The impact of centre based respite on occupational performance for people with dementia

Kristy Ness

Edith Cowan University

Follow this and additional works at: https://ro.ecu.edu.au/theses_hons

Part of the Clinical and Medical Social Work Commons

Recommended Citation

This Thesis is posted at Research Online. https://ro.ecu.edu.au/theses_hons/1024
2009

The Impact of Centre Based Respite on Occupational Performance for People with Dementia

Kristy Ness

*Edith Cowan University*

---

**Recommended Citation**


This Thesis is posted at Research Online.

http://ro.ecu.edu.au/theses_hons/1024
Edith Cowan University

Copyright Warning

You may print or download ONE copy of this document for the purpose of your own research or study.

The University does not authorize you to copy, communicate or otherwise make available electronically to any other person any copyright material contained on this site.

You are reminded of the following:

- Copyright owners are entitled to take legal action against persons who infringe their copyright.
- A reproduction of material that is protected by copyright may be a copyright infringement.
- A court may impose penalties and award damages in relation to offences and infringements relating to copyright material. Higher penalties may apply, and higher damages may be awarded, for offences and infringements involving the conversion of material into digital or electronic form.
Use of Thesis

This copy is the property of Edith Cowan University. However the literary rights of the author must also be respected. If any passage from this thesis is quoted or closely paraphrased in a paper or written work prepared by the user, the source of the passage must be acknowledged in the work. If the user desires to publish a paper or written work containing passages copied or closely paraphrased from this thesis, which passages would in total constitute and infringing copy for the purpose of the Copyright Act, he or she must first obtain the written permission of the author to do so.
COPYRIGHT AND ACCESS DECLARATION

I certify that this thesis does not, to the best of my knowledge and belief:

(i) Incorporate without acknowledgment any material previously submitted for a degree or diploma in any institution of higher degree or diploma in any institution of higher education;

(ii) Contain any material previously published or written by another person except where due reference is made in the text of this thesis; or

(iii) Contain any defamatory material.

(iv) Contain any data that has not been collected in a manner consistent with ethics approval.

The Ethics Committee may refer any incidents involving requests for ethics approval after data collection to the relevant Faculty for action.

Signed. ........................................

Date .............................
The Impact of Centre Based Respite on Occupational Performance for People with Dementia

Kristy Ness

A Report Submitted in Partial Fulfilment of the Requirements for the Award of Bachelor of Science (Occupational Therapy) (Honours), Faculty of Computing, Health and Science, Edith Cowan University.

Submitted September, 2009

I declare that this written assignment is my own work and does not include: (i) material from published sources used without proper acknowledgement, or (ii) material copied from the work of other students.

Signature: 

Date: 30-1-2009
Declaration

I certify that this literature review and research project does not incorporate without acknowledgement, any material previously submitted for a degree or diploma in any institution of higher education and that, to the best of my knowledge and belief, it does not contain any material previously published or written by another person except where due reference is made in the text.

Signature:

Date: ...30.11.2009...
Acknowledgements

I would like to acknowledge and thank the caregivers that participated in this study, Wendy Hudson (Manager Policy and Development) and Laurena Beech (Coordinator, Centre Based Respite) of Alzheimer’s Australia WA, and staff at Edith Cowan University for their assistance with this project.
# Table of Contents

**Centre Based Respite for Dementia: Systematic Review**  
Abstract ........................................ 1  
Introduction ..................................... 2  
Methods .......................................... 3  
  Inclusion Criteria ............................... 4  
  Methodological Quality Rating ............... 4  
  Data Synthesis and Analysis .................. 5  
Results ........................................... 5  
  Quality Assessment of Studies ............... 6  
  Interventions .................................. 7  
  Outcomes ...................................... 7  
Discussion ...................................... 8  
References ...................................... 9  
Guidelines for Contributions by Authors (Literature Review) 10

**Respite Improves Relationships for People with Dementia**  
Abstract ........................................ 11  
Introduction .................................... 12  
Methods ......................................... 13  
  Participants/ Recruitment ..................... 14  
  Data Collection ................................ 14  
  Data Analysis .................................. 14  
Findings and Discussion ....................... 15  
  Theme One: Interpersonal ...................... 15  
  Theme Two: Intrapersonal ...................... 18  
  Theme Three: Cognitive ....................... 21  
  Theme Four: Bio-mechanical ................... 23  
  Theme Five: Sensory-Motor .................... 25
Conclusion
References
Guidelines for Contributions by Authors (Research Report)

Appendices
Appendix A: Table 1. Description of included studies
Appendix B: Figure 1. Five Categories of performance components impacted by dementia
Appendix C: Interview Guide
Centre Based Respite for Dementia: A Systematic Review

Kristy Ness
Centre based respite for dementia: A systematic review

Abstract

Objective: To examine the literature regarding the relationship of centre based respite and occupational performance components and performance areas in people with dementia, as outlined by the Occupational Performance Model (Australia).

Method: Medline, CINAHL and PsycINFO as well as manual searches of reference lists from 2000 onwards were conducted. All levels of evidence reporting on outcomes for people with dementia published in English were selected. Quality assessment was conducted by two reviewers. A narrative review was possible.

Results: Eight studies reported on four outcomes of occupational performance. Quality of articles ranged from good to very strong. Findings were mixed with effect sizes ranging from small to very large (0.10 – 1.009).

Conclusions: The effectiveness of centre based respite in restoring or maintaining occupational performance for people with dementia is inconclusive. Future studies need to provide a holistic understanding of the role of centre based respite through the use of qualitative methods.

Key words: centre based respite, adult day care, dementia, occupational performance, systematic review.

Author: Kristy Ness

Supervisors:
Associate Professor Catherine Elliott
Dr Sonya Girdler

Submitted: 18 September, 2009
Centre based respite for dementia: A systematic review

Introduction
The number of people living with dementia is rapidly increasing, with one in four Australians aged over 85 currently living with the disease [1]. By 2016 dementia is expected to be the largest cause of disability burden in Australia [2]. Current health care policy places an emphasis on ‘healthy aging’ aimed at keeping older people living in the community as long as possible. This is not only more cost effective from a government viewpoint, but is also consistent with the wishes of the majority of elderly people themselves [2]. Centre based respite (CBR), also referred to as adult day care, is one community based service designed to assist people with dementia to continue living at home. The main goals include reducing loneliness and depression, enhancing or maintaining the skills required for daily living, maintaining nutrition and health care needs, as well as giving the caregiver a break from their day to day caring responsibilities. There are two models of CBR. The social model includes a range of social, physical, cognitive, musical and occupational activities such as cooking and gardening [3]. The medical model may also incorporate health assessments and occupational and physical therapy.

Dementia is complex and multifaceted. It impacts on all components of occupational performance. Occupational performance components comprise the personal skills that enable task performance, and provide the foundation for role performance. These include cognitive, intrapersonal, interpersonal, bio-mechanical and sensory-motor performance components [4]. In order to obtain a holistic and meaningful understanding on how CBR impacts a person with dementia, the Occupational Performance Model (Australia) was employed. This model is based on the principle that people fulfil roles by engaging in routines, tasks and activities. It addresses all occupational performance components as well as their interrelationship with occupational performance areas of self-maintenance, rest, productivity and leisure, and the individual’s occupational role’s [4].
Cognitive impairment is often considered to be the defining feature of dementia. Memory, decision making, judgement, verbal communication, thinking and reasoning skills progressively decline [5]. Due to the effects of dementia on cognition, intrapersonal performance components are impacted. Wandering, purposeless and inappropriate behaviour, irritability, anxiety, suspicion, night-time sleep disturbance and depression have been documented to be among the most common symptoms described by caregivers [6]. The marital relationship also becomes increasingly imbalanced, resulting in a decline in relationship quality, level of intimacy and companionship [7]. Disturbance of biomechanical components may include impairments of gait, balance, coordination and voluntary movement, which compound the psychological and cognitive difficulties. Significant changes to sensory-motor components including how people interpret what they hear, see, taste, and smell, predispose them to auditory hallucinations, problems with depth perception and visual misinterpretations [8]. These difficulties are associated with decreased ability to perform activities of daily living leading to increasing reliance on others.

In 2001, a literature review was conducted evaluating the effectiveness of adult day services in improving client functioning [9]. An updated review was considered warranted given the growing need to evaluate community based services that support individuals with dementia and their caregivers, as well as developing an understanding of what components of function are influenced by these programs. The objective of this review was to examine the literature relevant to understanding the relationship between CBR and cognition, intrapersonal, interpersonal, bio-mechanical, sensory-motor performance components and occupational performance areas of self-maintenance, rest, leisure and productivity for people with dementia.

Methods
To identify and locate relevant studies for inclusion, electronic searches of MEDLINE, CINAHL and PsycINFO were searched from January 2000 to May 2009. These dates have been chosen as the previous review did not include literature published after 1999. The main search terms were dementia, Alzheimer’s, adult day care and respite care. All
search terms were truncated, exploded and adjusted to match the specific databases being searched. Searches were restricted to published, English language literature. Papers presenting viewpoints, editorials, case studies, opinions or conference proceedings were not included. In addition to electronic searches, reference lists of all retrieved articles were manually searched to identify additional articles.

**Inclusion Criteria**

The results of the electronic and manual searches were reviewed, beginning with an assessment of each title and abstract to determine if the article met the inclusion criteria. If this was not possible, the full text of the article was reviewed. Studies were included if the focus of the research was on outcomes for people with dementia in relation to CBR attendance. The length and frequency of attendance was not restricted. Participants in the studies were limited to those where a diagnosis of dementia, or probable dementia was indicated in at least half of participants, and participants resided in the community.

