

The disconnect between evidence and practice: A systematic review of person-centred interventions and training manuals for care home staff working with people with dementia

Jane Fossey, Sarah Masson, Jane Stafford, Vanessa Lawrence, Anne Corbett, Clive Ballard.

Author details

- Jane Fossey, Psychological Services, Oxford Health NHS Foundation Trust, Oxford, OX4 2GX, UK
Associate Director of Psychological Services
- Sarah Masson, Psychological Services, Oxford Health NHS Foundation Trust, Oxford, OX4 2GX, UK
Trainee Clinical Psychologist
- Dr Jane Stafford, Psychological Services, Oxford Health NHS Foundation Trust, Oxford, OX4 2GX, UK
NHS Clinical Trials Programme Manager
- Dr Vanessa Lawrence, Health Service and Population Research Department, Institute of Psychiatry at King's College London, SE5 8AF, UK
Lecturer in Qualitative Social Sciences
- Dr Anne Corbett, Wolfson Centre for Age-Related Diseases, King's College London, SE1 1UL, UK
Lecturer in Dementia Research Communication
- Professor Clive Ballard, Wolfson Centre for Age Related Diseases, King's College London, SE1 1UL, UK
Professor of Age Related Diseases

Corresponding author

Professor Clive Ballard
clive.ballard@kcl.ac.uk

Key words

Dementia, Care homes, Person-centred Care, Training

Word count: 3013 words

Key Points:

- Training and interventions based on person-centred care can have a significant impact on agitation in people with dementia, as well as reducing use of antipsychotics
- Despite the wide availability of training programmes for care staff only three have been robustly evaluated
- There is an urgent need to align staff training with the evidence-base in order to provide consistent, effective person-centred care for people with dementia

Abstract

Background: One third of the 800,000 people with dementia in the UK currently reside in a care home. Provision of high quality treatment and care for these individuals has been identified as a priority. This clinical and political imperative relies on the development and nurturing of an appropriately skilled workforce.

Objective: To identify and review the quality of available person-centred intervention and training manuals which address neuropsychiatric symptoms and / or antipsychotic use for people with dementia in care homes. Secondly, to review clinical trials evaluating these manuals. The overall objective is to determine the availability of person-centred intervention and training manuals with clinical trial evidence of efficacy.

Data sources, eligibility criteria and methods: Interventions were identified using a search of electronic databases, augmented by mainstream search engines, reference lists, hand searching for resources and consultation with an expert panel. The specific search for published manuals was complemented by a search for Randomised Control Trials (RCT) focussing on training and activity-based interventions for people with dementia in care homes. Manuals were screened for eligibility and rated to assess their quality, relevance and feasibility.

Results: A meta-analysis of RCTs indicated that person-centred intervention and training manuals conferred significant benefit in improving agitation and reducing the use of antipsychotic drugs. Each of the efficacious packages included a sustained period of joint working and supervision with a trained mental health professional in addition to an educational element. However, of the 170 manuals that were identified, only 30 met the quality criteria and only four had been evaluated in clinical trials.

Conclusions: Despite the availability of evidence based training manuals, there is widespread use of person-centred intervention and training manuals which are not evidence-based. The failure to implement evidence-based interventions is extremely concerning. Moving towards a better skilled workforce in care homes is imperative to provide improved treatment and care for people with dementia and to support all clinicians working into these environments. Clearer guidance is needed to ensure that commissioned training and interventions are based on robust evidence.

Systematic review reference number: CRD42013004091

Introduction

Rationale

Dementia affects 35 million people worldwide¹ and this is expected to rise to 115 million by 2050²

It is a devastating condition leading to progressive cognitive decline, functional impairment and loss of independence. Dementia incurs an enormous personal cost to those affected and a worldwide financial cost in 2010 estimated at \$604 billion.³ In the UK alone there are currently 800,000 people with dementia, more than 250,000 of whom live in care home settings.⁴

Older people with dementia in care homes have complex needs which often require specialised treatment and care. For example cognitive and functional impairment often coexists with additional neuropsychiatric symptoms such as psychosis,⁵ aggression, agitation and depression.^{6,7} There is currently a high level of unmet need in these individuals. The quality of care for people with dementia living in care homes has been a matter for serious concern.⁸ and is likely to have contributed to an increase in neuropsychiatric symptoms and the widespread prescription of potentially harmful antipsychotic drugs.^{9,10} In order to address these issues high quality training and skills development for staff is essential to enable them to provide the best possible care for people with dementia and effective support to clinicians working with people in care home settings.

A number of governments around the world have published national dementia plans addressing treatment, care and research. Many of these have emphasised the importance of better treatment and care for people with dementia in care home settings. National Dementia Strategies in both France and England prioritise improvement in the quality of care and development of an informed, effective workforce for care.^{11,12} The UK National Service Framework for older people¹³ and NICE dementia guidelines¹⁴ also highlight the importance of training for care staff, and the need to improve access to effective non-pharmacological therapies in order to reduce unnecessary prescribing of antipsychotic medication to people with dementia. Care home regulators in the US have launched initiatives to tackle the same key issues.¹⁵ These recommendations have resulted in a proliferation of training programmes that are promoted to care providers, however the evidence to support their effectiveness is unclear.

Dementia represents a substantial financial burden to healthcare services worldwide, and it is therefore essential that this expenditure is focussed on interventions that are known to be effective. To increase the skills of the workforce, provision of training for all care staff in England, in line with the National Strategy, would cost an estimated £546,000,000 based on current median training costs and the current number of care homes in the UK, further emphasising the importance of focussing this resource on effective training interventions. It is therefore vital to have a clear understanding of the available intervention and training manuals and their related evidence of quality and efficacy in order to deliver clinical interventions, plan training and care, commission services, and ultimately to provide the best possible care for people with dementia. There are numerous important areas of training and best practice pertaining to people with dementia in care homes, the totality of which would

be difficult to address in one single review. We chose to focus on the implications for neuropsychiatric symptoms and antipsychotic use given the current clinical and political priority of these topics and the existence of clear consensus best practice guidelines for care delivery and treatment.

