

Full title: Influences on uptake of a community occupational therapy intervention for people with dementia and their family carers

Short title: Uptake of occupational therapy by people with dementia and their family carers

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Abstract

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Research ethics

Ethical permission for the primary data collection undertaken as part of the VALID research programme was obtained from the NRES Committee Yorkshire & The Humber REC reference: 12/YH/0492, in 2012. Ethical permission for the secondary data analysis completed for this study was obtained as a substantial amendment to the VALID research programme protocol, from the NRES Committee London-Camberwell-St Giles REC reference: 14/LO/0736, in 2015.

Consent

All participants provided written informed consent to be interviewed as part of the VALID research programme. A substantial amendment to gain approval for using these interviews in the secondary analysis completed for this study was obtained NRES Committee London-Camberwell-St Giles (REC reference: 14/LO/0736).

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Contributorship

Becky Field researched the literature, applied for ethical approval (substantial amendment) and completed the secondary data analysis. All authors contributed to the methodology of the study and interpretation of data. Becky Field wrote the first draft of the manuscript. All authors reviewed and edited the manuscript and approved the final version of the manuscript.

INTRODUCTION

Living well with dementia is promoted nationally and internationally (Department of Health, 2009; Global Action Against Dementia, 2013). UK health policy recommends post-diagnostic support to enable people to live well in the community for as long as possible (Department of Health, 2015; NHS England, 2017; Scottish Government, 2017; Welsh Government, 2017). This is important given that a cure for dementia is not imminent. A growing evidence base demonstrates that psychosocial interventions can benefit people with mild to moderate dementia, by improving cognition, performance in valued activities or daily living skills, maintaining quality of life or carer coping. (Clare et al., 2011;2017; Graff et al.,2006,2007; Streater et al.,2016).

Occupational therapists offer interventions to people living with mild to moderate dementia and family carers (Swinson et al.,2016;Streater et al.,2016;Yuill and Hollis,2011). The National Institute for Clinical Excellence and Social Care Institute for Excellence (2006) recommended occupational therapists provide skills training for activities of daily living. Also, the Memory Services National Accreditation Programme recommends people with dementia have access to occupational therapy and other psychosocial interventions such as reminiscence, life story work or cognitive stimulation therapy, for the cognitive, emotional, occupational and functional aspects of dementia (Hodge et al.,2016). Such interventions can be delivered by occupational therapists. The focus on the benefits of non-pharmacological interventions provides occupational therapists with an opportunity, to deliver services that improve lives and the experience of dementia (Collier and Pool, 2016). Understanding what may influence uptake of such interventions is important if people with dementia and their carers are to benefit from what occupational therapists can offer. Yet what supports the uptake of such interventions, specifically by people with mild to moderate dementia and their family carers, living in the community is poorly understood and limited research about this topic exists. 'Uptake', in this paper, is defined as initial acceptance of an offer, of intervention, support or services, rather than continued engagement or adherence to an intervention over time.

The Valuing Active Life in Dementia (VALID) Research programme

The VALID research programme adapted, developed and evaluated the clinical and cost-effectiveness of a community occupational therapy intervention for people with mild to moderate dementia and their family carers. It is the largest study of occupational therapy for people with dementia ever conducted in the UK. The intervention was based on that initially

developed by Graff et al. (2006) in the Netherlands. The intervention was designed to promote independence, meaningful activity and quality of life for people in the mild to moderate stages of dementia and family carers. In the UK, intervention involved approximately 10 tailored sessions with an occupational therapist in people's homes or local communities. Assessment included interviews with both people and structured observation of activity. This was followed by personalised goal setting, based upon assessment findings, then supported practice and strategy use to achieve goals. Further details of the intervention and associated research are described elsewhere (Wenborn et al.,2016). This paper reports a secondary, qualitative analysis of post-intervention, semi-structured interviews conducted with people with dementia and their carers in the UK, as part of the VALID programme's development phase, which involved adapting the Dutch intervention to the UK setting.

