procedure appears more rigorous, including significantly more search terms, and inter-rater reliability

figures for independently reviewed quality appraisal and data extraction, although this is possibly beyond the scope of what could be achieved in this context.

During a systematic review, papers are assessed for quality to establish the validity of their contribution to the literature (Carroll & Booth, 2015) and in my review I did so using established criteria for measuring qualitative rigour described by Dugmore et al. (2015) who used criteria from Mays and Pope (2000) and Critical Appraisal Skills Programme (CASP, 1998) checklist. This combination of criteria made for a more comprehensive list incorporating key factors from both lists, but makes for difficult comparisons between papers which use standard lists (e.g. Lawrence et al. (2012) which used CASP alone). Performing this evaluation was a challenging part of the process; I felt as though I was passing judgement on the work of more experienced researchers than myself, and this felt somewhat uncomfortable. I also noted that many papers part-met some of the criteria, and making a decision about whether this amounted to the criteria being awarded or not appeared somewhat subjective. I had support from my supervisors throughout this procedure but if I were to repeat this review with greater resources than those available during clinical training I would work more closely with another researcher in collaboration to reduce subjectivity throughout this process, repeating the procedure outlined by Lawrence et al. (2012) in which two reviewers independently assessed quality and their reliability was rated. Despite these challenges, the procedure of quality assessment developed my knowledge of a range of methods of conducting and presenting qualitative research, and increased my confidence in my professional opinion as a clinical psychologist trained in conducting and critically appraising research.

My initial review was to outline not only the mechanisms of psychosocial interventions for dementia but also issues relating to implementation and outcomes, as with the question posed by Dugmore et al. (2015). In writing up the results it was clear that the question generated too much content for the remit of the project, and after discussion with my supervisors it was decided to narrow the focus of the review on mechanisms of psychosocial interventions. This decision was a hard one as I had worked hard in extracting data relevant to a much broader question, and I felt as though this work would not be evidenced in my final report, however narrowing the question allowed for a much more detailed exploration of the question in the results and in the discussion, which made the report more interesting and a more useful contribution to what is known in the area of psychosocial interventions for people living with dementia.

Choosing an empirical research project

My background prior to clinical psychology training was largely clinical: I worked as a senior PWP in IAPT (supporting the management team to lead the PWP team). The research component of clinical psychology training filled me with anxiety due to my lack of experience in conducting research since my undergraduate days. My strategy to cope with this anxiety was to choose a research study in a familiar area where I might feel less deskilled and more confident, hence my initial attraction to this particular project, which was already in the early stages of conception by my supervisors. This research project was investigating the barriers to implementing NICE guidelines, an area which interested me greatly as my previous role was largely to support PWPs to carry out the requirements of their job, problem solve daily challenges and liaise between the service managers and clinicians to aid this process. I was intrigued by the opportunity to contribute research to the area of

service change within an IAPT context, having personally experienced particular challenges this can pose.

Bracketing the natural attitude

Bracketing is a strategy used in phenomenological qualitative research and is an attempt to identify and suspend the assumptions and attitudes of the researcher to minimise the influence of these assumptions on data collection and analysis and increase credibility (Fischer, 2009). My preconceptions about the study were that offering interventions to people with dementia in IAPT would be challenging, and I predicted that resources would be a large factor in this. I was unsure about whether offering this service to people with dementia was appropriate and felt clinicians may have a negative attitude or experience of it, however I also had direct experience of the resilience and creativity of IAPT staff and the ways CBT interventions can be adapted successfully, and so I was curious to see what current IAPT clinicians would have to say about the research question. After presenting the findings, I notice that some of my assumptions were supported by the data, such as lack of resources as a barrier, however I was pleasantly surprised to learn that the participants had wholly positive attitudes towards the principle of including people with dementia within their clinical practice, contrary to my initial concern about appropriateness and acceptability.

A common criticism of qualitative research is the presence of bias introduced by the perceptions of the researcher which inherently inform the analysis and findings of such research, a feature of such research which guidelines for enhancing rigour aim to minimise (Elliot, Fischer & Rennie, 1999). It is likely that my perceptions about working in IAPT influenced the data to some degree, despite the bracketing exercise, for example when participants described experiences similar to

my own, I questioned whether I followed up this line of inquiry too much, or indeed not enough, as a consequence: would another researcher have followed a different line of inquiry here? On the other hand, my IAPT experience brought a level of rapport building in the interview which could have resulted in more open and honest answers from the participants, and more valid data for analysis. I introduced credibility checks to help shine a light on biases where possible (Mays & Pope, 2000), however ultimately I believe the researcher always influences the data in qualitative research, these influences are inevitable and part of the process, and should be described openly to allow the reader to understand the researcher's perspective where possible (Fischer, 2009).

Implicit stigma

Initially during the interviews I noticed a sense of allegiance towards the participants; I identified with them professionally and I held a strong interest in the methods used to support them through changes in their job role. Looking back, I realise that mental health care for people with dementia was not as much a part of my reasons for being drawn to the study, it was more my focus on staff needs. Throughout the project I noticed a change in this stance; after immersing myself in the literature around the mental health needs of people living with dementia or MCI and the challenges of accessing meaningful mental health support, I developed a stronger sense of allegiance to the people with dementia, who were seemingly present in the room, but with voices that were never being heard. I started to question my own initial response to the research question during the bracketing exercise, moving from a stance that CBT for dementia in IAPT might not be appropriate, to recognising unmet needs of people living with dementia and MCI and a sense of sadness when I really understood how people living in such challenging

circumstances are being offered so little support (Alzheimer's Society, 2018). I believe that my initial tendency to neglect the perspectives of people living with dementia and focus on staff was in part a playing out of the implicit stigma in society as a barrier to including people living with dementia in services, which can be a problem in accessing healthcare as health professionals have been shown to hold stigmatising attitudes and assumptions about people with dementia and older adults (Collins & Corna, 2018).

