Occupational therapy interventions for adult informal carers and implications for intervention design, delivery and evaluation: A systematic review

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Abstract

Introduction

Informal carers provide vital support for patients, reducing strain on health and social care services. However, caring can detrimentally effect carers' health and wellbeing, thus policy advocates for improved carer support. Objective: to establish the published international evidence base regarding interventions for carers delivered by occupational therapists.

Method

English language studies published January 2010-January 2021 were identified against predetermined inclusion/exclusion criteria via searches of MEDLINE, EMBASE, CINAHL, PsychINFO, OTSeeker, Scopus, Web of Science and the Cochrane Library. Supplemental strategies: database alerts, hand-searching, searching of included papers' reference lists and citations, and contacting key authors. Two reviewers completed critical appraisal and produced a textual narrative synthesis of data using a convergent integrated method.

Results

38 papers were included, reporting 21 interventions. Most were dyadic, home-based interventions for carers of people living with dementia. Common intervention components included: assessment and goal setting, skill training, education, coping strategies, equipment provision, environmental adaptation, and signposting. Interventions improved outcomes for carers, however intervention design and evaluation require careful consideration to maximise carer benefits and capture intervention effects.

Conclusion

Occupational therapist delivered carer interventions enhance support and improve carer outcomes. Intervention and evaluation designs should include careful selection of outcome measures, avoidance of increased carer burden in dyadic interventions and acknowledgement of known barriers and facilitators to both carer and therapist intervention engagement.

Keywords

Occupational therapy, caregiver, systematic review, adult, intervention, support

Introduction

Informal carers are unpaid “lay people in a close supportive role who share in the illness experience of the patient and who undertake vital care work and emotion management” (Thomas et al., 2004). The estimated value of informal care significantly outweighed that of formal care provided via health and social services in 2015/6 and was valued at between £57-100 billion a year (Buckner & Yeandle, 2015; Office for National Statistics, 2018). This figure is likely to have increased. Prior to the Covid-19 pandemic, approximately 10% of the UK population – or 6.5 million people (Carers UK, 2019) – were carers. Restrictions introduced to protect those vulnerable to Covid-19, combined with reduced access to formal support, led to an estimated increase of 4.5 million additional informal carers in the UK (Carers Week, 2020). Informal carers play a vital role in facilitating hospital discharges, admission avoidance and enabling patients to remain living at home, thus reducing strain on services. They assist patients in maintaining their independence and wellbeing, provide emotional support and often take on a range of responsibilities including household tasks, meal preparation, managing medical appointments and medication, shopping, financial management and personal care (Carers UK, 2019).

However, providing this care can have detrimental impacts on carers’ health and wellbeing (Foley et al., 2021). During the Covid-19 pandemic, carers reported worsening mental (64%) and physical (58%) health (Carers UK, 2020). Alongside financial difficulties, fatigue, stress and problems balancing caring responsibilities with employment, informal carers also experience reduced happiness, poorer health and increased loneliness when compared to the general population (Carers UK, 2019; Foley et al., 2021; NHS 2019). Despite increasing emphasis on carer identification and support in recent policy, carers continue to report poor health and difficulties accessing support (Department of Health and Social Care, 2018; NHS 2019). Meeting the needs of carers is essential to ensure that they can manage their own health and wellbeing whilst also enabling them to provide care throughout the patient’s illness trajectory, and beyond into bereavement.

Occupational therapists are obligated to contribute to carer support and are well-placed to do so, often working closely with patients’ friends and family (RCOT, 2017). However, a lack of published evidence demonstrating the impact of occupational therapy for informal carers has previously been noted (Hall & Skelton, 2012), which may limit opportunities to develop new interventions and the presence of the profession in relation to carer support. Previous reviews have been completed regarding occupational therapy interventions for informal carers, but have either (a) related to support for particular subsets of carers (for example, specific patient diagnosis such as dementia [e.g. Raj et al., 2021]), (b) described potential interventions delivered by other professionals that could be utilised by occupational therapists (e.g. Hall & Skelton, 2012), or (c) focused on particular outcomes (e.g. Abrahams et al., 2018). Whilst these reviews provide valuable insights into the role and efficacy of occupational therapy interventions for informal carers, a comprehensive synthesis of published literature has not yet been completed.

This review’s objective is to establish the published international evidence base from the previous decade regarding interventions for informal carers delivered by occupational therapists. Adult carers are the focus as they comprise the majority of the UK informal carer population (Foley et al., 2021). The needs of young carers, or parents supporting children, are likely to differ significantly, as are the interventions designed to meet these needs; as such, these groups would benefit from separate reviews. This review considers the nature and breadth of relevant interventions, reported intervention outcomes, quality of eligible studies, barriers and facilitators to carer engagement and experiences of occupational therapists in delivering carer-focused interventions.

Methods

A systematic search of peer-reviewed English language research literature was completed by two reviewers. The protocol was registered (Prospero database: CRD42020203026, accessible at https://www.crd.york.ac.uk/prospero/display_record.php?RecordID=203026) and the PRISMA checklist used to ensure transparency in reporting (Moher et al., 2009).

Study identification

Initial scoping searches returned interventions addressing carers' physical and/or mental health; some related to occupational therapists working independently but some were also working as part of a multi-disciplinary team (MDT). Thus, papers that included distinct intervention by an occupational therapist within a wider group of professionals were considered as long as the contribution of the therapist was clearly defined and directly related to carers. As such, databases spanning multiple disciplines were searched: MEDLINE, EMBASE, CINAHL, PsychINFO, OTSeeker, Scopus, Web of Science and the Cochrane Library. Supplementary strategies included: database alerts, hand-searching (The British Journal of Occupational Therapy, January 2010-January 2021) and searching reference lists and citations of included papers. Hand-searching was utilised to check electronic search terms were comprehensive; results were cross-referenced with papers retrieved via database searches. Key authors (five contacted; two responses) were approached via email to enquire if further publications relating to eligible interventions were imminent and identify additional papers potentially eligible for inclusion. Due to time limitations grey literature was not included, however, scoping searches of Open Grey, ProQuest and Ethos returned minimal material.

Eligible papers were identified against predetermined inclusion/exclusion criteria (detailed in full as supplemental material: Appendix 1). Briefly, eligible papers were: related to adult (18+) informal carers for adult patients; English-language; empirical research (qualitative, quantitative or mixed methods); published between January 2010-January 2021; focused on interventions involving direct carer support from an occupational therapist (dyadic papers where occupational therapists directly supported patients only were excluded); and reported on intervention efficacy for carers via identification (qualitative) or measurement (quantitative) of outcome measures. Lower quality evidence such as editorials, opinion pieces, case studies and non-empirical material were excluded to increase strength of findings. Where full a randomised controlled trial (RCT) was available, associated feasibility or pilot studies were excluded so that the strongest level of evidence was included. Where RCTs were not available, feasibility and pilot studies were included to enhance comprehensiveness of the review whilst acknowledging their limitations.

A variety of search terms (see Appendix 1) were used for the term 'carer' as a previous systematic search by the reviewers identified a broad range of terms in use in papers (AMENDED FOR ANONYMITY, 2020).

After removal of duplicates, the first reviewer (XX) screened titles and abstracts against the inclusion criteria; the full text was read if eligibility was uncertain. If eligibility remained unclear, the paper was discussed with the second reviewer (YY) to reach consensus. Reproducibility of screening was established via review of a random sample (10%) of potentially eligible papers by the second reviewer (YY).

Data extraction

Data was extracted using a bespoke digital data extraction form, modified following successful utilisation in a previous systematic review (AMENDED FOR ANONYMITY, 2020). The reviewers individually extracted data from six (16%) eligible papers and compared findings to ensure a consistent and comprehensive approach. The first reviewer (XX) then completed data extraction for the remaining papers.

Data synthesis

Given the variety of study designs retrieved, a textual narrative synthesis of extracted data was completed using a convergent integrated method (Joanna Briggs Institute, 2019). Data were subsequently analysed for consistency and divergence between findings, gaps in the literature, and trends in methodological strengths and weaknesses across studies.

Critical appraisal

Critical appraisal was undertaken to assess studies for risk of bias and identify other methodological weaknesses potentially influencing the validity of findings. Appraisal of all included papers was completed by the first reviewer (XX) with a random sample (10%) appraised by the second (YY) to enhance reliability. Appraisal tools used depended on the study design and included:

1) The Critical Appraisal Skills Programme (CASP) suite: specifically, the Randomised Controlled Trial, Qualitative and Economic Evaluation checklists (CASP, 2021).
2) The Mixed Methods Appraisal Tool (MMAT) where a suitable CASP tool could not be found (Hong et al., 2018). The MMAT is a tool specifically developed for use in systematic reviews to facilitate appraisal of quantitative, qualitative and mixed methods studies within the same review.

To maintain comprehensiveness of the review, appraisal was not used to exclude studies; instead, methodological issues identified were analysed to determine the credibility of papers as evidence of an intervention’s efficacy. A standardized strength of evidence framework was not utilised, however credibility of the body of evidence was considered regarding (a) included study designs, (b) quality of individual studies and (c) consistency of the evidence.

Results

Searches yielded 38 eligible papers relating to 21 interventions (see Figure 1 – PRISMA flowchart), completed in: Australia (11), United States (8), Netherlands (4), United Kingdom (4), Brazil (2), Germany (2), Spain (2), Belgium (1), France (1), Italy (1), Hong Kong (1) and Japan (1). Included study designs: RCT (13), feasibility (6), pilot (6), qualitative (4), cost-effectiveness (2), mixed methods (2), process evaluation (2), hybrid implementation-effectiveness study (1), non-inferiority RCT (1) and a retrospective pre-test post-test design (1). An overview of study and intervention designs is available as online supplemental material (see Table 2).

INSERT PRISMA FLOWCHART/FIGURE 1 ABOUT HERE

Quality appraisal

For eligible RCTs, the nature of the interventions meant introduction of bias was unavoidable; only individuals collecting outcome data, and independent of intervention delivery, could be blinded to group allocation. Additional potential sources of bias in RCTs included: use of proxies to complete outcome measures e.g. carers (for patient-related outcome measures) or interventionists; attrition (although intention to treat analyses were often used); baseline differences between allocated groups despite randomisation; and intervention fidelity issues. Qualitative studies were largely well-reported, though reflexivity was not always discussed. All study designs appeared appropriate to meet stated aims. Quality appraisal summary tables are available as online supplemental material (see Appendix 2).

Participants

By far the majority of papers described interventions targeting carers of people living with dementia or non-specific cognitive impairment (31). Other patient groups included patients with hip fractures (2), Parkinson's disease (2), eating disorders (1), cancer (1) and stroke (1). Carer participants tended to be patients' spouses or adult children; the majority, in most studies, were women. Where reported, average carer age was 55+ years.

Intervention design

Most interventions were dyadic, addressing both the carer and patient (32 papers/15 interventions); others were carer-only (six papers/five interventions). Several papers reported the use of a pre-established intervention in a new context (e.g. patient group or country): for example the Community Occupational Therapy in Dementia intervention (COTiD; n=6 papers), the Care of Persons with Dementia in their Environments intervention (COPE; n=6 papers), and the Tailored Activity Program (TAP; n=4 papers).

Interventions offered support directly for the carer or support to facilitate caring, a distinction previously discussed elsewhere (Stajduhar, 2008); some addressed both aspects. Common components included: assessment of carer needs/concerns (using a variety of methods) and goal-setting; education and skill training (including: condition-specific knowledge [e.g. symptom management], positive risk-taking, task supervision, compensatory strategies, medication management, environmental adaptation, communication techniques, facilitation of specific activities of daily living [ADLs], helpful aids/equipment, problem-solving and task simplification); hands-on demonstration (e.g. manual handling); coping/stress management techniques; provision of adaptations, assistive technology and aids to facilitate caring; and signposting. Intervention periods spanned from one-off sessions to two years. The majority of papers described home-based interventions using home visits (28); others included group workshops on clinical sites (6), outpatient clinics (2), case-management (1) and ward-based information provision with telephone follow-up (1).

Most papers described occupational therapists as the sole interventionists (21). Others stated additional healthcare professionals involved in intervention development and delivery including nurses (n=7 papers), physiotherapists (4), therapy assistant practitioners (2), psychologists (2), social workers/welfare practitioners (2) geriatricians (1), neurologists (1), neuropsychologists (1), nursing assistants (1) and orthopaedic surgeons (1).

Outcome measures

Various outcome measures were used to evaluate intervention efficacy (see Table 3). In quantitative or mixed-method papers, measured concepts included: patients' condition-specific symptoms or behaviours (e.g. the Parkinson's Disease Questionnaire-39); carer/patient quality of life; carer depression, anxiety, pain and fatigue; ease of ADL completion; carer general health; and concepts focused on the carer role such as burden, mastery, upset, stress, strain and confidence. In dyadic interventions, patient outcomes predominated, with some papers including carer-specific measures as secondary outcomes only. Among carer-specific outcomes, the Zarit Burden Interview was the most commonly used, reported in 11 papers. Some study investigators developed their own measures, such as questionnaires to gauge patient/carer satisfaction. Several papers gathered qualitative data, either as the primary method of evaluation or to enhance understanding via interviewing a sub-sample of participants from large-scale RCTs. Semi-structured interview was the primary method of qualitative data collection; inductive thematic analysis the most commonly used analytic approach.

INSERT OUTCOME MEASURES TABLE/TABLE 3 ABOUT HERE

Intervention effects

Quantitative carer outcomes

<u>*Home-based interventions*</u>*:* Papers related to the TAP intervention consistently reported positive carer outcomes. The original study, which was not formally part of this review due to publication more than a decade prior, reported significant increases to self-perceived mastery and self-efficacy (Gitlin et al., 2008). A later follow-up RCT in the same country (USA) described significant reduction in carer distress with patients' behavioural symptoms and an improvement trend for other outcomes (Gitlin et al., 2018). Pilot and feasibility studies in Brazil and Australia reported positive outcomes (decreased carer burden and increased quality of life) and good carer engagement respectively, although with limited sample sizes these must be considered with caution (Novelli et al., 2018; de Oliveira et al., 2018).