LITERATURE REVIEW

There is evidence demonstrating the potential of occupational therapy to support people with mild to moderate dementia, and family carers, in the community (Graff et al., 2006. 2007). There is also evidence for other psychosocial interventions for people with dementia which can be delivered by occupational therapists, to support cognitive function (Streater et al., 2016;Yuill and Harris, 2011) achievement of meaningful goals (Clare et al., 2011, 2017), self-management (Sprange et al., 2015) or tailoring activities to reduce behavioural symptoms and functional dependence (Gitlin et al.,2018). Research about community service use and needs of people with dementia in the UK has reported outcomes or experiences of service use but not explicitly discussed influences on uptake of services (Corbett et al.,2012;Gilbert et al.,2017;Gorska et al.,2013;Innes et al., 2014). Chrisp et al. (2012) identified influences on the decision to first engage with the healthcare system by examining case studies of 20 carers of people with dementia attending UK memory clinics. This highlighted that the person with dementia not accepting symptoms, not wanting involvement of healthcare professionals and family resistance, could all constrain initial service engagement. Carers taking action, and responding to crises also supported engagement. Much of this research involved carers, but not both the carer and person with dementia (Chrisp et al., 2012;Gilbert et al.,2017). Evaluations of post-diagnostic support interventions reported by Gorska et al. (2013) and Innes et al. (2014) did involve both people with dementia and family carers. These interventions were found not always to have met needs or preferences. Concerns highlighted were the lack of alternative options to day care, locality, travel costs (Innes et al.,2014) and poor coordination of services and lack of staff continuity (Górska et al.,2013). Services offered at distant locations, or in unfamiliar environments have also been reported as being stressful and eroding independence

(Mountain and Craig, 2012). Overall, within this UK research, occupational therapy is not discussed specifically. Although Chrisp et al. (2012) described memory service provision as staffed by occupational therapists and consultant psychiatrists, influences on uptake or engagement with these specific services were not explicitly reported.

Gitlin et al.'s (2018) programme for carers was provided by occupational therapists in the USA, and the authors discussed whether carers being unable to continue with activities was a possible reason why positive effects were not maintained, but did not discuss influences on initial uptake. Gitlin and Rose (2014) examined carer readiness to use strategies, to modify behaviours of concern as part of an intervention delivered by occupational therapists. A rating system, modelled on the trans-theoretical model (Prochaska et al.,1992) was developed to reflect readiness to engage in strategies. The authors suggested that understanding caregiver readiness and factors associated with its change may be important considerations in psychosocial interventions. Although applied to carers only, the application of the trans-theoretical model (Prochaska et al.,1992) and concept of readiness to use strategies, in relation to dementia and psychosocial intervention, appears unique.

Also, the severity of dementia of the people with dementia being supported is not always described (for example, Chrisp et al.,2012;Gilbert et al., 2017;Gitlin and Rose, 2014). Thus it is not possible to know what proportion of the samples experienced mild to moderate symptoms of dementia. Therefore, despite some research in this area, there appears to be an absence of research focused on what may facilitate uptake of occupational therapy, or other psychosocial interventions, specifically aimed at people with mild to moderate dementia and their carers, in the community, in the UK. The secondary analysis of post-intervention interviews reported in this paper therefore aims to contribute to the evidence gap in this area.

STUDY AIMS

Within the context of the larger VALID programme's development phase, the aim of the interviews reported in this paper was to examine the acceptability of the intervention for participants in the UK, to inform its adaptation, prior to a randomised controlled trial. Using these interviews as a secondary data source, the aim of the analysis reported here was to:

- 1) Identify and explore influences on uptake of the VALID community occupational therapy intervention by people with mild to moderate dementia and their family carers
- 2) Identify implications for occupational therapy practice and research.

METHOD

Secondary data in the form of semi-structured paired interviews conducted with people with dementia and their carers, after they had participated in the community occupational therapy intervention, were analysed. Using pre-existing data is a valuable research method which can provide new insights into existing data and help investigate new research questions (Heaton, 2004; Lewis and Nicholls, 2014). The adequacy of the original data for this secondary analysis was carefully considered, as recommended by Lewis and Nicholls (2014). The interviews were originally conducted to examine the acceptability of the VALID intervention for participants in the UK. The decision to carry out a secondary analysis was informed by a recognition that non-linear responses are typical in qualitative interviews. Given this it seemed reasonable to explore whether participants discussed information relevant to issues of uptake, when being interviewed about acceptability of the intervention. Also, given the limited evidence about uptake of occupational therapy interventions by this client group, exploring existing, publicly funded, research data seemed worthwhile.