Objectives

This review incorporates two related but independent systematic reviews of available person-centred intervention and training manuals which address neuropsychiatric symptoms and / or antipsychotic use for people with dementia in care homes. The objective is to identify and review the quality of all available published manuals (Quality review) and to determine the evidence for efficacy of manuals which have been evaluated through clinical trial (Efficacy review).

Methods

Protocol and registration

The protocol is published online at:

<http://www.kcl.ac.uk/biohealth/research/divisions/wolfson/research/neurodegeneration/staff/ballardclove.aspx>

Quality review

Information sources

Manuals and training packages were first identified through searches of electronic databases described in Box 1. The search incorporated manuals available in a wide range of formats including books, DVDs, leaflets and packs.

Study selection

Eligibility criteria are summarised in Table 1. An initial screen excluded unsuitable manuals. Where multiple versions of a manual existed the most recent edition was included. The full content of the manuals was screened for eligibility by three independent reviewers and scored for the comprehensiveness of the intervention and degree of operationalisation. Studies taken forward received scores of three or more for both criteria, were deemed to provide broad person-centred interventions or training which address neuropsychiatric symptoms and or antipsychotic use for people with dementia in care homes and were suitable for practical implementation. Manuals were excluded if they focussed on a single aspect of care, such as bathing¹⁶ or did not include practical instructions for delivery.

Data collection process

A data extraction sheet was developed to summarise the relevant contents of the manuals. Data was extracted by one author (SM) and checked by two authors (JF and VL). The authors of the manuals were contacted to provide key information where necessary.

Data items

Extracted data were: (i) aim; (ii) type of intervention; (iii) intended outcomes; (iv) setting; (v) target population; (vi) format of manual; (vii) method of development; (viii) stated theoretical basis; (ix) evidence base. Manuals were then separated into categories according to the type of intervention or training identified.

Risk of bias in individual studies

The manuals were rated independently by three of the authors, to assess the risk of bias of individual studies, with good inter-rater reliability and concordance coefficients between raters (0.7 for raters JF and VL; 0.8 for JF and SM and 0.8 for VL and SM).

Summary measures

The type of research evidence available was noted for shortlisted manuals. The levels of evidence summarised were anecdotal, qualitative study, open trials, quasi experimental studies and RCTs. Those with quasi-experimental studies and RCT evidence meeting the inclusion criteria were evaluated in the efficacy review in the subsequent section of this paper.

Efficacy review

Information Sources

The information sources and search terms are summarised in Box 1. For all keywords a variety of alternative terms were also searched.

Eligibility criteria

All RCTs, and quasi-experimental studies with a control group which primarily address neuropsychiatric symptoms and or antipsychotic use for people with dementia in care homes and which were delivered primarily through interventions or training to improve the practice of care staff were included.

Data collection process and data items

Studies identified by the search strategy were reviewed by one of the authors (CB) and selected if they met the inclusion criteria. The selection of included studies was checked independently by a

second author (JS). Differences were resolved by consensus. Data pertaining to neuropsychiatric symptoms (agitation, psychosis, depression, global neuropsychiatric symptoms) or antipsychotic prescribing were extracted for meta-analysis.

Risk of bias in individual studies

The methodological quality of included studies evaluated with RCTs or a quasi -experimental design and with an available manual was assessed applying the Cochrane system as used by Corbett and colleagues¹⁷ **Error! Reference source not found.**using the headings 'Adequate Sequence Generation', 'Allocation Concealment', 'Blinding', 'Incomplete data' and 'Free of selective reporting', and with a red, amber, green traffic light rating system.

Synthesis of results

Meta-analysis was undertaken with the Comprehensive Meta-analysis (v2 Hewlett Packard) package for key neuropsychiatric outcomes (agitation, depression, total neuropsychiatric inventory) reporting standardized mean differences with 95% confidence intervals and for antipsychotic drugs (reporting odds ratios with 95% confidence intervals) when data were available from two or more RCTs or quasi experimental studies.

Results

Quality Review Results

Figure 1 shows the flow of studies through the selection process. 170 books, videos, DVDs, manuals and packs were identified as possible person centre intervention or training manuals for people with dementia. 58 manuals were initially excluded (Figure 1), and 112 manuals were assessed against the screening criteria, noting contents and structure. 49 of these were excluded following more detailed review. 63 manuals met the screening criteria and were rated against the six quality assessment criteria. 30 manuals were shortlisted, having obtained sufficient scores against the criteria. Of these 30 manuals only four were supported by evidence from randomized controlled clinical trials. The manuals and related evidence are described in more detail in Table 2.

Efficacy Review

Table 2 shows that seven RCT / quasi-experimental studies of person-centred intervention or training manuals (three of which were already selected through the manual review) were identified¹⁸⁻²⁴ Five of these studies were parallel group RCTs. Three studies evaluated the impact of person-centred care training on antipsychotic use, with two studies indicating significant reductions of 12.8%²⁴ and 21.5%²⁰

greater in the person-centred care training group than in those receiving usual care. A meta-analysis indicates a significant reduction in antipsychotic use across the three studies (Figure 2). Quantitative evaluation of agitation was undertaken in five studies of person-centred care training, but only four of these studies included the data in the paper^{20, 22, 23, 25} with an overall highly significant benefit in agitation evident across the studies (Figure 3). A beneficial impact in the treatment of depression was evaluated in a study including person-centred care training in assisted living environments, but was not reported specifically in any of the studies in care home settings. Only one trial reported global impact of person-centred care training on neuropsychiatric symptoms in people with dementia in nursing homes, reporting a significant 8.7 point improvement in the person-centred care training group compared to usual care. All six of the studies included in the meta-analysis received a 'Green' score for quality and risk of bias according to the Cochrane rating scale.

