

BMJ Open Occupational therapy for people with dementia and their family carers provided at home: a systematic review and meta-analysis

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ABSTRACT

Objective To determine the effect of occupational therapy provided at home on activities of daily living, behavioural and psychological symptoms of dementia (BPSD) and quality of life (QOL) for people with dementia, and the effect on family carer burden, depression and QOL.

Design Systematic review and meta-analysis.

Methods Eight databases were searched to February 2018. Randomised controlled trials of occupational therapy delivered at home for people with dementia and their family carers that measured ADL, and/or BPSD were included. Two independent reviewers determined eligibility, risk of bias and extracted data.

Results Fifteen trials were included (n=2063). Occupational therapy comprised multiple components (median=8 sessions). Compared with usual care or attention control occupational therapy resulted in improvements in the following outcomes for people with dementia: overall ADL after intervention (standardised means difference (SMD) 0.61, 95% CI 0.16 to 1.05); instrumental ADL alone (SMD 0.22, 95% CI 0.07 to 0.37; moderate quality); number of behavioural and psychological symptoms (SMD -0.32, 95% CI -0.57 to -0.08; moderate quality); and QOL (SMD 0.76, 95% CI 0.28 to 1.24) after the intervention and at follow-up (SMD 1.07, 95% CI 0.58 to 1.55). Carers reported less hours assisting the person with dementia (SMD -0.33, 95% CI -0.58 to -0.07); had less distress with behaviours (SMD -0.23, 95% CI -0.42 to -0.05; moderate quality) and improved QOL (SMD 0.99, 95% CI 0.66 to 1.33; moderate quality). Two studies compared occupational therapy with a comparison intervention and found no statistically significant results. GRADE ratings indicated evidence was very low to moderate quality.

Conclusions Findings suggest that occupational therapy provided at home may improve a range of important outcomes for people with dementia and their family carers. Health professionals could consider referring them for occupational therapy.

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INTRODUCTION

Providing support for people with dementia who live at home is an important, yet challenging issue of concern to people with

Strengths and limitations of this study

- Comprehensive searches were used that were not restricted to English language or by publication date.
- All studies had a high risk of bias with respect to lack of blinding of participants and therapists, and most had no assessor blinding, but this is known to be difficult to achieve in rehabilitation research.
- The overall quality of the evidence was assessed using the Grading of Recommendations, Assessment, Development and Evaluation (GRADE) criteria: study design, risk of bias, inconsistency, indirectness and imprecision, with the overall quality of evidence in this review ranging from very low to moderate.

dementia and their families, healthcare providers and policymakers.¹ It is estimated that in 2015, 46.8 million people were living with dementia worldwide with an international cost of ~US\$818 billion for that year.² People with dementia have significant difficulties with cognitive function, language and activities of daily living (ADL), and may have behavioural and psychological symptoms of dementia (BPSD) such as apathy, depression, agitation and anxiety.^{3–5} These changes in communication, function and in behaviours (which are often a response to, or communication of unmet needs) can be stressful and difficult for family carers to cope with.⁶

The majority of people with dementia live at home and are dependent on receiving care from family carers.^{7–9} Family members who take on the role of primary carer subsequently have reported increased rates of carer strain, physical and mental health problems, and experience difficulties in maintaining employment, leisure activities and family interactions which impacts their quality of life (QOL).⁸ With increasing numbers of people being diagnosed with dementia, the demand for research into approaches to enable



people to stay at home as long as possible and avoid institutionalisation with ensuing increases in healthcare costs is strong.^{1 2} However, for people with dementia to stay at home, family carers need support to optimise the person's independence in ADLs and to be able to understand and respond to changes in the person's behaviours and psychosocial needs, among the myriad of other day to day issues they need to attend to.

Research testing the effects of non-pharmacological interventions for people with dementia is expanding.¹ Non-pharmacological interventions may play a role in delaying functional decline, reducing the severity of BPSD and in supporting family carers.^{5 10} Systematic reviews of non-pharmacological interventions^{11 12} and the Clinical Practice Guidelines for Dementia in Australia¹³ have noted the potential of occupational therapy for people with dementia living in the community.^{14 15} Occupational therapists aim to improve the fit between occupation (eg, activities and roles), the person's capabilities, and the physical and social environment in which they live in order to optimise participation in valued activities, roles and relationships.¹⁶ For people with dementia, this process may involve helping them to identify activities they find meaningful, simplifying and implementing these activities in such a way that optimises their engagement in them, and removing stressors and distractions from the environment.^{14 15 17} It also involves collaborating with family carers to help them more readily recognise and adjust aspects of the activity and environment that enables this engagement and participation.^{15 17} Previous systematic reviews have considered the effect of any interventions delivered by a range of health professionals for maintaining occupations broadly to improve or maintain the person's health and QOL^{18 19}; the effect of occupational therapy interventions specifically on BPSD in a range of different environments²⁰; and the effect of any non-pharmacological intervention (including occupational therapy) on functional decline in people with dementia.²¹ These reviews either did not use meta-analysis,^{18 21} included studies with participants from both the community or hospital/aged care settings,¹⁸⁻²⁰ or did not consider outcomes for family carers.^{20 21}

A systematic review is needed that focuses specifically on the effects of occupational therapy provided at home for people with dementia and their family carers, to inform health professionals who provide support and referral for people with dementia in the community. This is important because identifying approaches to support people with dementia who live at home is a high priority of both consumers and the healthcare system.¹ The aim of this systematic review were to evaluate the effect of occupational therapy provided at home on the performance of ADL, BPSD and global QOL for people with dementia. It also aimed to determine the effect of this therapy on carer burden, depression and QOL.