Recruitment

Participants were recruited to participate in the occupational therapy intervention from two NHS sites in England, as part of the VALID programme's development phase, inclusion criteria for this are outlined in Box 1. During this development phase, all participants were offered the intervention. Information about the intervention and research participation was provided to potential participants by clinicians working in NHS memory services or community mental health services. These included nurses, doctors, clinical psychologists and occupational therapists. Researchers then contacted potential participants, visiting them to take signed informed consent before intervention began. Approximately two weeks after intervention completion, participants were telephoned and asked if they would agree to be interviewed. Eligible participants for these qualitative interviews were pairs willing to be interviewed together, who had all previously consented to be contacted by the research team, and were within two weeks of intervention completion.

Box 1: Inclusion criteria for participants in the VALID research programme (development phase).

People with dementia:

- Diagnosis of dementia: between 0.5-2 on the Clinical Dementia Rating scale (CDR)¹
- Capacity to give informed consent to participate
- Living in own home or sheltered accommodation
- Receives regular support of two hours a week or more from a family carer (friend relative or neighbour)
- Family carer agrees to take part in the intervention
- Speak and understand English

Family carers/other supporters:

- 18 years or above
- Capacity to give informed consent to participate
- Provides support two hours a week or more
- Willing and able to take part with the person they support
- Speak and understand English

¹ The CDR is a rating scale used to indicate severity of dementia as mild, moderate or severe (Morris 1993)

There were 130 pairs who participated in the intervention during the VALID programme's development phase, at three UK sites. The programme initially planned a purposive sample, including a range of characteristics (such as age, gender, caring relationship, banding of occupational therapists delivering intervention). However, the programme also required that interviews occur two weeks post-intervention, given some participants may struggle with memory. Also, the programme's timeline required progression onto a pilot trial. This meant seeking a purposive sample was not possible in practice. Therefore, a convenience sample was obtained by the VALID programme, made up of intervention participants who had agreed to be interviewed. All those who agreed to be interviewed, were interviewed, resulting in 17 interviews. It is not known how many were approached in total or how many declined. The 17 pairs who gave interviews were drawn from a pool of 92 pairs, from two of the sites. One site's participants (38 pairs) could not be approached for interview as they had all completed intervention more than two weeks previously, by the time necessary ethical amendments were obtained.

Ethical issues

NHS ethical approval was obtained for the primary data collection as part of the VALID research programme protocol in 2012 (NRES Committee Yorkshire & The Humber REC reference: 12/YH/0492). A substantial amendment to gain ethical approval for using these

interviews in this secondary analysis was obtained in 2015 (NRES Committee London-Camberwell-St Giles REC reference: 14/LO/0736).

Capacity to consent to participate in the VALID research programme and these post-intervention interviews, by people with dementia was assessed according to the key tenets of the Mental Capacity Act (2005). That is, participants were able to understand, weigh up and retain information long enough to make a decision and communicate their decision about participation.

Participants

The convenience sample obtained was made up of 34 people: 17 people with dementia, interviewed together with 17 family carers (see Table 1 for sample characteristics). The secondary analysis reported in this paper was completed on all of the 17 interviews obtained by the VALID research programme.

Table 1: Main characteristics of interview participants

Gender	
Female	7
Male	10
Type of relationship	
Spousal relationship	12
Parent-child relationship	4
Friend	1
Type of dementia	
Alzheimer Disease	11
Vascular dementia	1
Mixed type dementia	2
Missing data	3
Severity of dementia¹	
Mild	7
Moderate	5
Missing data	5

¹rating from the Clinical Dementia Rating Scale (CDR) (Morris, 1993)

Data Collection

The 17 interviews were conducted by members of the VALID research team, including the first author (who completed three). Length of interviews was not recorded for the total sample. Interviews were held with the person with dementia, and their family carer, together, mostly in the homes of the people with dementia. Paired interviews were organised because

the intervention required both people, participating together. Interviews were semi-structured, guided by an indicative topic guide (see summary in Box 2).

