

Psychological interventions for carers of
people with dementia: a systematic review
of quantitative and qualitative evidence

bacp

British Association for
Counselling & Psychotherapy

Ruth Elvish, Sammi-Jo Lever, Jodie Johnstone,
Rosanne Cawley, John Keady

Psychological interventions for carers of people with dementia: a systematic review of quantitative and qualitative evidence is published by the British Association for Counselling & Psychotherapy, BACP House, 15 St John's Business Park, Lutterworth, Leicestershire, LE17 4HB.

t: 01455 883300

f: 01455 550243

e: bacp@bacp.co.uk

w: www.bacp.co.uk

BACP is the largest professional organisation for counselling and psychotherapy in the UK, is a company limited by guarantee 2175320 in England and Wales, and a registered charity, 298361.

© British Association for Counselling & Psychotherapy 2012

Correspondence to:

Dr Ruth Elvish

School of Nursing, Midwifery and Social Work, University of Manchester,
Jean McFarlane Building, Oxford Road, Manchester M13 9PL

t: 0161 306 7884

e: ruth.elvish@manchester.ac.uk

This work is copyright. It may be reproduced in whole or in part for study or training purposes subject to the inclusion of an acknowledgment of the source and no commercial usage or sale. Reproduction for other purposes than those indicated above requires written permission of the copyright holder, application for which should be addressed to the Chief Executive at BACP.

ISBN-13: 978-1-905114-38-2

Acknowledgements

The authors would like to thank the British Association for Counselling & Psychotherapy for funding this review and Peter Bower (University of Manchester) for his support and guidance during the review process, especially in the compilation of the final report.

Thanks also to Cassandra Kenny (Secretary, School of Nursing, Midwifery and Social Work, University of Manchester) for her support with the preparation of this report.

Thanks also to Joanna Murray, Jill Manthorpe and Alison Brett for their constructive feedback on this report.

Contents

Executive summary	Page 2
Introduction	Page 3
Work upon which this review builds	4
Method	Page 6
Quantitative studies	6
Qualitative studies	6
1. Psycho-educational skill-building studies	6
2. Psychotherapy-counselling studies	7
3. Multicomponent studies	7
4. Technology-based studies	8
Results	Page 10
1. Psycho-educational skill-building studies	10
2. Psychotherapy-counselling studies	10
3. Multicomponent studies	15
4. Technology-based studies	15
Discussion	Page 22
The use of technology in the delivery of psychological interventions	23
Social support: a key mechanism of change?	23
Which interventions, and for whom do they provide benefit?	24
Geographical location of studies	24
Study findings and recommendations	24
<i>Research and training</i>	24
<i>Practice and policy</i>	25
References	Page 26
Appendices	Page 30
Appendix 1: Template of data extraction sheets	30
Appendix 2: Guidance checklist for critical appraisal (quantitative studies)	30
Appendix 3: Guidance checklist for critical appraisal (qualitative studies)	31
Appendix 4: Final scores for quantitative studies	31
Appendix 5: Final scores for qualitative studies	31
List of tables & figures	
Table 1: Diagnostic classification of younger people with dementia	3
Table 2: Diagnostic classification of older people with dementia	3
Table 3: Search terms used by Pinquart and Sörensen (2006)	4
Table 4: Search terms used by Gallagher-Thompson and Coon (2007)	4
Table 5: Search terms	6
Figure 1: Flow diagram of the literature search and retrieval	7
Table 6: Numbers of studies	7
Table 7: Example of the quality evaluation process (quantitative studies)	8
Table 8: Example of the quality evaluation process (qualitative studies)	9
Table 9: Psycho-educational skill-building carer intervention studies	11
Table 10: Psychotherapy-counselling carer intervention studies	14
Table 11: Multicomponent carer intervention studies	16
Table 12: Technology-based carer intervention studies	19
Figure 2: Processes of change/mediating factors	23

Executive summary

Background

Recent studies have provided promising findings about the impact of psychosocial interventions for older adult carers and carers of people with dementia. The aim of this review was to add to the substantive knowledge base by combining search criteria used by Piquart and Sørensen (2006) and Gallagher-Thompson and Coon (2007) to update the literature on psychological interventions for carers of people with dementia published between 2005 and 2011.