Where are the people with dementia?

Including service users in NHS service development is a key tenet of the NHS constitution in building services that address the concerns of the community (Department of Health, 2015) increasing accountability of services to the public and enhancing wellness and transitions of recovery for service users (Neech, Scott, Priest, Bradley & Tweed, 2018). Further, a particular advantage of qualitative research is the ability to give a platform to voices of individuals who are socially excluded (Barker, Pistrang & Elliot, 2016). In proposing this project I was asked whether service user involvement had been considered and after discussing this in supervision I felt that people living with dementia were not appropriate stakeholders to consult about this particular research question; we were interested in clinician views rather than service user views, and interviewing service users about their experience as well as clinicians was beyond the scope of the doctoral thesis. On the other hand, now my journey through this research has reached an end and I am more acutely aware of the discrimination people living with dementia and their carers face, and the consequences of this, I do feel that an opportunity has been missed to include voices that are rarely privileged. Exactly whether this is appropriate within this project is uncertain; the inclusion of service users within research development

should be meaningful to avoid tokenism which may undermine their participation (Neech et al., 2018). If I were to do this project again I would reconsider whether people living with dementia or MCI could perhaps be useful contributors to the development of the interview schedule or if they could be included in another meaningful way.

National surveys

The decision to include a survey at the beginning of the research was to investigate an implicit assumption driving the interviews that people with dementia are routinely excluded from IAPT services. The aim was to survey as many IAPT services as possible to conclusively understand the inclusion and exclusion criteria of services as well as calculate access rates of people living with dementia compared with prevalence rates in each region, as other researchers have done for access rates of older adults more broadly (Chaplin, Farquharson, Clapp & Crawford, 2015). Unfortunately the low response rate meant that while the data was somewhat informative as an indicator, it could not be used in the way it was intended. The survey was emailed to every IAPT service in England, and compiling a list of services and finding their contact details alone was a highly time consuming process, as data about each service from the IAPT national dataset had to be researched, many services were listed based on their trust location rather than service name, some services had changed providers and been cancelled or merged with other services, and many did not have an email address published on their website and had to be telephoned to get this information directly. Finally 176 services were contacted with six responding. The low response rate was disappointing as the time invested in the survey yielded so little data that this time may have been better spent expanding the research project in different ways, perhaps by recruiting more stakeholders for

interview such as commissioners, service managers, or even service users. 20 services were contacted to enquire about completing the survey and all stated the main barrier as lack of time in service meaning the survey was difficult to prioritise. This is consistent with other findings that health professionals find lack of time a significant barrier to responding to surveys in health research leading to low response rates (Cunningham et al. 2015). A further query about completing the survey from one service was lack of clarity about ethics requirements. It was felt that although NHS ethics was not required as advised by the Health Research Authority, service managers may have a different view of this, and may have been reluctant to release data without approval of the trust research and development board. Approaching every NHS trust to confirm participation of each IAPT service in the survey was beyond the scope of this research project, and may be a useful research study in future.

Conclusion

Conducting research within the NHS can be extremely challenging and the aim of the study to be mixed methods initially may have been ambitious for the particular requirements of the course. Despite these challenges and my initial anxiety, I enjoyed the process of planning, conducting and analysing research and I developed a sensitive and empathic knowledge of the extent to which the needs of people living with dementia or MCI are neglected by society and the way this is demonstrated by a lack of access to mental health services. Overall I feel the study went well and is a useful contribution to the knowledge about mental health support for people with dementia or MCI.

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Appendix A: Confirmation of ethical approval

From: King, John
Sent: 24 May 2018 11:18
To: Stott, Joshua; VPRO.Ethics
Cc: Baker, Samantha; Charlesworth, Georgina
Subject: Re: Ethics submission

Dear Josh,

Thank you for your amendment request. I am happy to approve it - please keep this email, which has been copied to the REC, as a record of the approval.

I see that you have used the updated GDPR-compliant templates for the information sheets and consent forms. Please ensure these are approved by the Data Protection team prior to recruitment.

Best wishes,

John

From: Stott, Joshua
Sent: 24 May 2018 10:43
To: King, John
Cc: Baker, Samantha; Charlesworth, Georgina
Subject: Fw: Ethics submission

Hi John,
I hope all is well. I attach an amendment to my original approved ethics application CEHP/2015/531.

I hope all is in order, but if not please do let me know.

It would be great if you could cc in Sam (ccd) here if you have questions as I will be on leave until 5th June and she will probably know the answers as it relates to her DClin....

Thanks for this

J

Dr Joshua Stott,
Alzheimer's Society CHPT Research Fellow/
Senior Clinical Tutor and Admissions Tutor
Doctorate in Clinical Psychology
University College London

From: MACPHERSON, Stephanie (HEALTH RESEARCH AUTHORITY)
<s.macpherson1@nhs.net>
Sent: 07 March 2018 10:52
To: Baker, Samantha
Subject: RE: HRA query

Dear Samantha,

HRA Approval is required where NHS employees or contractors will be participants in a study by virtue of their employment/ contract with that organisation.

HRA Approval is not required where the research involves NHS employees as participants solely by virtue of their qualifications, experience or professional capacity rather than in relation to their employment by a specific NHS organisation.

As such your questions about where the interviews take place is irrelevant as it is the nature in which the staff are being contacted which determines what approval is needed.

If you require any further information please let me know.