Box 2: Summary of the indicative topic guide	
Experience of intervention	
<ul style="list-style-type: none"> ➤ What did you think about the intervention after you had taken part in it? ➤ What did you expect when you agreed to the intervention? ➤ Was what happened different to what you expected? ➤ Did you get the support and help you needed from the intervention? 	
Timing	
<ul style="list-style-type: none"> ➤ What do you think about the timing of the intervention / did it happen at about the right time, or not? 	
Changes to the intervention	
<ul style="list-style-type: none"> ➤ Are there any suggestions you would make? ➤ Would you recommend it to other people? 	

All participants provided written informed consent at the time of interview. All interviews were audio-recorded, and professionally transcribed. Interviewers checked the transcripts for accuracy of transcription.

Data analysis

Thematic analysis, based on Braun and Clarke (2006) was conducted. Table 2 presents the different phases of analysis completed.

Table 2: Phases of thematic analysis (adapted from Braun and Clarke, 2006)

Phase 1	Familiarisation	Each transcript read several times and notes made about content and ideas for initial codes
Phase 2	Generating initial codes	List of initial codes produced, applied to each transcript, list edited iteratively until all relevant data coded ¹
Phase 3	Searching for themes	Codes grouped into potential themes; coded extracts tabulated to help identify themes.
Phase 4	Reviewing themes	Groupings of codes and themes adjusted; sub-themes identified when grouped codes related to an overall theme but also needed specific attention
Phase 5	Defining and naming themes	Confirming theme content; decision made to use quotes from participants' as theme names to engage readers
Phase 6	Reporting	Selection and presentation of most salient themes and sub-themes in this paper.

¹ This process was 'theory driven' (Braun and Clarke, 2006, p. 88) as a result of asking particular questions of the data, i.e. what did people say that appeared relevant to their uptake of the intervention.

The first author led the thematic analysis, discussing coding and theme development with co-authors during the course of analysis. NVIVO 10 software was used to store and organise data. To ensure quality, the data were handled comprehensively, i.e. all transcripts coded, all coded data tabulated, iterative analysis to create codes and themes, identifying patterns across and within transcripts and interrogating the data for accounts which did not fit into main themes (Silverman, 2010), was completed.

Findings

Four main themes and two sub-themes were identified. The first was about how the impact of dementia on people, wanting support to adjust or cope with symptoms, influenced uptake. Within this, a sub-theme related to the timing of intervention offer being important to uptake. The second theme concerned whether people were looking for new activities, or whether they felt they had enough activity. A sub-theme identified that previous experience of other interventions may influence uptake of this or future interventions. The third theme was about the limited initial expectations people appeared to have about the intervention. The final theme was about positive attitudes towards trying the intervention, even though some felt uncertain or worried about participation. These themes and sub-themes are now presented, alongside illustrative quotes from participants (identified by interview number, as interviews were paired).

Theme 1: 'Grabbing at straws and keen to take part' – impact of dementia and wanting support

A key theme related to the impact of dementia on people's lives. Participants appeared to be receptive to the intervention where they were struggling to adjust to the diagnosis or cope with symptoms such as memory difficulties, lack of initiative or reduced activity levels. These quotes illustrate how some people struggled to come to terms with diagnosis, or cope with symptoms, which seemed to have made them receptive to the intervention offer.

Wife (family carer): *"...she (the OT) helped us at an appropriate time because we were both very distressed when we got the news and talking to the OT she did really help.*

Husband (with dementia): *"The same really, it was a vulnerable time....[we were having] difficulty in making sense of it all and what the implications were....She (the OT) did not play it down but she didn't ... whereas it was a bit doom and gloom at this end, that lifted us and so we got to look forward to seeing her."*

(Interview 5)

When discussing her response to the offer of intervention and the timing of this, another wife explained how she struggled to cope with her husband's impaired ability to initiate activity, saying:

Wife (family carer): *"Well, for me, I suppose I was grabbing at straws really and I was very very keen to take part...."*

(Interview 15)

Sub-theme: 'Sooner rather than later': offering intervention early post-diagnosis

The timing of intervention offer also seemed to influence uptake, alongside people's experiences of adjustment, symptoms or coping. For most, it was important to offer the intervention early after diagnosis. The following quote illustrates this preference:

Wife (family carer): *"...I think she [the OT] came at the right time...rather sooner than later."*

(Interview 4)

However there was one example of participants feeling that the intervention may have been offered a little early, because the person with dementia had been confused between the different services offered post-diagnosis.