METHODS

Details of the protocol for this systematic review were registered on PROSPERO and can be accessed at www.crd.york.ac.uk/prospéro²² (online supplementary File 1). It describes prespecified review questions, search strategies, eligibility criteria, data extraction, data analysis and strategies for assessing risk of bias. We used the Preferred Reporting of Items for Systematic Reviews and Meta-Analyses (PRISMA)²³ as a guideline for reporting this review.

Patient and public involvement

There was no patient or public involvement in this review, although some authors have been family carers of people with dementia.

Eligibility criteria

We included only randomised controlled trials assessing the effect of occupational therapy for people with dementia and their family carers if therapy was delivered at the participant's home and aimed to optimise ADL of the person with dementia, and/or to manage BPSD. Interventions delivered in community facilities were excluded. We defined occupational therapy services as being predominantly (over 75%), delivered by a qualified occupational therapist, or under the supervision of a qualified occupational therapist. Occupational therapy could be compared with usual care, attention control, waitlist control, active control or another intervention. Studies were eligible if they addressed at least one of: ADL and/or BPSD. We considered BPSD in terms of the type, number or frequency of behaviours and measurement of anxiety and/or depression. Secondary outcomes included QOL for the person with dementia and their family carer, carer burden and depression. After scoping the available research, we also decided to report on family carer distress or upset. Trials had to be published in full text, peer-reviewed journals, or full reports of dissertations and could be published in any language. Conference abstracts were excluded.

Literature search and study selection

The search strategy used by the Cochrane Dementia and Cognitive Improvement Group²⁴ to identify trials and systematic reviews for dementia was adapted and combined with relevant search terms relevant to occupational therapy for each database. We searched Medline, Embase, the Cochrane Central Register of Controlled Trials, Cumulative Index to Nursing and Allied Health Literature, PsycINFO, Education Resources Information Centre, OTseeker, PEDro and clinical trial registries without restrictions to year or language, up to February 2018. An example of a search strategy for Medline can be seen as an in online supplementary file 2 figure 1. Searches of reference lists and hand searches of eight key journals were also done. A research assistant initially screened titles and abstracts to eliminate studies that were clearly ineligible. Two reviewer authors (SB and JW or

KL) then independently screened the remaining studies using full-text to confirm eligibility. Disagreements were resolved by consensus or if unsuccessful, a third reviewer (LL) was consulted.

Data extraction

A data extraction form was developed and used by a reviewer (SB) to extract relevant data from the included studies. This was then verified by a second reviewer (KL, LL or JW). Disagreements about the extracted data were resolved by discussion between the two authors involved in this process.

When multiple reports from the same study were found (eg, covering different measures or time-points), data were extracted from associated reports as relevant. When data were available from different time points following intervention within a single study, we referred to the first time point as 'after intervention' and referred to data at the second time point as 'at follow-up'. Details of the characteristics of included studies can be seen in online supplementary file 3 table 1: Characteristics of studies.

Assessment of risk of bias and quality of the evidence

Two review authors independently assessed the risk of bias in each study using the Cochrane Collaboration's risk of bias tool.²⁵ We used the Grading of Recommendation, Assessment, Development and Evaluation (GRADE)²⁶ approach to assess the quality of the evidence overall for risk of bias, inconsistency of results, indirectness, imprecision and other factors such as reporting bias (if sufficient trials were included in the meta-analysis). We used GRADpro software²⁷ to tabulate this information and decisions made about the quality of the evidence. In GRADE,²⁶ the authors start with the quality of evidence rated as 'high', and grade down in the presence of the factors listed above. However, authors can also grade up the confidence in the evidence some circumstances, such as when there is a large effect size.²⁸ The GRADE²⁶ ratings of high, moderate, low or very low, indicates how confident we can be in the effect estimates.

Data synthesis

We conducted meta-analysis if data were available within individual studies, and were in an appropriate format for this purpose. The rationale for excluding data from meta-analyses are explained in the results. We calculated effect sizes for continuous data using standardised mean differences (SMD) to enable pooling and comparison of the different outcome measures across individual studies. To facilitate interpretation of SMD we compared the SMD using Cohen's²⁹ rule of thumb where 0.2 represents a small effect, 0.5 a moderate effect and 0.8 a large effect. To assess statistical heterogeneity, we used the I^2 statistic. An I^2 value of <50% was considered indicated of relative homogeneity. Meta-analyses were still conducted in the presence of high statistical heterogeneity, but the quality of the evidence was downgraded. The random-effects model was used in all analyses due to heterogeneity

between studies. No sensitivity or subgroup analyses were specified in the protocol. Funnel plots were not used to test for publication bias because there were insufficient studies included in each comparison. Data analyses were undertaken using RevMan V.5.2.³⁰

