

Taking part in the Community Occupational Therapy in Dementia (COTiD-UK) intervention from the perspective of people with dementia, family carers and occupational therapists: a qualitative study

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Abstract

Aim

Community Occupational Therapy in Dementia (COTiD-UK) is a manualised intervention delivered to the person with dementia and their identified family carer primarily in their own home. The focus is on enabling both the person with dementia and their family carer to engage in personally meaningful activities. This qualitative study examines the experiences of people with mild to moderate dementia, their family carers and occupational therapists, of taking part in the COTiD-UK intervention.

Method

A purposive sample of 22 pairs of people with dementia and a family carer and seven occupational therapists took part in semi-structured interviews, that were audio recorded, transcribed and inductively analysed using thematic analysis.

Findings

Themes from the occupational therapist interviews relate to the COTiD-UK intervention philosophy and content, aspects of delivering it in practice and thinking ahead to it becoming usual practice. Themes from the pair interviews relate to the focus of COTiD-UK sessions on meaningful occupation and working together; and a sense of being able to plan to live well with dementia in the short- and longer-term as a result of the intervention.

Conclusion

This person-centred occupation focussed intervention was highly valued by people with dementia and their family carers and the occupational therapists delivering it.

Keywords

Qualitative, interviews, person with dementia, family carers, occupational therapy, psychosocial intervention

Introduction

Progression of dementia includes increasing difficulty with performing daily living tasks and meaningful activities (National Institute for Health and Care Excellence [NICE], 2018). Family carers are a crucial form of support in enabling people with dementia to stay within their own homes as their dementia progresses (Department of Health [DOH], 2009; 2012). For some family carers caring for a person with dementia can be rewarding, (Yap et al., 2010). Whilst others can find the increased stress and demands of caring leads to carer breakdown, and care home admission for the person with dementia (The Lancet Commission, 2017).

Non-pharmacological, multi-component, personalised interventions, which include cognitive, physical or social activities, can have a positive outcome on cognitive function, activities of daily living, delay admission to care homes and improve family carers' well-being (Oyebode & Parveen, 2019; Olazaran et al., 2010; Spijker et al., 2008). In the Netherlands, Graff and colleagues developed the Community Occupational Therapy in Dementia (COTiD) programme. A randomised controlled trial (RCT) demonstrated improved activities of daily living skills, quality of life, and mood in people with dementia; and improved quality of life, mood and sense of competence in family caregivers (Graff et al., 2006; 2007). COTiD was also found to be cost effective (Graff et al., 2008). This highlighted the potential value of occupational therapy being provided at an earlier point, and focussing on both the person with dementia and family carer. Therefore, COTiD had great potential for adaptation and adoption in the UK.

This study is embedded within a multi-centre, RCT that compared the clinical and cost effectiveness of Community Occupational Therapy in Dementia-UK version (COTiD-UK) to usual care (Wenborn et al., 2016). The RCT took place in 15 NHS Trusts across England. People with mild to moderate dementia were recruited together with a family carer as a pair. Participants were recruited via memory services and other health and social care services that support people with dementia and their families.

COTiD-UK is a manualised intervention focused on enabling meaningful occupation. It consists of up to 10 hours of community occupational therapy delivered over a period of approximately 10 weeks to the person with dementia and their family carer together. Each person identifies meaningful activities that are important to them through a narrative interview. The pair then agree joint and individual activity-based goals together with the occupational therapist. The sessions are delivered either in the person with dementia's home or in the local community – depending on the goals that have been set (Wenborn et al., 2016).

The COTiD-UK focus on meaningful occupation (activity) is core to occupational therapy. It involves facilitating a range of activities that participants can use inside and outside their home. The occupational therapist works in partnership with the pair, with each having their own need for meaningful activities, , hence COTiD-UK requires a high level of skill to deliver.

The aim of this study was to explore the experience of people with dementia, family carers and occupational therapists taking part in the COTiD-UK intervention. The objectives were to explore: 1) how people with dementia, their family carers and occupational therapists were involved in the COTiD-UK intervention; and 2) what meanings, beliefs and explanations people attach to the intervention. It was important to consider the participants' experience of taking part in this complex intervention as well as the statistical outcomes in order to fully interpret the results of the RCT (O'Cathain et al., 2014). The findings could also potentially inform the further development, refinement or delivery of this or other occupational therapy or non-pharmacological interventions.

Method

Design

This was a qualitative study, using semi-structured interviews with indicative topic guides, and inductive thematic analysis (Braun & Clarke, 2006).

