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'This is the peer reviewed version of the following article: Laver, K., Cumming, R., Dyer, S., Agar, M., Anstey, K. J., Beattie, E., Brodaty, H., Broe, T., Clemson, L., Crotty, M., Dietz, M., Draper, B., Flicker, L., Friel, M., Heuzenroeder, L., Koch, S., Kurrle, S., Nay, R., Pond, D., Thompson, J., Santalucia, Y., Whitehead, C. and Yates, M. (2016), Evidence-based occupational therapy for people with dementia and their families: What clinical practice guidelines tell us and implications for practice. *Aust Occup Ther J*. doi:10.1111/1440-1630.12309

which has been published in final form at

DOI:

<http://dx.doi.org/10.1111/1440-1630.12309>

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Abstract:

Background: The first evidence based Clinical Practice Guidelines and Principles of Care for People with Dementia in Australia have been released. The Guidelines detail a number of important evidence based recommendations for occupational therapists.

Aim: The aim of this paper is (1) to provide an overview of Guideline development, and (2) to describe the evidence supporting a recommendation for occupational therapy. Common characteristics of effective occupational therapy programs for people with dementia are described.

Methods: Guideline development involved adaptation of existing high quality guidelines developed overseas and 17 systematic reviews to ensure that the most recent high quality evidence was included. One of the systematic reviews involved examining the evidence for interventions to promote independence in people with dementia. Specifically, we looked at the evidence for occupational therapy and its effect on activities of daily living, quality of life and carer impact.

Results: A total of 109 recommendations are included in the Guidelines. Occupational therapy was found to significantly increase independence in activities of daily living and improve quality of life. Effective occupational therapy programs involve: environmental assessment, problem solving strategies, carer education and interactive carer skills training.

Conclusion: Occupational therapists working with people with dementia in community settings should ensure that their time is spent on those aspects of intervention that are shown to be effective.

Key words:

Alzheimer disease, Evidence Based Practice, Practice Guideline, Knowledge Translation

Introduction

Audits of clinical practice in Australia suggest that improvements in the quality and safety of care for people with dementia and their carers are required (Bridges-Webb, Giles, Speechly, Zurynski, & Hiramaneek, 2006; O'Connor, Griffith, & McSweeney, 2010). A national survey of 134 occupational therapists revealed that more than half of the respondents were either not at all confident or only a little confident that their knowledge of current research evidence about occupational therapy in dementia care was up to date (Bennett, Shand, & Liddle, 2011). More than half (51.5%) had no specialist training in the care of people with dementia (Bennett et al., 2011).

Evidence based occupational therapy draws on the combination of individual clinical expertise, patient values and expectations and the best external evidence (Sackett, Reosenberg, Gray, Haynes, & Richardson, 1996). Keeping up to date with the best external evidence is challenging for busy clinicians due to the sheer amount of evidence available. A study published in 2010 estimated that there were 75 trials and 11 systematic reviews published each day; these figures are steadily increasing (Bastian, Glasziou, & Chalmers, 2010).

Clinical practice guidelines aim to improve uptake of research evidence and can play an important role in evidence based practice by synthesising the available evidence and providing clinicians with recommendations for practice (Grol & Grimshaw, 2003). Adherence to clinical practice guidelines have been shown to improve both the quality and consistency of care for people with a range of different diagnostic conditions (Hubbard et al., 2012). While there are a vast number of guideline documents, it is important that clinical practice guidelines are trustworthy. Trustworthy clinical practice guidelines: clearly describe the processes of guideline development; report authorship, potential conflicts of interest and how these conflicts were managed; are informed by systematic reviews of the evidence; and, clearly reference the evidence underpinning recommendations (Gherzi & Anderson, 2015). Australia's National Health and Medical Research Council (NHMRC) detail 54 mandatory requirements that must be met in order for clinical practice guidelines to meet their standards and be considered for approval (National Health and Medical Research Council, 2011).