Regards Steph

Steph Macpherson

HRA Assessment Manager

Health Research Authority

Bristol HRA Centre | Level 3 | Block B | Whitefriars | Lewins Mead | Bristol BS1 2NT

T. 02079722505

M. 07747660859

E. s.macpherson1@nhs.net

W. www.hra.nhs.uk

Sign up to receive our newsletter [HRA Latest](#)

Appendix B: Survey recruitment email

Dear Service Manager

We are a research team at UCL conducting an exciting **national research project** to investigate the provision of talking therapies for people with dementia and mild cognitive impairment. This project is the first to investigate access to psychological therapy services for this client group. The survey should take **no longer than 5 minutes to complete**. We would be grateful if you could read the attached information and complete the survey which can be found

here: https://uclpsych.eu.qualtrics.com/jfe/form/SV_3kgGIGAqHWwtf

If your service does not work with people with mild cognitive impairment or dementia, please do still complete the survey as your responses will be just as important for our research.

Further information re the project is below and in the attached information leaflet:

People with mild cognitive impairment (MCI) or dementia often experience common mental health problems. Recent NICE guidelines have emphasised that CBT for anxiety and depression should be offered to people with dementia. We are a research team at UCL and the first to investigate access to psychological therapy services for these groups, which we hope will help us provide better support for people with MCI or dementia in the future.

The project is a five minute online survey gathering information from national IAPT services about their policy for working with people with MCI or dementia, and access rates of this client group (where applicable).

Please see the attached information sheet (INFORMATION SHEET 1) which briefly outlines more about the purpose of the study and what participation involves. You can complete the survey yourself or someone else can complete it on your behalf; all you need is five minutes and your most recent IAPT data report, where applicable.

If you have read the information and consent to participate, please complete the survey at a time convenient to you. **We will stop collecting this data in November 2018.**

As IAPT service managers and staff are very busy we will attempt to contact you about this study again to remind you to participate. If you would prefer to opt out of this study entirely please respond to this email and we will not contact you again; you do not need to give a reason.

Thank you for your time

Yours sincerely
Samantha Baker
Trainee Clinical Psychologist
University College London
Supervised by Dr Joshua Stott

Appendix C: Survey information sheet

Information Sheet for Adult Participants in Research Studies

UCL Research Ethics Committee Approval ID Number: CEHP/2015/531

You will be given a copy of this information sheet.

<p>Title of Study: Investigating the barriers and facilitators to providing CBT based interventions to people with mild cognitive impairment and dementia</p> <p>Department: UCL Division of Psychology and Language Sciences</p>	<p>Name and Contact Details of the Researcher: Samantha Baker 1-19 Torrington Place, WC1E 7HB Email: samantha.baker16@ucl.ac.uk</p> <p>Name and contact details of Principal Researchers/Supervisor: Dr Joshua Stott 1-19 Torrington Place, WC1E 7HB Email j.stott@ucl.ac.uk</p>
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We would like to invite you to participate in this doctoral research project. Before deciding it is important for you to understand why the research is being done and what participation will involve. Please read the following information carefully. You should only participate if you want to. Ask us if there is anything that is not clear or you would like more information. Thank you for reading this.

What is the aim of this research?

This research is looking the ability of people with mild cognitive impairment (MCI) or dementia to participate in cognitive behavioural therapy (CBT) or CBT-based interventions. Many people with MCI and dementia experience problems with depression and anxiety and other common mental health problems, and we are interested to find out whether treatment for these problems is offered within IAPT services. This might help us better understand the support available for this client group, and provide information about further support that might be needed for people with MCI or dementia.

This research project is focused on whether primary care CBT or CBT based interventions are routinely offered to people with MCI or dementia across England and whether the numbers of people with MCI or dementia accessing CBT in IAPT services is recorded. Where these records are available, we would like to find out the number of people with MCI or dementia who access IAPT services in each region.

Why have we approached you?

We have asked you to participate in this study as the service manager or representative of a service manager of an IAPT service in England which may or may not provide cognitive behavioural therapy (CBT) services to people with mild cognitive impairment (MCI) or dementia. We are inviting all IAPT services in England to take part.

Do I have to take part?

It is up to you whether or not to take part. If you do decide to take part you will keep this information sheet and be asked to indicate consent to participate as part of the survey, described below. You can

change your mind at any time without giving a reason. Not taking part will not incur any penalties to you or your service.

What will happen to me if I take part?

Participation involves completing a one-off online questionnaire which takes no longer than 10 minutes. The questionnaire asks questions about your service, your service policy regarding inclusion and exclusion criteria for people with a diagnosis of MCI or dementia, and whether access rates for this group are routinely recorded. If this data is available, the questionnaire then asks for this data. This data will then be compared with the numbers of people within the service borough, to help us estimate how many people with MCI or dementia are accessing support for common mental health problems.

Your personal information will not be needed for the research project.

What are the possible disadvantages and risks of participation?

The only expected disadvantage of taking part is the time involved could increase time pressures on the person who completes the survey, potentially increasing levels of stress in their day.

What are the possible benefits of participation?

While there are no immediate benefits for those people participating in the project, your contribution will be highly valuable to increasing knowledge about this client group and their wellbeing, as well as knowledge about IAPT services in England and the way that they operate. We hope that this research will improve our ability to support people with MCI or dementia and common mental health problems in the future.

What if something goes wrong?

We work hard to maintain the wellbeing of all of our participants. If you are unhappy with the way the project is being conducted and you wish to make a complaint, please raise your concerns with the researcher using the contact details above, or the research supervisor, Dr Josh Stott, at j.stott@ucl.ac.uk. If you feel your complaint has not been handled to your satisfaction you can contact the Chair of the UCL Research Ethics Committee at ethics@ucl.ac.uk

Will my participation be confidential?