Excluded studies

Several other promising intervention approaches did not meet inclusion criteria, including Reducing Disability in Alzheimer's Disease (RDAD),²⁶**Error! Reference source not found.** STAR-C²⁷ and Cognitive Stimulation Therapy.²⁸ Reasons for exclusion included studies focussed on specific domains, not focussing on neuropsychiatric symptoms or antipsychotic use, that they have been evaluated in non-care home settings or that they are interventions delivered directly to people with dementia rather than through care staff. These are described in more detail in Table 3.

Combined Quality and Efficacy Review

Only four of the available training and intervention manuals, met the stipulated quality criteria and had published clinical trial evidence of efficacy (Table 2). The Focussed Intervention of Training for Staff (FITS),^{20, 29} a ten month person-centred care training package delivered by a FITS therapist, a mental health professional who had undergone a specific ten-day training course. The RCT showed the intervention resulted in a 19.1% reduction in use of antipsychotic medication in the treatment group (95% confidence interval 0.5% to 37.7%). A collection of evidence-based protocols for integrating non-drug strategies into the care and treatment of older people with dementia, N.E.S.T.^{30, 18}**Error! Reference source not found.** and the related manual, 'Simple Pleasures', were evaluated in 60 people in a nursing home over ten weeks. The study showed improvements in agitation (CMAI p=.01) and depression (GDS; p=.001). The 'Simple Pleasures' manual¹⁹ was evaluated in a six month crossover RCT involving 40 individuals which demonstrated significant improvement in agitation compared to the control period (p=0.001). Improving Dementia Care³¹ is a practical training and staff development resource for use with care staff to develop an understanding of person-centred care principles and practice, as part of an RCT of person-centred care training and a specific care programme including Dementia Care Mapping (DCM) in 15 care homes²⁵. Outcomes showed a

reduction in symptoms of agitation in residents although the outcomes showed variability between sites (CMAI; $p=0.01$). DCM was utilised as part of this effective intervention, but in a way that is different from routine clinical implementation.²⁵ A further RCT of DCM using the more widely implemented method is ongoing in the UK. Three other training programmes have demonstrated evidence of efficacy in clinical trials, but are not available for general implementation.

Discussion

Summary of evidence

This review has identified robust evidence demonstrating the benefits of person-centred care intervention and training for improving agitation and reducing the use of antipsychotic medications in people with dementia living in care homes. However, this outcome was based on intervention studies performed on only a fraction of the training programmes that are currently available. Only 30 (18%) of the intervention and training manuals identified followed good educational and person-centred care principles and only four (2.3%) had clinical trial evidence of benefit. The importance of this is perhaps highlighted more starkly by highlighting the reverse statistic, that more than 80% of available intervention and training packages are of variable quality and 98% are not evidence based. The limited availability of high quality and in particular evidence-based interventions is extremely concerning. Healthcare and care home sectors are investing significant amounts of budget in training following the directive from the NDSE which highlighted it as a key area for improvement. Yet this investment is currently being spent largely on programmes that carry no evidence that they reduce or improve neuropsychiatric symptoms or influence antipsychotic prescription. If the UK is to meet the imperative of providing better social and medical care for people with dementia, basing care on evidence-based intervention training to improve person-centred care must be a priority. It is of particular importance that the interventions for which there is evidence of benefit were delivered over a period of at least four months and involve some on-going clinical supervision or support following training to embed implementation into care home practice. This suggests that commissioning “one-off” training packages or classroom based training is likely to be ineffective.

The meta-analysis clearly shows that person-centred intervention and training packages have a significant positive impact on both agitation and on reducing the use of antipsychotic medications, strongly reinforcing the value of this approach. The literature does not currently provide any evidence for the impact on psychosis, depression and quality of life. This is an important priority for further research. A recent department of health report also indicates that these types of training and interventions are likely to be highly cost-effective.³²

Based on the evidence reported in this review, there is a clear and urgent need for change in regulation and guidance for commissioners, the care home sector and health professionals on the most appropriate training to be delivered to care staff working with people with dementia. It is imperative to prioritise use of high quality intervention and training packages with established evidence of efficacy, and which include an element of on-going work with care home staff to embed the principles into routine practice.

Limitations

Limitations in review strategy

Although the review incorporated national and international English language intervention manuals, it is nevertheless a limitation that the review is limited to English language publication. The specific search for published manuals was also complemented by a search RCTs, focussing on training and activity based interventions for people with dementia in care homes, thereby mitigating the limitations of the manual review search strategy, to ensure that a broad international perspective was incorporated into the review. In addition, the nature of this review dictated that existing and published training programmes without available manuals were excluded. It is also important to note that a number of the manuals reviewed had a broader framework for care delivery than a specific focus of neuropsychiatric symptoms. It is therefore likely that wider benefits for the alleviation of distress were not captured by this review.

Risk of bias

As this review included qualitative ratings by individuals this may have raised potential personal bias in the ratings. However, this was minimised through the use of an established pro-forma.

Conclusions

In conclusion, there has been a welcome recognition of the importance of a well trained workforce to support people with dementia living in care homes. However, there is a major disconnect between the interventions that are routinely available and being commissioned, and the evidence base indicating benefit. It is important that people purchasing, commissioning and delivering psychosocial interventions and training packages have access to evidence-based approaches, and that we move to a set of standards where evaluation of the benefits of training for people with dementia is part of the accreditation process for training courses and packages. More rigorous standards are needed to ensure that the training that is provided is conferring benefit to people with dementia.

Acknowledgements

This paper summarises independent research funded by the National Institute for Health Research (NIHR) under its Programme Grants for Applied Research Programme (Grant Reference Number RP-PG-0608-

10133). The views expressed are those of the author(s) and not necessarily those of the NHS, the NIHR or the Department of Health. Clive Ballard and Anne Corbett were supported by the National Institute for Health Research (NIHR) Mental Health Biomedical Research Centre and Dementia Unit at South London and Maudsley NHS Foundation Trust and Institute of Psychiatry, King's College London.