Method

The following electronic databases were searched: Medline, PsycINFO, ERIC and PubMed. Inclusion criteria were developed to enable access to both quantitative and qualitative studies in order to provide a meaningful and clinically relevant review. Guidance checklists were developed in order to evaluate the quality of the selected studies. The development of these checklists was informed by relevant literature. Only English language studies were included. Data were extracted and synthesised by three of the research team using data extraction sheets.

Results

Twenty studies were identified, doubling the number of studies that have been examined and synthesised into review literature since the review undertaken by Gallagher-Thompson and Coon (2007). Consistent with previous work (Gallagher-Thompson and Coon, 2007), three categories of psychological intervention were identified: i) psycho-educational skill-building (n = 8); ii) psychotherapy-counselling (n = 1); and iii) multicomponent (n=6). In addition, there were studies that the researchers grouped into a newly created fourth intervention category which was named iv) technology-based (n = 5). Whilst cognitive-behavioural approaches were a significant influence within the psycho-educational skill-building and multicomponent categories, the model underpinning psychotherapy-counselling studies also focused on the marital unit and the marital relationship as targets for change.

Discussion

This review updates recent searches in this topic area. It particularly highlights developments in knowledge about the

processes of change within psychological interventions, and identifies a growth in studies that focus on interventions that are technology-based. Suggestions for future research include additional UK-based high quality studies in this field, a greater focus on the impact of counselling/psychotherapy with carers of people with dementia, and further studies that explore mediators and moderators within psychological interventions. In conclusion, 10 findings and recommendations were summarised as follows:

- Consistent with previous reviews on this topic area, the findings suggest that interventions underpinned by cognitive/cognitive-behavioural models can produce meaningful change.
- Multicomponent and technology-based interventions that use a combination of individual and group sessions are most effective.
- The qualifications of practitioners who delivered psychological interventions within this review are varied; standardisation of training/qualifications would be beneficial for clients and clinicians.
- Studies that explore and evaluate the impact that the mode of delivery has on process and outcome are called for, particularly in the use of technology.
- Further research is necessary that explores the processes of change within psychological interventions.
- An increase in the number of studies, possibly clustered around a programmatic multi-centre study measuring the impact of psychotherapy and counselling on carers of people with dementia, is required.
- The number of UK-based studies in this field should be increased, together with an examination of the cost-effectiveness of delivering various types of carer-focused interventions.
- There is a continuing need for public and social policy to focus on stigma and dementia within ethnic minority cultures, and particularly the impact of stigma on use and accessibility of services.
- In England, the commissioning strategy attached to the National Dementia Strategy should consider technology-based interventions as a support for carers of people with dementia.
- The updated findings for carer interventions from this review should be considered for inclusion in any revised national dementia guideline.

Introduction

In a recent report, the NHS Confederation (2010) included the following definition of dementia:

Dementia is a syndrome (a group of related symptoms) that is associated with an ongoing decline of the brain and its abilities. These include thinking, language, memory, understanding and judgement; the consequences are that people will be less able to care for themselves. (p5)

The most commonly occurring dementia in older and younger people is Alzheimer's disease (Alzheimer's Society, 2007), although there are many different causes of dementia which vary in their presentation and progression. A recent Alzheimer's Disease International report (Prince, Bryce and Ferri, 2011) has suggested that 36 million people with dementia, plus their families, are currently alive, with this number expected to rise significantly as the world's population ages. This report went on to call for an earlier diagnosis to enable people with dementia and their carers/families to take advantage of appropriate support programmes and services, such as the formation of new peer relationships in order to 'share feelings, information and coping strategies' (Prince, Bryce and Ferri, 2011, p28).

According to the Dementia UK report, the greatest risk for the acquisition of dementia is increasing age, with one in five people aged over 80 having a form of dementia (Alzheimer's Society, 2007). It is estimated that there are currently 683,597 people with dementia in the UK; this is representative of one person in every 88, or 1.1 per cent of the entire UK population (Alzheimer's Society, 2007). However, the Dementia UK report acknowledges that this may be a slight underestimate as the figure did not fully address the context of people with learning disabilities or people with dementia in NHS continuing care environments. Tables 1 and 2 provide an outline of the diagnostic classification for both younger (aged under 65 years) and older (65 years and above) people with dementia.