Outcomes of interest included 1) occupational performance components, including cognitive, intrapersonal, intrapersonal, bio-mechanical and sensory-motor, 2) occupational performance areas of self-maintenance, rest, leisure and productivity, and /or 3) family and caregiver perspectives on outcomes for people with dementia. Due to the paucity of literature on this topic, exclusion of articles was not made on study design, thus all articles irrespective of design have been included.

**Methodological Quality Rating**

Two reviewers, an experienced researcher and honours student, judged the quality of each study independently, using the assessment tool for quantitative studies developed by Kmet, Lee and Cook [10]. The checklist comprises 14 questions and a scoring system. Guidelines and instructions are provided and were used to assist the reviewers in answering questions and calculating assessment scores. The reviewers used the calculated score to define the quality as strong (>80%), good (70-80%) adequate (50-69%) or limited (<50%) [11]. The level of agreement reached between reviewers was 93 per cent and discrepancies were resolved by discussion. The level of evidence was determined based on the National Health and Medical Research Council guidelines [12]. The level
reflects the degree to which bias has been considered within the study design. A higher rating on the hierarchy means less bias apparent in the study.

**Data Synthesis and Analysis**

Due to insufficient data, lack of randomised control trials and control groups, a meta-analysis was not possible. Instead, a narrative review was undertaken to summarise findings and provide an assessment of methodological issues. Where sufficient data were provided, effect size was calculated using Gpower software [13]. Effect size was determined to be small (d=0.2), medium (d=0.5) or large (d=0.8) as described by Cohen [14].

**Results**

Electronic searches located 161 articles from MEDLINE, 184 from CINAHL and 171 from PsycINFO, with a total of 450 potential articles after accounting for duplicates. Using the stated inclusion criteria, titles and abstracts were reviewed, resulting in 428 articles judged ineligible. Main reasons for ineligibility included reporting on caregiver outcomes such as burden, depression and well-being, and the inclusion of primarily frail aged and not individuals with dementia. Full texts of the remaining 22 articles were reviewed for inclusion. Of these, eight met the inclusion criteria, reporting on both social and medical models of care.

Studies varied in their duration, design, frequency of attendance and activities offered. The majority of participants had a diagnosis of dementia or probable dementia, with severity only reported in two studies (mild to moderate). The average age of participants ranged from 74 to 80 years. The majority of studies were from the USA [15-18], two from Italy [19, 20], one from Korea [21] and Germany [22]. Details of included studies are provided in Table 1 (Appendix A).

**Quality Assessment of Studies**

Overall, the methodological quality of included studies ranged from good to strong (Appendix A). One randomised control trial (RCT), three quasi-experimental studies with
controls, and four pre-test/post-test studies without controls were included for review. For the most part outcome measures had sound psychometric properties. The objectives were clearly described as were details of subjects and comparison groups. Shortcomings included lack of blinding, randomisation and control groups as well as small sample size. Blinding of participants and investigators is difficult to overcome when their active involvement in the intervention is required. In a RCT, [17], randomisation was mentioned, however the details including the methods used were not described. In less than half (n=2) there was no justification provided for the sample size, although, most described details of drops outs or withdrawals.

**Interventions**

Intervention periods ranged from two to 18 months. Participants attended the centre from one day per week to daily, for an average of 6 hours per day. A social model of care was primarily utilised [15-20] with one study adopting the medical model [21] and another not specifying the type of day care [22].

**Outcomes (cognition, intrapersonal, interpersonal and self-maintenance)**

The object of this review was to examine the impact of CBR on cognition, interpersonal, intrapersonal, bio-mechanical, sensory-motor performance components, and occupational performance areas of self-maintenance, rest, leisure and productivity. However, only four of these domains (cognition, intrapersonal, interpersonal and self-maintenance) were reported in the literature.

Changes in cognition were evaluated in six of the eight included studies. For the most part, cognitive performance was unaffected by CBR attendance [15, 17, 19, 21]. In a RCT, Quayhagen et al. [17] reported no change in the areas of memory (immediate and delayed), verbal fluency and problem solving. Effect sizes were found to be small for fluency (0.423) and problem solving (0.13), medium for immediate memory (0.58) and very large for delayed memory (1.009). In a pre-test/post-test study without control by Higgins et al. [16], cognition was shown to worsen significantly (p<0.0001) over a 12 month intervention period. By comparison, a quasi-experimental with control study by
Zank and Schacke [22], a significant increase (p≤0.004) in cognitive functioning was reported, however the effect size can be regarded as small (0.18).

Intrapersonal performance components were evaluated in all studies, with conflicting findings. Centre based respite has been shown in some instances to significantly reduce behavioural and psychological symptoms, including delusions, anxiety, agitation, disinhibition, aberrant motor behaviour [19] and aggression [20]. Further, Femia and colleagues [15] reported a significant reduction (p<0.05) in night-time sleep disturbances, when comparing the day care group on attendance days, with the control. Although not significant, a tendency towards reduced incidence of agitated behaviour (p=0.054) on attendance days was also described [15]. In contrast, Higgins et al. [16] and Kim et al. [21] reported that behaviour problems can significantly increase, over ten week and 12 month intervention periods. Neither an improvement nor decline in behavioural symptoms has also been attributed to CBR. No change in behaviour as measured by the Memory and Behaviour Problem Checklist [23] was reported by both Zank and Schacke [22] and Quayhagen and colleagues [17]. Effect sizes were found to be small (0.10) and large (0.86) respectively.

In a quasi-experimental control group study, no significant difference in the duration or occurrence of depressive symptoms between the day care group and control were found [15]. The same study reported significantly lower (p=0.02) occurrence of depressive symptoms when comparing the adult day care group on service and non-service days. In line with this finding, significant reductions in depressive symptoms have been reported [20, 22]. Calculations however show the effect size to be small (0.24).

Quayhagen et al. [17] was the only study to measure interpersonal performance components. Through qualitative interviews, an increase in the ability of spousal caregivers to interact more effectively and talk more freely was described. However, The Marital Needs Satisfaction Scale [24] found that CBR attendance to have no effect on marital satisfaction. Effect size can be regarded as medium (0.53).
Finally, three studies reported the ability of a person with dementia to complete self-maintenance activities as an outcome. Although the measurement tools varied (Nuremberg Aging Observation Scale, Katz Basic Activities of Daily Living, Lawton’s Instrumental Activities of Daily Living and caregiver reports), all demonstrated no significant difference between the intervention and control groups after two and nine month intervention periods [15, 19, 22]. Insufficient data were provided to calculate effect size.

Discussion
The eight studies included in this systematic review, provide conflicting evidence for the impact of CBR on cognition, intrapersonal, interpersonal performance components and self-maintenance activities for people with dementia.

There are many possible reasons for the conflicting findings. It may be partly due to the methodological quality of studies. Firstly, the majority of studies did not employ a true experimental design, making identification causality between centre based respite and performance components difficult. Secondly, the research design needs to allow for the natural pattern of decline in dementia. A multiple baseline design would allow for measurement of the natural pattern of decline as well as the impact of CBR on dementia. Femia et al. [15], Kim et al. [21] and Mossello et al. [19], all reported unchanged cognition levels, suggesting CBR is potentially effective in maintaining cognitive abilities. Without utilising a design that measures both this decline and the impact of centre based respite this is unable to be quantified.

In terms of outcome measures, most were valid, reliable and appropriate for use for people with dementia, although the sensitivity of many is limited. Poor sensitivity of assessment tools will impact on the ability to accurately capture change from centre based respite. Quayhagen and colleagues [17] used only sections of the Weschler Memory Scale Revised (WMS-R). Low reliability of individual subtests and composite scores have been reported, limiting the interpretation of sub-tests [25]. Many outcome measures also relied on proxy reports whereby the caregivers or relatives provide
information or answer questions about, or on behalf of the person with dementia. Third party reporting adds another layer of interpretation. It has been shown that families providing care and who are burdened or stressed are more likely to report impairments. Measures that rely on this method, (Neuropsychiatric Inventory, Daily Record of Behaviour and CERAD Behavior Rating Scale for Dementia) may be subject to bias and potentially inaccurate results, by the over or underestimation of abilities of the person with dementia [26].

Elderly clients with a range of disabilities were included in the study by Zank and Schacke [22], making it difficult to generalise findings to a dementia specific population. The small sample size in the studies by Kim et al. [21], Mossello et al. [19] and Vespa et al. [20] must be considered when interpreting and generalising results. Other studies had adequate sample sizes.

Short intervention periods of eight [15, 17, 19] to ten weeks [21] were reported by half of the studies. It has been proposed that it may take some time for older persons to adapt to new activities at the start of interventions, and consequently there may be an initial increase in anxiety when only evaluating participation after short periods [27]. Intervention periods may be too short to allow for adequate participation in the program that is necessary to produce changes in outcomes. Also, given these short intervention periods, no long-term conclusions can be drawn on how CBR effects occupational performance.

This review has a number of limitations. Studies were located from only three databases, although it can be argued that these are most likely to provide quality research in the area. Additionally, the search was limited to published literature and did not include grey literature, manual searches of gerontology, dementia, therapy or nursing journals nor conference proceedings. Despite these limitations, this review provides valuable information that will contribute to improving the quality of care for people with dementia. There are few reviews that have focussed on the effectiveness of CBR for
people with dementia, and to our knowledge the only systematic review focussing on outcomes for people with dementia.