Participants

A purposive sample of pairs and occupational therapists were recruited. A sampling framework was developed to address the diverse characteristics of participants, intervention experiences and location:

Pairs of people with dementia and family carers

- Demographics: age, gender, relationship between the pair (i.e. spousal / non-spousal), cohabiting or not, ethnicity
- Occupational Therapist who had provided COTiD-UK: level of clinical experience / number of pairs COTiD-UK delivered to
- Number of COTiD-UK goals set and the number achieved / partially achieved / not achieved
- RCT site – to reflect geographical and urban / rural spread

Occupational therapists

- Level of prior clinical experience (categorised as: novice, experienced and clinical specialist) / number of COTiD-UK pairs seen (representing level of COTiD-UK experience in practice)
- RCT site

Recruitment

Pairs of people with dementia and family carers

The sampling framework was used to obtain a purposive sample of pairs. The first author identified potentially suitable pairs through discussion with the occupational therapists who delivered COTiD-UK within the RCT. The local COTiD-UK occupational therapist initially invited a pair, explained what would be involved, and provided the study Participant Information Sheet. If the pair expressed interest in participating, the occupational therapist obtained both parties' written permission to forward their contact details to the first or second author, (whichever was going to conduct the

interview). The interviewer contacted the pair by telephone to explain more about the interview and answer queries. If the pair agreed to take part, the practical arrangements for the visit were made, and confirmed by letter. At the start of the visit, the interviewer received informed, signed consent from both individuals.

Occupational therapists

The sampling framework described was used to obtain a purposive sample. The first author identified potentially suitable occupational therapists through the COTiD-UK supervision structure. She emailed an invitation to participate, explaining what would be involved. If the occupational therapist agreed, then she passed their contact details to the third author who conducted the telephone interviews. Written informed consent was received prior to the interview.

Data collection

Interview development and content

Indicative Topic Guides were developed by the research team to explore the participants' experience, views and opinions. It was important to maximise the opportunity for the person with dementia to participate in the interview to provide their own perspective. Strategies aimed at maximising response and recall were used (Nygard, 2006), including visual cues (Murphy et al., 2014). This strategy was further informed by the team's clinical experience, and knowledge of the COTiD-UK intervention and associated materials that would be readily available from the occupational therapists who had delivered the sessions. Relevant prompts to maximise recall included: a photograph of the occupational therapist who had delivered the sessions; picture prompts used by the occupational therapist during the narrative interviews and intervention sessions; the summary cards used when setting the COTiD-UK goals, and the agreed list of goals. Table 1 presents the questions, with example prompts.

Table 1 Semi-structured interview questions and example prompts

The occupational therapist interviews

Question

Can you remember what goals you have set with the pairs?
 In terms of the activities that you have engaged in with your pairs, can you tell me a bit more about them?
 How did the support and training you received influence your confidence and ability to deliver the intervention?
 Can you give me an example of something that worked well?
 Did you have any issues in terms of transition once intervention was complete?
 What do you think of the programme after having taken part?
 How the COTiD-UK involvement impact on practice?
 What aspects do you think are missing from the programme?
 If COTiD-UK was available to be used regularly in your service would you be interested in it
 Would you recommend COTiD-UK to other OTs working with people with dementia?

Example prompt

Were you able to achieve them, to what extent?
 What made it possible/not possible?
 Did the pairs work on activities independently?
 What factors influenced the activities you worked on?
 Did that change from pair to pair? How? What helped with that? - peer support, supervision, training materials?
 And something that did not work so well?

 How do you think it relates to OT core skills and philosophy, therapeutic use of activity?
 Work patterns, changing role within team?
 What would you change - concrete examples

 If so, which aspects – why? Barriers for implementation? Resource issues?, Facilitators?
 Reasons - anything else like to share?

The pairs interviews

Question

How do you feel about the goals / activities you did with (name of OT)?
 What was it like working together, and with (OT)?

 Were the visits with (OT) what you expected, or different? If so, in what way?
 Did the sessions with (OT) happen at the right time after the start of your memory problems/diagnosis for you both?
 What difference has taking part in these sessions with (OT) made to your lives?

 Do you think you will continue to do these activities (or similar) in the future?
 What did you like about the sessions with (OT)? And why?
 What did you least like about the sessions with (OT)? And why?
 Would you recommend these sessions with an OT to other people like yourselves?
 Is there anything else you would like to share with us about taking part in these sessions?

Example prompts

I see you like doing...., How did that work? Were these activities familiar or new to you?
 How did you all get along? How did you plan your sessions/activities? How did you agree on the activities – was it easy/difficult to agree?
 Have you seen an OT before? Feelings re: flexibility of COTiD-UK?
 Would it be better offered sooner or later? After diagnosis, what kind of services/support, if any, did you receive - explore what and reasons?
 Any reported positive or negative outcomes, changes in activity levels, independence, confidence, function?
 If so – why? If not –why? Explore reasons

 Explore reasons

 Explore reasons

 Explore reasons

OT = occupational therapy/therapist

Interviewers

Authors 1, 2 and 3 are registered occupational therapists, with clinical and research experience of working with people with dementia and their family carers. They were all involved in training and supervising the occupational therapists to deliver COTiD-UK, and authors 1 and 2 also delivered the COTiD-UK intervention within the RCT. These three authors each conducted a pilot interview and following a reflective discussion with an experienced qualitative researcher not involved in the COTiD-UK training or provision, these interview data were deemed to meet the required quality to be included in the final dataset.