The information collected from the survey will be used in a research report to outline the current provision of CBT services to people with MCI or dementia. If a service returns very small numbers of people accessing their service, then the service will be anonymised to minimise the possibility that these individuals are inadvertently identified. Services who do not collect data or who return large numbers of access rates of this client group will not be anonymised in the report however the report will not be used to offer judgement on the inclusion or exclusion criteria of any service.

Limits to confidentiality

Please note that assurances on confidentiality will be strictly adhered to unless evidence of potential harm is uncovered. In such cases the university may be obliged to contact relevant statutory bodies to report the potential for harm.

What will happen to the results of the research project?

The results will be written in a report and disseminated in the psychology community. The report will be published as part of a doctoral thesis. Data collected will be processed and stored for so long as it is required for the research project. Data will not be transferred outside of the EEA.

Data Protection Privacy Notice

The data controller for this project will be University College London. The UCL Data Protection Office provides oversight of UCL activities involving the processing of personal data, and can be contacted at data-protection@ucl.ac.uk. UCL's Data Protection Officer is Lee Shailer and he can also be contacted at data-protection@ucl.ac.uk.

Personal data will not be processed for the purposes of this project. If you have concerns about how data is being processed, please contact UCL in the first instance at data-protection@ucl.ac.uk. If you remain unsatisfied, you may wish to contact the Information Commissioner's Office (ICO). Contact details, and details of data subject rights, are available on the ICO website at: <https://ico.org.uk/for-organisations/data-protection-reform/overview-of-the-gdpr/individuals-rights/>

Contact for further information

If you would like to discuss any aspect of the project please contact the researcher, Samantha Baker at the details above. The project supervisor is Dr Joshua Stott and he can be contacted on j.stott@ucl.ac.uk or 1-19 Torrington Place, WCE 7HB.

If you decide to take part you will be given a copy of this information sheet and asked to indicate your consent to participate at the beginning of the online survey.

Thank you for reading this information sheet and considering to take part in this research study.

Appendix D: Survey including consent form

IAPT service survey

This study is investigating the provision of CBT therapy in IAPT services to people with common mental health problems and a diagnosis of mild cognitive impairment or dementia.

Dementia is defined as a progressive deterioration to the brain caused by disease, and might include symptoms like memory loss and problems with thinking, mood and changes to behaviour. A person with dementia may have a diagnosis of dementia, Alzheimer's disease, vascular dementia, mixed dementia, dementia with Lewy bodies or frontotemporal dementia. Dementia can be on a spectrum with some individuals experiencing mild symptoms with a small impact to their daily lives, through to individuals with severe levels of symptoms which require a great deal of support from family or services.

Mild cognitive impairment is described as an interim stage between normal cognitive ageing and dementia. This means memory problems unusual for a person's age, with otherwise normal cognitive function and daily living skills, and an absence of dementia.

We would like to gather information from IAPT services about how their service is structured with regards to this population. We are interested in whether you offer CBT to people who have a common mental health problem as well as a diagnosis of MCI or dementia in order to receive support for the mental health problem. The common mental health problem may or may not be associated with the dementia diagnosis. We are not investigating whether you offer support to people with dementia in order to treat dementia directly. Please answer the following questions using accurate information from your records.

Informed Consent Form for Adult Participants in Research Studies

UCL Research Ethics Committee Approval ID Number: CEHP/2015/531

You will be given a copy of this information sheet.

<p>Title of Study: Investigating the barriers and facilitators to providing CBT based interventions to people with mild cognitive impairment and dementia</p> <p>Department: UCL Division of Psychology and Language Sciences</p> <p>Name and Contact details of UCL Data Protection Officer: Lee Shailer data-protection@ucl.ac.uk.</p>	<p>Name and Contact Details of the Researcher: Samantha Baker 1-19 Torrington Place, WC1E 7HB Email: samantha.baker16@ucl.ac.uk</p> <p>Name and contact details of Principal Researchers/Supervisor: Dr Joshua Stott 1-19 Torrington Place, WC1E 7HB Email j.stott@ucl.ac.uk</p>
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Thank you for considering taking part in this research. The person organising the research must explain the project to you before you agree to take part. If you have any questions arising from the Information Sheet or explanation already given to you, please ask the researcher before you decide whether to join in. You will be given a copy of this Consent Form to keep and refer to at any time.

I confirm that I understand that by ticking/initialling each box below I am consenting to this element of the study. I understand that it will be assumed that unticked/initialled boxes means that I DO NOT consent to that part of the study. I understand that by not giving consent for any one element that I may be deemed ineligible for the study.

		Please tick
1.	I confirm that I have read and understood the Information Sheet for the above study. I have had an opportunity to consider the information and what will be expected of me. I have also had the opportunity to ask questions which have been answered to my satisfaction	
2.	I understand that I will be able to withdraw my data up to four weeks after completion of the survey.	
3.	Use of the information for this project only I understand that data gathered in this study will be held securely and anonymously. I understand that data provided will be affiliated with the service unless small amounts of data are received that could potentially identify service users, in which case the data will be reported anonymously.	
4.	I understand that my information may be subject to review by responsible individuals from the university for monitoring and audit purposes.	
5.	I understand that my participation is voluntary and that I am free to withdraw at any time without giving a reason.	