The total number of people with dementia in the UK is forecast to rise to 940,110 by 2021 and to more than 1.5 million by 2051, an increase of 38 per cent over the next 15 years and 154 per cent over the next 45 years (Alzheimer's Society, 2007). The NHS Confederation report (2010) suggests that at present up to 70 per cent of acute hospital beds in the UK are occupied by older people, and the Royal College of Psychiatrists (2005) previously highlighted that a fifth of all hospital patients will have some form of dementia.

The instigation and implementation of the National Dementia Strategy (NDS) in England (Department of Health, 2009) marked a significant step forward in public awareness, perception and expectation about 'living well' with dementia. Objective 7 of the NDS is concerned with 'implementing the Carers Strategy for people with dementia'. This objective reminded its audience

Table 1: Diagnostic classification of younger people with dementia

Diagnosis	Percentage of total
Alzheimer's disease	34%
Vascular dementia	18%
Frontotemporal dementia	12%
Alcohol-related dementia	10%
Lewy body dementia	7%
Other	19%

Adapted from the Dementia UK report (Alzheimer's Society, 2007, p29)

that there are more than 500,000 family members in England who care for a person with dementia, and that carers provide more than £6 billion a year worth of unpaid care. It is, therefore, perhaps unsurprising that objective 7 of the NDS (Department of Health, 2009) acknowledged that 'family carers are the most important resource available for people with dementia' (p49), and made the following key statements:

- Active work is needed to ensure that the provisions of the Carers Strategy are available for carers of people with dementia.
- Carers have a right to an assessment of their needs and can be supported through an agreed plan to support the important role they play in the care of the person with dementia. This will include good-quality personalised breaks.
- Action should be taken to strengthen support for children who are in caring roles, ensuring that their particular needs as children are protected.

As a context for this review of psychological interventions for carers of people with dementia, it is reasonable to say that during the 1980s the majority of the social science and practice literature focused on family (usually spousal and sibling) care at home for a relative with dementia, and the emotional, practical, financial and physical toll that this took on the carer. Stress and burden were the key concepts in the literature and many measurement scales were produced to identify these domains so that appropriate help and interventions could be put into place (Aneshensel, Pearlin, Mullan, Zarit and Whitlatch, 1995).

At the turn of the 1990s, Pearlin, Mullan, Semple and Scaff (1990) highlighted the concept of coping within the caring role. They viewed coping as comprising 'objective indicators', such as the perceived 'problematic' behaviour of the person being cared for, and 'subjective components', such as the carer's own feelings of being trapped in the caregiving role. It was this constant interplay between objective and subjective indicators that predicted 'successful' caring and coping, or otherwise. An alternative way of looking at this interplay is through the transactional model of stress and coping, which Morrissey, Becker and Rupert (1990) suggest best characterises the caring relationship. The transactional model builds on the work of Lazarus (1966) and, as the name suggests, views stress as resulting from a transaction between an individual and their environment. It is based upon a process of assessment or appraisal, in which an individual considers the nature of an event and decides whether it poses a threat, harm or a challenge. This period of consideration is known as the primary appraisal. If, as a result of this appraisal, a response is perceived as necessary,

Table 2: Diagnostic classification of older people with dementia

Diagnosis	Percentage of total
Alzheimer's disease	62%
Vascular dementia	17%
Mixed dementia (Alzheimer's disease and Vascular dementia)	10%
Dementia with Lewy bodies	4%
Frontotemporal dementia, including Pick's disease	2%
Parkinson's dementia	2%
Other types of dementia, e.g. alcohol-related, AIDS related	3%

Adapted from Harvey et al (2003, p1207)

the potential response is compared to the individual's available coping resources (secondary appraisal). A coping response is selected and its effect on the original demand is then assessed (reappraisal). Stress is only said to result when there is a perceived mismatch between the nature of the demand and the individual's ability to respond effectively to reduce the degree of perceived threat, harm or challenge. Using this approach the crucial determinant is not the objective nature of the demand (stressor) itself, but the appraisal of its impact. Hence, for example, a carer may be able to tolerate the seemingly stressful event of their partner's incontinence, but may be less well able to manage the social embarrassment that this evokes. In other words, events only become stressors when the mind identifies them as such. This distinction is important as it allows for the possibility of the same event being differently stressful for different people, or even for the same person at different times.