The need for clinical practice guidelines for dementia in Australia was identified as a priority area due to the high prevalence of the condition and the potential to improve dementia care in Australia (Australian Commission on Safety and Quality in Health Care, 2015). In February

2016, the National Health and Medical Research Council approved the first Australian Clinical Practice Guidelines and Principles of Care for People with Dementia (www.clinicalguidelines.gov.au/portal/2503/clinical-practice-guidelines-and-principles-care-people-dementia) (Guideline Adaptation Committee, 2016a). The Guidelines contain 109 recommendations; many of which are pertinent to occupational therapists. In addition, there is a specific recommendation relating to provision of occupational therapy services:

“People with dementia living in the community should be offered occupational therapy interventions which should include: environmental assessment and modification to aid independent functioning; prescription of assistive technology; and tailored intervention to promote independence in activities of daily living which may involve problem solving, task simplification and education and skills training for their carer(s) and family.”

This paper briefly describes development of the Clinical Practice Guidelines for Dementia in Australia and examines the evidence underpinning the recommendation for occupational therapy in further detail. We discuss implications for occupational therapists and describe challenges found in translating evidence based occupational therapy programs for people with dementia.

Methods

Guideline development

The Clinical Practice Guidelines for Dementia in Australia (Guideline Adaptation Committee, 2016a) were developed to guide assessment and management of people with dementia in community, residential care and hospital settings. The intended users of the Guidelines are staff working with people with dementia in the health and aged care sectors in Australia including medical specialists, nurses, aged care workers and allied health professionals.

The Clinical Practice Guidelines were developed using ADAPTE methodology, in which existing high quality guidelines are adapted for local use (The ADAPTE Collaboration, 2009). In this case, the 2006 National Institute for Health and Care Excellence (NICE) Guidelines were adapted (National Institute for Health and Care Excellence, 2006). As there has been a large volume of relevant literature published since the NICE Guidelines were published in 2006 a systematic search for evidence published since 2005 was conducted. An

additional search was conducted for literature relating to culturally and linguistically diverse and Indigenous populations to identify issues unique to Australia.

A multidisciplinary Guideline Adaptation Committee (including an occupational therapist with expertise in dementia care) was responsible for refining the scope of the Guidelines; considering new evidence from updated literature searches; reviewing the evidence; and, developing recommendations. When formulating recommendations the Committee considered the benefits and potential harms of the intervention, resource implications, equity, acceptability and feasibility.

Recommendations were classified as either: (a) evidence based recommendations, (b) consensus based recommendations or (c) practice points. Evidence based recommendations were assigned a grade to reflect the quality of the evidence supporting the recommendation using GRADE methodology (Schünemann, Brożek, Guyatt, Oxman, & editors, 2013). GRADE methodology offers a systematic and transparent method of judging the quality of a body of evidence. The body of evidence may be labelled as high, moderate, low or very low depending on multiple factors including risk of bias, inconsistency, indirectness and imprecision.

Systematic reviews of most relevance to occupational therapists

The Guidelines addressed a number of systematic review questions relevant to occupational therapy practice, including the evidence for strategies for promoting independence, cognitive rehabilitation, non-pharmacological interventions for behavioural and psychological symptoms of dementia and assessments and intervention for carers. Details of the methodology of the reviews and the results of all reviews are described briefly in the Clinical Practice Guidelines and in more detail in the associated Technical Reports (Guideline Adaptation Committee, 2016b). In brief, searches were conducted based on a protocol written a priori. For each question we searched PubMed, Medline, EMBASE and PsycINFO using a search strategy developed in consultation with an information specialist. We initially applied a filter in our search strategy to identify systematic reviews. We then identified the most appropriate systematic review to include based on recency, relevance and quality. We used the systematic review as a method of identifying primary studies and then ran an additional search to identify primary studies published after the search date used within the included systematic review. One person screened titles and abstracts to determine the studies that should be sought for review in full text. The same person then reviewed full text and decided

on included studies (seeking a second opinion where required). The same reviewer extracted information about the characteristics of the included reviews or studies, assessed methodological quality (using the Cochrane Risk of Bias tool (Higgins et al., 2011) for randomised trials or AMSTAR (Shea et al., 2007) for systematic reviews) and graded the overall body of evidence. Ethical approval was not required to conduct the reviews or guideline development.