	I understand that if I decide to withdraw, any data I have provided up to that point will be deleted unless I agree otherwise.	
6.	I understand the potential risks of participating.	
7.	I understand the direct/indirect benefits of participating.	
8.	I understand that the data will not be made available to any commercial organisations but is solely the responsibility of the researcher(s) undertaking this study.	
9.	I understand that I will not benefit financially from any possible outcome it may result in in the future.	
10	I agree that my anonymised research data may be used by others for future research. No one will be able to identify you when this data is shared.	
11	I understand that the information I have submitted will be published as a report and I wish to receive a copy of it. Yes/No	
12	I hereby confirm that I understand the inclusion criteria as detailed in the Information Sheet and explained to me by the researcher.	
13	I hereby confirm that: (a) I understand the exclusion criteria as detailed in the Information Sheet and explained to me by the researcher; and (b) I do not fall under the exclusion criteria	
14	I am aware of who I should contact if I wish to lodge a complaint.	
15	I voluntarily agree to take part in this study.	
16	I would like my contact details to be retained so that I can be contacted in the future by UCL researchers who would like to invite you to participate in follow up studies to this project, or in future studies of a similar nature.	

I have carefully read the above information and would like to proceed with the survey	
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Please tell us about your service.

What geographical area is your service commissioned to cover?

Who is the provider of your service?

- a. NHS trust
- b. Private enterprise
- c. Third sector organisation

How many people in total were referred to your service for the financial year 6th April 2017 – 5th April 2018?

How many people in total entered treatment at your service for the financial year 6th April 2017 – 5th April 2018?

Does your service have an upper age limit?

- a. No upper age limit
- b. Upper limit of <50 years
- c. Upper limit of 51-60 years
- d. Upper limit of 61-70 years
- e. Upper limit of 71-80 years
- f. Upper limit of 81-90 years
- g. Upper limit >90 years

How many older adults were referred to your service in the financial year 6th April 2017 – 5th April 2018?

How many older adults (aged 65+) entered treatment in your service in the financial year 6th April 2017 – 5th April 2018?

Does your service have a nominated worker with a special interest or role regarding:

- a. Older adults
- b. People with MCI or dementia
- c. No nominated roles in these areas

Please tell us about your service in relation to people with mild cognitive impairment or dementia.

1. Are people with dementia included or excluded from your service eligibility criteria for talking therapy support with a common mental health problem? Please select only one response, do not include people with MCI in this answer.
 - a. Our eligibility criteria state that people with dementia **can** receive our service
 - b. Our eligibility criteria state that people with dementia **cannot** receive our service
 - c. There is **no service policy** addressing the suitability of our service for people with dementia but **a referral would be considered and a service offered if appropriate**
 - d. There is **no service policy** addressing the suitability of our service for people with dementia and **a referral of this kind would be declined**
2. If yes (a or c are selected), do you collect data about how many people with dementia you offer a service to?
3. Are people with mild cognitive impairment (MCI) included or excluded from your service eligibility criteria for talking therapy support with a common mental health

problem? Please select only one response, do not include people with dementia in this answer.

- a. Our eligibility criteria state that people with MCI **can** receive our service
 - b. Our eligibility criteria state that people with MCI **cannot** receive our service
 - c. There is **no service policy** addressing the suitability of our service for people with mild cognitive impairment but **a referral would be considered and a service provided if appropriate**
 - d. There is **no service policy** addressing the suitability of our service for people with mild cognitive impairment and **a referral of this kind would be declined**
4. If yes (a or c are selected), do you collect data about how many people with MCI you offer a service to?
5. For services who do collect this data, what is the total number of people with dementia accessing your service for the financial year 2017/2018? If this year's data is not available, please enter the last available year's data and specify the year. Please do not include people with MCI in this answer.
6. For services who do collect this data, what is the total number of people with mild cognitive impairment accessing your service for the financial year 2017/2018? If this year's data is not available, please enter the last available year's data and specify the year. Please do not include people with dementia in this answer.
7. If your service collects this data but collates people with MCI and people with dementia in the same record, how many people with either an MCI diagnosis or dementia diagnosis accessed your service for the financial year 2017/2018? If this year's data is not available please enter the last available year's data and specify the year. Please combine both people with MCI and dementia in this answer.

Appendix E: Interview recruitment email

Subject line: Research interviews investigating therapist experiences of working with people with dementia

Dear service manager

We are a research team at UCL writing to invite your staff to participate in our research about **therapist experiences of providing CBT interventions to people with mild cognitive impairment (MCI) or dementia**. We would really appreciate if you could please circulate the attached poster to your team. If you are able to display the poster in staff communal areas this would be very helpful.

We are a research team at UCL and the first to investigate access to psychological therapy services for these groups, which we hope will help us provide better support for people with MCI or dementia in the future. You heard from us recently about a survey opportunity; this email contains details of the follow up to our study, conducted in London.

We are interested to interview qualified psychological wellbeing practitioners and high intensity CBT therapists who **HAVE and HAVE NOT** worked with people with MCI and dementia who are experiencing common mental health problems. You do not need a specialist knowledge of this area to participate.

Further details...

This research is important because people with MCI or dementia often experience common mental health problems, but little is known about how they might access mental health services. We are interested to find out about the experience, beliefs and opinions of therapists working in primary care CBT services who may or may not work with this client group. It is hoped that this research will help us provide better support for people with MCI or dementia in the future.

As I am aware IAPT service managers and staff are very busy I will attempt to contact you about this study again to remind you to please share the details with your team. If you would like to hear more about the study I would be grateful if you would contact me at this email address for more information.

Thank you for your time
Yours sincerely
Samantha Baker
Trainee Clinical Psychologist
University College London

Supervised by Dr Josh Stott

Appendix F: Interview recruitment poster

IAPT STAFF NEEDED....

FOR RESEARCH INTO PSYCHOLOGICAL THERAPIES AND DEMENTIA

WE ARE LOOKING FOR LONDON BASED....