Interviews

Interviews with the pairs were conducted face to face in the person with dementia's home by the first and second authors within two weeks of the pair's final COTiD-UK session. The telephone interviews were conducted by the third author with the occupational therapists whilst they were at varying stages of providing COTiD-UK. Encrypted audio recorders were used to record the interviews to maximise data security.

Data Analysis

The interviews were transcribed verbatim by a professional transcribing service. The transcripts were checked for accuracy and anonymised by the first and second authors. The qualitative software programme QSR Nvivo 11 was used to support coding, management and organisation of the data (QSR International Pty Ltd, 2012).

Inductive thematic analysis was used (Braun & Clarke, 2006) to generate themes for the two datasets (the pairs and the occupational therapists). Authors 1 and 2 developed an initial coding framework for each dataset after reading through the anonymised transcripts and independently identifying phrases and words that described the pairs and occupational therapists' COTiD-UK

experiences. These were then developed into codes such as 'changes in activity levels' (pairs) and 'its real OT' (occupational therapists). Authors 1 and 2 then independently coded half each of the two datasets, meeting as necessary to refine the coding framework to include any emergent issues. To maximise reliability, authors 1 and 2 discussed progress periodically by telephone with author 5, a very experienced qualitative researcher not involved in delivering the COTiD-UK intervention. This iterative process enabled the authors to refine the codes and develop the themes' content and definitions.

To ensure that the final analysis represents the breadth and depth of accounts collected and potential for valuable additional insights supporting fuller interpretation a selection of indicative findings for the occupational therapists were shared with the independent VALID Occupational Therapy Reference Group. The group were asked whether they "rang true", if they resonated with their own experience (verisimilitude), whether there was anything unexpected included or omitted, and whether they reflected their own practice. The Reference Group confirmed that the indicative findings resonated with their own practice experience in particular the themes of "using real OT", valuing the focus of using meaningful occupation, and the opportunity of working in partnership with the person with dementia and their carer. Similarly, a sample of indicative findings from the pair interviews were shared and discussed with the VALID Patient and Public Involvement Reference Group (PPI), comprising former spousal carers of people living with dementia. Again they were asked to check the verisimilitude of indicative findings, unexpected or omitted findings and how they may have reflected their own personal lived and caring experience. In their discussions, the PPI group articulated how and how far the indicative findings resonated with their own experience, in particular valuing the opportunity to tell their individual stories, to feel they were being listened to and being offered individualised goals to work on in partnership with the occupational therapist.

Findings

Occupational Therapists

The occupational therapists' prior level of clinical experience in working with people with dementia and family carers included one novice, four experienced and two clinical specialists. At the time of interview they had delivered COTiD-UK to between three and twelve pairs each. There was a wide geographical spread of areas with three covering urban and four covering rural areas. The occupational Therapist participant characteristics are summarised in Table 2.

Table 2 Characteristics of occupational therapist participants

| Occupational Therapist ID | Site | Level of OT Clinical experience | No of pairs worked with at time of interview |
|---------------------------|-------|---------------------------------|--|
| OT1 | Urban | CS | 10 |
| OT2 | Rural | E | 4 |
| OT3 | Urban | E | 9 |
| OT4 | Urban | CS | 12 |
| OT5 | Rural | N | 3 |
| OT6 | Rural | E | 10 |
| OT7 | Rural | E | 5 |

OT –Occupational Therapist, N- Novice, E-Experienced, CS-Clinical Specialist

Author 3 conducted the occupational therapist interviews between November 2016 and January 2017 which lasted between 34 and 54 minutes. The following themes were identified: (1) valuing the occupational focus of COTiD-UK; (2) timing and relationships; (3) achieving goals. These themes and their subthemes are summarised in Table 3.

Table 3. Themes and subthemes identified from the occupational therapist interviews

| Theme | Sub-theme |
|--|--|
| Valuing the occupational focus of COTiD-UK | Meaningful occupation |
| | Using occupational therapy core skills |
| | COTiD-UK is a complex intervention |
| | Focussing on the family carer as an occupational being |
| | Meeting the family carers own needs |
| | Developing the family carer's coping strategies |

Timing and relationships

Timing of diagnosis
Time to listen / to get to know people
Carrying out “activities”
Delivering COTiD-UK
Relying on other services / resources
The dyadic relationship
Collaborating

Achieving goals

Identifying potential goals
Selecting and prioritising
Writing goals
Achieving goals - factors that enable / hinder

Valuing the occupational focus of COTiD-UK

This theme relates to the content of the intervention itself, primarily its focus on occupation (activity) for both the person with dementia and the carer.