Exclusive licence

The Corresponding Author has the right to grant on behalf of all authors and does grant on behalf of all authors, a worldwide licence to the Publishers and its licensees in perpetuity, in all forms, formats and media (whether known now or created in the future), to i) publish, reproduce, distribute, display and store the Contribution, ii) translate the Contribution into other languages, create adaptations, reprints, include within collections and create summaries, extracts and/or, abstracts of the Contribution, iii) create any other derivative work(s) based on the Contribution, iv) to exploit all subsidiary rights in the Contribution, v) the inclusion of electronic links from the Contribution to third party material where-ever it may be located; and, vi) licence any third party to do any or all of the above.

Declaration of competing interests

All authors have completed the ICMJE uniform disclosure form at www.icmje.org/coi_disclosure.pdf and declare: no support from any organisation for the submitted work; CB has received research grants and honorariums from Lundbeck Pharmaceuticals and consultancy/honorariums from the following Pharmaceutical companies; Novartis, Acadia, Bial, Napp, Bristol-Myer Squibb, Otsuka and Servier. AC has received Speakers Honoraria from Novartis, Lundbeck and Bial Pharmaceuticals, and does consultancy for Acadia Pharmaceuticals and Department of Health (UK); no other relationships or activities that could appear to have influenced the submitted work.

Data sharing: No additional data available.

Ethics Approval: Not required.

Tables and Figure

Box 1: Search protocol

1. Electronic databases and off-line resources searched for quality and efficacy reviews:

- MEDLINE, PsycINFO, Web of Science, Embase, BioMedCentral, Clinical Trials.gov, British Nursing Index and the Cochrane Library.
- Generic search engines (Google and Google Scholar)
- Offline: scanning reference lists, hand searching of resources and consulting experts from dementia care—clinical, managerial, caring and academic backgrounds.

2. Search terms:

- Quality review: 'Dementia' in combination with 'Psychosocial', 'Intervention', 'Manual', 'Person-centred', 'Social interaction', 'Exercise' and 'Training'. The search incorporated manuals available in a wide range of formats including books, DVDs, leaflets and packs.
- Efficacy Review: Terms encompassing individual dementias, behavioural interventions and nursing homes. Alternative terms: Education & training, Education, Training, Physical training, Exercise, Social interaction, Care planning, Psychosocial intervention, Emotion oriented care, Creative therapies, Life story, History, Resolution, Resolution therapy, Engagement, Art, Art therapy, Activity, Stories, Storytelling, Music, Music therapy, Dance, Dolls and toys, Jabadoo, Mural and Simulated presence therapy.

3. Contact authors for intervention manuals where these were not available.

'What This Paper Adds' Box

What is already known on this subject:

- Training for care home staff is highlighted as a priority in national and international strategies for dementia to improve the quality of care received by people with dementia living in care homes
- Training is particularly seen as a key factor in reducing behavioural and psychological symptoms of dementia and antipsychotic prescriptions
- There is currently significant expenditure on training programmes yet it is unclear which programmes have supporting evidence to demonstrate their efficacy

What this study adds

- There is clear robust evidence to support the benefit of person-centred care training in improving the clinical outcomes or wellbeing of people with dementia living in care homes.
- 170 training manuals are currently available for use in care homes. Only four of these have supporting evidence of efficacy from an RCT
- This review highlights the need for further RCTs to examine the efficacy of training programmes and the imperative to define clear guidance to ensure training is evidence-based