QUALIFIED PSYCHOLOGICAL WELLBEING PRACTITIONERS AND

HIGH INTENSITY CBT THERAPISTS

TO TAKE PART IN RESEARCH INVESTIGATING PSYCHOLOGICAL THERAPY FOR PEOPLE WITH MILD COGNITIVE IMPAIRMENT (MCI) OR DEMENTIA.

- WE WOULD LIKE TO SPEAK WITH PEOPLE WHO HAVE AND HAVE NOT WORKED AS THERAPISTS WITH THIS CLIENT GROUP.
- WE AIM TO UNDERSTAND FACTORS THAT AFFECT PROVISION OF CBT BASED THERAPY FOR PEOPLE WITH MCI OR DEMENTIA, FROM THE PERSPECTIVE OF PWPS AND HI THERAPISTS.
- PARTICIPATION INVOLVES A SINGLE INTERVIEW OF 1-1.5 HOURS.
- INTERVIEWS WILL TAKE PLACE IN OCTOBER AND NOVEMBER 2018 AT A LOCATION CONVENIENT TO YOU.
- PLEASE CONTACT THE EMAIL ADDRESS BELOW IF YOU ARE INTERESTED AND WOULD LIKE TO FIND OUT MORE. DETAILS OF ANY CONTACT WILL BE KEPT COMPLETELY CONFIDENTIAL.

YOU WILL RECEIVE £20 IN SHOPPING VOUCHERS TO THANK YOU FOR PARTICIPATING.

ALL INTERVIEWS WILL REMAIN ANONYMOUS

PLEASE CONTACT....

SAMANTHA BAKER ✉ SAMANTHA.BAKER.16@UCL.AC.UK

THIS STUDY HAS BEEN APPROVED BY THE UCL RESEARCH ETHICS COMMITTEE - PROJECT ID NUMBER CEHP/2015/531



Appendix G: Interview information sheet for participants



Information Sheet for Adult Participants in Research Studies

UCL Research Ethics Committee Approval ID Number: CEHP/2015/531

You will be given a copy of this information sheet.

<p>Title of Study: Investigating the barriers and facilitators to providing CBT based interventions to people with mild cognitive impairment and dementia</p> <p>Department: UCL Division of Psychology and Language Sciences</p>	<p>Name and Contact Details of the Researcher: Samantha Baker 1-19 Torrington Place, WC1E 7HB Email: samantha.baker16@ucl.ac.uk</p> <p>Name and contact details of Principal Researchers/Supervisor: Dr Joshua Stott 1-19 Torrington Place, WC1E 7HB Email j.stott@ucl.ac.uk</p>
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We would like to invite you to participate in this doctoral research project. Before deciding, it is important for you to understand why the research is being done and what participation will involve. Please read the following information carefully. You should only participate if you want to. Ask us if there is anything that is not clear or you would like more information. Thank you for reading this.

What is the aim of this research?

This research is looking at the ability of people with mild cognitive impairment (MCI) or dementia to participate in cognitive behavioural therapy (CBT) or CBT-based interventions. People with MCI or dementia often experience common mental health problems like depression and anxiety, and we are interested to find out whether this client group can access CBT interventions. We would like to speak with clinicians to find out about their experience and their opinions of working with people with MCI or dementia and common mental health problems. You do not need to have worked with people with MCI or dementia in order to take part in this study and you do not need specialist knowledge of this client group. We are interested in clinicians' direct experience as well as the experience of people who have never worked with someone with MCI or dementia.

Why have we approached you?

We have asked you to participate in this study as a qualified Psychological Wellbeing Practitioner or CBT therapist who works in an IAPT service in England, who may or may not have direct experience of providing CBT or CBT based interventions to people with mild cognitive impairment (MCI) or dementia and common mental health problems. We are hoping to interview 15 participants for this study.

Do I have to take part?

It is up to you whether or not to take part. If you do decide to take part you will keep this information sheet and be asked to sign a consent form. You can change your mind at any time without giving a reason. Not taking part will not incur any penalties to you or your service.

What will happen to me if I take part?

If you are interested in taking part, please contact the researcher using the details above. We will have a short conversation to check that you meet the eligibility criteria, which is that you are a qualified PWP or CBT therapist in an IAPT service in London, and whether you have or have not worked directly with the client group; we hope to speak with clinicians with a range of experience in this area. The researcher will answer any questions you may have. If you still wish to take part, we will arrange a one-hour interview where you will be asked questions to find out a bit about your thoughts and opinions in providing CBT interventions to people with MCI or dementia and common mental health problems, whether you do or do not have direct experience with this client group. If you have not worked with this client group, we will still be interested to hear your thoughts and opinions about this work. The interview will take place at a confidential place of your choosing. This could be arranged at University College London, in your place of work, or over the telephone, a public library etc. It will take around an hour to complete all tasks. You can have a break at any point if you wish to.

A limited amount of personal information will be recorded for the research project. This will include your job role, the number of years you have been qualified as a clinician, and demographic information. Your name will be recorded along with a personal identifying number, and will be stored separately to your interview. This is only for the purpose of identifying your interview should you wish to withdraw your participation after the interview has been completed.

Will I be recorded and how will the recorded media be used?

This interview will be audio recorded and the content will be used for analysis and written into a report. The recording will be anonymous and kept separately from your consent form on a secure computer. No one will have access to the recordings apart from the researcher. The recordings will be kept for the duration of the project after which they will be securely destroyed when they are no longer needed. Any identifiable information included in the interview will be removed when the interview is transcribed and no identifiable information will be included in the interview. The intention is that the only person who might identify you from your comments in the published report is yourself.

What are the possible risks of participation?