Person with dementia: *"Yes I think it was a bit too much of a rush."*

Daughter (family carer): *"Because you was doing the Memory Clinic thing and then you kept getting them mixed up"*

Person with dementia: *"I did".*

Daughter: *"Because there was so many new people all coming along and I think, you know...maybe doing the 10week Memory Clinic thing and then after that maybe [having the intervention]."*

Person with dementia: *"Yes".*

(Interview 2)

Theme 2: "...we're trying to put a routine in" - Finding pleasurable and regular activity

This theme was about what people wanted to do, whether they were looking for new activities (for the person with dementia, or both people together). For those who wanted to establish a new activity, or maintain one, this encouraged receptiveness towards the intervention. The following quote highlights how this carer wanted to establish another social activity as part of her mother's routine,

Daughter (family carer): *"She (the OT) took you to the club didn't she?"*

Person with dementia: *“She did yes, yes.”*

Daughter: *“She took her a few times....cause my mum already goes to one club... but we said that she needed more, ‘cause we’re trying to put a routine in so we’ve found that’s a good thing...”*

(Interview 12)

Sub-theme: experience of other interventions

Some people referred to positive experiences with other psychosocial interventions, provided by the NHS, social care or voluntary sector. The following quote illustrates the impact of a positive previous experience of intervention, leading to receptiveness towards other potential offers of intervention:

Person with dementia: *“When I went to the Memory Clinic for 10 weeks....I enjoyed those, it was nice meeting other people and talking to others but whether there’s a chance of doing that again, I don’t know.”*

(Interview 2)

For others it seemed they felt they busy enough, and did not feel a need for this intervention, The following quote illustrates the influence of other interventions and activities being valued, leading to this person feeling less receptive to the intervention offered:

Wife (family carer): *“...we had decided we weren’t going to go on it [the intervention] really because we thought, well we are going out regular, we are going to all these memory cafes, we are doing several things, we are joining in with all that, and I really didn’t think it would make a lot of difference actually...”*

(Interview 14)

Theme 3: ‘We didn’t know what to expect’: limited expectations of intervention

This theme was about the limited initial expectations expressed about this intervention, by most of this sample. There were lots of examples of people saying things similar to ‘we didn’t have any expectations’, or ‘we didn’t know what to expect’, for example,

Husband (with dementia): *“I had no preconceived ideas at all about it”*

Wife (family carer): *“I was very nervous but she [the OT] soon made us feel at ease”*

Husband: *“I had no preconceived ideas at all about what it would be.”*

(Interview 5)

Despite these limited expectations, some participants, and all family carers, expressed the desire for emotional support, and/or education and information to help them understand symptoms, what to expect in the future or available services. So, although they had limited expectations or understanding of what this occupational therapy intervention may offer, they hoped to receive this sort of support, if not from this intervention, from other services.

A few people in the sample did express clearer expectations, which influenced their uptake of the intervention. For example:

Wife (family carer): *"...I was very excited about the idea of an OT coming into the house and I thought that the OT was going to lead activities... which I am sure would have been very, very productive..."*

(Interview 15)

Theme 4: 'Give it a go' – positive attitudes. This theme was about having a positive attitude that facilitated a willingness to try the intervention. When asked whether they would recommend the intervention to other people, many talked about 'giving it a go'. This attitude went alongside limited expectations or understanding of what the intervention might involve, or apprehension, and for all participants, no guarantee of a positive outcome.