Figure 1: Study selection

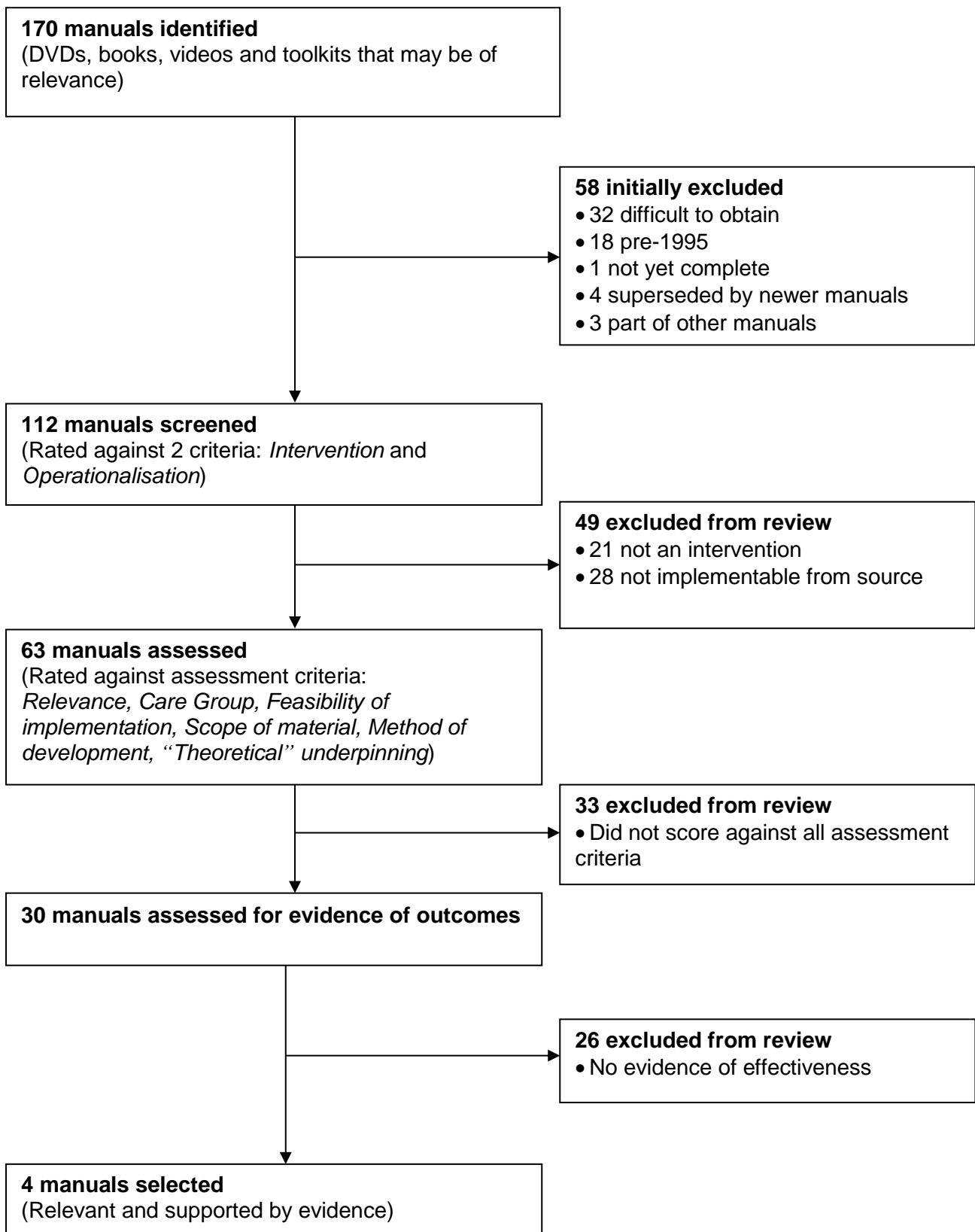


Figure 2: Meta-analysis of RCTs evaluating the effect of person-centred care interventions and training manuals on antipsychotic prescriptions

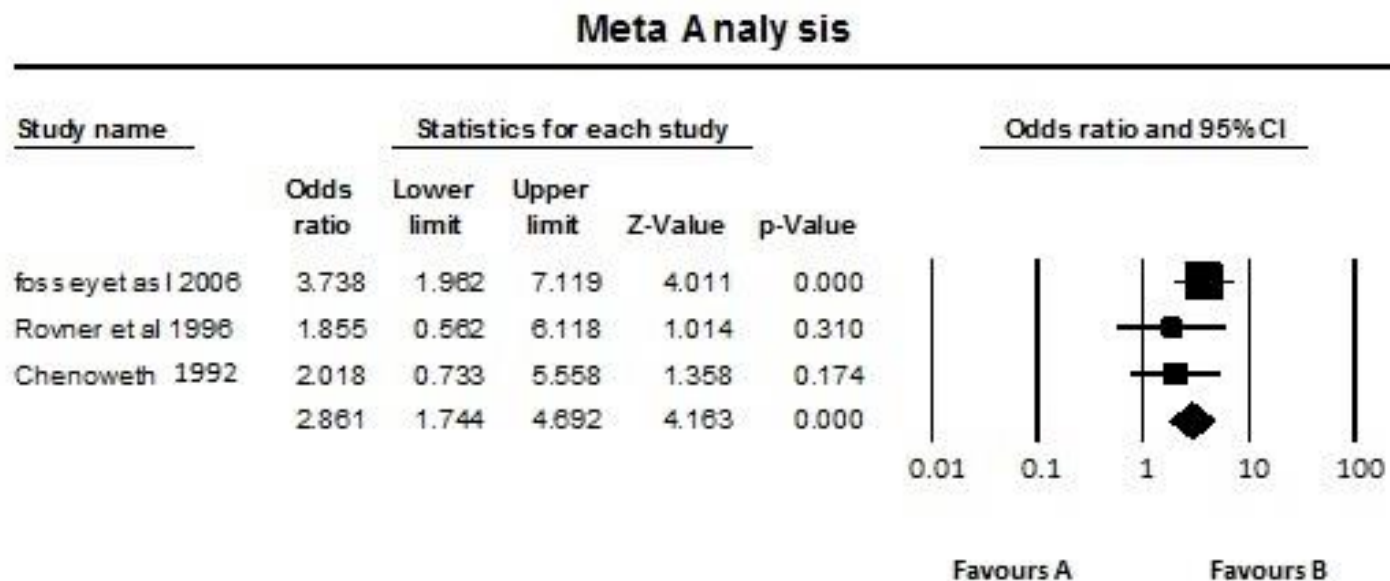


Figure 3: Meta-analysis of RCTS evaluating the effect of person-centred care interventions and training manuals on agitation in people with dementia living in care homes