RESULTS

Search results

Fifteen studies^{14 15 17 31–42} were eligible for inclusion from a total of 9737 articles identified from database searches and other sources (see online supplementary file 4: PRISMA flow diagram). A number of these studies reported the results of different outcomes for the same study in separate reports. Therefore, this review reports on the results of the 15 studies presented across 19 articles.^{11 15 17 31–46} All but one study were peer-reviewed articles published in English. The remaining study was published as a dissertation and was written in German. Three of the final studies selected required consensus and involvement of a third author to determine eligibility. Most studies that we excluded when examining the full-text, were excluded because the intervention was not provided in the person's home, or the intervention was not clearly 'occupational therapy' (which we defined as being predominantly (over 75%), delivered by a qualified occupational therapist or under the supervision of a qualified occupational therapist). A few studies were excluded because they were not randomised controlled trials.

Study characteristics

Participants

Of the 15 randomised controlled trials included in this review, 10 trials took place in the USA^{15 17 31–34 39 41} and other countries included Germany,^{35 36} The Netherlands,¹⁴ Hong Kong,³⁷ Wales,³⁸ Australia⁴⁰ and Brazil.⁴² A total of 2063 persons with dementia/family carer (majority dyads) were randomised and participated in the included studies. The majority of participants with dementia were aged over 75 years, had a medical diagnosis of mostly moderate stage dementia with Mini-Mental State Examination scores⁴⁷ between 11.3 and 22.73, and needed assistance with instrumental ADL (eg, cooking, shopping, managing finances) and to a lesser extent, basic ADL (eg, toileting, bathing, dressing). Most studies did not specify the type of dementia, although one focused on fronto-temporal dementia.⁴⁰ There was roughly equal male/female participants with dementia when looking across all studies. The intervention was delivered to the person with dementia and the family carer as a dyad in all but one study³⁸ that had some participants without family carers. Family carers were, on average, 65 years of age, lived at home with the person with dementia or at a minimum provided assistance or supervision to the person with dementia for several hours per week. Between 20% and 90% of carers were spouses. For further information, please refer to online supplementary file 3 table 1: Characteristics of studies.

**Table 1** Summary of intervention characteristics

Content/Approach	Approach: Most studies ^{14 15 17 31–36 39–42} utilised a dyadic approach to intervention involving both the carer and person with dementia in individually tailored and goal-directed interventions, informed by thorough assessment of both the carer and person with dementia. Content: In most studies ^{14 15 17 31–36 39–42} , the carer and person with dementia were supported to choose activities (activities of daily living or other meaningful activities) they wanted to improve. Carers were coached or trained to problem solve, present, cue and simplify activities, use compensatory strategies, and modify the environment to support activity engagement. They were shown how to generalise the learnt strategies to other areas. Carers also received training/information to address carer's identified concerns (eg, stress management, understanding dementia).
Number of sessions	Median=8 sessions Range=1–12 sessions, with 1 trial providing 24 sessions ³⁹
Most common length of time	1–1.5 hours/session (10 studies) Total intervention time most commonly ranged between 8–12 hours
Timeframe	5 weeks–6 months with one study providing intervention across 2 years ³⁹
Comparisons	Most compared occupational therapy to usual care, or attention control. One trial evaluated 10 occupational therapy sessions against an active control session involving a single home visit by an occupational therapist providing education ³⁵ and another compared occupational therapy plus collaborative care with collaborative care alone ³⁹ .
Training to provide interventions (range)	Seven studies ^{14 17 31 33 35 36 42} reported training of between 16–80 hours, with the median being 25 hours training. Other additional studies reported providing training but the hours were not reported.

Characteristics of interventions

All included studies utilised occupational therapy services, provided or supervised, by a qualified occupational therapist at least 75% of the time, with two trials^{32 33} also including some time with nurses. Most interventions were aimed at optimising the person with dementia's involvement in ADL and/or management of BPSD. Just over half of the studies used interventions based on theory.

From the summary of the characteristics of the interventions below in [table 1](#) it can be seen that occupational therapy comprised multiple components (as is typical of occupational therapy) and was provided across a median of eight sessions. Studies within this review used a range of different outcome measures as can be seen in [online supplementary file 3 table 1: Characteristics of studies](#).

Risk of bias within studies and quality of evidence

Most studies explained their randomisation procedure and concealed the allocation sequence. Blinding of participants and therapists was not possible due to the nature of the studies and therefore these studies may be subject to performance bias. Although a number of trials reported using assessor blinding, most of these also used measures that were self-report and were thus still susceptible to bias. A summary of the risk of bias across different criteria can be seen in [online supplementary file 5 figure 1: Risk of bias assessment](#). In addition, the majority had small sample sizes with the largest trial³³ having 272 participant-dyads and four studies having <100 participant-dyads. The evidence was assessed as between moderate and very low quality depending on the outcome, according to GRADE²⁶ due to the risk of bias,

inconsistent results between studies, and some imprecision (see [online supplementary file 6 table 1: GRADE profile- people with dementia](#) and [online supplementary file 7 table 1: GRADE profile-carers](#) for details).