Daughter (family carer): *"...I was very, not nervous but we were dubious of having somebody we didn't know every week, but my husband and I discussed it and we said it has been offered to us and we said we would try anything that is offered to us to help, and I am so glad that we did...."*

(Interview 7)

However, a few examples of people not wanting support, or of one person in the couple appearing reticent, initially, about intervention, but accepting the offer nevertheless were identified. Although all these people did accept the intervention, such accounts suggest that subsequent engagement in the intervention may be influenced by this perspective. The following quote highlights perhaps a personal disposition, of not wanting to discuss personal issues, but may also highlight dementia stigma. In this case, the interviewer asked if the person would recommend the intervention to others, and the person replied:

Person with dementia: *"Yes I would, but then again it depends on the circumstances concerned you know. I don't discuss anything like you have been, I*

won't discuss... I don't speak to my neighbours around here I would rather keep myself to myself. I know it's a poor attitude, but that's how it is."

(Interview 1)

In the full transcript of this interview, the person with dementia voices distrust of people visiting. It was unclear whether this was a symptom of dementia, or a long standing concern. Another person with dementia demonstrated some reticence about uptake, when asked about whether intervention had been offered at about the right time, saying:

Person with dementia: *"Oh dear, I don't know really. I mean to say, I suppose so, I don't know. Was it a bit early I would say I mean, I am not conscious of having any memory difficulties really."*

Husband (family carer): *"No, you have had a few difficulties"*

Person with dementia: *"Well there you are, other people notice but it is difficult for me to say"*

(Interview 17)

This analysis identified potential influences on uptake of this occupational therapy intervention as people wanting support, because they were struggling to adjust and/or cope with symptoms of dementia, and wanting to establish or maintain meaningful activities. Limited expectations did not prevent uptake in this sample and an attitude of 'give it a go' despite limited expectations of what intervention could offer, appeared to encourage uptake.

Discussion

This is the first UK study that has tried to identify influences on uptake of community occupational therapy, by people with mild to moderate dementia specifically, and their family carers together. This secondary analysis aimed to identify and explore influences on uptake within these 17 semi-structured interviews. Potential influences were identified. Findings suggest that uptake was influenced by participants wanting support, struggling to cope with symptoms, adjustment to the diagnosis, wanting activities to engage in and an attitude of being willing to give the intervention 'a go', despite uncertainty, apprehension and/or limited expectations. Most participants considered that this intervention should be offered early post-diagnosis. Although the sample all participated in the intervention, some ambivalence about uptake was expressed by a few within the sample. For some, ambivalence related to

uncertainty about what was involved, or having to accept the involvement of a professional within their life and home. Also, someone known and trusted may have influenced uptake; for example, where participants knew the professional offering this. The altruistic value placed on being asked to participate in research may also have influenced uptake.

Whilst limited research about uptake of occupational therapy interventions offered to both people with mild to moderate dementia and their family carers, together, in the UK exists, there are some studies evaluating or consulting about post-diagnostic interventions. These highlight locality, travel, and day care being the only option may be concerns (Innes et al., 2014;Górska et al., 2013;Mountain and Craig, 2012) These issues were not identified in this study, perhaps because this intervention was predominantly delivered in peoples' homes. It may be this positively influenced uptake, as people did not have to consider travel, the associated effort, potential stress and costs. This analysis identified concerns about managing the impact of dementia on everyday life, wanting support, both emotional and educational, and activities for the person for dementia to engage in alone or together with others. It may be that the carers responses to such concerns was central to uptake, similar to Chrisp et al.'s (2012) finding that initial engagement with services was supported when carers took action, or crises triggered engagement. Although the carers in this study did not report crises explicitly, they did discuss difficulties and coping with symptoms.