COTiD-UK, with its focus on using meaningful activity as the means and the end of the therapeutic process is seen as being “real Occupational Therapy” and what people are trained to do, as endorsed by one interviewee;

“It is OT you know, it’s pure OT’ (OT 3)

Four of the occupational therapists who usually worked in a generic role within a multidisciplinary team reported valuing the time COTiD-UK gave them to utilise their occupational therapy core skills, specifically the activity engagement focus, which a novice OT found reassuring;

“ because it’s so occupational focussed and it, it brings you back to what we should be doing. you know it’s what we trained to do“ (OT 5)

All the occupational therapists especially valued the opportunity to use specific occupational therapy core skills such as: assessment, activity analysis, activity adaptation, environmental

assessment and adaptation, therapeutic use of self and modelling techniques within COTiD-UK as described by this more experienced participant.

“I think certainly in terms of the core skills it--it is utilising you know it is based on our core skills..... more so than we're able to ..to these days with the-pressures and generic working” (OT 7)

Occupational therapists described the complexity of COTiD-UK, recognising that there are a number of inter-related component parts, many of which reflect occupational therapy core skills:

“the assessment, the information gathering side, the carer side...the focus around activity and skill maintenance and looking at planning for the future, it's all there bringing our skills” (OT 2)

All occupational therapists discussed the carer focus of COTiD-UK. This included recognising the carer as an individual with their own meaningful occupations (activities), meeting their own needs, and enabling them to develop their own coping strategies for the present as well as future. This was seen as important, and different to their usual clinical practice that focusses on enabling the practical aspects of the carer's caregiving role:

“I think including the carer for me was a big thing...them having you know some kind of occupation, you know their own roles” (OT 1)

The occupational therapists described the individual time they spent focussing on the carers' own need for meaningful activity and balance.

“I think the carer being listened to and their story having significance” (OT 3)

These individual sessions enabled the carer to open up, feel valued as an individual and provided opportunity to explore and develop their own coping strategies to support them in managing situations that were causing them stress or difficulties.

“I think because I’ve had more time to work with the carer about I guess their understanding and I guess how their, how they’re adapting, and reassuring them that they’re doing a good job” (OT 2)

These comments emphasise how COTiD-UK focuses on meeting the family carers’ own needs for meaningful activity, and the opportunity to enhance their own coping strategies to use on a daily basis or in specific situations, thus enhancing their own wellbeing.

Timing and relationships

This theme relates to the process of delivering COTiD-UK. This can be influenced in several ways, primarily related to timing and relationships.

In terms of timing in relation to the stage of dementia, most occupational therapists felt that providing COTiD-UK would be optimal in the earlier stages following diagnosis. They described the early to moderate stages of the disease progression as being more conducive to preventing risks in the future, with individuals and carers able to plan, organise, make adaptations and increase their awareness of support and strategies available.

“If you can get in there in those earlier stages and when there might not be you know real big problems happening for somebody or for the couple that actually overall that can be more effective because you can get things working better and you know their quality of life can be at a level where then those other problems then don't develop...” (OT 7)

However, another experienced occupational therapist felt that there needed to be awareness too about ensuring individuals and carers do not become too overwhelmed with information, advice and needing time to come to terms with the diagnosis.

“It hasn’t quite sunk in or they’re not quite sure what to do with it and they’ve got all this Information. Whereas I think if we can go out just a bit later when... they’ve kind of processed that” (OT 2)

In addition, the occupational therapists also valued the time that COTiD-UK provided for them to get to know the person with dementia and carer, enabling them to ‘really listen’ to their individual stories, to identify what was important to them, what they would like to work on individually or together and the opportunity to actually engage in activities with the pairs.

“It’s the actual not just giving the information but then actually seeing that through with them and actually practising the, the activity with them you know trying it out with them.” (OT 7)

However, the occupational therapists also acknowledged that when goals were not met within the COTiD-UK intervention timeframe of ten hours this was often dependent upon on other resources and services not being available as reflected by this participant:

“I’ve had to delay things a little bit, I was waiting for a piece of equipment to arrive so it was pointless me going to visit without this bit of equipment because I’d be eating into my hours” (OT 6)

Two aspects were identified as to how relationships affected the delivery of COTiD-UK.

Firstly, occupational therapists talked about how the pre-existing relationship between the pair themselves affected the intervention delivery. It was seen to be easier if the pair had a good relationship, as described here:

“Yeah when you've worked with both of them. And when they have a good relationship, I think that's quite key.” (OT 4)

Conversely, it could be more challenging to work with pairs whose relationship was less positive:

“there was one pair that was particularly difficult because there were lots of dynamics between them. I had to meet them individually, they had quite a controlling relationship and to get them in the same room was quite difficult” (OT 4)

Secondly, occupational therapists described how they worked together in a collaborative relationship with the pair, in order to identify, agree and achieve goals.