As the number of people living with dementia continues to rise, there is an increasing emphasis on providing care services to maintain these individuals in the community [2]. Centre based respite forms an important component of community care, and has been described as one intervention to maintain or improve occupational performance for people with dementia. This review aimed to explore the literature relevant to the impact centre based respite on occupational performance for people with dementia. The findings are inconclusive. It is not clear what performance components or areas are affected or how they are affected. Quantitative methods need to be complemented by in-depth exploration using qualitative methods, drawing on a holistic understanding of performance and performance components.

**Key points**

- Centre based respite forms an important part of community care to assist people with dementia to continue living at home.
- The limited literature concerning the relationship between centre based respite and occupational performance for people with dementia is inconclusive.
- In-depth exploration through qualitative methods is needed to explore this relationship.
References


Guidelines for Contributions by Authors
for Systematic Review

Australasian Journal on Aging
Australasian Journal on Ageing
Edited by: Susan Quine
Print ISSN: 1440-6381
Online ISSN: 1741-6612
Frequency: Quarterly
Current Volume: 28 / 2009

Top Author Guidelines

* Australasian Journal on Ageing * is the official English language journal of ACOTA, and publishes original research articles dealing with any area of gerontology and geriatric medicine. The Journal publishes papers in the following categories (word limits include text but not references, tables or figure legends). For each category implications for policy and/or practice must be drawn out.

**Invited Editorials** on policy or practice up to 3000 words (maximum of 10 references).

**Reviews** up to 3000 words (maximum of 50 references).

**Research:** original research papers up to 3000 words (maximum of 30 references). Priority will be given to brief research reports of up to 1500 words, with no more than one table or figure and 20 references or fewer, which can be printed in two journal pages.

**Policy and Practice Updates:** Articles up to 3000 words (maximum of 20 references), by an expert in the field which aim to update readers in the areas of professional practice or policy, and must be evidence based. Priority will be given to brief updates of up to 1500 words.

**Innovations in Aged Care:** Articles of up to 3000 words (maximum of 20 references) which describe and evaluate an innovation. Innovations can include new treatments, community and residential care programs, professional training courses and social policies, and must be evidence based. Priority will be given to brief reports of up to 1500 words.

**Letters to the Editor:** Up to 400 words (maximum of 10 references). These may be edited and are subject to reply.

**EDITORIAL REVIEW AND ACCEPTANCE**
The acceptance criteria for all papers are the quality and originality of the research and its significance to our readership. Except where otherwise stated, manuscripts are double-blind peer reviewed by two anonymous reviewers and the Editor. Final acceptance or rejection rests with the Editorial Committee, who reserve the right to refuse any material for publication. Manuscripts should be written so that they are intelligible to the professional reader who is not a specialist in the particular field. They should be written in a clear, concise, direct style. Where contributions are judged as acceptable for publication on the basis of content, the Editor and the Publisher reserve the right to modify typescripts to eliminate ambiguity and repetition and improve communication between author and reader. If extensive alterations are required, the manuscript will be returned to the author for revision.

**MANUSCRIPT SUBMISSION**
The *Australasian Journal on Ageing* is now using Manuscript Central for online submission and
Getting Started
1. Launch your web browser (Internet Explorer 5 or higher, Netscape 7 or higher, Firefox 1.0.4 or Safari 1.2.4) and go to the Manuscript Central homepage (http://mc.manuscriptcentral.com/aaja).
2. Log-in or click the "Create Account" option if you are a first-time user of Manuscript Central.
3. If you are creating a new account.
   • After clicking on "Create Account", enter your name and e-mail information and click "Next". Your e-mail information is very important.
   • Enter your institution and address information as appropriate, and then click "Next."
   • Enter a user ID and password of your choice (we recommend using your e-mail address as your user ID), and then select your area of expertise. Click "Finish".
4. If you have an account but have forgotten your log in details, go to "Password Help" on the Australasian Journal on Ageing Manuscript Central homepage and enter your email address. The system will send you an automatic user ID and password reminder.
5. Log-in and select "Corresponding Author Center."

Submitting Your Manuscript
Authors should note that Word 2007 is not yet compatible with journal production systems. Unfortunately, the journal cannot accept Microsoft Word 2007 documents until such time as a stable production version is released. Please use Word's 'Save As' option therefore to save your document as an older (.doc) file type.
6. After you have logged in, click the "Submit a Manuscript" link in the menu bar.
7. Enter data and answer questions as appropriate.
8. Click the "Next" button on each screen to save your work and advance to the next screen.
9. You are required to upload your files.
   • Click on the "Browse" button and locate the file on your computer.
   • Select the designation of each file in the drop down next to the Browse button.
   • When you have selected all files you wish to upload, click the "Upload Files" button.
10. Review your submission (in both PDF and HTML formats) before sending to the Journal. Click the "Submit" button when you are finished reviewing.

Getting Help with Your Submission
Each page of the Manuscript Central website has a 'Get Help Now' icon connecting directly to the online support system at http://mcv3support.custhelp.com. Telephone support is available 5 days a week through the US ScholarOne Support Office on: +1 434 817 2040, ext 167.

ETHICAL CONSIDERATIONS
Authors must state that the protocol for the research project has been approved by a suitably constituted Ethics Committee of the institution within which the work was undertaken and that it conforms to the provisions of the Declaration of Helsinki (as revised in Tokyo 2004), available at http://www.wma.net/e/policy/b3.htm. Australasian Journal on Ageing retains the right to reject any manuscript on the basis of unethical conduct of either human or animal studies.
All investigations on human subjects must include a statement that the subject gave informed consent. Patient anonymity should be preserved. Photographs need to be cropped sufficiently to prevent human subjects being recognized (or an eye bar should be used).
COPYRIGHT
Authors publishing in the Journal will be asked to sign an Exclusive Licence Form. In signing the form it is assumed that authors have obtained permission to use any copyrighted or previously published material. All authors must read and agree to the conditions outlined in the form, and must sign the form or agree that the corresponding author can sign on their behalf. Articles cannot be published until a signed form has been received. Authors can download the form here.

STYLE OF THE MANUSCRIPT
Manuscripts should follow the style of the Vancouver agreement detailed in the International Committee of Medical Journal Editors' revised 'Uniform Requirements for Manuscripts Submitted to Biomedical Journals: Writing and Editing for Biomedical Publication', as presented at http://www.ICMJE.org/.

Spelling: The Journal uses Australian spelling and authors should therefore follow the latest edition of the Macquarie Dictionary.
Units: All measurements must be given in SI or SI-derived units. Please visit the Bureau International des Poids et Mesures (BIPM) website at http://www.bipm.fr for more information about SI units.
Abbreviations: Abbreviations should be used sparingly - only where they ease the reader's task by reducing repetition of long, technical terms. Initially use the word in full, followed by the abbreviation in parentheses. Thereafter use the abbreviation only.
Trade names: Drugs should be referred to by their generic names. If proprietary drugs have been used in the study, refer to these by their generic name, mentioning the proprietary name, and the name and location of the manufacturer, in parentheses.

PARTS OF THE MANUSCRIPT
Manuscripts should be presented in the following order: (i) title page, (ii) abstract and key words, (iii) text, (iv) acknowledgements, (v) references, (vi) appendices, (vii) figure legends, (viii) tables (each table complete with title and footnotes) and (ix) figures. The text of original research articles should be divided into the following sections: Abstract, Introduction, Method, Results, Discussion, Acknowledgement (if applicable), Key Points and References. Footnotes to the text are not allowed and any such material should be incorporated into the text as parenthetical matter.

Title page
As articles are double-blind reviewed, material that might identify authorship of the paper should be placed on a cover sheet; this will be detached before the paper is sent to referees. The title page should contain (i) the title of the paper, (ii) the full names of the authors and (iii) the addresses of the institutions at which the work was carried out together with (iv) the full postal and email address, plus facsimile and telephone numbers of the author to whom correspondence about the manuscript should be sent. The present address of any author, if different from that where the work was carried out, should be supplied in a footnote. The title should be short, informative and contain the major key words. Do not use abbreviations in the title. A short running title (less than 40 characters) should also be provided.

Abstract and key words
Research articles. Abstracts should be 150 words or less and structured into sections preferably under the headings: Objective(s), Method, Results, Conclusion(s). Key Points (which must be included) are 3-4 dot points, which give the essential take-home messages of the paper.

Other articles. Editorials, Reviews, Policy and Practice updates and Innovations in Aged Care should be preceded by a short unstructured abstract of 150 words or less.

Key Words. Five key words, for the purposes of indexing, should be supplied below the abstract, in alphabetical order, and should be taken from those recommended by the Index Medicus Medical Subject Headings (MeSH) browser list at http://www.nlm.nih.gov/mesh/meshhome.html.

Acknowledgements
The source of financial grants and other funding must be acknowledged, including a frank declaration of the authors' industrial links and affiliations. The contribution of colleagues or institutions should also be acknowledged. Personal thanks and thanks to anonymous reviewers are not appropriate.