Synthesis of results

Effects of interventions are presented separately below for people with dementia and their family carers. All effects sizes were based on between-group differences measured *after* completion of the interventions, with seven studies^{33 35 37–39 43 44} providing data from one or more follow-up points beyond the completion of the intervention. Only data from 3-month or 6-month follow-up time points were included in the meta-analyses. No change scores were included. Thirteen studies^{14 15 17 31–34 36–38 40–42} compared occupational therapy with usual care or attention control and are presented first. Two studies are then presented that compared occupational therapy with another intervention.^{35 39}

Occupational therapy versus usual care or attention control

Activities of daily living

Nine randomised controlled trials examined an occupational therapy intervention provided at home, designed to improve, maintain or slow the deterioration of ADL of people with dementia. Meta-analysis of five studies found occupational therapy was more effective than usual care^{14 36 40 41} or attention control³² for improving overall ADL (basic and instrumental ADL combined) after completion of the intervention (SMD 0.61, 95% CI 0.16 to 1.05; low quality evidence) (see [figure 1](#)). Considerable heterogeneity was present ($I^2=85%$; $p<0.0001$)

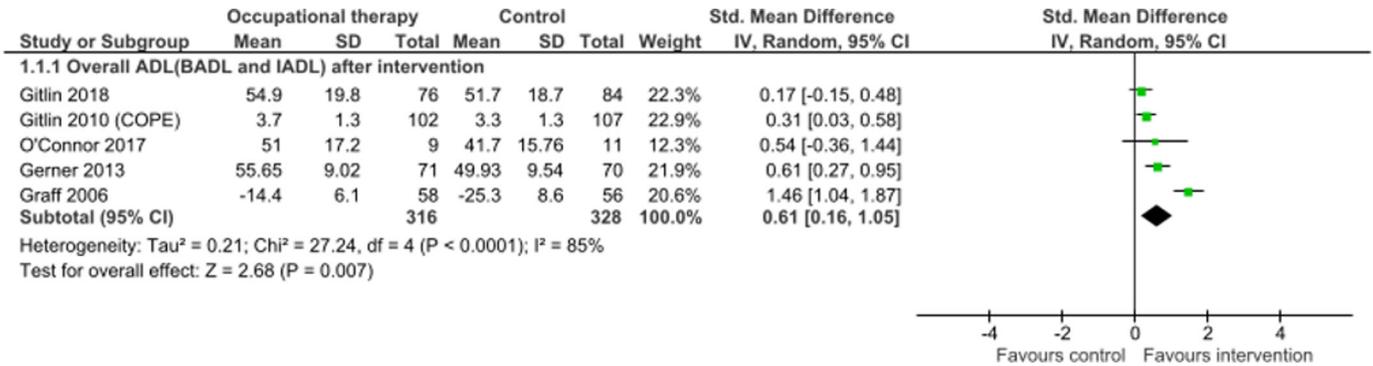


Figure 1 Overall activities of daily living (BADL and IADL combined). ADL, activities of daily living; BADL, behavioural and psychological symptoms of dementia; IADL, instrumental activities of daily living.

which on retrospective exploration, appeared to be influenced by one study¹⁴ that reported a large effect size. We explored the consequence of omitting this trial from the analysis; removal of the trial lowered statistical heterogeneity (I²=24%) and the overall effect remained positive (SMD 0.36, CI 0.15 to 0.57) though the size of the effect was smaller. Two of these studies also measured overall ADL at a further time point.^{14 36} One study¹⁴ reported between-group reduction in the deterioration in overall ADL 3 months from the commencement of occupational therapy (mean difference -13.6; 95% CI 15.8 to -11.3) on the interview of deterioration of daily activities outcome which has a score range of 0–44. The other study³⁶ that measured overall ADL using the Alzheimer's Disease Cooperative Study-Activities of Daily Living (ADCS-ADL), reported a mean between-group difference of 7.3 (95% CI 4.08 to 10.52) 3 months following commencement of occupational therapy. The effect of occupational therapy on BADL and on instrumental activities of daily living (IADL) are considered separately below.

Five studies^{17 31 32 40 41} measured basic activities of daily living (BADL) on its own (with some providing separate data for BADL as well as overall ADL).^{31 40 41} Meta-analysis found no between-group difference for BADL (SMD 0.13 95% CI -0.02 to 0.27; low quality evidence) and heterogeneity was not present. An additional study³⁴ that provided two visits versus usual care measured BADL reported a statistically significant effect in favour of the occupational therapy intervention group but data were not available to determine effect size. Meta-analysis of five studies^{17 31 32 40 41} resulted in a significant, small effect

size²⁹ for occupational therapy compared with usual care for IADL (SMD 0.22, 95% CI 0.07 to 0.37; I²=6%) and this evidence was of moderate quality (see online supplementary file 8: Instrumental activities of daily living).