“it was always in collaboration, you get to know the persons” (OT 1)

Achieving goals

This theme relates to the process of identifying, setting and achieving goals. The occupational therapists identified a range of factors that could impact on pairs identifying, selecting, prioritising and achieving goals, including: levels of insight, coming to terms with their diagnosis, underlying physical health conditions, level of ability, motivation and confidence, other appointments and pre-

existing routines/activities; and feeling of ownership of the goals set; as described by two participants:

“People aren’t well, or people go on holiday, so people take longer than anticipated” (OT 6)

Using the Specific, Measurable, Achievable, Realistic, Timed (SMART) format (Schut & Stam, 1994) to write goals, enabled the occupational therapists to clarify with pairs what would be realistic goals to set, and the capabilities and expectations of the pair within the COTiD-UK timeframe. The occupational therapists all emphasised the need to use specific strategies to support goal achievement such as breaking goals down step by step or using practicable modelling and problem-solving techniques as described below:

“But then I worked with them, you know, each time I went, we went through, they tried it, I tried it, to show them the kind of demonstration” (OT 1)

People with dementia and family carer pairs

Twenty-two pairs were interviewed. The age of people with dementia ranged from 58 to 91 years, the carers’ age ranged from 38 to 88 years. Eighteen of the pairs were in a spousal relationship and four carers were adult children. Seventeen pairs were white British and all but two pairs co-habited. The pairs’ characteristics are summarised in Table 4.

Table 4 Characteristics of people with dementia and family carer participants

| Pair ID | Site | PWD Demographics | | FC Demographics | | Therapist | | | Goals | | | |
|---------|------|------------------|-----------|-----------------|---------------------------|------------------------|---|----|-----------------|----------------|---|---|
| | | Gender | Ethnicity | Ethnicity | Relationship of FC to PwD | OT Clinical Experience | | | Goals set | Goals achieved | | |
| | | M | F | | | N | E | CS | No of goals Set | A | P | N |
| | | | | | | | | | | | | |

| | | | | | | | | | | | | | |
|-----|-------|---|---|-------------|-------------|--------|---|---|----|---|---|---|---|
| 001 | Urban | | X | Asian | Asian | Child | | | CS | 4 | 4 | | |
| 002 | Urban | X | | W.Brit | W.Brit | Spouse | | | CS | 5 | 3 | | 2 |
| 003 | Urban | | X | W.Brit | W.Brit | Child | | E | | 5 | 4 | | 1 |
| 004 | Rural | | X | W.Brit | W.Brit | Spouse | | E | | 5 | 5 | | |
| 005 | Rural | | X | W.Brit | W.Brit | Spouse | | E | | 2 | 1 | | 1 |
| 006 | Rural | X | | W.Brit | W.Brit | Spouse | | E | | 5 | 4 | 1 | |
| 007 | Urban | X | | Carib | Carib | Spouse | | | CS | 3 | 3 | | |
| 008 | Urban | X | | W.Brit | W.Brit | Spouse | | E | | 4 | 4 | | |
| 009 | Rural | | X | W.Brit | W.Brit | Spouse | N | | | 5 | 4 | | 1 |
| 010 | Rural | | X | W.Brit | W.Brit | Spouse | | E | | 6 | 4 | 1 | 1 |
| 011 | Rural | | X | W.Brit | W.Brit | Spouse | | E | | 4 | 4 | | |
| 012 | Rural | X | | W.Brit | W.Brit | Spouse | | E | | 3 | 3 | | |
| 013 | Urban | | X | Other white | W.Brit | Spouse | | | CS | 4 | 3 | 1 | |
| 014 | Urban | X | | Indian | Indian | Child | | | CS | 6 | 6 | | |
| 015 | Rural | X | | W.Brit | W.Brit | Child | N | | | 4 | 4 | | |
| 016 | Rural | X | | W.Brit | W.Brit | Spouse | | | CS | 4 | 4 | | |
| 017 | Urban | X | | W.Brit | Other Black | Spouse | | | CS | 4 | 4 | | |
| 018 | Rural | | X | W.Brit | W.Brit | Spouse | N | | | 4 | 1 | 3 | |
| 019 | Rural | X | | W.Brit | W.Brit | Spouse | N | | | 5 | 3 | | 2 |
| 020 | Urban | X | | W.Brit | W.Brit | Spouse | | | CS | 6 | 3 | | 3 |
| 021 | Rural | X | | W.Brit | W.Brit | Spouse | | E | | 4 | 3 | 1 | |
| 022 | Rural | | X | W.Brit | W.Brit | Spouse | | E | | 4 | 4 | | |

Interviews with the pairs were conducted face to face by the first two authors between February 2017 and October 2017 and lasted between 38 and 65 minutes. .