Clinical staff are always very busy, and it is possible that participating in the study might increase time pressures and work stress. The content of the interview relates to your clinical experience however some of the questions may cause distress if you have a personal connection to the client group for instance a family member who has been diagnosed with MCI or dementia. You are welcome to take a break or change your mind about participation at any point before, during or after the interview, without giving a reason. There is a small risk that you could be identified by colleagues from your comments in the finished report if your experience was very unusual and your work colleagues are aware of your particular experience.

What are the possible benefits of participation?

You will be reimbursed for your time in £20 of shopping vouchers. Your contribution will be highly valuable to increasing knowledge about this client group and their wellbeing, as well as knowledge about IAPT services in England and the way that they operate. We hope that this research will improve our ability to support people with MCI or dementia and common mental health problems in the future.

What if something goes wrong?

We work hard to maintain the wellbeing of all of our participants. If you are unhappy with the way the project is being conducted and you wish to make a complaint, please raise your concerns with the researcher using the contact details above, or the research supervisor, Dr Josh Stott, at

j.stott@ucl.ac.uk . If you feel your complaint has not been handled to your satisfaction you can contact the Chair of the UCL Research Ethics Committee at ethics@ucl.ac.uk

Will my participation be kept confidential?

Your participation will be kept confidential. Your employer will not be informed that you chose to participate, however if you choose to be interviewed at work you should obtain your employer's consent. The content of your interview will be anonymised and any identifiable information that may arise in the interview and recording will be removed from the record, for example the name of the service you work for. Your ideas will not remain confidential as they will be included in the written report, but your comments will always be anonymous.

We will not ask for information about individuals you have worked with, and all patient information should be kept confidential and not shared with the researcher. In the event that potentially identifying patient information is inadvertently shared this will be removed from the record immediately.

Limits to confidentiality

Please note that assurances on confidentiality will be strictly adhered to unless evidence of wrongdoing or potential harm is uncovered. In such cases the University may be obliged to contact relevant statutory bodies to report the potential for harm.

What will happen to the results of the research project?

The results will be written in a report and disseminated in the psychology community. The report will be published as part of a doctoral thesis. Data collected will be processed and stored for so long as it is required for the research project, no longer than three years. Data will not be transferred outside of the EEA.

Data Protection Privacy Notice

The data protection controller for this project will be University College London (UCL). The UCL Data Protection Office provides oversight of UCL activities involving the processing of personal data and can be contacted at data-protection@ucl.ac.uk. UCL's Data Protection Officer is Lee Shailer and he can also be contacted at data-protection@ucl.ac.uk.

Your personal data will be processed for the purposes outlined in this notice. The legal basis that would be used to process your personal data will be the provision of your written consent. You can provide your consent for the use of your personal data in this project by completing the consent form that has been provided to you.

Your personal data will be processed so long as it is required for the research project and will be anonymised as outlined above. If you are concerned about how your personal data is being processed, please contact UCL in the first instance at data-protection@ucl.ac.uk. If you remain unsatisfied, you may wish to contact the Information Commissioner's Office (ICO). Contact details, and details of data subject rights, are available on the ICO website at <https://ico.org.uk/for-organisations/data-protection-reform/overview-of-the-gdpr/individuals-rights/>

Contact for further information

If you would like to discuss any aspect of the project please contact the researcher, Samantha Baker at the details above. The project supervisor is Dr Joshua Stott and he can be contacted on j.stott@ucl.ac.uk or 1-19 Torrington Place, WCE 7HB.

Thank you for reading this information sheet and for considering to take part in this research study.

Appendix H: Interview schedule

Interview topic guide

Explain MCI and dementia definition

Dementia is a progressive or chronic deterioration in cognitive functioning beyond that expected of normal ageing, accompanied by deterioration in emotional control, social behaviour and motivation	MCI is an interim stage between ‘normal’ cognitive ageing and dementia, defined as memory problems abnormal for the person’s age, with otherwise normal cognitive function and activities of daily living, and an absence of dementia
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Participant demographics – to describe the sample

Age, gender, ethnicity, professional role, number of years clinical experience since qualifying

Older adults

Have you ever worked with older adults?

- Current role/previously
- How do you feel about working with older adults?

What is your experience of this?

- Engagement
- Outcomes
- Challenges
- Positives

What do you know about the evidence base for CBT for older adults/guidelines for older adults in IAPT?

Dementia

Have you had any training on working with people with MCI or dementia in this role or elsewhere?

How would you rate your confidence in working with this client group in this role?

How might MCI or dementia affect a person’s ability to engage in CBT services?

What do you know about the guidelines or evidence base for working with people with MCI or dementia in primary care?

Have you ever worked with a person with MCI/dementia in this role?

- YES - What is your experience of this?
- NO - What are your thoughts on this?
 - Positive experience
 - Challenges
 - Engagement
 - Outcome for client
 - Impact on wider job role

There is a body of evidence that suggests that working with people with MCI/dementia in primary care CBT can be beneficial for this client group and NICE recommends psychological support.

What are your thoughts about offering this service (things that might help and possible barriers)

- Aspects of your job role/individual factors (prompt: would you want to offer this service, how easy/difficult would this be for you to offer, your values, therapeutic orientation)
- Aspects of your training (prompt: your knowledge/skills/experience,)
- Service factors (prompt: e.g. service structure, eligibility requirements, training, time, opportunity, supervision, inter agency working, service culture)
- Social/cultural factors (prompt: ageing population, role of older adults in the community, role of care receivers in the community, the role of the NHS in the community, IAPT in the context of other mental health services i.e. dementia specific/older adult services)
- Organisational/Political context (prompt: such as the role of guidelines themselves, the changing provision of NHS services, demands on NHS staff) *how services are commissioned, the impact of this on workers, on a person's ability to access the service etc*