BPSD—occurrence of behaviours, depression and anxiety

Effects of interventions are presented separately below for different aspects of BPSD. Ten studies compared the effect of occupational therapy provided at home with usual care or attention control on behavioural and psychological symptoms. Six of the 10 studies measured occurrence of behaviours or psychological symptoms in terms of the number of behavioural or psychological symptoms, with authors obtaining data for one study³³ by contacting the study authors. Pooled analysis of data of these six studies^{15 31 33 40–42} (figure 2), demonstrated a small to moderate statistically significant between-group difference (SMD -0.32, 95% CI -0.57 to -0.08; moderate quality evidence) in the number of behavioural and psychological symptoms in favour of those receiving occupational therapy. Heterogeneity was high (I²=58%) likely reflecting the included studies application of different intervention programme with slightly different client groups. The psychological symptoms of depression and anxiety were also considered separately. Combined data from three studies^{15 38 44} comparing the effect of occupational therapy provided at home with usual care on depression experienced by people with dementia, yielded no significant differences between groups after the intervention (SMD -0.26, 95% CI -0.57 to 0.06; very low quality evidence). An additional study³⁷

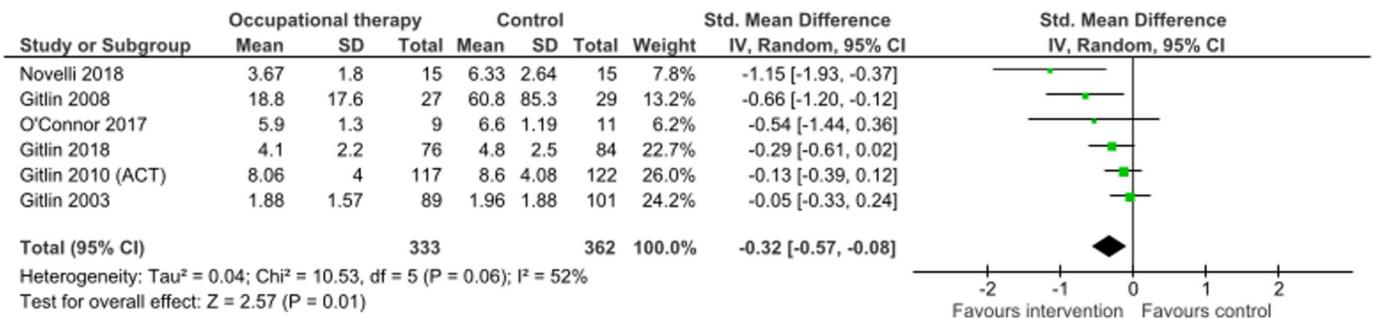


Figure 2 Number of behaviours and psychological symptoms.

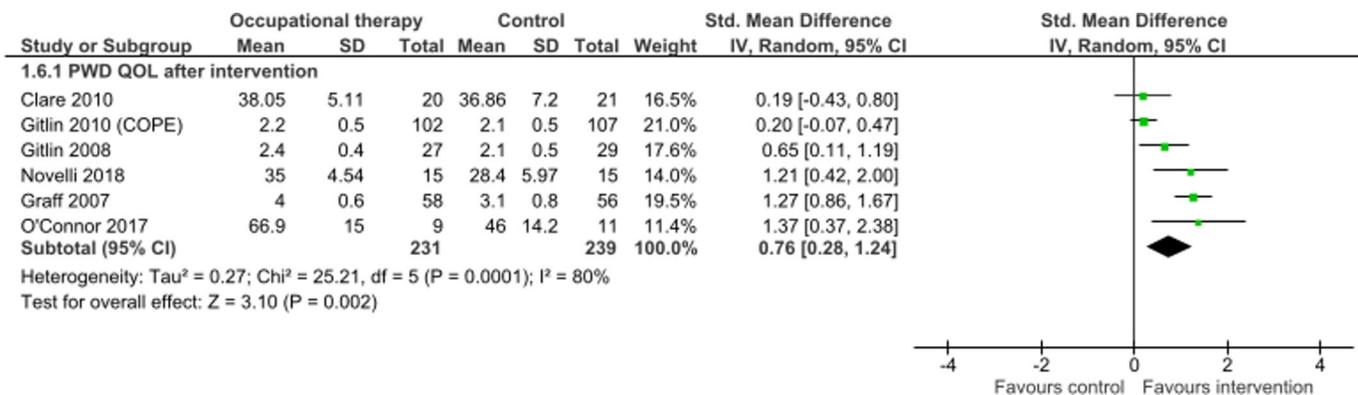


Figure 3 Person with dementia—quality of life.

that did not have data in a format that could be used in the meta-analysis, found no between-group difference for depression. Two studies^{38 44} measured depression at a follow-up time-point. One study³⁸ found no statistically significant effects, while the other⁴⁴ reported a reduction of depression (mean difference -3.0 ; 95% CI -5.07 to -0.93) 3 months following commencement of occupational therapy. Anxiety in people with dementia was measured using a separate scale in only one study which found no statistically significant between-group difference.³⁸

QOL for people with dementia

Seven studies^{15 32 37 38 40 42 44} measured QOL of people with dementia, after occupational therapy intervention. Pooled analysis of six of these studies^{15 32 38 40 42 44} providing occupational therapy at home revealed significantly better QOL than those in the control groups (SMD 0.76, 95% CI 0.28 to 1.24) (see figure 3). A high level of heterogeneity was present (I²=80%) (and remained after exploring possible reasons for heterogeneity), which in addition to risk of bias, prompted downgrading of the rating of the quality of this evidence to low. At follow-up, combined data from two studies^{38 44} showed a large, significant result (SMD 1.07, 95% CI 0.58 to 1.55; I²=30%) (figure 3). No statistically significant between-group differences in QOL was identified in the study by Lam *et al*³⁷ either immediately following the intervention or at follow-up, but results were not in the format to be able to be included in the meta-analysis.