The question most relevant to occupational therapy that was addressed within the development of the Guidelines was “For people with dementia, are there strategies for promoting independence that produce benefits/harms?” This question was addressed by specifying four different intervention approaches of interest *a priori*. These were: occupational therapy, exercise, electronic assistive technology and falls prevention. Our definition of occupational therapy was based on the definition used in the UK’s NICE Guidelines ‘one or more of the following interventions provided by an occupational therapist, 1) training of sensory-motor functions, 2) training of cognitive functions, 3) training of skills, 4) advice and instruction regarding the use of assistive devices, 5) counselling the caregiver’. In this paper we will present the findings for occupational therapy intervention only. Results will be discussed within the setting (residential vs community) and by reported outcome.

Results

Guideline recommendations

There were a total of 109 recommendations included in the Guidelines (Guideline Adaptation Committee, 2016a). Of these, 29 were evidence based recommendations, 7 were consensus based recommendations and 73 were practice points. Key themes within the Guidelines are: the need for timely diagnosis (and not dismissing symptoms as ‘part of ageing’); the importance of a healthy lifestyle and promoting independence; and, the importance of involving carers in all aspects of care. The Guidelines also provide recommendations for the management of behavioural and psychological symptoms of dementia and emphasise that symptoms should be prevented where possible and that non-pharmacological strategies to manage symptoms should be used in the first instance. One of the most effective interventions in dementia care is providing staff with in-depth training regarding the

symptoms of dementia, person-centred care and how to most effectively communicate with people with dementia and their carers.

Systematic review of occupational therapy interventions

The systematic review conducted for the Guidelines identified eight randomised controlled trials of occupational therapy interventions in total. These included one trial set in residential care and seven trials set in the community (Gitlin, Corcoran, Winter, Boyce, & Hauck, 2001; Gitlin et al., 2008; Gitlin et al., 2003; Gitlin, Winter, Dennis, Hodgson, & Hauck, 2010; Graff et al., 2006; Kumar et al., 2014; Nobili et al., 2004; Wenborn et al., 2013) .

Benefits and harms of occupational therapy intervention for people with dementia living in residential care

The systematic review identified one randomised controlled trial in which occupational therapy was provided for people in a residential care setting in the United Kingdom (Wenborn et al., 2013). This study conducted by Wenborn and colleagues involved 210 participants with advanced dementia who were assigned to intervention or usual care. Intervention involved an occupational therapy program designed to enable care home staff to increase activity provision. This included assessment of the environment, staff education in getting to know residents interests and abilities and planning activities. After the 12 week intervention period, there were no significant differences between groups in global cognition, quality of life or behavioural and psychological symptoms of dementia.

Benefits and harms of occupational therapy intervention for community dwelling people with dementia

The review (Guideline Adaptation Committee, 2016b) identified seven randomised controlled trials evaluating the efficacy of occupational therapy intervention for community dwelling people with dementia (Gitlin et al., 2001; Gitlin et al., 2008; Gitlin et al., 2003; Gitlin et al., 2010; Graff et al., 2006; Kumar et al., 2014; Nobili et al., 2004). Characteristics of studies are presented in Table 1.

The effect of intervention on outcomes is reported below:

Activities of daily living (ADL) function: Four of the trials (with 684 participants) examined the effect of occupational therapy intervention on activities of daily living function. When pooled they showed an overall small positive effect on ADL function (SMD 0.17, 95%CI

0.02 to 0.33). See Figure 1. The quality of the evidence was considered 'low' due to the risk of bias in some trials and the inconsistent results between trials. Measures were taken post intervention (range 6 weeks to 6 months) and included the Assessment of Motor and Process Skills and an adapted version of the Functional Independence Measure).

Quality of life (for the person with dementia): Pooling of four trials (with 456 participants) reporting quality of life outcomes found a statistically significant effect that is considered of moderate magnitude (SMD 0.62, 95%CI 0.43 to 0.81). See Figure 2. The quality of evidence was graded as 'moderate' due to the risk of bias in some studies. Measures were taken post-intervention (range 5 weeks to 4 months) and included the QOL-AD, DQOL and WHOQOL-BREF.

Carer impact: Pooling of four studies (with 547 participants) revealed no significant effect on carer impact (SMD -0.15, 95%CI -0.32 to 0.02). See Figure 3. The risk of bias in some studies meant that the overall quality of the evidence was considered 'moderate'. It should be noted that while the systematic review that we used to identify primary studies presented two studies as different studies it was later noted that they were in fact the same study reporting outcomes at different time points and hence should not both be presented in the same meta-analysis (Gitlin, Hauck, Dennis, & Winter, 2005; Gitlin et al., 2003). Removing the follow-up data (Gitlin et al., 2005) from the analysis results in little change to the overall result (SMD -0.17, 95%CI -0.37 to 0.02). This illustrates one of the limitations associated with using existing systematic reviews to identify studies and the reliance on these reviews to present accurate information.