References
We recommend the use of a tool such as EndNote or Reference Manager for reference management and formatting.
EndNote reference styles can be searched for here:
http://www.endnote.com/support/enstyles.asp
Reference Manager reference styles can be searched for here:
http://www.refman.com/support/rmstyles.asp

Personal communications and unpublished manuscripts are not acceptable. The Vancouver system of referencing should be used (examples are given below). In the text, references should be identified by numbers in square brackets (not as superscripts). If cited in tables or figure legends, number according to the first identification of the table or figure in the text. In the Reference list, number the references in the order in which they appear in the text. However, once a reference is cited, all subsequent citations should refer to the original number. All journal titles must be quoted in full (no abbreviations).
In the reference list, cite the names of all authors up to four. If there are five or more authors then list the first three followed by et al. Do not use ibid. or op cit. Reference to unpublished data and personal communications should not appear in the list but should be cited in the text only (e.g. Smith A, 2000, unpublished data). All citations mentioned in the text, tables or figures must be listed in the reference list. Authors are responsible for the accuracy of the references.

Prepare references as follows:
Journal article
1 Boldy D, Bartlett H. Residents' views and quality improvement in homes for older people. Managing Community Care 1999; 7: 35-37.
Book
Chapter in a book
Article in electronic format
Australian Qualifications Framework Advisory Board. Australian Qualifications Framework:

**Appendices**
These should be placed at the end of the paper, numbered in Roman numerals and referred to in the text. If written by a person other than the author of the main text, the writer's name should be included below the title.

**Tables**
Tables should be self-contained and complement, but not duplicate, information contained in the text. Number tables consecutively in the text in Arabic numerals. Type tables on a separate page with the legend above. Legends should be concise but comprehensive - the table, legend and footnotes must be understandable without reference to the text. Vertical lines should not be used to separate columns. Column headings should be brief, with units of measurement in parentheses; all abbreviations must be defined in footnotes. Footnote symbols: †, ‡, §, †† should be used (in that order) and *, **, *** should be reserved for P-values. Statistical measures such as SD or SEM should be identified in the headings.

**Figures**
All illustrations (line drawings and photographs) are classified as figures. Figures should be cited in consecutive order in the text. Figures should be sized to fit within the column (82 mm), intermediate (117 mm) or the full text width (170 mm). If supplied electronically, graphics must be supplied as high resolution (at least 300 d.p.i.) files, saved as .eps or .tif. Figures supplied as hard-copy only must be clearly labelled.

**Figure legends:** Type figure legends on a separate page. Legends should be concise but comprehensive - the figure and its legend must be understandable without reference to the text. Include definitions of any symbols used and define/explain all abbreviations and units of measurement.

**PROOFS**
It is essential that corresponding authors supply an email address to which correspondence can be emailed while their article is in production. If absent, authors should arrange for a colleague to access their email, retrieve the PDF proof and check and return them to the Publisher on their behalf.

Notification of the URL from where to download a portable document format (PDF) typeset page proof, associated forms and further instructions will be sent by email to the corresponding author. Acrobat Reader will be required in order to read this file, which can be downloaded (free of charge) from the following website:


The purpose of the PDF proof is a final check of the layout, and of tables and figures. Alterations other than the essential correction of errors are unacceptable at PDF proof stage. Excessive changes made by the author in the proofs, excluding typesetting errors, will be charged separately. The proof should be checked, and approval to publish the article should be emailed to the Publisher by the date indicated; otherwise, it may be signed off on by the Editor or held over to the next issue.

**OFFPRINTS**
A free PDF offprint will be supplied to the corresponding author. A minimum of 50 additional offprints will be provided upon request, at the author's expense. These paper offprints may be ordered online. Please visit [http://offprint.cosprinters.com/](http://offprint.cosprinters.com/), fill in the necessary details and ensure...
that you type information in all of the required fields.
If you have queries about offprints please email offprint@cosprinters.com

BLACKWELL AUTHOR SERVICES
Author Services enables authors to track their article, once it has been accepted, through the production process to publication online and in print. Authors can check the status of their articles online and choose to receive automated emails at key stages of production so they do not need to contact the production editor to check on progress. Visit http://www.blackwellpublishing.com/authors/journal.asp for more details on online production tracking and for a wealth of resources, including FAQs and tips on article preparation, submission and more.
Respite Improves Relationships for People with Dementia

Kristy Ness
Respite and Dementia 23

Respite improves relationships for people with dementia

Abstract

Dementia affects occupational performance by restricting one’s ability to carry out valued roles and activities. Centre based respite has been described as one intervention to maintain or improve occupational performance and prevent or delay institutionalisation for people with dementia. The purpose of this study was to explore the impact of centre based respite on occupational performance components as outlined by the Occupational Performance Model (Australia) for people with dementia. Five spousal caregivers, recruited through Alzheimer’s Australia WA, participated in semi-structured interviews. Data was analysed using framework analysis techniques. Findings revealed centre based respite attendance can positively influence marital relationships, mood, socialisation and sleep habits for people with dementia. Future research is required that examines the efficacy of interventions that focus on occupational performance components for people with dementia within a centre based respite environment.

Key words: adult day care, dementia, occupational performance model, respite.

Author: Kristy Ness
Supervisors:
Associate Professor Catherine Elliott
Dr Sonya Girdler
Submitted: 18 September, 2009
**Respite Improves Relationships for People with Dementia**

**Introduction**

As the number of people living with dementia continues to rise, there is growing recognition of the need to provide appropriate and meaningful community services to support these individuals (Carroll & Willday, 2007). Centre based respite (CBR) services form an important component of community care. These services are designed to maintain an individual’s ability to live at home in the community. This is achieved through a program of activities aimed at enhancing or maintaining the skills required for daily living, providing physical, intellectual, emotional and social stimulation and maintaining nutrition and health care needs (Carroll & Willday).

Dementia is complex and multifaceted. It impacts on all components of occupational performance. The Occupational Performance Model (Australia) is a conceptual model that is based on the premise that people fulfil roles by engaging in routines, tasks and activities of self-maintenance, productivity, leisure and rest (Chapparo & Ranka, 1997a). Occupational performance components comprise the personal skills that enable task performance, and provide the foundation for role performance. These include cognitive, intrapersonal, interpersonal, bio-mechanical and sensory-motor domains (Chapparo & Ranka, 1997a). Performance deficits in any one domain may affect occupational performance by restricting one’s ability to carry out valued roles (Chapparo & Ranka, 1997a).

The extensive cognitive, intrapersonal, interpersonal, bio-mechanical, and sensory-motor difficulties experienced by people with dementia have been widely documented (Davis, Hoppes, & Chesbro, 2005; De Vugt et al., 2003; Finkel, 2000; Oakley, Duran, Fisher, & Merritt, 2003). However, research examining the effects of CBR on occupational performance components for individuals with dementia is limited. To date research has produced conflicting findings.

CBR programs have been shown to be largely ineffective in increasing cognitive abilities or stemming cognitive decline (Quayhagen et al., 2000). However, research has suggested there is potential for CBR to improve intrapersonal performance components, particularly behavioural and psychological symptoms including delusions, anxiety,
agitation, disinhibition and aggression for people with dementia (Mossello et al., 2008; Vespa, Gori, & Spazzafumo, 2002). Conversely, others have reported no change (Quayhagen et al.) or increased behavioural problems attributed to CBR attendance (Higgins et al., 2005).

Little attention has focused on the impact of CBR on interpersonal relationships between the caregiver and the person with dementia. Qualitative data has shown CBR attendance can improve marital relationships, however, quantitative outcome measures have found no effect of CBR attendance on marital satisfaction (Quayhagen et al., 2000). To date, there is no research exploring the impact of CBR on biomechanical or sensory-motor performance components.

Given the scarcity of literature and the conflicting findings, it is important that research examines which specific occupational performance components are impacted by CBR, to contribute to quality service provision for people with dementia. This study aims to explore the impact of centre based respite on cognitive, intrapersonal, interpersonal, sensory-motor and bio-mechanical performance components for people with dementia, as reported by spousal caregivers.

**Methods**

A qualitative, naturalistic approach was employed to explore spousal caregiver perspectives of the impact of CBR on occupational performance for people with dementia. This methodology was considered appropriate as it recognises the spousal caregiver as the expert in relation to their partners functioning (Pope & Mays, 2006). As little is known about this topic a qualitative approach allowed for the exploration of the thoughts, feelings, and experiences of spousal caregivers to provide a valuable insight and in-depth understanding of the phenomena (Pope & Mays). The Occupational Performance Model (Australia) (Chapparo & Ranka, 1997b) was employed as a theoretical framework, allowing a holistic and meaningful understanding on how CBR impacts a person with dementia.
Participants/ Recruitment

Participants in this study were recruited through Alzheimer’s Australia WA CBR service. Alzheimer’s Australia WA is a not-for-profit organisation that assists people throughout Western Australia who struggle with the daily challenges of dementia (Alzheimer’s Australia WA, 2004b). Alzheimer’s Australia WA CBR services employ the principals of the ‘Eden Alternative’ care model (Alzheimer’s Australia WA, 2004a). Through this model, people with dementia are supported to maintain their well-being and abilities through opportunities for social interaction, community engagement, and close and continuing contact with animals, birds and children, in a homelike environment (Alzheimer’s Australia WA, 2004a). The centre operates six days per week, from 8:00am to 5:00pm and transport is provided for those living within the catchment area (Alzheimer’s Australia WA, 2004a).