Caregiving, and the process of living with dementia, are not static events. As suggested by the Alzheimer's Society (2007), it is important to be reminded that there is no cure for most types of dementia, and advancing age is the most notable risk factor for their acquisition. Whilst dementia has been classified as a usually progressive condition and clustered into a number of transitory stages, carers and people with dementia face an uncertain trajectory through these stages, not knowing how quickly (or otherwise) the dementia will progress nor which 'stage' will be the most stressful. For example, some carers report the time leading up to, and immediately after, a diagnosis as the most stressful time in the entire caregiving trajectory (Williams, Nolan and Keady, 1995). For others, it is the situation faced when locating a care home or facing a loved one's death. Each person, relationship and situation will be different, and each person involved in the process of living with dementia will have a different reaction and meaning attached to the situation that is encountered. This diversity explains why transactional models of stress and coping have been highly influential in the caring literature, as they help to direct and target interventions at different times in the caring relationship.

This review is timely as the evidence base for interventions aimed at carers of people with dementia is perhaps best described as emerging (National Institute for Health and Clinical Excellence (NICE)/Social Care Institute for Excellence, 2006). A meta-analysis at the beginning of this century suggested that interventions had no significant effects on carer burden (Acton and Kang, 2001). However, the findings of two subsequent meta-analyses present a picture of interventions that demonstrate small to moderate effects upon psychological morbidity and caregiver knowledge (Brodsky, Green and Koschera, 2003), and burden, depression, knowledge and subjective wellbeing (Pinquart and Sörensen, 2006). Most recently, Gallagher-Thompson and Coon (2007) suggested that there is enough evidence to recommend a range of interventions underpinned by psychological models. However, some of the difficulties in providing an evidence base for interventions for carers of people with dementia are described by Zarit and Femia (2008). Firstly, these authors note that there are 'mismatches' in studies between the 'real' outcomes and those measured. Secondly, they emphasise that the heterogeneous nature of carers with regard to characteristics, background and psychological wellbeing makes study design a challenge. Thirdly, they remind us that 'caregiving is not a disorder' (p6), suggesting that studies sometimes target depression and burden in those for whom these are not priorities, or who do not even experience these difficulties at all.

Work upon which this review builds

The contribution of Pinquart and Sörensen (2006), and Gallagher-Thompson and Coon (2007), has influenced the

scope and direction of our reported review. Pinquart and Sörensen (2006) undertook a meta-analysis of a broad range of interventions for carers of people with dementia. They identified 127 studies using the search terms shown in Table 3.

Pinquart and Sörensen (2006) concluded that caregiver interventions could have small but meaningful effects on burden and depression, and also increase knowledge and subjective wellbeing. They highlighted the importance of deciding on specific or broad goals for interventions, and stated that further knowledge is needed about the importance of the length of an intervention, and the impact of different components/ combinations of components within multicomponent interventions. At around the same time, Gallagher-Thompson and Coon (2007) examined interventions for carers of older adults, which were underpinned by psychological theories of change. They identified 19 studies using the search terms in Table 4. Notably, Gallagher-Thompson and Coon (2007) included a substantially smaller number of studies in their review compared with Pinquart and Sörensen (2006). This appears to be due to differences in inclusion criteria, in particular: i) Gallagher-Thompson and Coon (2007) only included interventions that were underpinned by a psychological model, and ii) Pinquart and Sörensen (2006) included studies with outcome measures that were not primarily focused on the caregiver.

Gallagher-Thompson and Coon (2007) concluded that: i) the majority of studies in their review used psycho-educational skill-building interventions; ii) the most effective interventions were programmes that targeted specific components of caregivers' quality of life alongside some combination of skill building, education and support; iii) psycho-educational skill-building, psychotherapy/counselling and multicomponent interventions could all be recommended; and iv) cognitive-behavioural interventions were effective for caregivers with significant levels of depression. Gallagher-Thompson and Coon (2007) found that the largest average effect size, within the interventions that they reviewed, was in the psychotherapy/counselling category, although it is important to note that only three studies

Table 3: Search terms used by Pinquart and Sörensen (2006)

(1) Dementia or Alzheimer's disease
<i>and</i>
(2) Caregiver or carer or caregiving
<i>and</i>
(3) Intervention or trial or support or training