The following themes were identified: (1) achieving goals; (2) working together; (3) the effect of dementia, and are summarised in Table 5.

Table 5. Themes and subthemes identified from the interviews with people with dementia and family carer pairs

| Theme | Sub-theme |
|------------------------|--|
| Achieving goals | Identifying what is important to the pair Setting goals |
| Working together | Achieving goals Valuing the occupational therapist's approach Pairs as active participants within the process Engaging in activities together |
| The effect of dementia | Recognising the signs Dementia impacting on activity engagement Engaging in activity is also affected by physical health Timing COTiD-UK delivery |

Achieving goals

People with dementia and carers valued the opportunity to talk with, and set meaningful goals with, the occupational therapist as the following carer reflected:

“A lot of what mum and I spoke about were quite similar in what were important to us it was a little bit easier to come up with these goals because they were quite similar” (pair 001 – carer)

Pairs identified factors that they felt had been taken into account by the occupational therapist for the goals set to be realistic and achievable, including: their physical health condition, the severity of dementia, and their pre-existing routines and activities, as illustrated by the spouse of a woman living with dementia:

“well we did make plans but unfortunately the first time we had to cancel, she had a urine infection and was quite poorly..... It interfered with what we planned” (pair 022-carer)

Carers identified a range of strategies used by the occupational therapists as being crucial to achieving their set goals. Such support included: providing information and signposting, developing problem solving and enabling approaches, completing referrals to services as well as jointly working alongside the pairs, as reflected by one pair:

“I think for me it's just made me try to not just go down that straight path but to find other ways around things and to think things through differently” (pair 020 – carer)

Conversely, comments from pairs acknowledged that achieving their goals were often hindered due to: their physical health problems; delays in waiting for local resources or services required to achieve goals, for example equipment provision or a therapeutic group, as noted by one of the people living with dementia.

“Yes, we haven't done that, 'cos we can't, we've tried to get on... I think there was one here but of course they're full up, nearly everybody wants to learn to use a computer” (pair 018-person with dementia)

Working together

Accounts from pairs valued the occupational therapist's flexible, open and honest approach and communication skills, including: listening, and understanding the situation of those taking part in the intervention, and what matters to them; normalising the conversation and their situation; motivating and enabling them to go at their own pace as described below by participants living with dementia:

“I find I was able to talk to her...really talk to her, no inhibitions” (pair 011-person with dementia)

Discussion with pairs also showed how COTiD-UK gave them opportunities to be active participants working both with the occupational therapist and also independently on their own initiative throughout. Some reported that the occupational therapist's supportive and enabling approach gave them confidence to work on their goals by themselves as reflected below:

*“Yeah, it wasn’t bad, because we just got on with it. So next time we came we had it organised isn’t it? .. (carer) “ Yeah and she saw the progress you know, we had made.”
(Person with Dementia - pair 017)*

Other pairs described that having the occupational therapist working alongside them step-by-step to actually engage in their chosen activities, gave them much more confidence to achieve goals.

“Because I don't think you would have gone, joined this thing would you? She sort of encouraged you and she said 'I'll go with you again' and she took you and she said 'I'll come and take you again' (pair 002–carer)

The effect of dementia

Many pairs relating their stories described how they had first noticed the signs of dementia, in terms of how it affected the person’s ability to carry out familiar activities:

“we were in the garden, I thought whatever is he trying to do there? and it was a bit of a shock, he didn’t know where to put the plug in to mow the grass” (pair 021 carer)

People with dementia described how their ability to carry out previously familiar or valued activities was affected:

“well the thing is I was driving all the time, it was a big setback for me...just got in the car and went...and now I can’t (pair 001-person with dementia)

Family carers also described how the symptoms of dementia such as memory impairment, and the impact on carrying out activities had affected their own roles and the subsequent need to provide practical support with everyday tasks such as dressing, paying bills.

“We seem to be doing things for him, everything now, prompting... I'm more like his mum these days” (pair 022-carer)

The impact of other physical or medical conditions on the person’s ability and opportunity to engage in meaningful activities was also highlighted:

“I haven’t enjoyed the best of health for the last eighteen months and now I’ve got the pacemaker fitted” (pair 009-person with dementia)

The pairs discussed the optimal time to be offered COTiD-UK in relation to the severity of dementia. The majority felt that it was of most use and best provided in the earlier stages following diagnosis. This was because they were then able to plan and adapt to changes in the future and still focus on engaging in their own valued activities as reflected below:

*“by the time this project started and the OT came along obviously you weren’t driving and other things were happening. You know your vision had got worse and you weren’t reading and writing and it seemed to be good timing in helping us work on these”
(pair 010-carer)*

Some people with dementia felt that COTiD-UK would not have been useful any earlier e.g. immediately after diagnosis as they felt time is needed to fully come to terms with the diagnosis and potential changes in their future, such as the ability to drive and make financial decisions:

“And another thing too is of course that it can be variable can’t it, because for any, person that’s going into this process, you know at the beginning it might be a bit difficult and so you might want a gap, you know?” (pair 017-person with dementia)

Discussion

This qualitative study explored the experience of occupational therapists and pairs of people with mild to moderate dementia and their family carer of taking part in the COTiD-UK intervention, as delivered within the VALID RCT.