A letter of invitation was sent by an independent representative from Alzheimer’s Australia WA to nine spousal caregivers. They were asked to reply if they did not wish to take part in the study. If a reply was not received within one week, the researcher contacted potential participants to ask if they would like to be involved. Interested individuals were provided with an information sheet and signed a declaration of informed consent. A short screening interview was conducted to ensure all participants met the following criteria. 1) spouse of a person diagnosed with dementia, 2) ‘primary caregiver’ (that is the person that provided the most assistance to the care recipient), 3) care recipient had a diagnosis of irreversible and progressive dementia for greater than six months, 4) care recipient attended Alzheimer’s Australia WA CBR service for greater than eight weeks.

Five spousal caregivers (three women and two men) of people with dementia were purposely recruited to participate in this study. Caregivers ages ranged from 62 to 78 years (mean=73, SD= 5.57) and care recipients from 61 to 82 years (mean=74, SD= 7.31). Three care recipients had a diagnosis of Alzheimer’s type dementia, two were unspecified. The length of time since diagnosis ranged from two to eight years (mean=5, SD=2.29). Three care recipients attended CBR one day per week, one attended once a week, and one attended three days per week. Two care recipients utilised the centre bus for transport to and from the centre. Two caregivers utilised additional respite services for
their spouse. One used in-home respite and a second day centre one day per week. Another utilised one-to-one in-home respite services three times per week.

The research protocol was approved by Edith Cowan University, Computing Health and Sciences Ethics Sub-Committee and Alzheimer’s Australia WA Board of Management.

Data Collection

Individual, semi-structured interviews were conducted with each participant. This allowed participants to ‘tell their own story’ and describe their experiences, perspectives and interpretations in detail (Holloway, 2005). Four participants were interviewed on two occasions. The purpose of the second interview was to explore emerging issues in greater depth and clarify and confirm previous information (Morse & Field, 1996). All interviews were conducted at a place nominated by the participant, either in their home or at Alzheimer’s Australia WA. The interview guide (Appendix C) was based on the Occupational Performance Model (Australia) and explored the impact of dementia on cognition, intrapersonal, interpersonal, bio-mechanical and sensory-motor performance components as well as the impact CBR had on these components. Socio-demographic information was collected through structured questions. Interviews were between 60 and 90 minutes in duration and were audio-taped with permission from participants. Piloting of the interview protocol supported the usefulness of the questions in ensuring the objectives of the study were achieved.

Data Analysis

Framework analysis as described by Ritchie and Spencer (1994) was utilised to analyse interview transcripts. Framework analysis is a well-defined procedure that provides systematic and visible stages, so others can be clear about the ways in which the results are obtained from the data. Framework analysis involves five distinct and interconnected stages. Firstly, familiarisation involved the researcher listening and transcribing interview tapes, reading and re-reading notes and transcripts, and listing key ideas and recurrent themes. Secondly, a thematic framework was identified. Key issues, concepts and themes were developed from a priori themes derived from the Occupational
Respite and Dementia 28

Performance Model (Australia), and from emerging issues raised by participants. Thirdly, indexing involved applying the thematic framework to the data, using textual codes to identify specific pieces of data that corresponded with the differing themes. Fourthly, the original data was distilled into summaries and used to create charts. These charts, arranged thematically, contained summaries of participant views and experiences. Finally, mapping and interpretation of data was conducted to interpret the data as a whole through searching for patterns, associations, concepts and explanations in the data set (Ritchie & Spencer).

Due to the constraints of this research for an honours project, exhaustive exploration of the topic was not possible (Morse, 1994). However, trustworthiness of the research process was demonstrated by its credibility, dependability, confirmability and transferability (Guba, 1981). Credibility of the research was enhanced through repeated interviews with four participants, member checking to verify data interpretation, bracketing preconceived ideas, and the use of a research journal. Member checks occurred with four participants after interview transcription and analysis. Participants in most cases confirmed the accuracy of the findings. Where there was a discrepancy, participants had the opportunity to change the way in which the comments were represented. Dependability was addressed by maintaining an audit trail to describe the decisions made throughout the research process. Confirmability was demonstrated by keeping a journal and member checks. Purposive sampling and detailed description of participant’s demographics helped to establish the transferability of findings.

Findings and Discussion

Corresponding with the overlying conceptual framework, data was analysed according to five broad categories: interpersonal, intrapersonal, cognitive, bio-mechanical and sensory-motor. The impact of dementia on occupational performance components is illustrated in figure 1 (Appendix B). Participant’s names have been replaced by pseudonyms to ensure anonymity.

Theme One – Interpersonal

Interpersonal performance refers to the continuing interaction between a person and others during task performance and includes interaction among individuals in
relationships such as marriages, families, communities and organisations both formal and informal. This incorporates sharing, cooperation, empathy and verbal and non-verbal communication (Ranka & Chapparo, 1997).

**Intimacy and companionship.** The diagnosis of dementia dramatically impacted on the couple's relationship. Caregivers described a loss of intimacy, friendship and companionship. They talked with sadness of the loss of the reciprocal aspects of their relationships. Caregivers described their spouse as no longer the equal or sharing partner they once were and for the most part felt they were now a caregiver rather than spouse and friend. Many caregivers also needed to constantly supervise their spouse to ensure their safety and support their spouse in most activities of daily living. Caregivers expressed how the need to spend almost all of their time with their spouse had negatively affected their relationship. Lucy explained how her husband would at times move to the back room of the house to get some breathing space. Participants provided many examples of the negative impact dementia had on their relationship:

*Every day it is constant thinking for two. We can't have an intelligent conversation because he can't keep up...I mean we talk but it's not really meaningful like it was before. I feel as if I've lost my best friend. I think one of the saddest parts of Alzheimer's is you lose that closeness....He depends so much more on me now. He doesn't like being away from me. That does stress him out a bit.* (Mary)

Jack explained how difficult it was when at times his wife did not recognise who he was:

*There have been a couple of days where she does not know who I am. She told one of our daughters, “I don’t know who this person is but he keeps wanting to hold my hand. He keeps wanting to take me down for coffee”... I don’t relish the time when she does not know completely who I am... I have done all my crying and I don’t mind admitting it...but you just have to take the good with the bad.*

Research suggests that as dementia progresses there is increasing reliance on others. The caring role primarily falls to one's spouse, resulting in martial imbalance and
a decline in relationship quality, level of intimacy and companionship (De Vugt et al., 2003; Garand et al., 2007). Deterioration of the marital relationship significantly increases the risk of institutionalisation (Garand et al., 2007).

CBR for many caregivers, positively influenced their relationship with their spouse. The time apart had given them both much needed personal space and allowed them the opportunity to pursue their own interests. CBR attendance had given the couple something meaningful to talk about, sharing what they had done during the day, positively influencing communication and interaction. Caregivers also felt their spouse was more relaxed and they felt more patient, and better able to cope with the demands of caregiving after their spouse attended CBR. Eileen explained:

*When I moan at him I feel awful, but it [CBR] gives us that breathing space where he can go out and be happy and I can go and do what I want to. He loves it there. Sometimes we are very pleased to see the back of one another.*

Improved positive feelings towards their spouse and enhanced spousal communication following CBR attendance is consistent with qualitative research by Quayhagen et al. (2000). Quayhagen and colleagues (Quayhagen et al., 2000) suggested CBR increases the ability of couples to interact more effectively and talk more freely with each other. However, these findings conflict with quantitative findings from the same study that found CBR attendance to have no effect on marital satisfaction (Quayhagen et al., 2000). Decreased marital relationship quality including decreased level of affection and perceived caregiver burden is linked with greater likelihood of care recipient institutionalisation (Spruytte, Van Audenhove, & Lammertyn, 2001). Therefore, increasing marital relationship quality through interventions such as CBR may increase wellbeing and prevent or delay institutionalisation of people with dementia.

**Socialisation.** Many caregivers explained that the progression of dementia resulted in reduced social contacts for their spouse. Past friendships gradually diminished and some described family as not visiting as frequently as they would like:
Dementia is a lonely illness. Relatives, they drop you like a hot potato. We don’t see many people...they might ring up, so it’s amazing with the illness...it has disappointed me. (Jack)

Many caregivers described a rationale for the loss of social contacts. Due to their spouses’ reduced social skills, some caregivers felt social interactions were too difficult for their spouse to engage in. Another caregiver explained that they were excluded from many social events as family and friends felt they may be inappropriate for the person with dementia. In addition, people with dementia no longer participated in hobbies and attended social groups and clubs they once enjoyed such as weekly bowls and gardening clubs. Collectively, these factors limited opportunities for social interaction resulting in social isolation for both the caregiver and person with dementia.

Past friendships remained for a minority of care recipients with only a few friends and family continuing to visit regularly and talk about the “good old times”:

When we were down south on the property he was talking to his brothers, all about the naughty things they used to get up to as kids and it was great. I just left them to it. (Mary)

The centre was highly valued as it provided a supportive environment which fostered friendships and provided meaningful social opportunities. The centre was a place for people with dementia to go during the day, preventing boredom and promoting a sense of acceptance being with friends and others ‘like themselves’. Caregivers described socialisation as one of the major benefits their spouse received from attending the centre. Graham explained:

Social interaction, for the five hours she is there. That is the real benefit.
It’s all about keeping up with people and social interaction with people that understand what she is going through.