COTiD, in contrast, has shown limited evidence of efficacy beyond the Netherlands where effectiveness was first demonstrated in terms of multiple carer-related outcomes and cost (Graff et al., 2007). No significant differences in quantitative outcome measures were reported in subsequent German and UK trials (although positive qualitative data was reported from the latter) (Voigt Radloff et al., 2011a, 2011b; Wenborn et al., 2021). Another attempt at adapting COTiD with additional physiotherapy and social work components resulted in a failed trial (the Social Fitness Programme); a parallel process evaluation suggested numerous barriers to intervention delivery and significant recruitment difficulties (see Table 2, supplementary material) (Donkers et al., 2018). An Italian feasibility study reported a significant difference in carers' sense of competence post-COTiD, though with a small sample size (n=27) it is unclear whether a similar result would be achieved in an RCT (Pozzi et al., 2019).

The original COPE intervention trial reported significant increases in carer wellbeing and confidence (Gitlin et al., 2010b); subsequent trials in Australia and USA reported significant improvement in carer-perceived changes (on the Perceived Change Index) (Clemson et al., 2020; Fortinsky et al., 2020). A "non-inferiority RCT" reported an adapted COPE intervention using telehealth input from occupational therapists was not inferior to face-to-face delivery (Laver et al., 2020).

Other significant carer-related outcomes reported from home-based interventions included: improved carer quality of life at three months (Occupational Therapy in Parkinson's Disease/OTiP, RCT [Sturkenboom et al., 2014, 2016]) and significant increase in carer health-related quality of life (the Home-bAsed Reablement Program/I-HARP, pilot study [Jeon et al., 2020]). The Alzheimer's Disease Multiple Intervention Trial by Callahan et al. (2017) (ADMIT, RCT), a pilot study by Nishida et al. (2017) and the Developing an Intervention for Fall-Related Injuries in Dementia (DIFRID, feasibility study) by Allan et al., (2019) reported no significant differences between groups for positive carer outcomes.

Notably, multiple papers describing dyadic, home-based interventions reported significantly increased carer burden in comparison to control groups, including DIFRID, I-HARP and a feasibility study of a falls-prevention programme (Wesson et al., 2013) – the latter reporting an almost doubling of carer burden for the intervention group. The majority of studies also reported that even when a positive outcome was achieved, it was often not maintained long-term; researchers speculated that this may be due to changes in the health and functioning of patients (and by extension, the carers' needs) over time.

Other interventions: An RCT of a case-management intervention (occupational therapist assessment and treatment of dyads from various outpatient clinics), found no significant changes in outcomes, although use of social care support increased in the intervention group; the author considered this a positive sign that dyads were more willing to accept help and had been successfully signposted to these resources (Lam et al., 2010). A multicomponent rehabilitation programme based in an outpatient clinic reported non-significant outcome changes for carers but stated that 60% showed improved or stable burden and distress by programme end (Cornelis et al., 2018).

More positive findings were associated with an RCT of a pre-discharge educational training programme for the carers of new hip fracture patients, with greater decreases in anxiety and depression over time for intervention group carers (Martín-Martín et al., 2014). A feasibility study of another hip fracture instructional workshop was also well-received, with evidence of improved carer knowledge in relation to delivering care following a hip fracture (Ariza-Vega et al., 2020). An educational programme for dementia carers reported improved knowledge (in relation to a range of topics) and physical health in intervention carers, although sample sizes were small (DiZazzio-Miller et al., 2017, 2020). A pilot study examining the transferability of the UK-developed Collaborative Care Skills Training workshop to Australia reported significant increases in use of adaptive coping strategies post-programme and trends towards improved carer outcomes for carers of people living with eating disorders (n = 15) (Pépin & King, 2013). An RCT of a ward-based educational intervention for stroke patients and their carers reported no significant carer outcomes (Eames et al., 2013). Table 2 (supplementary material) provides further information on carer-related intervention outcomes.

Qualitative carer outcomes

Qualitative feedback from carers was almost always positive. Carers described how interventions facilitated positive interactions with the patient (Corvol et al., 2018; O'Connor et al., 2019), a sense of being in control (O'Connor et al., 2019), new skills and knowledge (and that these were useful) (Burgess et al., 2020; Clare et al., 2019; Rahja et al. 2020a), increased patient confidence and independence (which they appreciated) (Corvol et al., 2018) and reported their enjoyment of therapeutic relationships with occupational therapists (Burgess et al., 2020; Clare et al., 2019). Carers appreciated flexibility in the timings of intervention components (e.g. home visits or individual sessions) (Morency et al., 2020), consideration of, and tailoring to, their particular situation (Morency et al., 2020), continuity (Jeon et al., 2020), advice being specialist but accessible (Jeon et al., 2020), good communication from interventionists (Burgess et al., 2020) and validation from professionals regarding their caring role (Rahja et al., 2020a).

However, while carer engagement was generally high, some studies identified barriers, reported by interventionists, study investigators or carers themselves. These included: time pressures (for carers) (O'Connor et al., 2019; Voigt-Radloff et al., 2011b), high carer stress/worry (Jeon et al., 2020), difficulties within patient-carer relationships (Clare et al., 2019; Voigt-Radloff et al., 2011b), carers feeling unable to talk about patients in front of them (Jeon et al., 2020), low carer belief in potential intervention effectiveness (Voigt-Radloff et al., 2011b), unwillingness to accept change or support (Donkers et al., 2018; Voigt-Radloff et al., 2011b), and reluctance to address actual or potential patient disease progression (O'Connor et al., 2019). Sometimes professionals acted as barriers by gatekeeping: one paper described how professionals, wary of increasing carer burden, felt reluctant to refer carers to the intervention study despite its potential benefits (Donkers et al., 2018). Another noted that although carer support had been an intended intervention component, it was often neglected by interventionists due to a lack of operational detail in the protocol (Allan et al., 2019). Other papers reporting on dyadic interventions noted that, on occasion, carers would use intervention sessions as respite despite the intention that activities would be completed jointly with the patient, perhaps emphasizing the time pressures and lack of day-to-day respite carers can access (Corvol et al., 2018).

No known harmful effects were reported as a result of intervention participation in any of the papers.

Occupational therapists' experiences

Of the papers that reported feedback from interventionist occupational therapists, therapists appeared to value the opportunity to participate (Burgess et al., 2020). They appreciated being given time to practice core skills ("real OT") and form deeper relationships with patients and carers

(Burgess et al., 2020). Facilitators to occupational therapist participation included: confidence in their skills (Van't Leven, 2011); intervention familiarity (Van't Leven, 2011); managerial support (Culph et al., 2020; Van't Leven, 2011); belief the intervention was useful for patients and carers (Van't Leven, 2011); and positive relationships with other MDT members (where applicable), bolstered by shared working environments (Culph et al., 2020). Barriers included: intervention elements or procedures perceived as overly-complex (Van't Leven, 2011); time pressures (Van't Leven, 2011); low patient/carer motivation (Donkers et al., 2018; Voigt-Radloff et al., 2011a); delays in accessing onward services, community resources or equipment (Burgess et al., 2020); and poor communication between/access to other MDT members (Culph et al., 2020; Donkers et al., 2018). Therapists commented on the importance of carer involvement in dyadic interventions and impact of dyads' relationships on intervention success (Burgess et al., 2020; Clare et al., 2019).

Cost

Reporting of financial costs was variable but suggested potential financial benefits from adopting evaluated interventions on a larger scale. Gitlin et al. (2010a) found the TAP intervention costed less than similar contemporary dyadic interventions, with reduced time per day spent caring; Rahja et al. (2020) similarly found COPE implementation reduced carer time away from employment, potentially benefitting the Australian health and social care system. Clare et al. (2019) suggested functional gains via the GREAT intervention could save health and social care costs via patients' functional gains if Willingness-To-Pay values were ≥£2500.

Discussion

This review aimed to establish the international published evidence base relating to interventions for adult informal carers delivered by occupational therapists. Findings indicate a range of interventions have been developed and evaluated, utilising a variety of intervention designs to improve carer outcomes. While outcomes varied between individual papers, the evidence suggests the overall impact of occupational therapy for carers through these interventions is positive, that carers value the input of occupational therapists and that occupational therapy could be a safe and cost-effective option for improving carer support. Additionally, therapists themselves appear to enjoy delivering these interventions and the opportunity to use core professional skills.

One major finding of the review is the importance of carefully considering outcome measures to ensure intervention effects are successfully captured. Another key finding was that success of an intervention in one context does not guarantee the same when introduced elsewhere. Outcomes indicated the efficacy of interventions varied by country: for example, despite significant success in the Netherlands where it originated (Graff et al., 2007), COTiD outcomes suggested reduced efficacy in subsequent German and UK RCTs (Voigt-Radloff et al., 2011a; Wenborn et al., 2021). The reasons for this appear complex. A process evaluation for the German RCT linked poorer outcomes to various possible explanations, including better baseline functioning of patients than the original study (Voigt-Radloff et al., 2011b). The COTiD UK team received very positive qualitative feedback from participating dyads, but quantitative outcome measures indicated COTiD was no more effective than treatment as usual; the authors questioned if, rather than the intervention being ineffective, the selected outcome measures (which differed from the original COTiD RCT) were not appropriate to detect intervention effects (Wenborn et al., 2021). In the case of two large trials (Clare et al., 2019; Wenborn et al., 2021), qualitative data proved useful in detecting intervention effects where quantitative outcome measures did not, suggesting qualitative components should be included in evaluations.

Interestingly, the outcome measure most frequently used was the Zarit Burden Interview (ZBI) (Zarit, Reever & Bach-Peterson, 1980). The ZBI can be a useful outcome measure but its use and interpretation should be considered carefully, taking into account the potential for patient deterioration; most papers related to interventions for carers of people with dementia, wherein symptom severity (and hence carer burden) is likely to increase over time regardless of health or social care intervention. While most interventions lasted for a period of months, evaluation often continued for up to a year after intervention commencement, a timeframe in which the needs of patients could conceivably change and intensify. Cornelis et al. (2018) considered stable ZBI scores to indicate a positive effect on dementia carers given the extended length of their intervention (maximum 12 months).

In anticipation of deterioration, some interventions included components related to preparing carers for the future (e.g. the TAP and COPE interventions) however effects were not always maintained longer term. Maintenance of positive effects post-intervention may be an important factor for intervention developers to consider, though achievement of a positive outcome in the short-term (and hence meeting the immediate needs of a carer) without demonstrating long-term maintenance still contributes to improved carer support and is not without value. Evidence that effects are not always maintained post-intervention may reflect that the needs of carers can change over time in response to a range of factors (e.g. lifestyle change or disease progression).

The majority of papers described dyadic, home-based interventions. This review suggests that care must be taken when designing dyadic interventions to avoid unduly increasing burden on carers.

Professionals in a multidisciplinary feasibility study by Allan et al. (2019) suggested joint initial assessment by professionals to reduce duplication and avoidance of complex or overly long outcome measures, which carers sometimes must also complete on behalf of the patient where insight is unreliable (Allan et al., 2019). Interestingly, poor implementation of carer support was also noted in this paper, despite being an intended component; researchers attributed this to a lack of clarity about how professionals should deliver this. This implies that (a) therapists must have clear understanding of how to operationalise carer support for it to be effective, (b) care must be taken to ensure interventions intended to support a dyad do not inadvertently transition into becoming primarily patient-focused and (c) that while use of the ZBI should be well-considered in terms of outcomes, it can also help as a process measure, detecting when an intervention design is burdensome for carers. Benefits of a dyadic approach can include patients and carers working together constructively, deepened understanding, acknowledgement of each other's needs and improved relationships (Clare et al., 2019; Corvol et al., 2018; O'Connor et al., 2019); however, carers can also struggle to express themselves in front of patients (Jeon et al., 2020), pre-existing relationship dynamics can affect intervention success (Voigt-Radloff et al., 2011b; Clare et al., 2019) and carers can disengage, misunderstanding the purpose of therapeutic sessions, instead treating them as respite (Corvol et al., 2018). This last point is particularly pertinent given the reported importance of carer engagement for the success of dyadic interventions (Burgess et al., 2020; Clare et al., 2019).

One paper described a failed trial of a dyadic intervention (Donkers et al., 2018) while another presented a trial of a previously successful Dutch intervention which did not yield any improved outcomes in a different context (Voigt-Radloff et al., 2011a). In both cases, process evaluations proved valuable in analysing why these interventions were not successful (see Table 2). Similarly, papers describing implementation and staff perspectives on barriers and facilitators to intervention delivery provided useful insights to inform future intervention development and study design. When designing evaluations, capture and publication of this valuable data should be considered to provide transparency and help guide future research.

Limitations

Though measures were taken to enhance the methodological quality of this review, limitations remain. Exclusion of non-English language papers may mean relevant papers were missed. Additionally, though minimal relevant material was found during scoping searches of grey literature, its exclusion may have increased publication bias (Paez, 2017). The decision to limit searches to the last decade was made after scoping searches; this pragmatic choice ensured completion of the review within the project timescale given the volume of papers retrieved. This meant papers reporting the original RCTs of some interventions fell outside of the given timeframe and hence were not included. However, these papers were read and considered during data synthesis to ensure reviewers held the necessary understanding of intervention development and any previous outcomes associated with them.

The review eligibility criteria meant some papers were excluded that may have contributed useful knowledge but did not fulfil all requirements for inclusion; for example, some papers indicated occupational therapists were involved in an intervention as part of an MDT, but their role or specific contributions were unclear. Use of the TIDieR checklist to enhance clarity in intervention reporting may help ensure future papers are not excluded on a similar basis (Hoffman et al., 2014).

Some of the papers in the review were pilot or feasibility studies. These were included to ensure comprehensiveness of interventions reported in the literature. However, these studies are rarely sufficiently powered to enable definitive conclusions about the effects of an intervention (nor are they designed to do so), or whether they will deliver similar outcomes in a subsequent RCT; as such their efficacy findings should be treated with caution (Thabane et al., 2010).

Finally, papers relating to interventions for young carers were excluded. The needs of young carers are likely to differ from adult carers and would benefit from a separate review. Similarly, many papers were discovered during scoping searches relating to supportive occupational therapy interventions for parents or other individuals caring for children but fell outside the remit of this review. Subsequent reviews synthesizing these studies may provide further valuable insight into the impact of occupational therapy interventions for informal carers.