Carer depression

Six studies^{15 33 35 38 41 44} contributed data about family carer depression. Combined, five of these trials^{15 33 38 41 44} yielded no statistically significant difference between occupational therapy and control groups for depression immediately following the interventions (SMD -0.33 , 95% CI -0.71 to 0.04; very low quality evidence). Heterogeneity was high (I²=76%) which when explored, appeared to be influenced by one study⁴⁴ that reported a large effect size. Combined data from three studies at either 3-month⁴⁴ or 6-month follow-up^{33 38} found no between-group difference for depression (SMD -0.50 , 95% CI -1.24 to 0.23; I²=87%; p=0.16). This evidence was of low quality.

Carer burden

Four studies^{15 33 41 42} contributed data to the meta-analysis considering family carer burden with no statistically significant between-group difference found immediately after the intervention (SMD -0.06 , 95% CI -0.31 to 0.18; I² 35%; low quality evidence). Two further studies^{34 37} used the Zarit Burden Interview⁴⁸ but did not have data that could be used in the meta-analysis. One of these studies³⁷ found no statistically significant difference between groups, whereas the other³⁴ reported that family carers receiving occupational therapy had significantly lower levels of burden at post-test than carers receiving usual care. As a further measure of carer burden, three studies^{15 40 41} measured the hours family carers spent 'on duty' with no statistically significant difference between groups (SMD -0.20 , 95% CI -0.46 to 0.06; I²=56%; low evidence). These three studies also measured the hours 'doing things' for (or providing attention to) the person with dementia which showed a statistically significant difference (SMD -0.33 , 95% CI -0.58 to -0.07 ; I²=41%). This evidence was of low quality.

Carer distress or upset with behaviours

Data from six studies^{15 17 31 33 41 42} that measured the amount of upset or distress family carers felt with respect to the behaviours or psychological symptoms of the person with dementia, were combined and demonstrated a small, statistically significant result in favour of those receiving occupational therapy and this evidence was of moderate quality (SMD -0.23 , 95% CI -0.42 to -0.05 ; I²=41%) (figure 4).

Carer QOL

Only three studies measured overall QOL of the family carers of people with dementia.^{37 42 44} Pooled data from two of these studies^{42 44} produced a large, significantly significant between-group difference after the intervention (SMD 0.99, 95% CI 0.66 to 1.33; I²=2%) and this evidence was of moderate quality (see figure 5). In comparison, no statistically significant between-group differences in family carer QOL was identified in the study by Lam *et al*³⁷ either immediately following the case management intervention provided by occupational

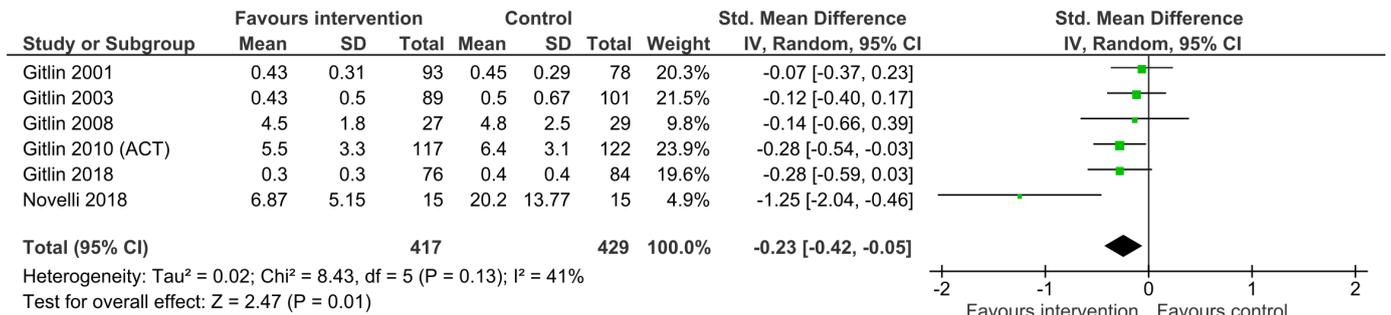


Figure 4 Carer distress or upset with behaviours

therapists or at follow-up, but data were not in a format that could be included in the meta-analysis.

Adverse events

Two studies^{14,32} indicated there were no adverse events or harms related to the occupational therapy intervention. No harms were reported in the remaining studies.