In Australia, CBR is primarily based on a social model, where social stimulation is one of the main aims of this service. Thus, it is not surprising that caregivers in the current study reported socialisation as one of the major benefits their spouse received from attending the centre. For older people social interaction greatly enhances their
overall quality of life and self-esteem, and decreased symptoms of depression and loneliness (Farquhar, 1995; Kitwood, 1988). Williams and Roberts (1995), argued friendships are established within CBR, allowing people with dementia to engage in reciprocal relationships, increasing their social network and enabling a sense of identity and purpose. Therefore, clearly staff within CBR need to facilitate and encourage peer friendships to increase wellbeing and decrease social isolation for people with dementia (Williams & Roberts, 1995).

**Communication.** Caregivers consistently described the negative impact of dementia on their spouses’ ability to communicate. Difficulties such as finding the right words, concentrating, and not being able to understand all of what was being said, contributed to the deterioration of relationships with family and friends. Eileen described how at times she was unable comprehend what her husband was saying and often ‘gave up trying to understand’.

*Before I could understand him. I’m being honest now, sometimes I don’t know what he is trying to tell me. Whereas before I could sort of work it out.*

Following and contributing to conversations was also difficult for some people with dementia:

*Just following conversation, dwelling on the past. He gets things wrong...He doesn’t understand what is on T.V or what people are talking about. He will ask after, what was going on or what was being said.*

(Mary)

Caregivers in this study reported CBR to have little impact on the ability of their spouse to communicate. Although CBR attendance gave the person with dementia something meaningful to talk about, it had no influence on word finding difficulties or the ability to understand what others were saying.
Theme Two – Intrapersonal

Intrapersonal performance refers to the internal psychological processes during task performance. This may include emotions, self-esteem, mood, affect, rationality and defence mechanisms (Ranka & Chapparo, 1997).

Sleep: Spousal caregivers described changes in sleep habits as a prominent feature of dementia. For some, sleep increased substantially with the onset of dementia including day-time napping, earlier bed-time and waking later in the morning:

This has been a huge change. He will have a long sleep in the afternoon. I have to make sure he doesn’t sleep longer than 2 ½ hours, otherwise he will just sleep all afternoon. He won’t get out of bed till I get up, then sometimes I have to say, “Get up!” (Eileen)

Conversely, two participants described wandering and consequent sleepless nights, as a constant and major concern for the safety and wellbeing of their spouse. Caregivers took precautions to ensure their spouse was safe such as locking doors, providing supervision and identification bracelets:

She gets up five or six times a night. I have hidden her keys and I hide my keys and so she can’t get out, because back in February she got out at about one night between 10:30 and 11. She would walk down to the railway line, nighty, no shoes on. It’s quite a mind boggling thing to have to search. I have had to look around town until 3 o’clock in the morning. It’s unreal and it is frightening I can assure you. (Jack)

For those caregivers who reported their spouse had extra sleep and naps during the day, they noted on CBR days they awakened earlier. Caregivers felt that attending the centre gave their spouse motivation and purpose to get up in the morning:

If he is going to the centre, half past seven we get up, go and have a shave and fiddle around. If he is not going to the centre, half past eight I will have to say “Come on you’ve got to get out of bed, have your tablet”. I have to nag him. (Eileen)

Mary explained how because her husband was unable to nap at the centre and during the day was settled and more tired than usual when he returned home:
When he comes home he is tired, it makes him a nice tired. He is settled when he comes home from the centre. Well, he hasn’t had the chance to have his afternoon sleep, so he will come home three, half past three and will often go and have a lay down. (Mary)

Caregivers who reported their spouse had a tendency to wander and wake frequently at night, felt energy levels and sleep habits remained unchanged after CBR attendance.

This finding is inconsistent to those of Femia and colleagues (2007), who reported CBR attendance decreased night-time sleep disturbances on attendance days in comparison to the control who received no services. Wandering and night-time sleep disturbances have been described by caregivers as one of the most distressing symptoms of dementia (Eustance et al., 2002; Gallo, Schmidt, & Libon, 2008), highlighting the importance of integrating activities such as purposeful physical activity within CBR to improve this domain for people with dementia and their caregivers (Femia et al., 2007).

**Mood (Anger, agitation, frustration, aggressiveness):** Some caregivers described their spouse as frequently showing signs of anger and agitation. Several caregivers thought this behaviour resulted from frustration at not being able to find the words to communicate effectively. Others stated the change in behaviour may be due to their spouse being unable to fulfil previously valued roles and expectations such as maintaining the garden or housework. Eileen expressed that her husband found it particularly difficult to allow others to assist with or complete these tasks for them:

*He does get ratty when he can’t do things he used to be able to do. It must be hard relying on other people to do things for him, especially me.*

Caregivers reported several instances where their spouse had vented their frustration, through verbal and occasional physical aggression. However, these caregivers ‘did not take this personally’, attributing this ‘acting out’ to the dementia and not their loved one.
In the last few years he has been becoming very frustrated and angry....just starting to become a little bit aggressive....he has hit me twice, but I think that is just a one off. (Mary)

After an initial period of 'settling in', caregivers described a positive change in the mood of their spouse as a result of CBR attendance. The centre provided the opportunity for their spouse to participate in meaningful occupation and identify with the valued role of a club member. Caregivers felt their spouses enjoyed attending the centre and noticed that often they return in ‘good spirits’. For some, this elevation in mood continued for a number of days following CBR attendance. Eileen described her husband looked forward to his ‘centre days’ for the entire week. Their spouses enjoying CBR attendance was also important to caregivers in giving them permission to let go of their caring responsibilities for a short time:

He is happy, and that shows I think in the morning he is waiting for the transport to pick him up. And he jumps up and will say, “Here they are!” He is happy to go which makes me happy. I felt bad leaving him there until I saw how much he was enjoying it. And I’m not allowed to get Alzheimer’s and go to ‘The Club’. It is his Club, not mine. Oh, I love the way he said “No, no you’re not coming”. The centre is the one place he feels comfortable, that’s his thing you see. (Eileen)

Lucy attributed the increase in the mood of her husband on attendance days to the homelike environment, outings and animals at the centre:

Of his own accord he said “that was a really good day. That was the best”. He just kept saying it. They went for a bus run and had a BBQ....he really liked it. See you have animals [at the centre] and he loves animals.

As abilities decline for people with dementia, participation in meaningful occupations becomes challenging, resulting in negative health consequences such as depression, agitation and confusion (Svanstrom & Dahlberg, 2004). Phinney, Chaudhury and O’Connor (2007) argued that engagement in meaningful activity for people with dementia is vital for their health and well-being. For spouses in this study, CBR provided them with the opportunity to engage in meaningful occupation, thereby possibly
decreasing negative health consequences and increasing wellbeing. Mossello et al. (2008), reported centre based respite to be effective in reducing anxiety, agitation and aggression for people with dementia. However, our findings contradict those of Kim and colleagues (2002), who reported behaviour problems, notably agitation, to significantly increase with centre based respite attendance.

Two caregivers also described a marked reduction in anxiety and agitation when the CBR bus was utilised to transport their spouse to and from the centre. Mary explained of the previous difficulties she had getting her husband to attend the centre and the vast improvement once he was picked up by the bus:

“I was going to stop [attending the centre] because it was too traumatic. Before I would take him there, and he would be shouting and screaming the whole way there. He used to think I would stay. “What time will you pick me up” he would say. 3:00, and he would say “Oh that is ridiculous, I will walk home”. Since he has been picked up, it has completely changed, it has been just wonderful, otherwise I don’t think he would be there.

Quayhagen and colleagues (2000) noted the lack of transport provision may be one of the primary reasons CBR is discontinued. Collectively these findings highlight that service providers may need to consider the provision of transport as a strategy to enable participation in CBR programs and possibly reduce agitation and anxiety for people with dementia.

**Theme Three – Cognition**

Cognitive performance refers to the interaction of and between mental processes used during tasks including thinking, perceiving, recognising, remembering, judging, learning, knowing, attending and problem solving (Ranka & Chapparo, 1997).

**Memory.** Caregivers had difficulty articulating how dementia had impacted on their spouse’s memory. Most stated dementia had mainly affected short-term memory and described the onset of this loss as gradual. Caregivers described their spouse as forgetting what they had for lunch, losing items, forgetting people’s names and repeating the same questions and stories:
I noticed he was losing his memory, so it has been a conscious five or six years. It’s just worse. I can’t really put it any plainer than that. It’s just worse, I think the progress is slow. (Mary)

Graham described his wife’s memory loss of memory to be quite rapid. He described it was particularly difficult to see his wife deteriorate within a matter of months. Graham’s wife had gone from working and leading an active life to not being able to complete basic tasks such as reading, writing and making a cup of tea:

She couldn’t read, write, add-up or tell the time. All that happened within six months. It was a major change. It is not normal to have a change so severe.

Along with the problems with memory, caregivers described their spouses as showing symptoms of confusion and disorientation within familiar environments such as their home:

She will say where am I, where am I, where is the bed and she is in the bedroom, she is going around the bed but doesn’t know where to get in on her side. (Jack)

Initiation. Caregivers provided many example of how their spouses progressively lost the ability to initiate everyday tasks such as showering and dressing:

He has lost his initiative, if I ask him to do something, he will do it, but he can’t do anything off his own bat. (Mary)

Caregivers felt attending the centre did not influence the cognition of their spouse. Mary reported that their husband “still has trouble remembering whether he attends the centre or not”. Eileen reported that there had been no change as far as she could tell.