Appendix I: Interview participant consent form



Informed Consent Form for Adult Participants in Research Studies

UCL Research Ethics Committee Approval ID Number: CEHP/2015/531

<p>Title of Study: Investigating the barriers and facilitators to providing CBT based interventions to people with mild cognitive impairment and dementia</p> <p>Department: UCL Division of Psychology and Language Sciences</p> <p>Name and Contact details of UCL Data Protection Officer: Lee Shailer data-protection@ucl.ac.uk.</p>	<p>Name and Contact Details of the Researcher: Samantha Baker 1-19 Torrington Place, WC1E 7HB Email: samantha.baker16@ucl.ac.uk</p> <p>Name and contact details of Principal Researchers/Supervisor: Dr Joshua Stott 1-19 Torrington Place, WC1E 7HB Email j.stott@ucl.ac.uk</p>
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Thank you for considering taking part in this research. The person organising the research must explain the project to you before you agree to take part. If you have any questions arising from the Information Sheet or explanation already given to you, please ask the researcher before you decide whether to join in. You will be given a copy of this Consent Form to keep and refer to at any time.

I confirm that I understand that by ticking/initialling each box below I am consenting to this element of the study. I understand that it will be assumed that unticked/initialled boxes means that I DO NOT consent to that part of the study. I understand that by not giving consent for any one element that I may be deemed ineligible for the study.

		Please tick
17.	I confirm that I have read and understood the Information Sheet for the above study. I have had an opportunity to consider the information and what will be expected of me. I have also had the opportunity to ask questions which have been answered to my satisfaction	
18.	I understand that I will be able to withdraw my data up to four weeks from the date of the interview.	
19.	I consent to the processing of my personal information (<i>my job role, my demographic information, my number of years' experience as a qualified clinician</i>) for the purposes explained to me. I understand that such information will be handled in accordance with all applicable data protection legislation.	
20.	Use of the information for this project only I understand that all personal information will remain confidential and that all efforts will be made to ensure I cannot be identified in the final report. I understand that my job role will affiliated with my comments in the final report.	

	I understand that my data gathered in this study will be stored anonymously and securely.	
21.	I understand that my information may be subject to review by responsible individuals from the University for monitoring and audit purposes.	
22.	I understand that my participation is voluntary and that I am free to withdraw at any time without giving a reason. I understand that if I decide to withdraw, any personal data I have provided up to that point will be deleted unless I agree otherwise.	
23.	I understand the potential risks of participating and the support that will be available to me should I become distressed during the course of the research.	
24.	I understand the direct/indirect benefits of participating	
25.	I understand that the data will not be made available to any commercial organisations but is solely the responsibility of the researcher(s) undertaking this study.	
26.	I understand that I will not benefit financially from any possible outcome it may result in in the future.	
27.	I understand that I will be compensated for my time spent in the study including if I choose to withdraw for £20 of shopping vouchers.	
28.	I understand that the information I have submitted will be published as a report and I wish to receive a copy of it. Yes/No	
29.	I consent to my interview being audio recorded and understand that the recordings will be: <ul style="list-style-type: none"> - Stored anonymously, using password-protected software for the duration of the project, accessed only by the researchers - destroyed when no longer needed for the purposes of the study, within three years 	
30.	I hereby confirm that I understand the inclusion criteria as detailed in the Information Sheet and explained to me by the researcher.	
31.	I hereby confirm that: <ul style="list-style-type: none"> (c) I understand the exclusion criteria as detailed in the Information Sheet and explained to me by the researcher; and (d) I do not fall under the exclusion criteria 	
32.	I have informed the researcher of any other research in which I am currently involved or have been involved in during the past 12 months.	
33.	I am aware of who I should contact if I wish to lodge a complaint.	
34.	I voluntarily agree to take part in this study.	

Name of participant

Date

Signature

Researcher

Date

Signature

Appendix J: Transcript and NVivo coding example

P: So that's IAPT right. Laughs. So it's kind of like ok that's another thing that's been introduced that we're supposed to be doing. Erm yeah so basically I suppose what I'm trying to say is that more will always be expected of the IAPT services but I can't see that the funding is going to grow, probably stay consistent but I can't see that it's going to grow so that where the issues lie. Erm, I'm just thinking about other things that might affect it. I think in a positive way the fact that people are maybe a bit more aware of dementia and the effect it has and how it can have an affect on mental health problems means that people are more likely to actually think about psychology, which is good because it means that people at least are given the opportunity to still have a decent quality of life even though they've got this condition. However the issue then there lies - it comes back to the same issue where actually this is what we're promoting but we're not necessarily putting more funding in so we can offer the support that we are saying is available.

S: So there's kind of an acknowledgement that people with MCI or dementia should be entitled to a better quality of life, CBT might be a good way to go about that but not really the resources to back that up?

P: Yeah exactly. That's what I think. Erm. I'm just trying to think about just generally what - and I suppose, we've just got more research I think a lot more money is being plugged into dementia research and this sort of research as well, probably hence them realising that actually psychology is great for it. Erm. But yeah I'm wondering whether perhaps kind of - I dunno actually well, whether a specific service could be developed for it on it's own, but there are older adult services and my thoughts are whether they actually cover that sort of work? I don't know. Yeah. So those are my thoughts.

S: Okay. Erm, let me just check whether there's anything else. I think you've mentioned most of it. The last prompt I've got here is around maybe in terms of political kind of context, around the changing provision of NHS services but you've kind of touched on that when you've just mentioned there are older adult services, but are they doing this kind of work? It sounds like you're not really sure?

P: Yeah, I don't know actually to be honest.

S: So is there something around how they're linked up then?

P: Yeah we're not very - well, all the services I've worked in I've never really been that linked up with any of the older adult services. They're there and I have referred into them, but we just didn't