Meta Analysis

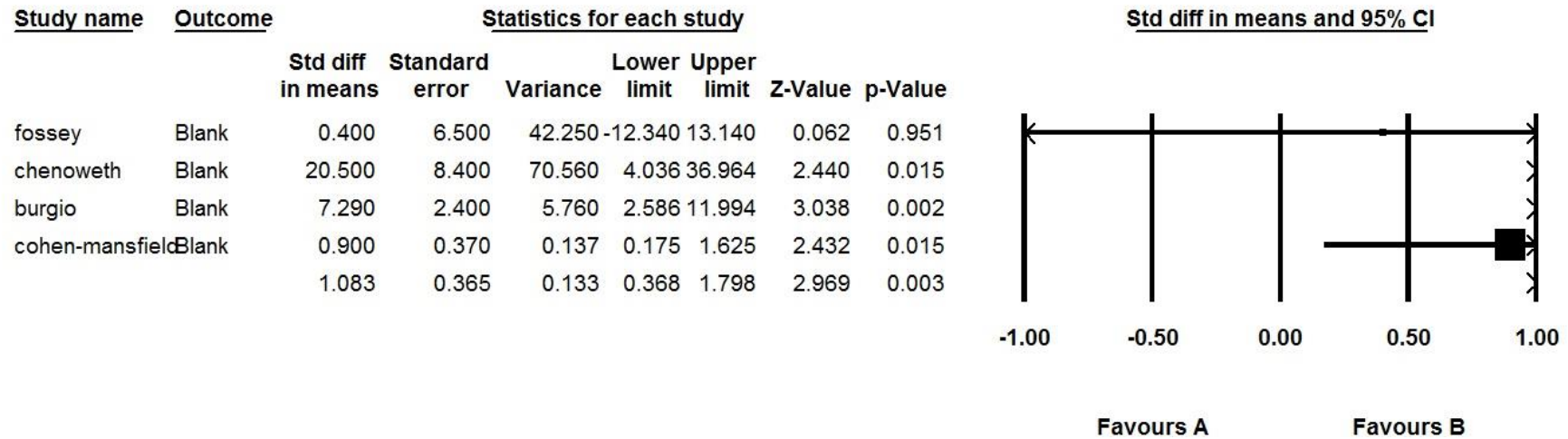


Table 1: Study eligibility and assessment criteria

ELIGIBILITY CRITERIA	
Initial exclusions	(i) unavailable for inspection and difficult to obtain; (ii) not yet complete; (iii) incorporated as part of other manuals; (iv) had been superseded by newer manuals.
Screening criteria	(i) Intervention: Extent to which the manual provides a clear, complete intervention, which can be used as a standalone resource (ii) Operationalisation: Extent to which the intervention can be directly implemented from the manual
Final inclusions	(i) Score of three or more on screening criteria (ii) Provide broad person-centred care training and approaches to improving person-centred activities for people with dementia in care homes. (iii) Demonstrable design for direct implementation with appropriate training, or provide sufficient information about the details of an activity that could be undertaken.
Final exclusions	(i) Manuals with detailed principles / theory but no clear instructions about delivery were excluded. (ii) Manuals with specific interventions focusing on only a single aspect of care.
Assessment criteria	
Relevance (goal outcomes)	Relevance of the manual to improving key clinical outcomes and/or wellbeing of people with dementia Error! Reference source not found.
Care Group	Specificity of the manual to people with dementia living in care homes
Feasibility of implementation	Ease of implementation of the intervention, in terms of the materials, resources, flexibility and level of training/support required
Scope of material	Extent and level to which the manual focuses upon a psychosocial intervention
Method of development	Level of rigour in the method of manual development
“Theoretical” underpinning	Level to which the intervention relates theoretical rationale to practice
Evidence of outcomes	Level of evidence of relevant outcomes/ effectiveness

Table 2: RCTs of person-centred care intervention manuals

Manual	Paper	Study description	Length of intervention	Training required	Effect	Cochrane score
RCTs for interventions with available manuals						
N.E.S.T Approach: Dementia practice guidelines for disturbing behaviours; incorporating: Simple Pleasures: A multilevel sensorimotor intervention for nursing home residents with dementia ³⁰	Buettner & Ferrario (1998) ¹⁸	RCT in nursing home unit, 60 clients, one treatment group (30) received recreational therapy in groups tailored to their needs, one control (30)	30 weeks	Ten week training programme for care staff facilitated by certified therapeutic recreation specialist	Significant improvements compared to control group in: Cognitive function: <i>MMSE</i> (.426; p=.001) Agitation: <i>CMAI</i> (.149; p=.01) Depression: <i>Geriatric Depression Scale</i> (.284; p=.001)	Green
A subset of NEST : Simple Pleasures: a multilevel sensorimotor intervention for nursing home residents with dementia.. ¹⁹	Buettner (1999). ¹⁹	Randomized crossover design. Intervention tested in two 40-bedded units.	6 months	Volunteer groups provided with 30 minute Dementia Education Programme in use of items	Significant improvements in agitation scores: <i>Cohen Mansfield Agitation Inventory</i> (+1.3; p=.001)	Red
Evidence-based approaches for improving dementia care in care homes. ²⁹	Fossey et al ²⁰	RCT 12 nursing homes (138 participants) One Treatment group (Training and support intervention delivered to staff over 10 month period) and one Control group.	10 months	Training and support delivered to nursing home staff over 10 months by a psychologist, OT or nurse	Reduction in neuroleptic use: Average reduction in neuroleptic use in treatment group: 19.1% (95% confidence interval 0.5% to 37.7%)	Green
Improving Dementia Care: a resource for training and	Chenoweth, et al (2009) ²⁵	15 care sites with 289 residents were randomly allocated to person-centred care, dementia-	4 months	Two-day training sessions in person-centred care for two care staff selected by	Reduction in agitation in people with dementia in residential care: <i>Cohen Mansfield Agitation Inventory</i> (13:6, 3.3-23.9; p=0.01)	Green

professional development ³¹		care mapping, or usual care		managers as competent and interested with ongoing support and supervision for 4 months		
Dementia Care Mapping ³³	Chenoweth et al (2009) ²⁵	15 care sites with 289 residents were randomly allocated to person-centred care, dementia-care mapping, or usual care	4 months	Support to implement DCM as a tool for improved person centred care planning over 4 months		Green
RCTS of interventions without available manual						
Unavailable	Burgio et al (2002) ²²	Quasi experimental study with control group in 88 residents and 106 certified nursing assistants.	6 months	Four week behaviour management training	Reduction in resident agitation during care interactions	Green
Unavailable	Cohen-Mansfield et al (2007) ²³	Study examined the efficacy of a systematic algorithm for providing individualized, non-pharmacological interventions for reducing agitated behaviours in nursing home residents with dementia. Placebo-controlled study conducted in 12 nursing home to 167 residents	Interventions were provided for ten days during the four hours of greatest agitation.	Delivered by an external team	Statistically significant decreases in overall agitation in the intervention group relative to the control group from baseline to treatment ($F(1,164) = 10.22, p = .002$). Implementation of individualized interventions for agitation resulted in statistically significant increases in pleasure and interest ($F(1,164) = 24.22, p < .001$; $F(1,164) = 20.66, p < .001$).	Green
Unavailable	Rovner et al (1996) ²⁴	Programme designed to reduce the prevalence of antipsychotic drugs and restraints. It is practical, feasible and appears to improve the lives of people with	6 months	Delivered by an external team	Reduction in exhibition of behaviour disorders. Reduction in antipsychotic prescribing	Green

		dementia living in nursing homes. RCT with six-month follow-up. 89 participants allocated to the AGE programme or control group				
--	--	---	--	--	--	--