Harms: Two of the studies reported that there were no harms associated with intervention (Gitlin et al., 2010; Graff et al., 2006). Other studies did not report any data on the presence or absence of adverse events.

What are the components of evidence based occupational therapy for people with dementia?

In order to form a recommendation regarding occupational therapy for people with dementia, we examined the characteristics of the intervention of the four (of seven) studies that demonstrated significant improvements in activities of daily living or quality of life. It can be seen that effective studies involved environmental assessment and modification with prescription of assistive devices where necessary, problem solving strategies to optimise performance in activities of daily living, carer education regarding the symptoms and impact

of dementia and interactive carer skills training to support the carer to provide optimal care. The majority of participants in the included studies had mild to moderate symptoms of dementia.

Based on the information available, the committee formed an evidence based recommendation for occupational therapy for community dwelling people with dementia. There was insufficient information regarding occupational therapy for people living in residential care facilities to consider forming a recommendation.

Discussion

The Clinical Guidelines for Dementia in Australia are the first evidence based guidelines for dementia care to be approved by NHMRC. The Guidelines contain a combination of evidence based recommendations, consensus based recommendations and practice points that are highly relevant to occupational therapists in community, hospital and residential care settings. The Guidelines contain a specific recommendation for occupational therapy; the recommendation incorporates the components of intervention that are effective. The occupational therapy programs that the evidence demonstrated were effective involve environmental assessment and modification, problem solving strategies to optimise performance in activities of daily living, carer education regarding the symptoms and impact of dementia and interactive carer skills training to support the carer to provide optimal care. Interventions that have demonstrated change are typically scheduled over at least five consultations and are tailored to the needs of the individual. There are other recommendations that are of relevance to occupational therapists. The Guideline Adaptation Committee acknowledged that several of the interventions recommended could be provided by a number of different professionals and as such avoided naming health professionals within the recommendations where possible. This raises opportunities for occupational therapists to lead initiatives outside of the traditional scope of occupational therapy practice such as leading staff training programs and running information and support programs for people with dementia.

In their survey of current occupational therapy practice, Bennett and colleagues found that occupational therapists conducted environmental assessment and modification most of the time, that strategies to enhance ADL performance were used some of the time and that carer education was involved some of the time (Bennett et al., 2011). Whether or not the therapist actively engaged the carer in skills building was not addressed within the survey.

Occupational therapists reported that they spent most of their time on assessment. There were a range of other interventions used by occupational therapists (such as perceptual retraining and cognitive retraining) that are not well supported by the evidence (Bahar-Fuchs, Clare, & Woods, 2013)).

The main implications of the Guidelines recommendation for occupational therapy are for community based occupational therapists who have the scope to visit people with dementia and their carers in their own home environment on a number of occasions. Community based occupational therapists should ensure that their care is systematic, is tailored to the needs of the individual and carer and reflects the Guideline recommendation. Assessment processes should be streamlined and primarily revolve around identifying: what are the key issues the person and their carer are experiencing and what are the current functional capabilities of the person with dementia. Occupational therapists should dedicate as much time as possible to intervention. Occupational therapists should avoid spending time on activities which have not demonstrated improved outcomes for the person with dementia such as cognitive retraining (Bahar-Fuchs et al., 2013).

Occupational therapists in acute settings do not typically have the scope to conduct multiple home visits and thus are unlikely to be able to implement this recommendation. However, admission to hospital is frequently associated with functional decline and so occupational therapists may play a key role in reviewing the home environment and providing additional support and training for carers to manage changes in the person's capabilities.

We identified only one study examining the efficacy of occupational therapy for people in residential care which failed to demonstrate improved outcomes (Jennifer Wenborn et al., 2013). While we were unable to form a recommendation for occupational therapy in this setting in this case there is insufficient information from randomised controlled trials upon which to draw conclusions. Occupational therapists in residential care settings will find multiple other recommendations helpful including recommendations regarding non-pharmacological management of behavioural and psychological symptoms of dementia.