Occupational therapy versus comparison intervention

Two studies compared occupational therapy provided at home for people with dementia and their family carers to either a smaller dose of occupational therapy³⁵ or to a different intervention³⁹ and were therefore not included in the meta-analyses described above. Their results are described here. One study³⁵ compared 10 visits by an occupational therapist (using the same intervention described by Graff *et al*¹⁴) with one-session provided by the same occupational therapy interventionists. For the comparisons group, the occupational therapist explained a 10-page leaflet and talked with participants about individual problems related to the needs of the person with dementia and their family carer. They were also given advice about staying active, maintaining social contacts and contacts with dementia services. No statistically significant between-group differences were found for persons with dementia or family carers for any outcome after completion of the intervention or at later follow-up. There were no adverse events or harms related to the occupational therapy intervention.³⁵ The second study³⁹ compared up to 24 sessions of occupational therapy over a 2-year period, with collaborative care. Collaborative care included individualised non-pharmacological management of behaviours and medication if needed. At the 24-month endpoint there were no between-group differences in ADL, physical function, depression, anxiety or mortality.

DISCUSSION

This systematic review provides evidence that people with largely moderate stage dementia who commonly received between 8 and 12 hours of multicomponent occupational therapy at home (median of 8 sessions) had improvements in a number of key outcomes. They were better able to carry out overall ADL, IADL and importantly carers reported fewer behaviours and psychological symptoms, and better QOL compared with those receiving usual care or attention control. However, no clarity yet exists about the effect of occupational therapy on the specific psychological symptoms of depression or anxiety in people with dementia. Similarly, it is unclear if occupational therapy improves family carer depression. No improvement in carer burden was found using measures such as the Zarit Burden Interview,⁴⁸ however, family carers reported less hours assisting the person with dementia. They also had less distress from behaviours and a large improvement in QOL. Cost-effectiveness was not a focus of this review but two studies had an additional paper reporting the interventions were cost-effectiveness.^{45, 46} Evidence ranged from very low to moderate quality indicating that future research could impact the estimates of effect.

Strengths and weaknesses of this systematic review

This review was conducted with a high level of rigour and considered a broad range of outcomes of interest to consumers and healthcare providers. However, as with many non-pharmacological interventions, blinding participants and therapists in the individual studies could not be achieved. This introduces the potential for expectation bias that may lead to an overestimation of results.⁴⁹ In most cases, due to the nature of the outcome measures, people with dementia and their family carer were providing the data thereby complicating the efforts

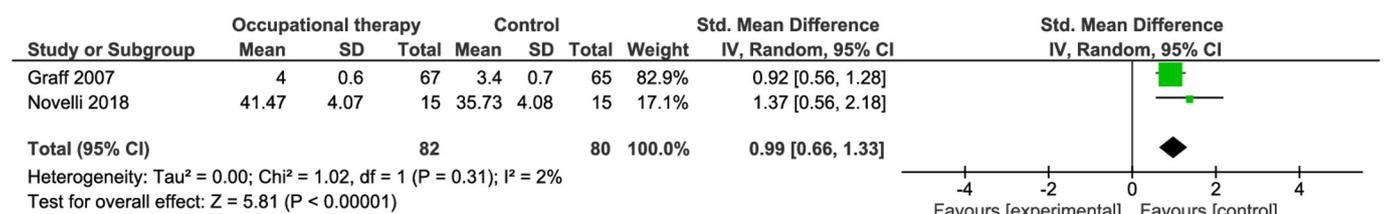


Figure 5 Carer quality of life.



to use blinded assessors. Karlawish *et al*⁵⁰ warn that there is the potential for bias to be introduced when family carers are providing proxy data for people with dementia. In future, trials could consider use of objective measures where possible (eg, performance-based measures of ADL), although this is not possible for measures such as depression and QOL. We decided to conduct meta-analyses even when heterogeneity was high, but to reflect this in the GRADE judgements about the quality of the evidence.²⁶ For the majority of outcomes, the quality of evidence was graded down due to the risk of bias most of the included studies, and in some cases, moderate to high levels of heterogeneity. For example, there was a high level of statistical heterogeneity for the outcomes of overall ADL (postintervention and at follow-up) and for QOL of the person with dementia (postintervention). Although this review did not limit the searches by date or language, the possibility of publication bias still exists. An assessment of publication bias was not carried out, in part due to the small number of studies, and this should be taken into consideration when interpreting the results. In addition, we identified a number of eligible trials that could not be included in the meta-analyses due the data not being in a suitable format^{34 37} or due to use of different comparison groups.^{35 39} Results from the meta-analyses in this review should be interpreted with this in mind. Finally, this review focused specifically on occupational therapy provided in the home and did not include studies carried out in community-based facilities. This would be an important addition for future research.