Table 3: Key excluded intervention manuals

Manual	Paper	Study description	Length of intervention	Training required	Effect	Reason for exclusion
Bathing without a battle: Person-directed care of individuals with dementia ¹⁶	Hoeffler et al (2006) ³⁴	RCT: 15 homes (69 residents) Two Treatment Groups (staff trained to provide person-centred showering and person-centred bed bath), one Control Group (usual practice)	Intervention delivered over three month period (averaging approx. eight hours per study subject per intervention)	Support staff trained for six weeks in showering intervention and for six weeks in towel bath intervention	Significant improvements in care giving outcomes (comparing mean change on care giving outcomes): Gentleness: Caregiver Bathing Behaviour Rating Scale (16.22; p<.01) Verbal support: Caregiver Bathing Behaviour Rating Scale (12.0; p<.01) Perception of Ease: Care Effectiveness Scale (6.12; p<.01)	Intervention focussed on a specific aspect of care
Reducing Disability in Alzheimer's disease (RDAD): A	Teri et al (2003) ³⁵	RCT 153 people residing in the community (115 intervention, 96 control)	Intervention delivered over three month period	Caregivers provided with 18 hour-long sessions over	Significant improvements in physical functioning (mean difference 19.29; CI 95%: p<0.001)	Not implemented in care home residents

manual for therapists ²⁶				three month period	Reduction in depression: CANE (-1.03; p=.02)	
STAR-C Treatment of depression and anxiety in persons with dementia ²⁷	Goyder et al (2012) ³⁶	Feasibility study: 2 care homes; 25 staff members; 32 residents. Eight week STAR programme, baseline and follow up measures.	Intervention delivered over an eight week period	Two workshops delivered to care staff by psychologist and OT; 120 minutes further training	Reduction between baseline and follow-up in: Depression: <i>CSDD</i> $t(31) = 3.403$; $p=.002$ Anxiety: <i>RAID</i> $t(31)=.874$; $p=.389$ Behavioural problems: <i>RMBPC</i> $t(31)=4.15$; $p=.013$	Pilot open study with no control
Making a difference: an evidence-based programme to offer cognitive stimulation therapy (CST) to people with dementia. The manual for group leaders ²⁸	Spector et al (2003) ³⁷	RCT:201 participants One treatment group (7 week 14 session programme delivered to 115 participants) One control group (86 participants).	14 session programme, running twice for 45 minutes over seven weeks	N/A programme delivered by research team	Significant improvements in: Cognitive function: <i>MMSE</i> (+1.14, s.d.=0.09, $p<.05$); <i>ADAS-Cog</i> (-2.37, s.d=.87, $p<.01$) Quality of Life <i>QoL-AD</i> (+1.64, s.d.=.78, $p<.05$)	Delivered directly to people with dementia. Main focus not neuropsychiatric symptoms
Wheelchair biking for the treatment of depression evidence-based protocol ³⁸	Fitzsimmons (2001) ³⁹	RCT: 40 residents, one treatment group (two week trial of biking therapy) 1 control group.	15 minutes, once a day, five days per week for two weeks	A Certified Therapeutic Recreation Specialist developed	Treatment group- significant improvements in depression: <i>Geriatric Depression Scale</i> : Control group increase (+.70)	Intervention focussed on a specific aspect of care

				the protocol for the programme and trained staff from range of professional backgrounds	Treatment group decrease (-3.47) Significant at p<.000 level	
--	--	--	--	---	---	--

References

1. World Health Organisation. Dementia: A Public Health Priority. UK WHO and Alzheimer's Disease International; 2012.
2. Alzheimer's Disease International Consortium. Alzheimer's Disease Internayional World Alzheimer's Report. London: Alzheimer's Disease International; 2009.
3. Wimo A, Prince MJ, Alzheimer's Disease International. *World Alzheimer Report 2010: the global economic impact of dementia*. Alzheimer's Disease International; 2010.
4. Knapp M, Prince M, Albanese E, Banerjee S, Dhanasiri S, Fernandez J, et al. Dementia UK: A report into the prevalence and economic cost of dementia in the UK produced by Personal Social Services Research Unit (PSSRU) at the London School of Economics and the Institute of Psychiatry at King's College London . London: Alzheimer's Society; 2007.
5. Margallo- Lana M, Swann A, O'brien J, Fairbairn A, Reichelt K, Potkins D, et al. Prevalence and pharmacological management of behavioural and psychological symptoms amongst dementia sufferers living in care environments. *Int J Geriatr Psychiatry* 2001;16(1):39-44.
6. Buettner L, Fitzsimmons S. Mixed behaviors in dementia: the need for a paradigm shift. *J Gerontol Nurs* 2006;32(7):15-22.
7. Buettner L, Fitzsimmons S, Dudley WN. Impact of underlying depression on treatment of neuropsychiatric symptoms in older adults with dementia. *Research in Gerontological Nursing* 2010;3(3):221.
8. National Audit Office. *Improving services and support for people with dementia*. London: The Stationary Office Ltd.; 2007.
9. Alzheimer's Society. *Dementia Care in Care Homes*. London: Alzheimer's Society; 2007.