Considerable research has examined the impact of CBR on cognition. Our findings reflect those by Femia and colleagues (2007), and Quayhagen et al. (2000) who concluded that cognitive performance is unaffected by CBR attendance. This contrasts with Higgins et al. (2005), who reported cognition to worsen significantly after 12 months of CBR attendance. Although caregivers did not report CBR to affect cognition, dementia is progressive in nature, therefore if cognition levels remain unchanged it may
suggest CBR can potentially be effective in maintaining cognitive abilities (Kim et al., 2002).

**Theme Four - Bio-mechanical**

Bio-mechanical performance refers to the operation and interaction of physical structures of the body such as range of motion, muscle strength, grasp and endurance (Ranka & Chapparo, 1997).

Eileen and Lucy gave examples of the negative impact of dementia on the bio-mechanical performance of their spouses. They explained their husbands had developed unsteady, shuffling gait leading to an increased number of falls:

_He's quite unsteady on his feet, now I noticed. Like yesterday when we went to the cinema, going down the stairs ... he loses balance and falls on the chair and I have to pull him up. His balance is not so good anymore._

(Eileen)

The majority of caregivers however reported their spouse did not experience problems with bio-mechanical performance components. Although dementia had a profound impact for the individual with dementia and their spouse, participants in this study were unable to identify any links between CBR attendance and bio-mechanical performance components.

**Theme Five - Sensory-motor**

Sensory-motor performance refers to the operation and interaction of and between sensory input and motor responses including the registration of sensory stimuli regulation, appropriate motor responses, and coordination (Ranka & Chapparo, 1997).

**Delusions/ Hallucinations.** Hallucinations and delusions including talking to others who were not there and a fixation on things that were not real were reported by two caregivers. Jack explained the impact of his wife talking to herself:

_She will continually talk to herself. We might be just about ready to go out the front door and she's saying “Are the other people coming down the street?” I will say, “There are no other people here”. “Oh, I thought they_
might want to come down for a coffee”. I don’t know what you would do about it.

Although dementia had a profound impact for the individual with dementia and their spouse, participants in this study were unable to identify any links between CBR attendance and sensory-motor performance components.

Conclusion

The purpose of this qualitative study was to explore the impact of CBR attendance on occupational performance components for people with dementia. Overall, findings suggest CBR can positively influence interpersonal performance components of relationships and socialisation as well as intrapersonal performance components of sleep and mood for people with dementia.

As this study is qualitative in nature, results cannot be generalised to other settings. Nevertheless, this study provides important insights and contributes to an understanding of the impact of CBR on occupational performance components, and provides a basis for future research. Research is now required that examines the efficacy of interventions within CBR to improve or maintain occupational performance. From an occupational therapy perspective, this study has highlighted that CBR has positive implications for caregivers and for people living with dementia.

Historically cognitive decline has been commonly viewed as an inevitable and expected consequence of the aging process. However, understanding the impact of interventions such as CBR on occupational performance may lead to enhanced wellbeing for people with dementia and their caregivers and possibly prevent or delay institutionalisation.
References


Guidelines for Contributions by Authors
Research Report

OTJR: Occupation, Participation and Health
Guidelines for Contributions by Authors

OTJR: Occupation, Participation and Health Guidelines for Contributors

OTJR: Occupation, Participation and Health invites manuscript submissions that conform to its purpose and scope without regard to the professional affiliations of authors. Five types of contributions are considered: (a) full-length or feature articles; (b) brief reports; (c) letters to the editor; and (d) technical notes.

Manuscripts will be acknowledged on receipt. Following preliminary review, they will be sent to members of the editorial board. Notification of disposition may take between 2 and 3 months after acknowledgment. Accepted manuscripts will be published only on receipt of signed copyright assignment forms from the authors. The copyright so conveyed includes any and all subsidiary forms of publication, such as electronic media. Authors will have the opportunity to review typeset page proofs of the manuscript before publication. Page proofs MUST be returned within 48 hours of receipt. Delayed return of page proofs will result in forfeiture of the author's opportunity for pre-publication review. OTJR: Occupation, Participation and Health reserves the right to make or request editorial changes in all manuscripts accepted for publication.

Manuscript Preparation

The following are guidelines for developing and submitting a manuscript. Manuscripts that do not conform to these guidelines will be returned to the author without review.

(1) Authors should submit the manuscripts prepared in accordance with the Publication Manual of the American Psychological Association, 5th edition (http://www.apastyle.org). When appropriate, it should be indicated in the text that institutional ethical review board approval was obtained and standard ethical procedures were followed when conducting the research. In addition, the following guidelines should be followed:

(2) Use only TIMES NEW ROMAN 12-point font size.

(3) Double-space everything, including references, quotations, tables, and figures.

(4) Have 1-inch margins all around on each page.

(5) Submit electronically in Microsoft Word by e-mail to Jane Case-Smith at o*editor@aotf.org.

(6) Manuscripts should be submitted electronically in three to four document files, as appropriate.

(a) Document #1: Cover letter: A cover letter should accompany articles, abstracts, or review manuscripts indicating that the material is not currently under consideration for publication. Place author's names, positions, titles, place of employment, and full contact information of the corresponding author (address, phone, fax, and e-mail) in the cover letter so that the manuscripts may be reviewed anonymously.

(b) Document #2: Title page: It should include the full title of the manuscript. The title page also should list the key words, acknowledgments, and grant/contract support, as well
as information concerning previous presentation of the material at symposia or conferences.

(c) Document #3: The body of the article, including the abstract. Please insert a page header with an abbreviated manuscript title and page number on each page. Include references in this document. Primary references from credible, scientific sources should be used.

(d) Document #4 (if appropriate): Figures should be submitted in camera-ready form; TIFF or JPEG format is preferred. Each image must be a separate, stand-alone file, named to match the figure number listed in the text (e.g., figure1.jpg). Figure legends should not be included in the graphic file. A resolution of 300 dpi is required for quality reproduction; line art should be at least 600 dpi.

(7) Authors bear full responsibility for the accuracy of references, quotations, tables, and figures.

(8) A copyright release form must be signed by all authors and mailed or faxed to the Editor on submission of the article. A PDF version of the form can be obtained on the journal’s web site (http://www.otjronline.com).

(9) Neither the American Occupational Therapy Foundation (http://www.aotf.org) nor the OTJR: Occupation, Participation and Health editorial staff can assume responsibility for statements or opinions expressed by authors.

(10) Authors should retain copies of all material submitted to guard against loss. OTJR: Occupation, Participation and Health cannot assume responsibility for lost manuscripts.

(11) Authors must inform the American Occupational Therapy Foundation if tables, photos, or illustrations have been previously published. Material reprinted from other publications (including electronic media) must be accompanied by a letter of permission from the publisher, which extends non-exclusive worldwide rights to reprint the material for all forms of media now or hereafter developed to the American Occupational Therapy Foundation.

(12) Address all editorial correspondence to:
Jane Case-Smith, EdD, OTR/L, FAOTA
Editor, OTJR: Occupation, Participation & Health
Division of Occupational Therapy
School of Allied Medical Professions
Ohio State University
453 West 10th Avenue, 406 Atwell Hall
Columbus, OH 43210
Phone: (614) 292-0357; Fax: (614) 292-0210
E-mail: otjr.editor@aotf.org

Specific Guidelines by Type of Contribution

Feature Articles. Full-length research articles should generally not exceed 5,000 words (20 double-spaced typewritten pages, including tables, references, and figures). Each article must be accompanied by an abstract
that clearly, completely, and succinctly summarizes the material that follows. Abstracts for empirical and theoretical studies should be no more than 150 words in length. Authors also should designate three or four identifying key words not found in the title for indexing purposes. Pages should be numbered consecutively (except for figures) in the following order: title page (page 1), abstract (page 2), text (beginning on page 3), references (new page following text), appendices (each on a new page), and tables and figures (each on separate pages). This arrangement is necessary for copy processing and does not represent how the manuscript will appear in print. Each manuscript page should be identified (except the figures) by typing the first two or three words from the title in the upper right-hand corner above the page number.

Briefs. OTJR: Occupation, Participation and Health will publish expanded abstracts of theses, dissertations, and unpublished papers where content therein is consistent with the journal's aim and scope. Submitted manuscripts in this category must be limited to 1,000 words, include a brief abstract, and be as succinct, accurate, and informative as possible. Briefs reporting empirical research should contain a description of the problem, method, results, and conclusions. The sample, research design, test instruments, research apparatus, or data-gathering procedures also should be specified. Include important findings, statistical significance levels, inferences, and conclusions, as appropriate.

Letters to the Editor. Letters must be limited to 500 words and should provide thoughtful scientific criticism, rebuttal, or personal data relating to research articles or commentary published in OTJR: Occupation, Participation and Health. No more than five citations and references can be included. Unless specifically indicated to the contrary, all letters will be assumed to be for publication and will be subject to the same editorial revision policies as other manuscripts.

Technical Notes. Occasionally, researchers may wish to inform readers about statistical, data processing, or methodological techniques or modifications that will improve or facilitate their research efforts. Submissions in this category must conform to OTJR: Occupation, Participation and Health style and be limited to five double-spaced pages.