Strengths and weaknesses in relation to other studies

To the best of our knowledge, this systematic review is the first to focus on the effects of occupational therapy delivered in the home on ADL, BPSD and QOL for people with dementia, and to consider the effect on family carer's QOL, burden and depression. Our review findings are consistent with results of a systematic review reported by McLaren *et al*²¹ that focused on a range of different interventions (including but not focused on occupational therapy) designed to delay functional decline in people with dementia living in the community. It concluded that interventions covered in their review, can delay functional decline and may improve QOL for people with dementia. In addition to including more recent studies our analyses included a broader range of outcomes relevant to the primary care population. Similarly, our results extend the results reported in a systematic review by Kim *et al*²⁰ that included studies based across both the community and hospital settings, examining the effects of occupational therapy on behavioural symptoms or depression. By focusing just on occupational therapy provided in the home and examining a broader range of outcomes, this review may be more informative for primary care providers and for health professionals within the hospital system referring on to community-based care. The results of our review also correspond with the recent recommendations of the Clinical Practice Guidelines for Dementia

in Australia,¹³ although our review has also indicated that occupational therapy reduced the number of behaviours or psychological symptoms that occurred for people with dementia (but not depression or anxiety). This review is also in line with the recommendations of the Social Economic Report of the Social Economic Council of the Ministry of the Netherlands⁵¹ that recommend that people with dementia living at home should be offered occupational therapy.

Implications for clinicians and policymakers

Referral to occupational therapy for people with moderate stage dementia and their family carers should be considered to support and optimise the person's ability to carry out everyday activities and to improve their QOL while living at home. Occupational therapy in the studies in this review, like many approaches in occupational therapy, comprised multiple components. Therapists worked with both the person with dementia and their family carer to identify their goals, tailor and adapt activities for the person with dementia, and modify the environment in order to sustain their engagement and participation.^{14 31} Occupational therapists also provided support to the family carer as an individual however benefits on carer burden is still to be clarified. While efforts might be made to identify which 'component' of occupational therapy provides benefit, occupational therapy's strength is in its integrated approach to analysing occupation (activity), the physical and social environment and its resources, and abilities of the individual, to guide intervention.¹⁶ Seven of the studies^{14 17 31 33 35 36 42} reported the training time occupational therapists needed to provide the interventions ranging from 16 to 80 hours with the median being 25 hours. Translating this research into practice will need to consider the knowledge and skill of occupational therapists involved; feasibility and preparedness of organisations to implement the use of multiple occupational therapy home visits; availability of sufficient funding or models of care that would enable multiple home visits; and awareness by other health professionals to refer to occupational therapy, where it is available.⁵²⁻⁵⁴ Effort to scale up use of occupational therapy provided in the home is complex and would require a well-skilled workforce, and responsive referral and funding models. This has implications for the training currently provided by occupational therapy schools and dementia-specific training organisations and the education of stakeholders about the full scope of occupational therapy practice for this client group.

Directions for future research

The maximum length of follow-up of randomised controlled trials considered in this systematic review with data available was 24 months postbaseline,³⁹ although no statistically significant results were found. Most trials measured outcomes immediately after completion of the interventions and did not have further follow-up. Randomised controlled trials with longer follow-up,

maintenance phases, accompanied by cost effectiveness studies, will allow the long-term effects of these interventions to be determined. The potential for floor or ceiling effects should also be considered in future research. It is possible that significant results for IADL but not for BADL were due to participants in the relevant studies being more independent in BADL than IADL at baseline, with less scope for improvement. Similarly in the study by Voigt-Radloff *et al.*,³⁵ participants had a low need for assistance in overall ADL at outset compared with other studies^{14 32} leading the authors to query the presence of a floor effect. Questions remain regarding what stage of the illness trajectory people may benefit most from occupational therapy and the dosage of this intervention has not yet received sufficient attention. A number of studies in this review showed a reduction in the number of behavioural or psychological symptoms, but it was not reported which type of behavioural or psychological symptoms these most commonly were. The majority of studies that measured behaviours and psychological symptoms reported the overall number, severity or frequency of behavioural or psychological symptoms (or some combination of these), and some measured anxiety and depression separately. Trialists who have collected information that would allow analysis about the type of behavioural or psychological symptoms influenced by these interventions should consider publishing this additional information, even if in a journal's supplementary files. All but one trial³⁸ delivered the intervention to people with dementia and their family carer as a dyad and the benefit for people with dementia living alone could be investigated further. Two trials^{35 36} transferred the successful Dutch home-based occupational therapy programme¹⁴ into a multicentre practice context. One of these trials³⁶ finding statistically significant benefit for ADL (but not as large an effect size) and the other³⁵ found no statistically significant results. Replication studies will add to our understanding of these outcomes. It must also be noted that the majority of the studies in this review were undertaken in developed countries where access to occupational therapy with capacity for delivering evidence-based interventions is significantly greater than can be found in developing countries. However encouragingly, one trial⁴² which replicated the 'Tailored Activity Program' intervention in Brazil reported positive results. Testing these interventions in other contexts and cultures should therefore be an important priority for the research agenda. Finally, successful translation of complex interventions such as occupational therapy into practice needs research that is informed by knowledge translation frameworks, consults multiple stakeholder groups including people with dementia and their family carers from the beginning, and addresses questions of both effectiveness and translation.⁵²

CONCLUSIONS

In summary, there is evidence that occupational therapy provided in the home may help optimise performance

of ADL of people with dementia, reduce behaviours and psychological symptoms (but not depression and anxiety) and contribute to improving their QOL. It can also have beneficial effects on family carer's distress with behaviours, number of hours assisting the person with dementia, and improve family carer's QOL. However, translation of this knowledge to practice will require further research to determine the most cost-effective model of therapy, and how the challenges to its delivery might be overcome.

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