Conclusion

Informal carers play a vital role in supporting patients, but improved carer support is required to ensure carers can manage their own health and wellbeing alongside providing support for patients. Occupational therapist delivered interventions can play a key role enhancing support for informal carers and improving outcomes, although intervention and evaluation design should be carefully considered, drawing upon lessons learned from the existing international evidence base. This review provides evidence that occupational therapy interventions are a safe and potentially effective option for improving carer support.

Key findings

- Occupational therapy interventions can successfully improve outcomes for informal carers
- Outcome measures must be considered carefully to ensure intervention effects are successfully captured
- When designing dyadic interventions care must be taken to ensure burden on carers is not increased
- A variety of barriers and facilitators affect carer engagement and intervention delivery by occupational therapists

What this paper adds

This review synthesizes international data from the past decade relating to carer-targeted interventions delivered by occupational therapists. Carer support is increasingly emphasized as a priority for health and social care services; this review provides evidence that occupational therapy is a potentially effective option for improving carer support but suggests that intervention design and evaluation must be carefully considered to achieve this.

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Figure 1. PRISMA flow diagram (based on Page et al., 2021).

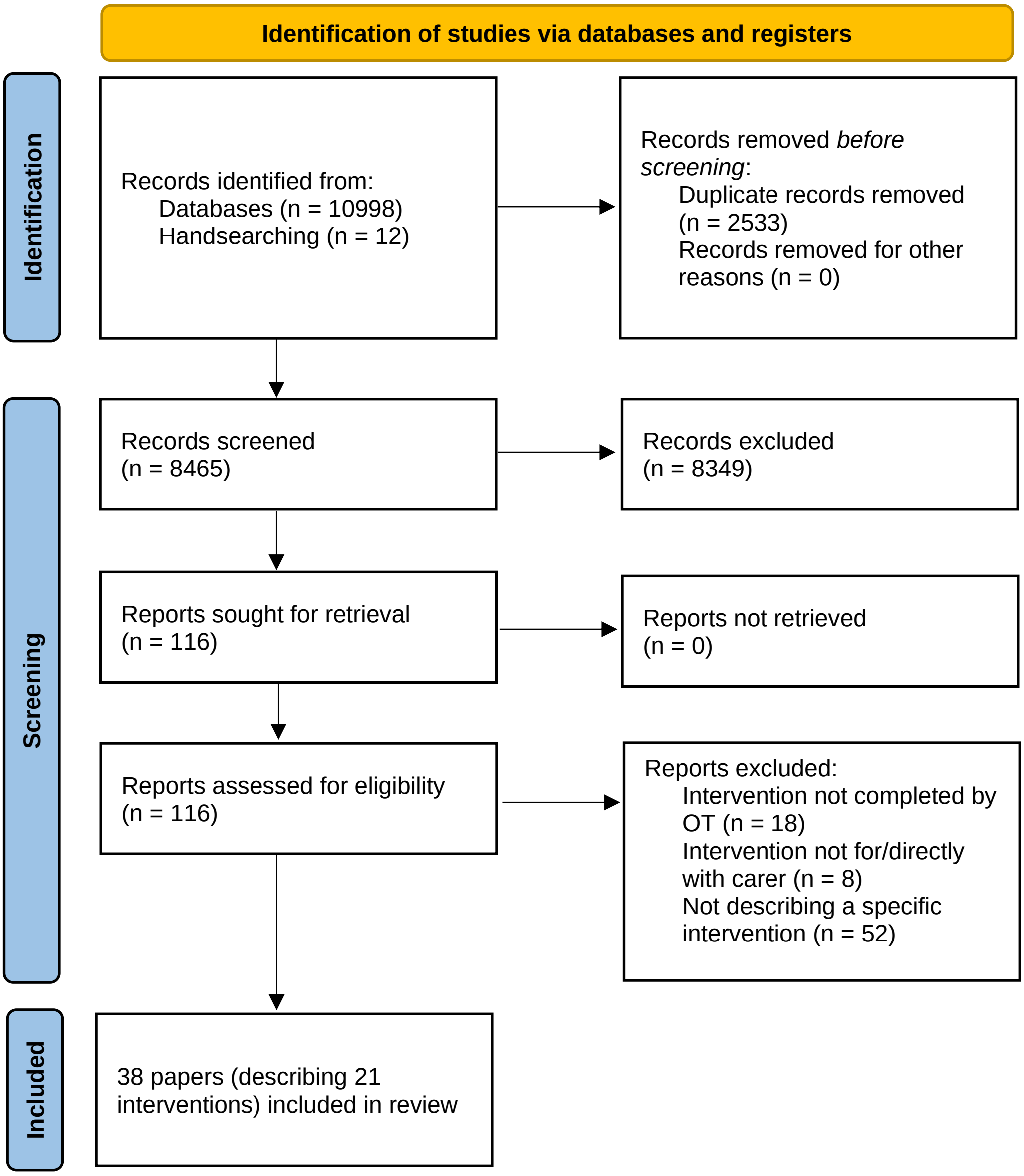

Table 2. Summary of eligible papers, including intervention designs and outcomes. Papers are grouped by intervention and then chronological order in terms of publication.

Study	**Aim and design**	**Carer recruitment**	**Participant characteristics**	**Intervention (OT element)**	**Intervention implementation and carer-specific outcomes**
Tailored Activity Program (TAP)					
Gitlin et al. (2010a) USA	**Cost-effectiveness study** (linked RCT pre-2010). Aim: To evaluate to cost-effectiveness of the TAP for people living with dementia and their carers	Via media advertising and mailings from social services	N=60 (30 in intervention group, 30 on wait list). **Intervention:** Average age = 62.8 yrs. M=5, F=25. Spouses = 16. **Control:** Average age = 67.9 yrs. M=2, F=28. Spouses = 21. **Patient group:** dementia	**TAP intervention:** OT delivered eight home visits over four months. Included: assessment of patient, carer and home environment; identification of three activities of interest; tailoring these activities to the patient's abilities. Carers were educated about dementia and behaviours and received skill training (e.g. activity simplification, problem-solving and communication skills). Caregivers were also given support to prepare for future deterioration and how to generalise strategies learned **Other Healthcare Professionals (HCPs) involved?** No (OT facilitated)	Average intervention cost = $941.63 per dyad (less than other similar contemporary patient-carer interventions). Carers saved an hour a day "being on duty" (being vigilant) at a cost of $1.10/day and an hour per day "doing things" for the patient at a cost of $2.37/day (using incremental cost-effectiveness ratios). Concluded TAP was cost-effective. **Note:** original RCT (Gitlin et al., 2008) also suggested other benefits for carers, including improved mastery, self-efficacy and increased use of techniques taught through TAP (simplification techniques).
Gitlin et al. (2018) USA	**RCT.** Aim: To determine whether a home-based activity programme (TAP-VA) would reduce behavioural symptoms and functional dependence of veterans with dementia and caregiver burden	Via Veteran Affairs services	N=160 (76 in intervention group). Average age = 72.4 yrs. M=4, F=156. Spouses = 139. **Patient group:** dementia	**TAP-VA intervention:** OT delivered up to eight in-home sessions over four months. Included: assessment of patient, carer and environment (two sessions); production of an assessment report and activity prescriptions, wherein carers learned how to facilitate patient involvement in activities, manage situational distress and understand behavioural symptoms (four sessions); concluded with training carers to simplify activities and use strategies for particular care challenges (two sessions) **Other HCPs involved?** No (OT facilitated)	7.02 sessions (length = 75.5 minutes per session, range = 15-180 minutes) completed on average. 62 dyads completed > 3 sessions (considered minimum number for treatment effect). **4 months:** Significantly reduced distress with behavioural symptoms in intervention group (-0.07, p = 0.03). No other statistically significant differences between groups but a trend towards better scores in the intervention group. **8 months:** No significant differences between groups.
de Oliveira et al. (2018) Brazil	**Pilot study.** Aim: To evaluate the efficacy of the tailored activity program–outpatient version (TAP-O) for dementia patients **Control group?** Yes	From community medical centres using media advertising	N=21 carers (12 in intervention group). **Intervention:** M=1, F=11. Average age = 56.8 yrs. **Control**:	**Adapted TAP intervention:** OT administered in a hospital outpatient setting rather than patient's home. Consisted of eight sessions over three months (condensed programme). Control group participated in psychoeducation group sessions led by an OT	Significantly reduced carer burden for the intervention group (32.45 to 22.73 *p* = 0.003 vs control group: 20.40 to 21.90 *p* = 0.10).

Study	Aim and design	Carer recruitment	Participant characteristics	Intervention (OT element)	Intervention implementation and carer-specific outcomes
			M=5, F=5. Average age = 60.7 yrs. **Patient group:** dementia	**Other HCPs involved?** No **-** a psychiatrist helped administer outcome measures but did not facilitate the intervention.	
Novelli et al. (2018) Brazil	**Pilot study.** Aim: To evaluate the effects of the Tailored Activity Program-Brazilian version (TAP-BR) on behavioural symptoms and quality of life in persons with **dementia** and caregiver burden **Control group?** Yes	Media announcements	N=15 carers per group (30 total). M=2, F=28. Average age = 65.97 yrs. **Patient group:** dementia	**TAP intervention** (see above): delivery appeared consistent with original RCT **Other HCPs involved?** No (OT facilitated)	Carer quality of life significantly improved (intervention: 38.67 to 41.47 vs. control: 36.53 to 35.73, *p* = 0.02). Caregiver burden was significantly higher in the control group after 4 months (but it was not reduced in the intervention group – intervention: 30.33 to 30.40, *p* = 0.5, control: 32.47 to 35.33, *p* = 0.02).
O'Connor et al. (2019) Australia	**Feasibility study.** Aim: To explore the feasibility of implementing the Tailored Activity Program with a cohort of people with frontotemporal dementia and their carers (dyads) **Control group?** No	Via a dementia research group, memory clinic and magazine advert	N=20 (9 in intervention group). **Intervention:** M=2, F=7, average age=59. **Control:** M=6, F=5, average age = 66. Spouses = 18, ex-spouses = 1, daughters = 1. **Patient group:** frontotemporal dementia	**TAP intervention** (see above): delivery appeared consistent with original RCT **Other HCPs involved?** No (OT facilitated)	**On average:** 1) 7.44 home visits (length: 73 minutes) completed. 2) $46.01 AUD/dyad spent on activity materials. All carers engaged with TAP and actively implemented intervention strategies. 96.3% (26/27) prescribed activities were used during TAP; 63% were still used by sessions 7-8. No significant change observed for carer time spent "doing things" or feeling "on duty". **Therapist observations:** Carers appeared to find TAP increasingly useful as sessions went on, demonstrating increasing skill mastery over time **Qualitative themes included:** carer-perceived benefits *(positive experiences, sense of being in control, positive interactions with the patient)*; carer engagement in TAP *(and importance of this)*; barriers to uptake/implementation *(lack of time, reduced readiness to engage with process, reluctance to address disease progression, carer perception activity is unsuccessful);* and strategies used by the carer to engage the patient *(types and range used, how these developed)*.
Community Occupational Therapy in Dementia (COTiD)					
Van't Leven et al. (2011) The Netherlands	**Qualitative interview study.** Aim: To define barriers to and facilitators for implementing the Community	OTs recruited from original RCT	N=17 occupational therapists. Average age = 48 yrs (range = 35-60 yrs).	**COTiD intervention**: OT delivered 10x 60-minute sessions over five weeks. Included: diagnostics and goal setting, identification of activities care and patient wanted to work on, modification of the home environment, identification of potential compensatory strategies to facilitate	**Occupational therapists:** Identified barriers: feelings of incompetence *(regarding the intervention or dementia itself)*; intensity of treatment *(time constraints, diagnostic instruments, may take longer to produce results than dyads expect)*; adherence and feasibility *(difficult using some of the diagnostic instruments, doubts about use of narrative interviews for treatment planning, questioning extent of adherence required).*

Study	Aim and design	Carer recruitment	Participant characteristics	Intervention (OT element)	Intervention implementation and carer-specific outcomes
	Occupational Therapy in Dementia (COTiD) guideline for people with dementia and their carers		**Patient group:** dementia	patient involvement in daily activities (four sessions); teaching the patient how to improve performance of activities and carer training (six sessions). Carer support included: training in cognitive and behavioural interventions, effective supervision and problem solving; practical support; emotional support; and coping strategies **Other HCPs involved?** No (OT facilitated)	Facilitators: positivity about COTiD intervention guideline *(support for modelling intervention phases and carer involvement);* evidence for COTiD's effectiveness *(helps OTs to promote in contacts with physicians and managers);* external support *(from managers and other departments and positive feedback from referring clinician).* **Managers and physicians:** Barriers: low knowledge about OT and COTiD; availability of and contact with OTs; financial resources. Facilitators: good outcomes from occupational therapy and the COTiD intervention.
Voigt-Radloff et al. (2011a); (2011b) Germany	**RCT.** Aim: To compare the benefits and harms of a 10-session community occupational therapy programme for patients with Alzheimer's disease with the impact of a one session consultation at home in German routine healthcare	5 memory clinics, 1 municipal hospital and a private neurology practice	N=141 (71 in intervention group). **Intervention:** M = 24, F=47, average age= 64.9. **Control:** M=17, F=53, average age=64.5. Spouses = 80, children = 52, other = 9. **Patient group:** Alzheimer's disease	**COTiD intervention**: OT delivered two 60-minute sessions per week for 10 weeks. Included: assessment of patient, carer and their environment; identification of therapeutic goals (3-4 sessions); treatment phase (5-6 sessions), including environmental adaptation, compensatory strategies and adaptation of activities. Carers received practical and emotional support and training in effective supervision, problem solving, facilitating activities and coping strategies via cognitive-behavioural strategies **Other HCPs involved?** No (OT facilitated)	61 (86%) dyads completed the intervention. Interventionists rated carer adherence to the intervention as: 5 hindering, 15 neutral, 47 facilitating (criteria devised by study team). No significant differences on outcome measures between groups. Process evaluation suggested several potential explanations: difficulty engaging the patient, varying quality/completion of therapeutic intervention components, day-to-day functioning of patients was better than the original study at baseline, and difficulty training the carer. The latter related to: carer not accepting support, being over-stretched or not present at sessions, unwillingness to try something new, difficulties in the relationship between family and carer.
Donkers et al. (2018) The Netherlands	**RCT.** Aim: To describe the lessons learned from a failed trial which aimed to assess the effectiveness of the Social Fitness Programme (SFP) developed to improve social participation in community-dwelling older people with cognitive problems and their carers	Via general practices, memory clinics, home care and social welfare organisations and meeting places for people with dementia	N=17 (8 in intervention group). Note: study did not meet recruitment targets and was ended early. **Patient group:** older people with cognitive impairments (non-specific diagnosis)	**Social Fitness Programme (SFP) intervention:** Modelled on COTiD with additional interdisciplinary components, including: interdisciplinary home visits, discussion between professionals regarding the intervention plan, PT delivery of the Coach2Move programme, and practical support from the welfare professional. Carer-specific elements included: coaching carers in problem solving, compensatory strategies and coping skills, education and advice on dementia, and help to facilitate increased social participation for both patient and carer **Other HCPs involved?** Yes - a physiotherapist (PT) assessed and provided treatment if	The trial ended early due to recruitment difficulties. Process evaluation findings: - Recruitment difficulties likely due to (a) low patient motivation to increase social participation and (b) referring professionals' fear that carer participation would worsen carers' pre-existing burden - Adherence to intervention guidelines by OTs was deemed sufficient. - **Barriers to intervention delivery:** lack of patient motivation; increased carer burden; unwillingness of the patient to switch to a new PT; changing patient status during the intervention; interdisciplinary working difficulties; little chance for clinicians to build up experience with the intervention; limited availability of suitable organised community social activities. - **Facilitators to intervention delivery:** motivation of patient and carer to accept support and contribute to research; motivated professionals; improved collaboration during the intervention; goal setting; and additional attention for the carer.