Occupational therapists valued the occupational focus of COTiD-UK, describing it as ‘real OT’. They discussed various aspects that affected its provision, namely timing and relationships, as well as the factors and strategies that enabled goal achievement. The pairs valued the occupational therapists’ approach and being able to work together to identify and achieve their activity-based goals, and discussed their experience of how dementia affects activity engagement.

There was some overlap between the occupational therapists’ and pairs’ themes, albeit they tended to use different language to describe the same things.

Both the occupational therapists and pairs recognised the effect and impact of dementia as well as other physical health conditions on the ability to carry out activities. Occupational therapists used therapy-specific language to describe how they had taken these factors into account when identifying and setting goals with the pair. They explored realistic expectations with the pair, taking time to explore potential barriers, to encourage the pair’s ownership of the goals, to enhance motivation. The pairs reflected how the occupational therapist had taken into account their limitations to agree realistic goals with them, and provided advice on managing or adapting to these in order to achieve their valued activities.

Pairs reported feeling that the occupational therapist had really listened to what they had said, and understood what was important to them when agreeing their goals, referring to 'working together'. They valued how the therapist had enabled them to go at their own pace as well as feel in control by being active partners within the process. Occupational therapists provided similar examples of facilitating pairs to take the lead and initiative within the theme of 'collaborating'. These examples illustrate how the principles underpinning the current shift to enabling people to have more control over their own health and well-being and receiving more personalised care, can be put into practice (DOH, 2019).

Both groups felt that the optimal time for COTiD-UK was in the earlier stages of dementia. It had to be at the point that pairs recognised the impact of dementia on carrying out familiar or meaningful activities, and thereby the need for input; but not so early on that pairs had not had the time to absorb the diagnosis. Most people express a wish to know their diagnosis (Pinner & Bouman, 2003). A timely diagnosis is important so that the person with dementia and their family can benefit from interventions to reduce or delay symptom progression, and access support services (The Lancet Commission, 2017). The appropriate support provided at the optimal time can reduce carer stress and subsequent care home admission. It is important for people with dementia and their families to plan for the future. COTiD-UK contributes to this by providing the carer with skills and coping strategies to use in the short and longer-term, as well as adapting the environment to optimise activity engagement. UK Memory Assessment Services accreditation standards require: "Access to in-depth assessment of occupational functioning" {Standard 123}; "Input from psychologists and occupational therapists is sufficient to provide evidence-based interventions" {179}; "Access to advice and support on assistive technology and telecare solutions to assist people with activities of daily living" {187}; and "Carers are offered an assessment, and intervention(s) if appropriate, for their psychological, emotional and social needs" {190} (Royal College of Psychiatrists, 2020). The

provision of occupational therapy interventions such as COTiD-UK contribute to meeting these standards.

Participants had valued the opportunity to carry out activities together. Pairs described this in terms of it encouraging them to actually take part, learning useful coping strategies, and thereby building their confidence in activity engagement. This highlights the use of activity as both the means and the end of the occupational therapy process. The occupational therapists talked about having the opportunity to utilise their core skills of activity analysis, adaptation and grading (Pentland, Kantarzis, Clausen & Witemyre, 2018). They described adapting and grading activities, and using strategies to enable goal achievement, including: breaking goals down into simpler achievable steps, having an end product or output to work towards, and illustrating goals in pictorial format rather than text. They described COTiD-UK as 'being real OT', using their core skills to enable pairs to engage in valued everyday activities or occupations in order to achieve optimal positive change. The therapists varied as to how much the COTiD-UK emphasis on activity and use of the occupational therapy unique core skills differed to their usual practice with those working in generic roles noting the biggest difference.

The occupational therapists emphasised the COTiD-UK focus on working with the carer as an individual in their own right, with a need to engage in their own meaningful activities. This was often in contrast to their usual practice which considered carers purely in terms of performing their carer role and tasks. Four of the occupational therapists usually worked in predominantly generic roles and therefore saw the greatest change from their usual practice. There is a challenge in balancing the need to work within a multidisciplinary team whilst maintaining the profession's focus on occupation within the therapeutic process (Pettican & Bryant, 2007; Parkinson et al., 2009). The majority of occupational therapists working with people with dementia and their carers in the UK combine profession-specific and generic roles; with the top two ranked generic tasks being risk

assessment, and carer support and advice (Swinson et al., 2016). In the same survey, the top three ranked profession-specific tasks were assessment, environmental adaptation, and community-based interventions. Carer-focused interventions were not listed as profession-specific activities, but categorised as an generic activity. One obvious explanation for this is that the usual median time of 2.5 hours of occupational therapy provision is a quarter of the ten hours allocated for COTiD-UK delivery (Swinson et al., 2016). This additional time therefore provides the time and opportunity to work with both the person with dementia and the carer to meet their own meaningful activity goals.