Revised January 2008
Table 1: Description of included studies

<table>
<thead>
<tr>
<th>First author, year of publication, country</th>
<th>Design</th>
<th>Participants</th>
<th>Intervention</th>
<th>Outcome measures</th>
<th>Results</th>
<th>Methodological Quality</th>
</tr>
</thead>
<tbody>
<tr>
<td>Femia [15] 2007 USA</td>
<td>Quasi-experimental pre-test/post-test (n=201) Experiment= adult day centre (n=133) Comparison = no services (n = 68)</td>
<td>• Diagnosis of dementia • Reside in community • No day service use prior to intervention</td>
<td>Adult day care (social model), 2x week, 4 hrs day, 8 weeks. • 30 mins physical activity • 1-2 hrs social activities • 1 hr cognitive activities</td>
<td><strong>Cognition</strong> • MMSE <strong>Intrapersonal: Behaviour</strong> • Daily record of behaviour <strong>ADL</strong> • Caregiver reports (measure designed for study)</td>
<td>Cognition No significant difference <strong>Intrapersonal: Behaviour</strong> Significant decrease in duration night-time sleep problems (p&lt;0.05) No significant difference in duration or occurrence of agitation or depression. <strong>ADL</strong> No significant difference</td>
<td>Strong quality (score=22/24). Adequate sample size. Conclusion limited due to missing data, no randomisation.</td>
</tr>
</tbody>
</table>

<p>| Higgins [16] 2005 USA | Before and After (n=21) | • Medical diagnosis of dementing illness • Reside in community. • Mean age 77.3 | Adult day care (social model), 1 x week, 12 months. • Cognitive/physical activities • discussion groups • singing/ music | <strong>Cognition</strong> • MMSE <strong>Intrapersonal Behaviour</strong> • CERAD Behavior Rating Scale for Dementia | Cognition Significantly declined (p&lt;0.0001) <strong>Intrapersonal Behaviour</strong> Significantly declined (p= 0.007). | Strong quality (score 17/20). Analytical methods and results not described in detail, conclusions not supported by results. Drop-outs |</p>
<table>
<thead>
<tr>
<th>Study</th>
<th>Design</th>
<th>Participants</th>
<th>Intervention</th>
<th>Outcomes</th>
<th>Results</th>
</tr>
</thead>
<tbody>
<tr>
<td>Kim [21]</td>
<td>2002, Korea</td>
<td>Before and After (n=13)</td>
<td>Adult day care, 1000 to 1600 Mon to Fri, 10 weeks. Moderate to mild dementia by medical model</td>
<td>MMSE (version), Cognition (agitated behaviour), Intrapersonal function size.</td>
<td>Good quality (score=14/20), Small sample size, subject characteristics not described. Results not supported by reasons reported.</td>
</tr>
<tr>
<td>Mossello [19]</td>
<td>2008, Italy</td>
<td>Quasi-experimental, Pre-test/post-test (n=60)</td>
<td>Adult day care, experimental (social model), 2-6 days per week for 8 hours.</td>
<td>MMSE, Intrapersonal function, ADLs.</td>
<td>Strong quality (score=21/22), Small sample size.</td>
</tr>
</tbody>
</table>
RCT, parallel group (n=103 dyads)
Experiment= early stage day care (n=16), active cognitive stimulation (n=21) or dyadic counselling (29). Control= waitlist (n=15)

- Diagnosis of dementia (mild to moderate)
- Score above 100 on Mattis Dementia Rating Scale
- Average age 74.1

Early Stage day Care
(social model) 8 weeks, 4 hours per week.
- Social time
- Physical exercise
- Outings
- Community involvement.

Active cognitive Stimulation
1 hour per day, 5 days per week, 8 weeks

Dyadic counselling
Dual seminar group and individual meetings, to discuss, support and problem solve.

Activities of Daily Living

Significant reduction on psychotropic drugs prescribed.

ADL/IADL
No difference

Cognition:
- Wechsler Memory Scale-Revised
- Dementia Rating Scale
- 1 minute word recall
- Geriatric coping schedule

Cognition
No change

Intrapersonal: behaviour
No change

Interpersonal
Enhanced communication and interaction between caregiver and patient.

Intrapersonal:
- Memory and Behaviour Problem Checklist

Strong quality (score 22/26). Evaluators blinded to the treatment. Participants not blinded as need to know what service was received. Randomisation methods not described, small sample size, subject characteristics not described in detail.

Interpersonal
- Qualitative semi-structured interview.
Waiting-list control group: 3 weeks

Vespa [20] 2002 Italy
Before and After (n=18)
- Diagnosis of dementia or probable dementia (DSM-IV)
- Degenerative nature (NINCDS-ADRDA).
- Mean age 77

Adult Day Care (social model). Daily, 9 hours per day, for at least 12 months. Activities:
- Music
- Re-motivation and socialisation
- Discussion
- Occupational activities
- Psychomotor activities

Intrapersonal: Behaviour
- Cohen-Mansfield Agitation Inventory (CMAI)
- The Cornell Depression Scale

Intrapersonal: Depression
- Significant difference in CMAI scale (p<0.001). Significantly reduced agitated verbal behaviour (p<0.013) and aggressive behaviour (p<0.023).
- Significant reduction in depressive symptoms (p<0.014)

Woodhead [18] 2005 USA
Before and After (n=94)
- Diagnosis of dementia
- MMSE <24
- Community residing
- Average age 79.6

Adult Day Care (social model). At least 2 x week 4hrs day.
- Physical activity
- Social activity
- Engaging activity

Intrapersonal (behaviour)
- Daily Record of Behaviour

Intrapersonal (behaviour)
- Significant increase in positive behaviours. Engaging activities had significant association with increase in

Strong quality (score 17/20). Small sample size, subject characteristics inadequately described.
Zank [22]
2002
Germany

Quasi-experimental longitudinal with matched controls (n=83)

- Experiment: adult day care (n=43)
  Control: usual home-based community care(n=40)

- 79% day care and 63% control group had dementia.
- Mean age both groups 79.5 years

- Watching and listening activity

Geriatric day care plus usual home-based community care. Day care at least 2x week for 9 months. Day care tailored for individual care recipient.

Cognition
- MMSE (German version)
- Nuremberg Aging Inventory

Intrapersonal: Depression
- The Montgomery Asberg Depression Rating Scale (MADRS)

Behaviour
- Memory and Behaviour Problem Checklist

ADL’s
- Nuremberg Aging Observation Scale

Significant association between increased amounts of day care and restless and mood behaviours.

Cognition
- Significant effect (p≤0.004) in cognitive functioning due to recognition of words.
- Follow-up – no significant difference in memory.

Intrapersonal
- Significant effect on depression (p≤0.006).
- Follow-up no significant differences in depression or behaviour.

ADL’s
- No change.

Good quality (score 22/28).
Drop outs reported with reasons
Conclusions limited due to missing data. No blinding, no randomisation.

Confounding. No control group.
Figure 1. Five categories of performance components impacted by dementia.

The Impact of Dementia on Occupational Performance Components

Interpersonal
- Intimacy and Companionship
  - 'I just nag'
  - 'It has brought us closer'
- Socialisation
  - 'Dementia is a loneliness'
  - 'We don't see many people'
- Communication
  - 'Lost the art of conversation'
  - 'The words are all tangled'

Intrapersonal
- Sleep
  - 'He sleeps a lot'
  - 'A lot more tired'
  - 'Gets up in the middle of the night'
  - 'Just wanders off'
- Mood
  - 'He is becoming frustrated and angry'
  - 'He is more agitated as time goes on'
  - 'Doesn't like being away from me'

Cognitive
- Memory
  - 'Not as strong as he used to be'
  - 'He shuffles'
  - 'He is not balanced'
  - 'Good balance, no falls'
- Initiation
  - 'Lost his initiative and independence'
  - 'He can't do anything off his own bat'

Bio-mechanical
- 'Massive change'
- 'It's just worse'
- 'He shuffles'
- 'He is not balanced'

Sensory-motor
- Delusions/Hallucinations
  - 'She talks to the mirror'
  - 'She had a fixation on horses'
  - 'Upset because she thought someone was hurting the horses'
Interview Guide

Demographic Information
- Age
- Sex
- Length of marriage/relationship
- Length of time spouse has been diagnosed with dementia
- Type of dementia and severity of dementia
- Other medical conditions
- Days per week spouse attends centre
- Length of time spouse has attended centre based respite
- Transport arrangements to the centre based respite program
- Other services provided for the person with dementia

Dementia and occupational performance components
Introduction:
- Review of information already known including information on personal life history of person with dementia

1. Can you describe the changes you have noticed in your spouse since receiving the diagnosis of dementia? (seek examples of the following)
   - Mood
   - Behaviour
   - Emotional reactions
   - Communication
   - Social interaction
   - Sleep patterns
   - Memory/remembering
   - Ability to independently do things (level of assistance now)
2. Given the changes you have noticed, how has this affected your relationship?

Centre based respite on occupational performance components

Introduction:

- Clarify length of time and number of months spouse has attended day centre

3. What is NAME like when he/she returns home from the centre?
   
a. Mood

b. Behaviour
   - Wandering
   - Anxiety/ agitation

c. Emotional reactions

d. Communication
   - Ability to express emotions
   - Amount and quality of conversation

e. Social interaction

f. Sleep patterns

g. Memory

h. Ability to independently do things
   - ADL’s (washing, dressing, grooming, toileting, eating)
   - IADL’s (shopping, cooking, housework, laundry, transport)

i. Sleep habits and energy levels
   - Waking you up at night
   - Inability to fall asleep
4. Do these changes (mentioned above) differ on the day/s following day centre attendance?

5. With NAME attending the day centre, how has this affected your relationship
   - Time apart

**Overall Wellbeing**

6. How would you describe NAME overall wellbeing since attendance at the Mary Chester Centre?

**Final**

Are there any other comments that you would like to make?