Study	Aim and design	Carer recruitment	Participant characteristics	Intervention (OT element)	Intervention implementation and carer-specific outcomes
		and their carers		appropriate (onward referral by OT); a welfare professional (e.g. social worker) if needed for social support	- All but one interviewed participant was satisfied with the intervention. Two carers did not have all personal goals formulated at baseline addressed during the programme. - Concluded that the SFP did not "fit" in three ways: 1) clients found framing the intervention on social intervention threatening; 2) intervention was too complex to be delivered as intended; and 3) tension between the programme being tailored to the patient and carer whilst being evaluated as a fixed study design.
Pozzi et al. (2019) Italy	**Pilot study.** Aim: To assess the applicability in Italy of the COTID programme on occupational performance of people with dementia and their caregivers (COTiD-IT programme) **Control group?** No	Convenience sample of people on COTiD programme	N=27. Average age = 56.7 yrs, M=9, F=18. **Patient group:** dementia	**COTiD intervention**: OT delivered 10 sessions of home-based OT. First four sessions bi-weekly, including assessment of the patient and goal setting. Sessions 5-10 focused on facilitating improved functional performance, including environmental modification, compensatory strategies, problem-solving and education/training for carers **Other HCPs involved?** No (OT facilitated)	Only significant difference for carers was in sense of competence (from 77.19±13.27 pre-intervention vs. 82.56±12.57 post-intervention, p = 0.005).
Wenborn et al. (2021)/ Burgess et al. (2020) UK	**Mixed method RCT.** Aims: To estimate the clinical effectiveness of COTiD-UK relative to treatment as usual; To examine the experiences of people with mild to moderate dementia, their family carers and occupational therapists, of taking part in the COTiD-UK intervention	Via NHS services (primarily memory services), voluntary and charitable bodies and a dementia research portal; qualitative study used purposive sampling from RCT	N=468 (249 in intervention group). Average age = 69.1 yrs, range: 29-94 yrs. M=23%, F=77%. Spouses = 72.6%, adult children = 22.2%. N=22 carers completed qualitative study; Age range = 38-88 yrs. Spouses = 18, adult children = 4. **Patient group:** dementia	**COTiD intervention**: OT delivered up to 10 hours of therapy, delivered flexibly, over 10 weeks. OT completed assessment of each member of the dyad and home environment, then facilitated goal setting. Dyads were then supported to achieve goals: for some carers this entailed development of problem-solving and coping strategies. Evaluation regarding goal achievement was completed in the final session **Other HCPs involved?** No (OT facilitated)	**Intervention fidelity:** moderate, with some variation between sites and therapists. 9% of intervention dyads did not reach the goal-setting phase. Non-adherence rate: 4.6%. An average of 4.09 goals were set (range 1-13) for adhering dyads. 90.8% of goals were fully or partially achieved. Goals not achieved/only partially achieved were often due to difficulties accessing other services or community resources. **Carers:** Primary and secondary outcomes similar between groups at all time points; no evidence that COTiD-UK was more effective than treatment as usual. The researchers questioned if there are more appropriate ways to measure outcomes for this kind of study. **Qualitative data** Dyads: 1) appreciated being able to talk to, and set goals, with OTs. Support received to achieve goals: information provision, signposting, learned new approaches/skills, referrals. 2) spoke about factors that hindered goal achievement, such as illness and delays in accessing local services/resources. 3) valued therapists' approach, demeanour and communication skills. Intervention boosted independence and initiative in some dyads; others appreciated step-by-step support from the OT.

Study	Aim and design	Carer recruitment	Participant characteristics	Intervention (OT element)	Intervention implementation and carer-specific outcomes
Care of Persons with Dementia in their Environments (COPE)					
Gitlin et al. (2010b) USA	**RCT.** Aim: To test a nonpharmacologic intervention for people living with dementia and their carers that realigns environmental demands with patient capabilities	Media adverts? and mailings via social agencies	N=237 dyads (outcome data collected from 209 at 4 months 102 in intervention group). Average age = 62.2 yrs. M=28, F=186. **Patient group:** dementia	**COPE intervention**: OT delivered up to 10 sessions over four months. Initial sessions: assessment of patient, carer and home environment; identification of caregiving challenges; formulation of action plans ("COPE Prescriptions"). Follow up sessions included caregiver education and caregiver training, such as: problem-solving, communication, how to engage patients in activities, task simplification, environmental modification and stress reduction. Final sessions reviewed progress and how to plan ahead for potential future deterioration **Other HCPs involved?** Yes - one session with an advance practice nurse (information provision; screening of patient for health issues and polypharmacy)	Average of 9.31 face-to-face sessions completed per dyad (mean duration = 68.24 minutes) and 3.25 telephone sessions (mean duration = 20.15 minutes). COPE cost estimated at $537.05 per dyad. **4-month outcomes:** Improved wellbeing (adjusted mean difference: 0.22, p = 0.002). Improved confidence using activities (adjusted mean difference: 0.81, p = 0.002). **9-month outcomes:** No statistically significant differences between groups. Carers reported participation a positive experience (both groups). COPE carers reported self-perceived improvements in: disease understanding, confidence managing behaviours, life feeling easier, ability to care, patient quality of life and ability to keep patient at home.
Clemson et al. (2020); Culph et al. (2020); Rahja et al. (2020a); Rahja et al. (2020b) Australia	**Hybrid implementation-effectiveness study.** Aim: To evaluate the effects (in terms of implementation, participant experiences, costs and benefits) of an evidence-based program, Care of People with Dementia in Their Environments (COPE), into health services **Control group?** No; compared outcomes to previous trial (Gitlin et al., 2010b)	Via service providers; eligible dyads identified by OTs. Qualitative study: stratified purposive sampling from larger COPE trial	N=104 dyads (85 completed programme). Age: <65 yrs: 30, 65-74 yrs: 22, 75-84 yrs: 45, 85+ yrs: 7. Spouses = 74, parents = 22, siblings = 3, other = 3. **Patient group:** dementia	**COPE intervention**: delivery appeared consistent with original RCT **Other HCPs involved?** Yes - nurses – see above	31 OTs implemented the programme at least once (82%). 18 (58%) provided the programme three or more times. 7.5 sessions were completed with dyads on average (range = 3-10). Average of face-to-face time = 13.49 hrs. On average three activity prescriptions addressed. **Carers:** Carer engagement and enthusiasm for the programme were rated positively (median 4/5). Significantly higher scores on Perceived Change Index post-intervention (33.0 pre-intervention vs. 45.5, p = <0.001). **Costs:** Reduced time spent away from paid employment for carers. Findings suggested the Australian health and social care system would benefit from COPE implementation. **Qualitative data:** Average carer 'value' rating: 3.8/4 (4 being most positive score) Carers valued the programme and appreciated the focus on stress management, coping techniques, validation and learning new ways of helping the person with dementia. Both carer and patient found re-engagement of the patient with meaningful activities positive. The programme encouraged carers to be less risk-averse, which appeared to result in greater wellbeing for the patient. Carers noted the programme had made it more

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					feasible for the patient to continue being cared for at home and to re-engage with previous roles at home and in the community.
Fortinsky et al. (2020) USA	**RCT.** Aim: To test the COPE intervention for people living with dementia in a Medicaid and state revenue-funded home and community-based service (HCBS) programme	Via Connecticut Home Care Program for Elders (CHCPE) – those eligible informed by care managers	N=291 (145 in intervention group). Average age = 61.7 yrs (intervention), 62.7 yrs (control). **Patient group:** dementia	**COPE intervention**: delivery appeared consistent with original RCT **Other HCPs involved?** Yes - advanced practice nurse - see above	101 (78%) of dyads completed all OT visits (with 12% completed eight or nine, 10% completing 7 or fewer). **4 months:** Carers had statistically greater perceived change for the better in the intervention group (3.2 vs 3.0, p = < 0.001). No other significant differences between groups. **12 months:** No significant differences between groups for carers. No COPE effects from 4 months were sustained to 12 months.
Laver et al. (2020) Australia	**"Non-inferiority RCT".** Aim: To determine whether delivery of a dyadic intervention for people living with dementia and their carers using telehealth was noninferior to delivery of the same program using traditional face-to-face delivery through home visits	Via memory clinic, aged care wards within a tertiary hospital, community-based dementia education service, local council newsletters	N=63 dyads (31 in adapted intervention/telehealth group). Average age = 70.66 yrs (control), 69.47 yrs (adapted intervention). M=15, F=48. **Patient group:** dementia	**Adapted COPE intervention:** Altered schedule to fewer, longer sessions – OT delivered eight sessions over up to 16 weeks, approximately 60 minutes each. Home visit group received all sessions face-to-face. Telehealth group received first two as home visits, the rest via videoconferencing **Other HCPs involved?** No – which is different to usual COPE, (has two sessions with a nurse). Patient instead assessed by the referring service	**Implementation:** Time spent delivering the intervention similar between groups (337.4 minutes for home visit group vs. 307.9 for telehealth). However, therapist's travel time significantly reduced (255.9 minutes for home visit group vs. 77.2 minutes for telehealth). **Carers:** No statistically significant differences between groups for primary outcome measure, the Caregiving Mastery Index (score difference between groups – 0.09, 95% confidence interval). No significant difference in scores for any of secondary outcome measures. Overall no evidence to suggest telehealth version of intervention was inferior to face-to-face delivery.
Other interventions					
Lam et al. (2010) Hong Kong	**RCT.** Aim: To evaluate a case management (CM) model for people with mild dementia	Via psychogeriatric outpatient and memory clinics at a teaching hospital	N=102 (59 in intervention group). **Intervention**: M=14, F=45. **Control:** M=13, F=30. Ages not provided.	**Case management**, consisting of OT: assessment of patient and carer; advice on safe performance of self-care, environmental modification, behavioural management, communication techniques; training for carers on home-based cognitive stimulation (reinforced by home visit and phone calls); follow-up at hospital clinics; encouragement for participants to be registered with local support services; accessibility via a	Median number of follow-ups by type: home visit (3), telephone (8), outpatient clinic (2). **4 months:** No significant changes in carer burden, quality of life or General Health Questionnaire (GHQ) scores. **12 months:** No significant changes in carer burden or quality. Increased GHQ score in case management group (average increase of 1.0, p = <0.05) but not in control group. **Both:**

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			Patient group: dementia	hotline and interlinking with other care professionals on behalf of participants **Other HCPs involved?** No (OT facilitated)	Significantly higher use of social care support in case management group – specifically paid helpers and day care – at both 4 and 12 months.
Eames et al. (2013) Australia	**RCT.** Aim: To evaluate the effects of an education package which utilised tailored stroke information and reinforcement opportunities on the knowledge, health and psychosocial outcomes of stroke patients and carers	Two acute stroke units	**Intervention** N=31 carers. M=32, F=39, average age = 55.2 years yrs. **Control** N=30 carers. M=31, F=36, average age = 61.4 years yrs. Genders combined (patients and carers). **Patient group:** stroke	**Tailored information provision** by OT for stroke patients/carers with reinforcement via a) telephone contact up to three times post-discharge (monthly intervals) and b) a telephone number participants could call with questions. Telephone support included discussion of useful strategies (e.g. breaking down tasks), correcting misinformation and encouraging healthy behaviours **Other HCPs involved?** MDT helped identify eligible participants but not involved in intervention delivery	On average, the written component was seen as the most useful component while talking to someone via telephone post-discharge was least useful. No significant differences between groups for stroke knowledge or caregiver strain.
Pépin & King (2013) Australia	**Pilot study.** Aim: To examine measure the effectiveness of the Collaborative Care Skills Training workshops for carers of people living with eating disorders and their transferability to Australian services **Control group?** No	Via eating disorder services, private practitioners and newspaper adverts	N = 15 (M = 4, F = 11). All mothers/fathers of an adult ED patient (8 were mother/father dyads of the same patient). Average age = 51.29 yrs. **Patient group:** eating disorders	**Collaborative Care Skills Training workshops**. OTs co-facilitated a programme of workshops across six consecutive weeks (2.5 hour sessions). Sessions consisted of education, skill-training (e.g. motivational interviewing, functional analysis, coping strategies, problem solving), and ‘homework’ tasks **Other HCPs involved?** A clinical psychologist co-facilitated the workshops	Non-significant decrease in: psychological distress; nutritional difficulties; use of maladaptive coping strategies and expressed emotion (e.g. critical comments towards the patient). Significant increase in use of adaptive coping strategies (mean: 38.00 at baseline vs. 44.87 post-programme, *p* = <0.01). Significant reduction in patient dysregulated behaviour (mean: 8.79 at baseline vs. 7.53 at 8-week follow up, p = <0.05). No change to self-rated guilt or social isolation. Non-significant trend towards increased belief the patient could change. Workshops appeared acceptable (participants rated them highly).
Wesson et al. (2013) Australia	**Feasibility study.** Aim: To conduct a pilot randomized control trial exploring the design and feasibility of a novel approach to fall prevention for people	Via a memory disorder/ cognitive disorder/ aged care clinic and a dementia	N = 22 (11 in each group). Ages not provided. M = 3, F = 8 (both groups). Relationship to the patient not stated.	**Tailored 12-week programme to reduce falls.** OT component: six home visits and three telephone contacts. OT completed the Westmead Home Safety Assessment to assess for environmental fall hazards, provided small aids (e.g. sensor lights) and a home safety booklet that provided recommendations tailored to the patient’s cognitive ability. OT discussed behavioural issues	Mean number of home visits: 10 (average length = 57.5 minutes) and 3.5 phone contacts (average length = 12.9 minutes). 50% of participants implemented 50% or more of the home safety recommendations. Higher carer stress was linked to lower adherence. All participants reported that they enjoyed the programme. No serious adverse events were reported. **Carers:** Increased burden score in intervention group at follow-up (approximately twice that of control group – 19.14 vs. 11.64)