Study limitations and strengths

Telephone interviews may inhibit responses particularly given the absence of non-verbal and visual cues which could affect the richness of data generated, and means of interpreting participants' verbal responses (Novick, 2008), hence why this method was not utilised with the pairs. However, this method does enable research to include more geographically-dispersed participants as with the occupational therapists in this study, enabling purposeful and appropriate sampling strategies to be used (Block & Erskine, 2012). Telephone interviews were set up around the occupational therapist availability and did not appear to inhibit probing or in-depth discussions with the occupational therapists.

The pairs sample was not representative of the UK population in terms of ethnicity, as most pairs were white British. However, it can be difficult to recruit ethnic groups as the RCT eligibility criteria required participants to be fluent in English (Redwood & Gill 2013).

One strength of the study is its involvement of people with dementia. To mitigate limited recall, the interviewers used a variety of strategies including visual prompts. Inclusive techniques such as these enhance the involvement of people with dementia as conversation partners to elicit their views and opinions (Phillipson & Hammond, 2018). It could be argued that interviewing the pairs together may

have inhibited honesty, however the interviewers utilised strategies to support the voice of the person with dementia. These included; checking that the person with dementia agreed with what the family carer had said; noting non-verbal signs of agreement i.e. nodding their head or smiling; observing when they perhaps were wanting to say more and inviting their contribution whilst balancing the need to avoid making the person with dementia feel under pressure. Although the family carer often took the lead in answering, interviewers noted they often actively encouraged the person with dementia to express their views, for example, turning around to the person with dementia and asking if they agreed or encouraging them to speak if they had a different viewpoint. Family carers were keen to express that it was not just their opinion or views that mattered. There was no apparent difference of views between the person with dementia and their family carer for example each highlighted valuing the occupational therapist approach and communication in enabling them to set goals meaningful to each other.

This study enabled people with dementia to express their own views in their own words, enabling them to act as active, insightful and meaningful contributors throughout the interview process. Interviews and analysis were undertaken by three researchers who were experienced in working with people with dementia and family carers and had either provided COTiD-UK intervention or delivered the training. This could potentially be seen as being biased about the outcome, understanding the COTiD-UK intervention process did equip the interviewers to probe in more critical detail during the interviews. It also supported understanding the occupational therapy-focussed shorthand language used by the occupational therapists, and may have engaged those participants more as they knew they were being interviewed by a fellow occupational therapist. Including an 'external' researcher in the analysis team allowed scrutiny to check for potential 'insider bias' in conducting both of the interviews and analysis.

Implications for practice

The positive experiences reported by the pairs in this study indicate the importance of adopting a collaborative approach to facilitate people with dementia and their carers being actively involved in the intervention process. Utilising goal setting strategies which focus on the needs and preferences of pairs both as separate individuals and jointly can enable interventions to be more person-centred, and target outcomes that reflect activity engagement and participation of importance to the individuals rather than focussing on impairment. The study also highlights the importance of service timing, to ensure that health and social care professionals deliver interventions and enable access to appropriate support at the right time following the diagnosis of dementia. This maximises the opportunity for people with dementia and their families to continue with their valued activities, and to plan accordingly for the future.

Conclusion

This study explored the experiences of taking part in the COTiD-UK intervention from the perspective of people with dementia, their family carer and occupational therapists, all of whom identified positive features of working within a person-centred occupation-focussed intervention. They were able to identify specific impacts on the lives of both people with dementia and their carers from being able to engage with activities they themselves identified as having value for them, exploring ways they could sustain these activities further and being enabled to plan ahead to live well with dementia. The occupational therapists highly valued the intervention in that it provided them with the time and opportunity to utilise and to have the value endorsed of their core

occupational therapy skills and expertise to enable people with dementia and their family carers to engage in meaningful valued occupations.

Declarations

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Declaration of Conflicting Interests

The authors declare they have no competing interests.

Ethical Considerations

Approval was granted on 10th December 2015, REC Ref: 14/LO/0736, by London – Camberwell St Giles Research Ethics Committee. The recruitment documents were reviewed by the VALID Public and Patients Involvement Reference Group.

Consent for publication

Written informed consent for anonymised views to be published was given by all interviewees.

Availability of data and material

Not applicable.

Authors Contributions

Omitted for peer review stage, to be reinstated for publication

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