It is important that occupational therapists realise that there are usually several years between diagnosis and death (Brodaty, Seeher, & Gibson, 2012) and that promoting independence is a valid goal of treatment for people with mild to moderate severity dementia. Occupational therapists should also have the confidence that small changes to a person's environment or activities can have significant positive consequences and that certain occupational therapist

delivered interventions have been shown to improve quality of life for people with dementia. Occupational therapists should allocate their time according to those interventions with clear evidence of benefit while considering client preference.

Translational work conducted in the United States and the Netherlands provides highly useful information around implementation of occupational therapy programs shown to be effective in high quality research studies (Döpp et al., 2015; Gitlin, Jacobs, & Earland, 2010; Van't Leven et al., 2012). Gitlin and colleagues found that translation was 'labour intensive' and required significant resources in terms of building strong partnerships between the research team and the clinicians (Gitlin et al., 2010). Training was also time consuming and changes in staffing and policies created further challenges. Yet, translation was deemed moderately successful and clinicians reported that involvement in the project had enriched their practice. Implementation of the 'community occupational therapy program for people with dementia and their caregiver' (COTiD) program in the Netherlands was also reported to be challenging. Focus groups and interviews with staff identified multiple barriers to delivering the COTiD intervention. Occupational therapists reported a lack of confidence in delivering the program and difficulty providing the number of consultations expected (Van't Leven et al., 2012). The Netherlands research group found that training programs for occupational therapists needed to be supplemented by ongoing coaching and more education about dementia to improve the chances of therapists delivering the program (Döpp et al., 2015). These studies suggest that barriers to translation and strategies to overcome these barriers are context-specific. The findings also suggest that education alone is insufficient and that other intervention strategies may be required. Reviews of implementation strategies more broadly reveal that there is no single method guaranteed to result in success and that the best chances of success are with the use of tailored intervention strategies which may include audit and feedback, printed educational materials, educational outreach, local opinion leaders, and reminders (Grimshaw et al., 2012).

Within the field of dementia care the evidence base is growing and remains dynamic thus providing the opportunity for clinicians and researchers to develop and test innovative approaches. The Committee identified a number of areas for further research which are relevant to occupational therapists including the need for more research on transitions in care, physical and cognitive rehabilitation, driving, non-pharmacological interventions for changed behaviours such as apathy and anxiety and the needs of specific groups, such as people from culturally and linguistically diverse backgrounds.

Acknowledgement: This work was supported by the National Health and Medical Research Council (NHMRC) Partnership Centre on Dealing with Cognitive and Related Functional Decline in Older People (grant no. GNT9100000).

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Table 1: Characteristics of studies

	Participant characteristics	Number of treatment sessions	Environmental assessment and modification	Problem solving strategies to optimise ADL	Carer education	Carer skills training
Gitlin 2001 N=171	Mean age 78 Female: 66% MMSE not reported	5 home visits	✓	✓	✓	✓
Gitlin 2003 N=255	Mean age I:80, C:82 Gender I:72%, C:64% Mean MMSE I:12, C:13	5 home visits over 6 months + 1 phone call	✓	✓	✓	✓
Nobili 2004 N=39	Mean age I:74, C:75 I: 60%, C:59% female Mean MMSE I: 11, C:12	1 (90 mins)	✓	✓	✓	✓
Graff 2006 N=135	Mean age I: 79, C:77 56% female Mean MMSE 19/30	10 over 5 weeks	✓	✓	✓	✓
Gitlin 2008 TAP N=60	Mean age 79 43% female Mean MMSE 12/30	6 over 4 months	✓	Not reported although strategies generalised	✓	✓
Gitlin 2010 COPE N=237	Mean age 82 68% female Mean MMSE 13/30	≤9 over 16 weeks†	✓	✓	✓	✓
Kumar 2014‡ N=77	Mean age 69 20% female severity:70% 'mild'; 30% 'moderate'	10 sessions over 5 weeks	x	x	x	X

† Also included one to two nurse home visits

‡ The intervention in the study by Kumar and colleagues involved relaxation, physical exercise, practice of activities of daily living, practice of household tasks, cognitive exercises and recreational activities