Study	Aim and design	Carer recruitment	Participant characteristics	Intervention (OT element)	Intervention implementation and carer-specific outcomes
	with mild dementia living in the community **Control group?** Yes	service network	**Patient group:** dementia	with carers and provided strategies e.g. task simplification and/or education on patient's abilities **Other HCPs involved?** Physiotherapist prescribed, progressed and monitored adherence to strength and balance exercises for the patient (5 home visits)	Increased uptake of use of routines and briefer instructions in intervention group.
Martín-Martín et al., (2014) Spain	**RCT.** Aim: To examine the effectiveness of an occupational therapy intervention program in reducing emotional distress in informal caregivers of hip fracture patients	Within 24hrs of admission for hip fracture	N=93 carers per group (184 total). **Intervention:** M=11, F=82, average age: 51.6 yrs. **Control:** M=25, F=68, average age = 57.25 yrs. **Patient group:** hip fracture	**Pre-discharge carer educational training programme**: OT delivered training in: manual handling techniques, positioning, facilitating ADLs, and advice on aids and adaptations. Structure: 30-minute educational briefing (control and intervention groups), 45-minute training session and twenty-minute consolidation sessions (intervention only). Written and graphic summaries of the programme were provided **Other HCPs involved?** No (OT facilitated)	**One month:** Carer anxiety increased for both groups, although lesser for intervention group (intervention: 26.9% to 29.5%, control: 25.8% to 37.3%). **Three months:** anxiety decreased to a greater extent in the intervention group (intervention: 19.8%, control: 32.1%). Depression gradually decreased over time: to a greater extent in intervention group (one month: intervention 36.6% to 21.6%, control 36.6% to 28.9%; three months: intervention 14%, control 25.9%). **Six months:** depression and anxiety similar for both groups.
Sturkenboom et al. (2014); Sturkenboom et al. (2016) The Netherlands	**RCT.** Aim: To assess the efficacy of an occupational therapy intervention in improving daily activities of patients with Parkinson's disease and to evaluate fidelity, treatment enactment and the experiences of participants to identify factors that affect intervention delivery and benefits	From 10 hospitals in nine different regions	N=180 (117 in intervention group). **Intervention:** average age = 67 yrs, M=37, F=80. **Control:** average age=65 yrs, M=21, F=42. **Patient group:** Parkinson's disease	**OTiP trial**: OT delivered a tailored programme (maximum of 16 hours over 10 weeks). Predominantly focused on the patient but carer needs in supporting patient's ADL engagement were assessed and addressed if needed. Consisted of: diagnostic phase (weeks 1-2), goal setting/treatment planning (week 2) and a therapeutic phase (individualised interventions for the patient and carer delivered, weeks 3-10). Carer-specific elements included information provision (e.g. about the disease, aids and adaptations and possible care resources) and skill training to support and supervise the patient when engaging with ADLs. **Other HCPs involved?** No (OT facilitated)	Each OT treated a median of 7 patients. Mean treatment dose = 8.5 sessions (SD = 2.2). Mean direct intervention time = 9.4 hours. Lowest adherence for intervention steps was observation of the patient's activity with the carer (completed in 51% of cases). 70% of recipients perceived the frequency, period of intervention and level of carer involvement adequate. Only 36% of carers stated there had been treatment goals focused on them. 41% felt that their ability to cope with caring had not improved or only improved slightly. Main factors identified as affecting the intervention process and benefits were: 1) treatment dose, 2) carer involvement and 3) the therapist's competencies to facilitate a successful treatment. **Carers:** No significant differences between groups for outcome measures except improved quality of life in the intervention group at 3 months (mean difference between groups: 0.06, p = 0.006 Carers appeared satisfied with the intervention (mean score 7.9 out of 10, SD = 1.5).
Callahan et al. (2017) USA	**RCT.** Aim: To determine whether collaborative care plus 2 years of home-based occupational	Via 10 primary care practices and one	N=180 (91 in intervention group).	**ADMIT trial:** OT delivered three cycles of home-based intervention over two years. Cycle 1: 8 90-minute sessions every other week for 16 weeks. Cycle 2: 8 home visits every four weeks. Cycle 3: eight visits over the full year. Issues between	Median completed home visits = 18. Median total duration of sessions = 20.7 hours. Average session length = 68.5 minutes (median of 17 telephone contacts between visits). **Carers:** No significant differences for Generalized Anxiety Disorder (GAD-7) or Patient Health Questionnaire (PHQ-9) scores for carers, though difference between groups for PHQ-9

Study	Aim and design	Carer recruitment	Participant characteristics	Intervention (OT element)	Intervention implementation and carer-specific outcomes
	therapy delays functional decline for people living with Alzheimer's Disease	senior care practice	Intervention: Average age = 56 yrs, Spouses = 20 Control: Average age = 59.1 yrs, spouses = 28. **Patient group:** Alzheimer's Disease	visits were addressed via telephone. Carer concerns were identified using the Occupational Profile Checklist. Carer-specific support focused on education and training: using lists and routines, discussion of communication, education about dementia and associated symptoms, facilitating transfers safely, medication management, and teaching carers how to give instructions and modify patient behaviour. **Other HCPs involved?** No (OT facilitated)	score at 12 months approached significance (intervention: 3.65 vs. usual care: 4.79, p = 0.06).
DiZazzo-Miller et al. (2017)/ DiZazzo-Miller et al. (2020) USA	**RCT** (though small sample). Aim: To examine the effectiveness of the Family caregiver Training Program (FCTP) for caregivers of people with dementia	Unclear	N=36 (18 in intervention group). Age range = 18-65+ yrs (no average given, mode = 55-64 yrs category in each group). **Intervention:** M=7, F=11. **Control:** M=2, F=16. **Patient group:** dementia	**Family Caregiver Training Programme (FCTP)**: OT delivered a 2-hour training session consisting of three modules (communication, eating and feeding, nutrition; transferring and toileting; dressing, bathing and grooming). Carers given hands-on demonstrations and practice sessions. Case studies used to reinforce learning. **Other HCPs involved?** Unclear	Significant improvement in knowledge and knowledge maintenance at 3 months in intervention group (post-test: 66.98 in control group vs. 82.03, p = 0.001, 3-months: 66.05 in control vs. 84.31, p < 0.001). No significant differences between groups for confidence, though evidence of increased confidence over time for both (not maintained 3 months post intervention). No significant difference detected for carer burden, depression and occupational performance or satisfaction. Significant increase in score for physical health for the intervention group (13.17 pre-test vs. 16.22 post-test, p < 0.001) but no other quality of life domains. Positive feedback received on: amount of information, instruction given being clear, holding participant interest and the in-person workshop approach in both control and intervention groups. However, both groups reported a preference for online learning.
Nishida et al. (2017) Japan	**Pilot.** Aim: To develop a home-visit occupation-based programme and determine its effectiveness for people living with dementia and their carers **Control group?** No	Via two community centres	N=11 (2 drop outs). Average age = 62.5 yrs. M=1, F=9. Spouses = 4, children = 3, other = 2. **Patient group:** dementia	**Occupation-based home visit program:** OT delivered eight 1-hour sessions over eight weeks. Programme included: identification of activities meaningful to the client and carer needs (first two sessions); facilitation of selected activities; teaching carers supervision and communication strategies (including verbal or visual cueing, activity simplification and encouragement of the patient). Last session consisted of re-evaluation of patients and carers **Other HCPs involved?** No (OT facilitated)	Dyads received 8.9 home visits on average. Carer burden scores decreased but not statistically significant (baseline: 39.0 vs post-intervention: 33.0, p = 0.09). Significant increase in carer scores for the Canadian Occupational Performance Measure subscales for performance (baseline: 2.6 vs post-intervention: 6.0, p = 0.01) and satisfaction (baseline: 2.5 vs post-intervention: 7.4, p = 0.01).

Study	Aim and design	Carer recruitment	Participant characteristics	Intervention (OT element)	Intervention implementation and carer-specific outcomes
Cornelis et al. (2018) Belgium	**Retrospective pre-test post-test study.** Aim: To determine whether the multicomponent rehabilitation programme of a memory clinic had positive outcomes for people with dementia and carers **Control group?** No	Memory clinic patients	N=30. Ages and genders not provided. Spouses = 24, children = 6. **Patient group:** dementia	**Multicomponent rehabilitation programme based at a memory clinic:** OTs were involved in delivery of a tailored programme (up to 25 sessions including at least two home visits over one year maximum). OT and psychologist completed initial assessment to establish patient and carer goals, plus psycho-education of carers and rehabilitation of the patient. Carer-specific intervention included: teaching cognitive and behavioural strategies to help support patient autonomy, environmental adaptations and assistive technology. At the end of the programme goal achievement was evaluated **Other HCPS involved?** Yes - a geriatrician, neurologist, social worker and psychologist. The social worker completed at least one counselling session and participants received a 6-monthly visit from the geriatrician or neurologist	22 dyads completed the programme. Mean number of sessions = 15.1 (8.7 were OT-lead). **Carers:** No significant differences in carer burden or distress post-test. However, approximately 60% of carers scores for these either improved or remained stable by the end of the programme.
Corvol et al. (2018) France	**Qualitative study using semi-structured interviews.** Aim: To explore the usefulness of specialized Alzheimer teams (SATs) as viewed by the patient and their main carer	Purposive sample of people receiving support from a specialized Alzheimer team (SAT)	N=13. Average age = 71.3 yrs (range: 56-93). M=4, F=9. Spouses = 11, daughters = 1, nieces = 1. **Patient group:** Alzheimer's Disease	**Specialized Alzheimer Team (SAT):** OTs co-delivered 12-15 sessions (approx. 1 hour) at least weekly for three months. Sessions 1-3: OT initial assessment and formulation of rehabilitation goals (patient and carer). A nursing assistant then followed a treatment plan devised by the OT, which could include environmental adaptation, carer training/education and compensatory strategies. Final assessment completed by the OT **Other HCPs involved?** Yes - 6 nursing assistants, 4 nurses. Nurses assisted in optimizing planned care and obtaining social support	Both patients and carers had few expectations of the programme, in part due to the progressive nature of the disease. Carers had varying levels of involvement with sessions. Positive feedback was received regarding: the clinicians; improvements seen in patient mood, cognition or behaviour; and useful tips/strategies learned during sessions. However, not all carers utilised advice or recommendations from the OT or wanted to be involved. Some carers used the sessions as respite instead of attending. Findings suggest that the programme allowed carers to step back and re-evaluate their interactions with, and understanding of, the patient and their condition, empowering the carer. Feedback from dyads prompted changes amongst clinicians to facilitate greater carer involvement. Authors stated that functional autonomy may not be the priority or expectation for dyads (they may rather prioritise patient mood, behaviour, quality of life and quality of patient-carer interactions).
Allan et al. (2019) UK	**Feasibility study.** Aim: To develop and investigate the feasibility and acceptability of the DIFRID (Developing an Intervention for	An Emergency Department , via paramedics, primary care and	N=11. Spouses = 6, children = 2, other = 3. Ages and genders not stated. **Patient group:** dementia	**DIFRID trial:** OT delivered up to four sessions in the patient's home over a 12-week period. Commenced with holistic assessment of patient, home environment and carer needs. An MDT meeting followed to determine goals and facilitate onward referrals if appropriate. A programme of activities was planned and carried	Poor implementation of carer support and minimal evidence carer needs explored; attributed to "a lack of explicit attention to this in the study paperwork". Average Zarit Burden score slightly increased by follow-up (baseline mean: 27.0 with SD 11.9, range: 15-2, follow-up: 29.7, SD 11.9, range: 10-46). **Professionals:** 1) Felt that carer burden/duplication could have been reduced by joint OT/PT baseline assessment