Research about community based dementia services has often only involved carers (Chrisp et al., 2012;Gilbert et al., 2017) and even where interventions involved both the person with dementia and family carer, the research reported carer accounts only, and did not discuss influences on initial uptake (Gitlin et al., 2018;Gitlin and Rose, 2014). In contrast, the VALID programme's decision to carry out paired interviews, and this secondary analysis to identify influences on uptake, represent attempts to seek the perspectives of both people involved in a paired intervention.. During these interviews, there were occasions where accounts about dementia and the need for intervention differed between the pair. Whilst all this sample participated in intervention, a few accounts suggested a reticence on the part of the person with dementia to accept the offer of intervention initially, compared to their carer. Chrisp et al. (2012) found initial engagement with services could be constrained by carers feeling the person with dementia did not accept or acknowledge dementia related symptoms. Other researchers note divergent understandings between people with dementia and carers, as well within individuals (Lishman et al., 2016;Robinson et al., 2005). Such divergent perspectives may influence responses to offers of occupational therapy, or other psychosocial interventions.

Implications for practice and research

To help inform practice, further research is needed to enhance understanding about why people with mild to moderate dementia and their carers may accept or reject offers of interventions occupational therapists offer. Such research is required so people with dementia and their carers can benefit from the evidence based interventions available (Clare et al.,2017;Gitlin et al.,2018;Graff et al., 2006;Sprange et al.,2015;Streater et al.,2016). Occupational therapists need to be confident in methods for motivating people with dementia to participate in therapy (Collier and Pool, 2016), and how to respond to people's needs at different stages of dementia. Gitlin and Rose's (2014) work on carer readiness to use strategies could be applied to people with mild to moderate dementia, to examine influences on their readiness to engage in occupational therapy or other psychosocial interventions that require uptake and continued engagement from both people. Further research or service evaluations could explore whether monitoring or less intensive interventions allow professionals to build relationships over time, encouraging uptake, and audit could examine potential reasons for declining interventions. Qualitative research, using interview, observational or focus group methods could further explore the perspectives of both people with dementia and their carers about adjustment, coping and support needs. Such research could enhance understanding about what occupational therapy interventions, or other post-diagnostic support, these people would want and, feel ready to engage with.

Limitations

The limitations of this secondary analysis include findings being based on a convenience sample of participants from the VALID research programme. That is, the views of those who did not complete intervention, or more variation in sample characteristics (such as caring relationship, age, dementia type) were not obtained. Total numbers of those approached for interview and those who declined and length of interview were not recorded. This sample only captures the views and perspectives of those who opted in to be interviewed, who chose to participate in the intervention, which excluded people who did not speak or understand English. This secondary analysis cannot offer insight into why people rejected offers of intervention. Purposive sampling to achieve maximum variation and/or seeking further interviews until data saturation may have resulted in additional codes or themes. However, after coding all 17 transcripts new codes were not identified. Participant validation of analysis did not take place, although this is a method suggested to potentially enhance credibility (Lewis et al.,2014). The time and resources available for this doctoral research and the time between data collection and secondary analysis meant this was not feasible. The first author developed the codes and themes, which were discussed with all authors, but more than one person coding a proportion of transcripts can enhance credibility.

Conducting paired interviews, with the person with dementia and their family carer together could be viewed as a limitation. Family carer accounts did dominate; in all the interviews, the carer spoke more than the person with dementia. Some difficulties with recall and remaining alert by the person with dementia, were demonstrated during interviews. Understanding the extent to which the person with dementia's response was influenced or 'led' by the carer, was not possible, as the majority were conducted by other researchers and as a consequence body language and eye contact could not be taken into account. However, interviewing both people together does represent an attempt to seek perspectives from people with dementia themselves, about an intervention they were involved in.

Conclusion

This secondary analysis of 17 existing qualitative interviews with people with dementia and family carers who participated in a community occupational therapy intervention in the UK identified some preliminary ideas about influences on uptake of this intervention. These included participants wanting support, and a willingness to 'give it a go' despite uncertainty, apprehension and limited expectations. More research is needed to examine why people with mild to moderate dementia and family carers may or may not be ready to engage in interventions aiming to contribute to their quality of life, and what occupational therapists can do to facilitate uptake. Such information could assist with the development of new interventions to meet people's needs, at different stages of the disease trajectory.

Key findings

- Uptake of occupational therapy by people with dementia may be influenced by each person's adjustment, coping or support needs
- To facilitate uptake, occupational therapists need to respond to these influences

What the study has added

This is the first study to try and identify influences on uptake of community occupational therapy, by people in the UK with mild to moderate dementia and their family carers.

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