10. All Parliamentary Group. *Always A Last Resort': Inquiry into the prescription of antipsychotic drugs to people with dementia living in care homes*. London; 2008.
11. National Plan for "Alzheimer and related diseases" 2008-2012 <http://www.alzheimer-europe.org/Policy-in-Practice2/National-Dementia-Plans/France#fragment-1-> (accessed 5 February 2013)
12. Department of Health. *Living Well with Dementia: A National Dementia Strategy*. ; 2009.
13. Department of Health. *National Service Framework for Older People*. London: HMSO; 2001.
14. National Collaborating Centre for Mental Health. *Dementia :The NICE-SCIE guidelines on supporting people with dementia and their carers in health and social care*. London: The British Psychological Society and Gaskell; 2011. Report No.: National Clinical Practice Guideline Number 42.
15. Centre for Medicare and Medicaid Services Office of Clinical Standards and Quality. *CMS 2012 Nursing Home Action Plan: Action Plan for Further Improvements of Nursing Home Quality*. USA: Department of Health and Human Services; 2012
16. Barrick AL, Rader J, Hoeffler B, Sloane PD, Biddle S. *Bathing without a battle: person-directed care of individuals with dementia*. Springer Publishing Company; 2008.
17. Corbett A, Stevens J, Aarsland D, Day S, Moniz-Cook E, Woods R, et al. Systematic review of services providing information and/or advice to people with dementia and/or their caregivers. *International Journal of Geriatric Psychiatry*. 2012;27(6):628-636.
18. Buettner L, Ferrario J. Therapeutic recreation-nursing team: A therapeutic intervention for nursing home residents with dementia. *Annual in Therapeutic Recreation* 1998;7:21-8.
19. Buettner L. Simple pleasures: A multilevel sensorimotor intervention for nursing home residents with dementia. *Am J Alzheimers Dis Other Demen* 1999;14(1):41.

20. Fossey J, Ballard C, Juszczak E, James I, Alder N, Jacoby R, et al. Effect of enhanced psychosocial care on antipsychotic use in nursing home residents with severe dementia: cluster randomised trial. *BMJ* 2006;332(7544):756-61.
21. Chenoweth L, King MT, Jeon YH, Brodaty H, Stein-Parbury J, Norman R, et al. Caring for Aged Dementia Care Resident Study (CADRES) of person-centred care, dementia-care mapping, and usual care in dementia: a cluster-randomised trial. *The Lancet Neurology* 2009;8(4):317-25.
22. Burgio LD, Stevens A, Burgio KL, Roth DL, Paul P, Gerstle J. Teaching and maintaining behavior management skills in the nursing home. *Gerontologist* 2002;42(4):487.
23. Cohen-Mansfield J, Libin A, Marx M,S. Nonpharmacological treatment of agitation: a controlled trial of systematic individualized intervention. *Journal of Gerontology: Medical Sciences* 2007;62A(8):908-16.
24. Rovner B, Steele C, Scmuely Y, Folstein M. A randomized trial of dementia care in nursing homes. *Journal of American Geriatri Society* 1996;44:713.
25. Chenoweth L, King MT, Jeon YH, Brodaty H, Stein-Parbury J, Norman R, et al. Caring for Aged Dementia Care Resident Study (CADRES) of person-centred care, dementia-care mapping, and usual care in dementia: a cluster-randomised trial. *The Lancet Neurology* 2009;8(4):317-25.
26. Teri, L., McCurry, S.M., Logsdon, R.G., Moore MS, Tyll T, Ebel S, Thomas, D. & Jordan, J. *Reducing Disability in Alzheimer's Disease (RDAD). A Manual for Therapists*. University of Washington S; 2003.
27. Teri L. STAR-C. Treatment of Depression and Anxiety in Persons with Dementia 2002;.
28. Spector A, Thorgrimsen L, Woods R, Orrell M. Making a difference: an evidence-based group programme to offer cognitive stimulation therapy (CST) to people with dementia: the manual for group leaders 2006;.
29. Fossey J, James I. Evidence Based Approaches to Improving Dementia Care in Care Homes. *Alzheimer's Society* 2008;.

30. Buettner L, Fitzsimmons S. *N.E.S.T. Approach. Dementia Practice Guidelines for Disturbing Behaviors. Needs, Environment, Stimulation, Techniques*. State College, PA: Venture Publishing Inc.; 2009.
31. Loveday B, Kitwood T, Bowe B. *Improving dementia care: A resource for training and professional development*. Hawker Publications; 1998.
32. Matrix Evidence. An economic evaluation of alternatives to antipsychotic drugs for individuals living with dementia. London: NHS Institute of Innovation and Improvement; October 2011.
33. Brooker D, Surr C. *Dementia care mapping: Principles and practice*. Bradford: University of Bradford 2005;.
34. Hoeffler B, Talerico KA, Rasin J, Mitchell CM, Stewart BJ, McKenzie D, et al. Assisting cognitively impaired nursing home residents with bathing: effects of two bathing interventions on caregiving. *Gerontologist* 2006;46(4):524.
35. Teri L, Gibbons LE, McCurry SM, Logsdon RG, Buchner DM, Barlow WE, et al. Exercise plus behavioral management in patients with Alzheimer disease. *JAMA: The Journal of the American Medical Association* 2003;290(15):2015-22.
36. Goyder J, Orrell M, Wenborn J, Spector A. Staff training using STAR: a pilot study in UK care homes. *International Psychogeriatrics* 2012;1(1):1-10.
37. Spector A, Thorgrimsen L, Woods B, Royan L, Davies S, Butterworth M, et al. Efficacy of an evidence-based cognitive stimulation therapy programme for people with dementia. *The British Journal of Psychiatry* 2003;183(3):248-54.
38. Fitzsimmons S, Buettner L. *Wheelchair Biking for the Treatment of Depression Evidence Based Protocol*. The University of Iowa, Gerontological Nursing Interventions Research Centre: ; 2002.

39. Fitzsimmons S. Easy rider wheelchair biking. A nursing-recreation therapy clinical trial for the treatment of depression. *J Gerontol Nurs* 2001; May;27(5):14-23.