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	Fall-Related Injuries in Dementia) intervention **Control group?** No	other healthcare professionals		out to fulfil selected goals. Planned carer-specific input included: training (getting up after a fall, positive risk, managing patient resistance to engaging), carer assessment and identification of support services, upskilling with regards to falls management and prevention **Other HCPs involved?** Yes - physiotherapists delivered up to 4 sessions; therapy assistants/assistant practitioners delivered up to 14	2) Raised concerns about specific measures being complex, unclear or repetitive (though they were largely completed). Carer added: the process "was a bit long and drawn out".
Clare et al. (2019) UK	**RCT.** Aim: To determine whether or not cognitive rehabilitation is a clinically effective and cost-effective intervention for people with mild to moderate Alzheimer's disease or vascular or mixed dementia, and their carers	Via NHS services (including memory clinics and older age psychiatry services), support groups, a charitable organisation and a dementia research network	N = 474 (238 in intervention group). **Intervention:** Average age = 68.5 yrs. M = 75, F = 163. Spouse/partners = 167, children = 58, other = 13. **Control:** Average age = 69 yrs. M = 67, F = 169. Spouse/partners = 164, children = 60, other = 12. **Patient group:** Alzheimer's disease and dementia	**GREAT trial:** OT delivered 10 sessions over three months followed by four maintenance sessions over six months. Following initial assessment of the patient and goal identification, cognitive rehabilitation was used to maximise patient function. Carers assisted patients in working to achieve goals between sessions. Carers-specific components included: discussion of carer well-being and stress, education, identification of strategies to manage stress, signposting to further support. When carers were not directly present they were kept informed regarding session content. **Other HCPs involved?** Yes - a nurse also helped deliver the intervention sessions; the other nine interventionists were OTs	Retention was 94% at 3 months, 90% at 9 months. 90% of participants completed at least 10 sessions, with 70% completing all 14. Therapy sessions lasted between 43-120 minutes, average = 75.5 minutes (SD = 12.4) Cost-effectiveness: No evidence of cost-effectiveness with regards to QALY gains, though intervention was potentially cost-effective in relation to functional gains from the perspective of health and social care and societal costs when Willingness-To-Pay values were ≥£2500. Average intervention cost over 9 months per patient was £1736. No between-group statistically significant differences for carer outcomes. **Therapists reported:** 1) The importance of carer engagement for intervention success. Therapy logs indicated that the carer-patient relationship may have influenced the likelihood of poor/good outcomes. 2) That support provided to carers included education, socioemotional support, onward referral to other services (including social services to seek respite). Therapists also mentioned occasionally needing to manage patient-carer relationship conflict. **Carers reported:** 1) Enjoying the therapeutic relationship with therapists and finding education about dementia beneficial. 2) Increased patience with the patient and reduced conflicts and misunderstandings. 3) Appreciating being able to talk and being offered support, and therapists stating that other carers also experienced similar problems. 4) Strategies provided were particularly useful if they reduced caregiving burden. 5) Sessions helped carers develop a "problem-focused and practical viewpoint". 6) How strategies had been successful in increasing the confidence and independence of patients, which was seen as beneficial. 7) That they appreciated the flexibility and person-centred approach.

Study	Aim and design	Carer recruitment	Participant characteristics	Intervention (OT element)	Intervention implementation and carer-specific outcomes
Ariza-Vega et al. (2020) Spain	**Feasibility study.** Aim: To develop and test feasibility for a post-hip fracture inpatient instructional workshop for caregivers of older adults with hip fracture **Control group?** No	Ward nurses (acute hospitals); posters	N = 210 (103 completed outcome measures). Average age = 52.1 yrs. M = 32, F = 70. Children = 74, spouse or partner = 11, grandchild = 3, niece or nephew = 3, other = 12. Patient group: hip fracture	**Post-hip fracture instructional workshop:** OT delivered 60-90 minute workshops consisting of 1) education on hip fracture and recovery (including hip anatomy, pain management, devices to aid ADLs and the home environment) and 2) practicing hands-on skills to facilitate safe manual handling, completion of ADLs and mobility. Balance and strength exercises were also demonstrated. Content was individualized to the needs of participants **Other HCPs involved?** Yes - orthopaedic surgeon and nurse helped develop workshops; PT helped deliver them	>90% of carers answered all three knowledge questions correctly following workshop completion. Median utility and satisfaction rating: 10 (maximum score). 78% of carers scored the workshop 10. **Qualitative feedback**: general satisfaction with workshop design; suggestions for improvement (longer sessions; additional resources for those caring for patients who are less independent).
Jeon et al., (2020) Australia	**Pilot study.** Aim: To test feasibility and potential effects of the interdisciplinary Home-bAsed Reablement Program (I-HARP) for people living with mild cognitive impairment or mild/moderate dementia and their carers **Control group?** Yes	Multiple sites inc. memory and outreach clinics plus public announcements in Sydney area	N = 18 (9 carers per group). Average age = 64 yrs, M = 3, F = 15. **Patient group:** dementia and non-specific cognitive impairment	**I-HARP:** Series of OT home visits of 1.5hrs each (OT delivering 5-6 of these), plus ≤A$1000 worth support for home modifications and assistive technology. Components included: assessment of the patient and environment, creation of a tailored multi-disciplinary plan and two individualised carer support sessions **Other HCPs involved?** Yes - nurse delivered 3-4 hours of programme and neuropsychologist delivered 1 hour of programme. 12 sessions in total (including OT element)	Average cost of intervention delivery: A$4500 (inc. home modifications and assistive technology, which constituted an average of A$476.50). **4 months:** Increase in carer burden in the intervention group. Improved health-related quality of life (HRQOL) for carers in both groups. **12 months:** HRQOL increased in intervention group and declined in control group (effect size 1.40). Minimal change to depression or EuroQol-5D utility scores. Further increase to carer burden. **Qualitative feedback:** Overall positive. Barriers included: carers feeling unable to talk about the patient in front of them, patients struggling to understand intervention's purpose, and high carer stress/worry. Facilitators included: positive relationships with clinicians, a hands-on approach, continuity, and the clinician advice being specialist but accessible.
Morency et al. (2020) USA	**Feasibility** study. Aim: To explore a six-session wellness intervention for caregivers of cancer patients undergoing hematopoietic stem cell transplantation (HSCT) entitled Ready to CARE (Connect,	Via transplant co-ordinators and social workers	N = 20 at baseline, 14 completed intervention. Average age = 59.3 yrs. M = 8, F = 12. Patient group: cancer	**CARE intervention:** OT-facilitated adaptive coping of carers via six sessions focused on self-selected strategies addressing stressors/buffers to wellbeing. Strategies were based within four wellbeing domains (physical, psychological, social and spiritual). After introducing the intervention rationale (session 1), carers selected goals and created action plans to fulfil these with support and guidance from the OT (sessions 2-6). Carers also offered support to practice selected activities (e.g. meditation).	14 (74%) of carers completed the intervention within an 8-week period. Carers set an average of 8.3 goals; the most common topics these related to were physical activity (15 carers – 56 goals), stress management (8 carers – 22 goals) and caregiving activities (8 carers – 18 goals). Carers accepted opportunities to practice only 8% of the time (12/158 sessions). Interviews suggested five main themes: appreciation of focus on the carer; and that the intervention a) was tailored to the carer's situation, b) led to insights that changed perspectives or affirmed feelings, c) allowed carers to focus on goals/taking action instead of worrying, and d) fostered self-care. However, carers also reported struggling to find time for the intervention, despite flexibility being offered in terms of session timings.

Study	Aim and design	Carer recruitment	Participant characteristics	Intervention (OT element)	Intervention implementation and carer-specific outcomes
	Actively Relax, and Exercise) **Control group?** No			**Other HCPs involved?** No (OT facilitated)	50% of carers completed outcome measures at the 2nd timepoint (patient admission to hospital), but this improved (90% and 80% at timepoints 3 and 4 respectively).
O'Connor et al. (2020) Australia	**Feasibility study.** Aim: To examine the functional basis of apathetic and disinhibited behaviours in frontotemporal dementia for four patient-carer dyads and to explore the acceptability of a Positive Behaviour Support (PBS) intervention **Control group?** No	Via a frontotemporal dementia research group	N = 4. Average age = 64.4 yrs. M = 1, F = 3. All lived with the patient and were spouses. **Patient group:** frontotemporal dementia	**PBS intervention:** Initial OT assessment was via functional assessment of behaviours and observations of the patient in the home environment. An individualized Positive Behaviour Support (PBS) plan targeting disinhibited or apathetic behaviours was then developed and completed over a 3-month period over 5-7 home visits. Carers received education and skill training to facilitate management of behaviours **Other HCPs involved?** No (OT facilitated)	Average session length = 80 minutes (range = 45-160 minutes). All carers implemented at least one behavioural support plan (3 per patient); two implemented all three plans. Carers appeared to develop enhanced skills when dealing with challenging behaviours. Carers appeared to feel PBS was an acceptable intervention and felt they had benefitted from it. Three felt no changes were needed, one suggested more examples of potential strategies "to manage things" would have been beneficial. Carer distress associated with patient apathy (M = −23%, range −23% to −43%) and disinhibited behaviours (M = −27%, range 14% to −57%) decreased.

Table 3. Outcome measures used in eligible studies. BID: Beck Depression Inventory; BADLS: Bristol Activities of Daily Living Scale; CES-D: Center for Epidemiologic Study Depression Scale; CMI: Caregiving Mastery Index; COPM: Canadian Occupational Performance Measure; CSI: Caregiver Strain Index; EQ5D: EuroQol five dimensions; EDSIS: Eating Disorders Symptom Impact Scale; GAD-7: Generalized Anxiety Disorder 7-item; GAS: Goal Attainment Scaling; GHQ-28: Goldberg General Health Questionnaire; GADS: Goldberg Anxiety and Depression Scale; HADS: Hospital Anxiety and Depression Scale; NPI: Neuropsychiatric Inventory; PCI: Perceived Change Index; PWI-A: Personal Well-Being Index for Adults; QOL-AD: Quality of Life Scale in Alzheimer's disease; RUD: Resource Utilisation in Dementia; RSS: Relatives Stress Scale; SCQ: Sense of Competence Questionnaire; SF-12: Short-Form 12 Health Survey Questionnaire; TMSI: Task Management Strategy Index; WHOQOL-BREF: The World Health Organisation Quality of Life-Brief; UPCC: Utrecht Proactive Coping Competence Scale; ZBI: Zarit Burden Interview. Note: papers reporting process evaluations or additional outcomes from the same study are presented together with the original paper.

To right: Papers Below: Outcome measures	Gitlin et al. (2010a)	Gitlin et al. (2018)	de Oliveira et al. (2018)	Novelli et al. (2018)	O' Connor et al. (2019)	Van' t Leven et al. (2011)	Voigt-Radloff et al. (2011a/b)	Pozzi et al. (2019)	Wenborn et al. (2021)	Burgess et al. (2020)	Donkers et al. (2018)	Gitlin et al. (2010b)	Clemson et al. (2020)	Culph et al. (2020)	Rahja et al. (2020a)	Rahja et al. (2020b)	Fortinsky et al. (2020)	Laver et al. (2020)	Lam et al. (2010)	Eames et al. (2013)	Pépin & King (2013)	Wesson et al. (2013)	Martín-Martín et al., (2014)	Sturkenboom et al. (2014/6)	Callahan et al. (2017)	DiZazzo-Miller et al. (2017/20)	Nishida et al. (2017)	Cornelis et al. (2018)	Corvol et al. (2018)	Allan et al. (2019)	Clare et al. (2019)	Ariza-Vega et al. (2020)	Jeon et al., (2020)	Morency et al. (2020)	O' Connor et al. (2020)
	TAP					COTiD (and SPF)						COPE							Other interventions																
ADL Knowledge Test																										X									
BADLS																										X									
BDI																										X									
Caregiver Confidence Scale																										X									
Caregiver Vigilance Scale (Vigilance Items)					X																														
CES-D		X																																	
CMI																		X																	
COPM																								X		X									
Cost	X															X																			
CSI																				X															
EQ5D (and variants)																								X								X	X		
GAD-7																									X										
GADS																							X												

To right: Papers Below: Outcome measures	Gitlin et al. (2010a)	Gitlin et al. (2018)	de Oliveira et al. (2018)	Novelli et al. (2018)	O’ Connor et al. (2019)	Van’ t Leven et al. (2011)	Voigt-Radloff et al. (2011a/b)	Pozzi et al. (2019)	Wenborn et al. (2021)	Burgess et al. (2020)	Donkers et al. (2018)	Gitlin et al. (2010b)	Clemson et al. (2020)	Culph et al. (2020)	Rahja et al. (2020a)	Rahja et al. (2020b)	Fortinsky et al. (2020)	Laver et al. (2020)	Lam et al. (2010)	Eames et al. (2013)	Pépin & King (2013)	Wesson et al. (2013)	Martín-Martín et al., (2014)	Sturkenboom et al. (2014/6)	Callahan et al. (2017)	DiZazzo-Miller et al. (2017/20)	Nishida et al. (2017)	Cornelis et al. (2018)	Corvol et al. (2018)	Allan et al. (2019)	Clare et al. (2019)	Ariza-Vega et al. (2020)	Jeon et al., (2020)	Morency et al. (2020)	O’ Connor et al. (2020)
GAS																														X					
GHQ-28																							X												
HADS									X															X											
Investigator-developed measure(s)												X	X		X		X	X		X	X											X		X	
Knowledge of Stroke Questionnaire																				X															
NPI				X																															
NPI-C (Clinician-completed)		X															X																		
PCI												X	X				X	X																	
PWI-A																			X																
QOL-AD								X																											
Qualitative data					X					X	X				X														X		X		X	X	X
Quality of Life Scale				X																															
RUD							X																												
RSS																															X				
SCQ							X	X	X																										
SF-12							X	X																											
TMSI																						X													
The Brief COPE EDSIS																					X														
WHOQOL-BREF																										X					X				
UPCC																								X											
ZBI		X	X	X				X											X			X		X			X	X		X			X		

<u>**APPENDIX 1**</u>

Inclusion criteria

Inclusion criteria	**Rationale**
Papers relating to interventions that target carers specifically (or if for patient-carer dyads, independently evaluate the effect of the intervention on the carer)	The review is intended to focus on interventions for carers and their effect on the carer themselves
Papers/studies that relate to adult carers supporting adult patients	Interventions primarily targeting a) adult carers for children and b) young carers necessitate separate reviews. Potential areas for intervention and how interventions are conducted are likely to vary considerably between these groups
Papers including interventions where outcomes were measured (quantitative) or identified (qualitative)	This review aims to provide information to show how outcomes were measured or identified and the efficacy of the interventions examined
Interventions that involve occupational therapists	The purpose of the review is to identify interventions led by occupational therapists or including a defined occupational therapy component in order to inform future practice
Editorials, opinion pieces, case studies and non-empirical material	The review will exclude lower quality evidence to increase the strength of the findings
Interventions for informal/unpaid carers	The focus of the review is informal carers. The needs – and potential interventions to address these needs – are likely to differ between informal carers and paid care staff due to differences in their caring roles and their relationship to the patient
English language only	Papers will be in English only due to constraints in time (the PI also holds a part time clinical role as an OT) and to ensure the effective use of resources
Empirical research papers (qualitative, quantitative and mixed method studies)	The review aims to be as comprehensive as possible
Papers from 2010-present	This review aims to cover contemporary research to ensure its relevance to current practitioners/those involved with occupational therapy services. Furthermore, any recent changes to national healthcare policies in relation to how healthcare professionals support informal carers are more likely to be reflected in research from this period.

This review aims to establish:
a) the extent to which occupational therapists are involved in interventions targeting adult informal carers as described within research literature
b) the quality of research evidence that has been produced relating to these interventions
c) the nature and breadth of these interventions
d) information relating to the efficacy of these interventions reported within the literature.

The review aims to focus primarily on interventions led or delivered by occupational therapists. However, it is acknowledged that occupational therapists often work as part of a multi-disciplinary approach. As such, papers that included a distinct intervention by an occupational therapist within a wider group of professionals were also considered as long as the contribution of the therapist was clearly defined and directly involving carers. For example, a study examining a multidisciplinary intervention for carer-patient dyads was excluded if the occupational therapy element only involved the patient. There was no specific threshold for intensity/frequency of therapeutic input by occupational therapists required in multidisciplinary studies for inclusion but occupational therapists had to be delivering a component specifically targeting carers and their role within this intervention had to be considered clear. Studies where carers were included solely to facilitate improved outcomes for the patient (for example, assisting patients to complete an exercise/rehabilitation programme) without clear incorporation of a well-defined component designed to address carer-specific needs were not considered; the review aims to provide insight into the contribution of occupational therapists to carer-specific support (though it is acknowledged that carers may find participation in such programmes supportive through improvement of patient wellbeing and/or independence).

For further detail, please see the **PICOTS** below:
P (Population): Adult informal carers for adult patients (18+ years of age)
I (Intervention): Occupational therapy interventions developed to improve outcomes for/wellbeing of informal carers
C (Comparator): Standard care (where comparator present)
O (Outcomes): Any outcome measure used to demonstrate the efficacy/effect of the intervention including measures of quality of life, health (physical or psychological, e.g. measures of anxiety, depression, physical disability), carer-specific outcomes (e.g. carer strain or burden), process or outcome data related to the delivery of the intervention or the experience of the occupational therapist delivering it (e.g. staffing implications, views of the therapist in relation to delivering the intervention). Both quantitative and qualitative data will be included
T (Time): Interventions of any length will be considered
S (Study Design): Qualitative or quantitative empirical research

Search terms used in database searching

Search terms		
Profession		Population *'OR' between terms*
(IN TITLE OR ABSTRACT) Occupational therap* (Allows occupational therapy, occupational therapist, occupational therapists)	**AND**	(IN TITLE OR ABSTRACT) Carer* (allows carers) Caregiver* (allows caregivers) Supporter* (allows supporters) Informal Famil* (allows family, families, familial) Lay* (allows layman, laymen) Spous* (allows spouses, spousal)
Expanders: similar terms *		
Limiters: 2010-2021, English language, adult carers for adult patients only, interventions delivered by occupational therapists		

APPENDIX 2

Table A: Summary of quality appraisal using CASP tool for qualitative studies.

Selected articles	Was there a clear statement of the aims of the research?	Is a qualitative methodology appropriate?	Was the research design appropriate to address the aims of the research?	Was the recruitment strategy appropriate to the aims of the research?	Was the data collected in a way that addressed the research issue?	Has the relationship between researcher and participants been adequately considered?	Have ethical issues been taken into consideration?	Was the data analysis sufficiently rigorous?	Is there a clear statement of findings?	Appraisal summary
Van't Leven et al. (2011)	Yes	Yes	Yes	Yes	Yes	Can't tell	Can't tell	Yes	Yes	Data saturation, ethical approval/issues and examination of the researcher's own role not discussed. However, design appropriate for aims, findings clear and paper valuable re: insight into study implementation.
Burgess et al. (2020)	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Well-designed and well-reported qualitative paper.
Rahja et al. (2020)	Yes	Yes	Yes	Yes	Yes	Can't tell	Yes	Yes	Yes	Data saturation and examination of the researcher's own role not discussed. However, design appropriate for aims, findings clear and paper valuable re: insight into intervention participation.
Corvol et al. (2018)	Yes	Yes	Yes	Yes	Yes	Can't tell	Yes	Yes	Yes	Examination of the researcher's own role not discussed in detail. May have benefitted from additional reporting re: data analysis.

Table B: Summary of quality appraisal using CASP tool for randomised controlled trials (RCTs).

Selected articles	Did the study address a clearly focused research question?	Was the assignment of participants to interventions randomised?	Were all participants who entered the study accounted for at its conclusion?	Blinding – were participants (P), investigators (I) and assessors (A) blinded?	Were study groups similar at the start of the RCT? (Carers)	Apart from the intervention, were each group treated equally?	Were the effects of the intervention reported comprehensively?	Was the precision of the estimate of the intervention/treatment effect reported?	Do benefits of the intervention outweigh the harms/ costs? (Carers)	Appraisal summary/comments
Randomised controlled trials										
Callahan et al. (2017)	Yes	Yes	Yes	P – No I – No A - Yes	Yes	Yes	Yes (Though difficult initially to separate out carer outcomes)	Yes	No particular benefit or harm found	Cannot discount possible bias as single-blind. Intervention was vs. TAU. Had to use study protocol to clarify carer outcome measures.
Clare et al. (2019)	Yes	Yes	Yes	P – No I – No A - Yes	Yes	Yes	Yes	Yes	Quantitative data demonstrated no benefit; qualitative suggests helpful	Intervention was vs. TAU. Cannot discount possible bias as single-blind. For primary outcomes, patient and carer report was accompanied by therapist report of goal attainment.
DiZazzo-Miller et al. (2017)/(2020)	Yes	Yes	No attrition reported	P – No I – No A - Unclear	Some group differences re: gender ratio and age.	Yes – intervention later repeater for control group	Yes	Yes	No harm found; evidence of gains to QoL and knowledge	Unclear reporting re: who gathered outcome data. If this was the interventionists, they would not have been blinded to group allocation. Small sample sizes, researchers justify by stating sample size decision made using a power analysis calculated using data from their feasibility study. Combined with 2020 paper which reports a further outcome from the original study.
Donkers et al. (2018)	Yes	Yes	N/A - Trial not completed	P – No I – No A - Yes	Yes (until trial ended prematurely)	Yes	Yes	Yes	Trial incomplete. No harms apparent	Trial did not complete – paper largely describes process evaluation. Utilised protocol to supplement this where methodology not fully reported in main

Selected articles	Did the study address a clearly focused research question?	Was the assignment of participants to interventions randomised?	Were all participants who entered the study accounted for at its conclusion?	Blinding – were participants (P), investigators (I) and assessors (A) blinded?	Were study groups similar at the start of the RCT? (Carers)	Apart from the intervention, were each group treated equally?	Were the effects of the intervention reported comprehensively?	Was the precision of the estimate of the intervention/treatment effect reported?	Do benefits of the intervention outweigh the harms/ costs? (Carers)	Appraisal summary/comments
										paper (provided as additional file). Intended to be intervention vs. TAU, then control group to receive intervention after last assessment.
Eames et al. (2013)	Yes	Yes	Yes	P – No I – No A - Yes	Largely, intervention group slightly younger on average	Yes	Yes	Yes	No particular benefit or harm found	Intervention was vs. TAU. Cannot discount possible bias as single-blind. Some positive outcomes for patients, but no particular significant outcomes for carers (burden only carer-specific outcome measure).
Fortinsky et al. (2020)	Yes	Can't tell - (randomised but method unclear)	Yes (modified intent to treat analysis used)	P – No I – No A - Yes	Unclear - more female carers in intervention group; higher levels of depressive symptoms in control group	Mostly – effect of care managers using COPE prescriptions unknown?	Yes	Yes	Small but significant benefits; however any adverse effects (if any) not clearly reported	Intervention compared to treatment as usual. Majority of outcomes relied on patient/carer report (and may have introduced bias). Cannot discount possible bias as single-blind.
Gitlin et al. (2010)	Yes	Yes	Yes	P – Unclear (unlikely?) I – No A - Yes	Unclear	Yes	Yes	Yes	Small benefit but no adverse effects	Cannot discount possible bias as single-blind. Majority of outcomes relied on carer report (and may have introduced bias). Control group intervention used.
Gitlin et al. (2018)	Yes	Can't tell	Yes	P – No I – No A - Yes	Yes	Yes	Yes	Yes	Yes	Cost-effectiveness of COPE has been investigated elsewhere. Cannot discount possible bias as single-blind. Control group intervention used.
Lam et al. (2010)	Yes	Yes	Yes	P – No I – No A - Yes	Smaller control group but	Control group received	Yes	Yes	No harm found;	May have benefitted from more detailed reporting of what the home visit the control group received consisted of.

Selected articles	Did the study address a clearly focused research question?	Was the assignment of participants to interventions randomised?	Were all participants who entered the study accounted for at its conclusion?	Blinding – were participants (P), investigators (I) and assessors (A) blinded?	Were study groups similar at the start of the RCT? (Carers)	Apart from the intervention, were each group treated equally?	Were the effects of the intervention reported comprehensively?	Was the precision of the estimate of the intervention/treatment effect reported?	Do benefits of the intervention outweigh the harms/ costs? (Carers)	Appraisal summary/comments
					demographics appear relatively similar	one visit for home safety, otherwise the same			minimal benefits	Cannot discount possible bias as single-blind. One case manager for 59 dyads for 4 months – median number of follow-ups by type are reported but would be interesting to know how long was spent for each and if intensity of intervention was felt to be feasible with only one case manager.
Laver et al. (2020)	Yes	Can't tell (randomised but method unclear)	Yes (though ITT/imputation unclear?)	P – No I – No A - Yes	Yes – (Small differences re: gender but otherwise similar)	Yes	Yes	Yes	Small benefit but no adverse effects	Trial compared same intervention delivered in two different ways. Majority of outcomes relied on carer report (and may have introduced bias). Cannot discount possible bias as single-blind.
Martín-Martín et al. (2014)	Yes	Yes	Yes	P – No I – No A - Yes	More men in control group but otherwise similar	Control group received 30 minute briefing, otherwise the same	Yes	Yes	No harms found; evidence of benefit	Cannot discount possible bias as single-blind. Note OT was not included within the hospital protocol for hip fracture, so 30-minute briefing given to control group is not TAU.
Sturkenboom et al. (2014)/ (2016)	Yes	Yes	Yes	P – No I – No A - Yes	Yes	No OT for control group at all ?is this usual	Yes	Yes	No harms but minimal improvement to carer outcomes	Intervention appeared to be vs. TAU but control group was reported to have no occupational therapy during the study period – unclear if this is truly TAU (would community therapy normally see these patients if required? Was this prevented during the study period?) Physical therapy was monitored as a confounding factor

Selected articles	Did the study address a clearly focused research question?	Was the assignment of participants to interventions randomised?	Were all participants who entered the study accounted for at its conclusion?	Blinding – were participants (P), investigators (I) and assessors (A) blinded?	Were study groups similar at the start of the RCT? (Carers)	Apart from the intervention, were each group treated equally?	Were the effects of the intervention reported comprehensively?	Was the precision of the estimate of the intervention/treatment effect reported?	Do benefits of the intervention outweigh the harms/ costs? (Carers)	Appraisal summary/comments
						treatment				(as well as levodopa equivalent dose). Cannot discount possible bias as single-blind. Combined with process evaluation paper.
Voigt-Randloff et al. (2011a)/(2011b)	Yes	Yes	Yes	P – No I – No A - Yes	Yes – except for financial status	Yes	Yes	Yes (for group mean differences)	No particular benefit or harm found	Cannot discount possible bias as single-blind. Some measures relied on self-report but did have additional analysis from masked research assistants who assessed recordings of task performance. Control group intervention used. Combined with process evaluation paper.
Wenborn et al. (2021)	Yes	Yes	Yes – Intention to Treat (ITT) not used but data analysed by treatment allocated	P – No I – No A - Yes	Yes – mild difference in gender ratios between groups but otherwise very similar	Yes	Yes	Yes	No particular benefit or harm found	Cost-effectiveness of COTID-UK has been investigated elsewhere, as has intervention fidelity and qualitative experiences relating to study participation. Intervention compared to treatment as usual (TAU).
Pilot/feasibility studies										
de Oliveira et al. (2018) **PILOT**	Yes	Yes	Yes	P – No I – No A - Yes	Slightly more males and non-relatives in intervention group	Control group received psychoeducation group sessions	Yes	Yes	No harms reported, some benefits but small sample size (pilot study)	All outcomes reported from pilot studies must be treated with caution. N=11 in intervention group.

Selected articles	Did the study address a clearly focused research question?	Was the assignment of participants to interventions randomised?	Were all participants who entered the study accounted for at its conclusion?	Blinding – were participants (P), investigators (I) and assessors (A) blinded?	Were study groups similar at the start of the RCT? (Carers)	Apart from the intervention, were each group treated equally?	Were the effects of the intervention reported comprehensively?	Was the precision of the estimate of the intervention/treatment effect reported?	Do benefits of the intervention outweigh the harms/ costs? (Carers)	Appraisal summary/comments
Novelli et al. (2018) **PILOT**	Yes	Yes	Yes	P – No I – No A - Yes	Above average education levels for participating carers ?generalisability	Yes	Yes	Yes	No harms reported, some benefits but small sample size	All outcomes reported from pilot studies must be treated with caution. N=15 in intervention group.
Jeon et al. (2020) **PILOT**	Yes	Yes	Yes	P – No I – No A - Yes	Yes	Control group offered a book and film vouchers	Yes	Yes	No harms reported, some evidence of benefits	Confidence intervals used contributed to uncertainty in relation to results interpretation. All outcomes reported from pilot studies must be treated with caution. N=9 in intervention group.
O'Connor et al. (2019) **FEASIBILITY/PILOT**	Yes	Yes – exact method of randomisation not clear	Yes	P – No I – No A - Yes	Intervention group slightly older and more males. Otherwise similar	Control group received telephone contacts over course of study	Yes	Yes	No harms reported, some benefits but small sample size	All outcomes reported from pilot studies must be treated with caution. N=9 in intervention group.
Wesson et al. (2013) **FEASIBILITY/PILOT**	Yes	Yes	Yes	P – No I – No A - Yes	Yes	Yes	Largely, some measures missing at follow up	Yes	No harms reported, burden doubled in intervention group	All outcomes reported from pilot studies must be treated with caution. N=11 in intervention group. Intervention vs. TAU. May have benefited from capture of qualitative data. ?burden increase for carers caused by intervention or incidental.

Table C: Summary of quality appraisal using CASP tool for economic evaluations.

Selected articles	Was a well-defined question posed?	Was a comprehensive description of the competing alternatives given?	Does the paper provide evidence that the programme would be effective?	Were the effects of the intervention identified, measured and valued appropriately?	Were all important and relevant resources required and health outcome costs for each alternative identified, measured in appropriate units and valued credibly?	Were costs and consequences adjusted for different times at which they occured?	Was an incremental analysis of the consequences and cost of alternatives performed?	Was an adequate sensitivity analysis performed?	Are the costs translatable to your setting (UK)?	Appraisal summary/comments
Gitlin et al. (2010)	Yes	Evaluated costs of intervention only	Yes	Yes	N/A	N/A	Intervention vs. control	Yes	Unclear	Note: outcomes of analysis are reported in main paper and Table 2.
Rahja et al. (2020)	Yes	Examined if intervention would be of net benefit to society	Yes	Yes	Yes	Yes	Intervention vs. normal practice	Yes	Unclear	Note: outcomes of analysis are reported in main paper and Table 2.

Below: Individual amended Mixed Methods Appraisal Tools (MMAT) completed for studies deemed less appropriate for CASP tools (non-relevant fields from tool deleted for brevity).

1) Allan et al. (2019)

Category of study designs	**Methodological quality criteria**	**Responses**			
		Yes	No	Can't tell	Comments
Screening questions (for all types)	S1. Are there clear research questions?	X			
	S2. Do the collected data allow to address the research questions?	X			
	Further appraisal may not be feasible or appropriate when the answer is 'No' or 'Can't tell' to one or both screening questions.				
1. Qualitative	1.1. Is the qualitative approach appropriate to answer the research question?	X			
	1.2. Are the qualitative data collection methods adequate to address the research question?	X			Authors justify use of FG vs interviews
	1.3. Are the findings adequately derived from the data?	X			
	1.4. Is the interpretation of results sufficiently substantiated by data?	X			Very detailed
	1.5. Is there coherence between qualitative data sources, collection, analysis and interpretation?	X			
3. Quantitative non-randomized	3.1. Are the participants representative of the target population?	X			
	3.2. Are measurements appropriate regarding both the outcome and intervention (or exposure)?	X			
	3.3. Are there complete outcome data?	X			For purpose of study
	3.4. Are the confounders accounted for in the design and analysis?	X			
	3.5. During the study period, is the intervention administered (or exposure occurred) as intended?	X			Largely, and well-reported, but some issues using GAS, low evidence of carer support and other issues
5. Mixed methods	5.1. Is there an adequate rationale for using a mixed methods design to address the research question?	X			Very well explained rationale.
	5.2. Are the different components of the study effectively integrated to answer the research question?	X			
	5.3. Are the outputs of the integration of qualitative and quantitative components adequately interpreted?	X			
	5.4. Are divergences and inconsistencies between quantitative and qualitative results adequately addressed?	X			

	5.5. Do the different components of the study adhere to the quality criteria of each tradition of the methods involved?	X			

2) Ariza-Vega et al. (2020)

Category of study designs	**Methodological quality criteria**	**Responses**			
		Yes	No	Can't tell	Comments
Screening questions (for all types)	S1. Are there clear research questions?	X			
	S2. Do the collected data allow to address the research questions?	X			
	Further appraisal may not be feasible or appropriate when the answer is 'No' or 'Can't tell' to one or both screening questions.				
3. Quantitative non-randomized	3.1. Are the participants representative of the target population?	X			
	3.2. Are measurements appropriate regarding both the outcome and intervention (or exposure)?	X			
	3.3. Are there complete outcome data?	X			
	3.4. Are the confounders accounted for in the design and analysis?	X			
	3.5. During the study period, is the intervention administered (or exposure occurred) as intended?	X			
5. Mixed methods	5.1. Is there an adequate rationale for using a mixed methods design to address the research question?	X			Use of open-ended questions justified
	5.2. Are the different components of the study effectively integrated to answer the research question?	X			
	5.3. Are the outputs of the integration of qualitative and quantitative components adequately interpreted?	X			
	5.4. Are divergences and inconsistencies between quantitative and qualitative results adequately addressed?	X			
	5.5. Do the different components of the study adhere to the quality criteria of each tradition of the methods involved?			X	

3) Clemson et al. (2020) – note Culph et al. (2020) is a linked mixed methods study (examines same intervention from perspectives of interventionists)

Category of study designs	**Methodological quality criteria**	**Responses**			
		Yes	No	Can't tell	Comments
Screening questions (for all types)	S1. Are there clear research questions?	X			
	S2. Do the collected data allow to address the research questions?	X			Compared outcomes to original COPE RCT – "hybrid implementation-effectiveness study"
	Further appraisal may not be feasible or appropriate when the answer is 'No' or 'Can't tell' to one or both screening questions.				
3. Quantitative non-randomized	3.1. Are the participants representative of the target population?	X			
	3.2. Are measurements appropriate regarding both the outcome and intervention (or exposure)?	X			
	3.3. Are there complete outcome data?	X			For purpose of study
	3.4. Are the confounders accounted for in the design and analysis?	X			
	3.5. During the study period, is the intervention administered (or exposure occurred) as intended?	X			Detailed information re: fidelity and implementation available

4) Cornelis et al. (2018)

Category of study designs	**Methodological quality criteria**	**Responses**			
		Yes	No	Can’t tell	Comments
Screening questions (for all types)	S1. Are there clear research questions?	X			
	S2. Do the collected data allow to address the research questions?	X			
	Further appraisal may not be feasible or appropriate when the answer is ‘No’ or ‘Can’t tell’ to one or both screening questions.				
3. Quantitative non-randomized	3.1. Are the participants representative of the target population?	X			However relatively small sample size (n=30)
	3.2. Are measurements appropriate regarding both the outcome and intervention (or exposure)?	X			May have benefitted from qualitative feedback
	3.3. Are there complete outcome data?	X			
	3.4. Are the confounders accounted for in the design and analysis?			X	
	3.5. During the study period, is the intervention administered (or exposure occurred) as intended?	X			

5) Culph et al. (2020)

Category of study designs	**Methodological quality criteria**	**Responses**			
		Yes	No	Can't tell	Comments
Screening questions (for all types)	S1. Are there clear research questions?	X			Very clearly stated
	S2. Do the collected data allow to address the research questions?	X			Lower number of nurses recruited but reflected intervention
	Further appraisal may not be feasible or appropriate when the answer is 'No' or 'Can't tell' to one or both screening questions.				
1. Qualitative	1.1. Is the qualitative approach appropriate to answer the research question?	X			
	1.2. Are the qualitative data collection methods adequate to address the research question?	X			
	1.3. Are the findings adequately derived from the data?	X			
	1.4. Is the interpretation of results sufficiently substantiated by data?	X			
	1.5. Is there coherence between qualitative data sources, collection, analysis and interpretation?	X			
5. Mixed methods	5.1. Is there an adequate rationale for using a mixed methods design to address the research question?	X			Used to enhance researcher understanding of team dynamics. Note no direct oversight by research team when diagrams drawn.
	5.2. Are the different components of the study effectively integrated to answer the research question?	X			
	5.3. Are the outputs of the integration of qualitative and quantitative components adequately interpreted?	X			
	5.4. Are divergences and inconsistencies between quantitative and qualitative results adequately addressed?	X			
	5.5. Do the different components of the study adhere to the quality criteria of each tradition of the methods involved?				N/A. Researchers used novel diagrams to

					explore question

6) Morency et al. (2020)

Category of study designs	**Methodological quality criteria**	**Responses**			
		Yes	No	Can't tell	Comments
Screening questions (for all types)	S1. Are there clear research questions?	X			
	S2. Do the collected data allow to address the research questions?	X			Only one OT offered treatment - ?scalability and replicability
	Further appraisal may not be feasible or appropriate when the answer is 'No' or 'Can't tell' to one or both screening questions.				
1. Qualitative	1.1. Is the qualitative approach appropriate to answer the research question?	X			
	1.2. Are the qualitative data collection methods adequate to address the research question?	X			
	1.3. Are the findings adequately derived from the data?	X			
	1.4. Is the interpretation of results sufficiently substantiated by data?	X			Table of quotes provided
	1.5. Is there coherence between qualitative data sources, collection, analysis and interpretation?	X			
4. Quantitative descriptive	4.1. Is the sampling strategy relevant to address the research question?	X			
	4.2. Is the sample representative of the target population?	X			
	4.3. Are the measurements appropriate?	X			
	4.4. Is the risk of nonresponse bias low?			X	Low response rate for x1 surveu (hospital admission)
	4.5. Is the statistical analysis appropriate to answer the research question?				N/A – Feasibility study with limited statistical analysis required
5. Mixed methods	5.1. Is there an adequate rationale for using a mixed methods design to address the research question?	X			
	5.2. Are the different components of the study effectively integrated to answer the research question?	X			
	5.3. Are the outputs of the integration of qualitative and quantitative components adequately interpreted?	X			

	5.4. Are divergences and inconsistencies between quantitative and qualitative results adequately addressed?	X			
	5.5. Do the different components of the study adhere to the quality criteria of each tradition of the methods involved?			X	

7) Nishida et al. (2017)

Category of study designs	**Methodological quality criteria**	**Responses**			
		Yes	No	Can’t tell	Comments
Screening questions (for all types)	S1. Are there clear research questions?	X			
	S2. Do the collected data allow to address the research questions?	X			
	Further appraisal may not be feasible or appropriate when the answer is ‘No’ or ‘Can’t tell’ to one or both screening questions.				
3. Quantitative non-randomized	3.1. Are the participants representative of the target population?	X			Pilot – small sample study (n=9 after drop outs)
	3.2. Are measurements appropriate regarding both the outcome and intervention (or exposure)?	X			
	3.3. Are there complete outcome data?	X			
	3.4. Are the confounders accounted for in the design and analysis?			X	E.g. didn’t look at impacts of different types of dementia
	3.5. During the study period, is the intervention administered (or exposure occurred) as intended?	X			

8) O’Connor et al. (2020)

Category of study designs	**Methodological quality criteria**	**Responses**			
		Yes	No	Can’t tell	Comments
Screening questions (for all types)	S1. Are there clear research questions?	X			
	S2. Do the collected data allow to address the research questions?	X			
	Further appraisal may not be feasible or appropriate when the answer is ‘No’ or ‘Can’t tell’ to one or both screening questions.				
1. Qualitative	1.1. Is the qualitative approach appropriate to answer the research question?	X			
	1.2. Are the qualitative data collection methods adequate to address the research question?	X			
	1.3. Are the findings adequately derived from the data?	X			
	1.4. Is the interpretation of results sufficiently substantiated by data?	X			
	1.5. Is there coherence between qualitative data sources, collection, analysis and interpretation?	X			
3. Quantitative non-randomized	3.1. Are the participants representative of the target population?	X			Note small sample size – pilot study (n=4). Could consider seperating SD and bvFTD cohorts.
	3.2. Are measurements appropriate regarding both the outcome and intervention (or exposure)?	X			
	3.3. Are there complete outcome data?	X			
	3.4. Are the confounders accounted for in the design and analysis?			X	
	3.5. During the study period, is the intervention administered (or exposure occurred) as intended?	X			Pilot study
5. Mixed methods	5.1. Is there an adequate rationale for using a mixed methods design to address the research question?	X			To enhance understanding of experience of participation
	5.2. Are the different components of the study effectively integrated to answer the research question?	X			
	5.3. Are the outputs of the integration of qualitative and quantitative components adequately interpreted?	X			
	5.4. Are divergences and inconsistencies between quantitative and qualitative results adequately addressed?	X			
	5.5. Do the different components of the study adhere to the quality criteria of each tradition of the methods involved?			X	

9) Pépin et al. (2013)

Category of study designs	**Methodological quality criteria**	**Responses**			
		Yes	No	Can’t tell	Comments
Screening questions (for all types)	S1. Are there clear research questions?	X			
	S2. Do the collected data allow to address the research questions?	X			
	Further appraisal may not be feasible or appropriate when the answer is ‘No’ or ‘Can’t tell’ to one or both screening questions.				
3. Quantitative non-randomized	3.1. Are the participants representative of the target population?	X			
	3.2. Are measurements appropriate regarding both the outcome and intervention (or exposure)?	X			
	3.3. Are there complete outcome data?			X	Discussion mentions “qualitative feedback” but not clearly reported in paper?
	3.4. Are the confounders accounted for in the design and analysis?			X	
	3.5. During the study period, is the intervention administered (or exposure occurred) as intended?	X			

10) Pozzi et al. (2019)

Category of study designs	**Methodological quality criteria**	**Responses**			
		Yes	No	Can’t tell	Comments
Screening questions (for all types)	S1. Are there clear research questions?	X			
	S2. Do the collected data allow to address the research questions?	X			
	Further appraisal may not be feasible or appropriate when the answer is ‘No’ or ‘Can’t tell’ to one or both screening questions.				
3. Quantitative non-randomized	3.1. Are the participants representative of the target population?	X			Pilot study – small sample size (n=27)
	3.2. Are measurements appropriate regarding both the outcome and intervention (or exposure)?	X			
	3.3. Are there complete outcome data?	X			
	3.4. Are the confounders accounted for in the design and analysis?			X	
	3.5. During the study period, is the intervention administered (or exposure occurred) as intended?	X			