Table 4: Search terms used by Gallagher-Thompson and Coon (2007)

(1) Caregiver or caregiving or family caregiver or carer or caring or care
<i>and</i>
(2) Dementia or Alzheimer's or frail or elder or cognitively impaired or cognitive impairment
<i>and</i>
(3) Intervention study or evaluation study or experimental design or quasi-experimental design or memory clinic or counselling or psychoeducation or technology or support group or psychotherapy or care management or case management or multicomponent or environmental

were included within this category. The average effect size for multicomponent interventions was relatively low, but it again should be noted that only two studies were reviewed within this category, and the outcome measures were solely focused on depression.

In summary, consistent with other works (Schulz, Martire and Klingler, 2005; Sörensen, Pinguart and Duberstein, 2002), Gallagher-Thompson and Coon (2007) concluded that the most effective interventions were those that targeted specific components of caregivers' quality of life, and included some combination of skill building, education and support. Their review highlighted the need for further investigation into: i) the impact of individual components within multicomponent studies; ii) the mechanisms of change within interventions; and iii) interventions that are most effective for people from various ethnic and cultural backgrounds. The review by Gallagher-Thompson and Coon (2007) also raises particular

questions about: i) identifying appropriate interventions for carers supporting people at different stages of illness; ii) identifying the characteristics of those who benefit most; and iii) understanding the theoretical underpinning for the impact of technology-based interventions.

Following discussion and direction from the funder, this review will add to the substantive and relatively contemporary literature by combining (and then augmenting) search and inclusion criteria from the studies by Pinguart and Sörensen (2006) and Gallagher-Thompson and Coon (2007), in order to undertake a review of psychological interventions for carers of people with dementia. The focus of the review by Gallagher-Thompson and Coon (2007) reflects more closely the area of literature of interest to the funding body for the current review. The remainder of this review therefore makes greater reference to, and more links with, the work of Gallagher-Thompson and Coon (2007).

Method

Prior to undertaking this review, the methodology and parameters of the review were agreed with the funding body, the British Association for Counselling and Psychotherapy. The work includes quantitative and qualitative studies, and aims to synthesise relevant policy, theory, research and practice literature to enable a broad understanding of the issues and to maximise applicability of the findings. Specifically, the review will update and develop two previous substantive reviews on this topic area by Pinquart and Sørensen (2006) and Gallagher-Thompson and Coon (2007). By updating and extending these findings, this review will focus on studies that investigate psychological interventions for carers of people with dementia published between 2005 and 2011. This review was conducted in two phases.

Phase one applied and assimilated search criteria similar to the earlier reviews on this topic area by Pinquart and Sørensen (2006) and Gallagher-Thompson and Coon (2007). Accordingly, criteria for inclusion were as follows:

- The care receiver had a dementia.
- The primary/significant focus of the outcome measures was a psychosocial measure of carer wellbeing.
- The intervention was underpinned by a psychological theory of change.
- Paper in English language.
- Consistent with Gallagher-Thompson and Coon (2007), the study used random assignment (Yon and Scogin, 2007). However, unlike Gallagher-Thompson and Coon (2007), the researchers decided to include studies for which an effect size could not be computed. This enabled emphasis on articles that provided clinically relevant and meaningful outcomes, as not all studies report effect sizes and it is not always possible to compute them from available data. However, in most other ways, these studies are robust. Therefore, inclusion of these studies has helped to collate a meaningful and relevant clinical research picture.

Phase two identified and incorporated qualitative studies published between 2005 and 2011. The inclusion criteria were as in phase one above, excluding points two and five, and with two additional criteria:

- Primary method of analysis employed was a qualitative method.
- Original, empirical data.

In order to update previous reviews on this specific topic area, literature published between 2005 and 2011 was searched using the terms shown in Table 5. In addition, new search terms were added and searched for (Table 5, bold type). The electronic databases Medline, PsycINFO, ERIC and PubMed were used to conduct the search.

The results yielded more than 1,000 articles to be reviewed for relevance. The abstracts of these articles were read and assessed against each of the inclusion/exclusion criteria. Following this 'screening' process, the full texts of 48 of these studies were deemed as potentially relevant, and were thus examined further.

Of the 48 studies identified as potentially relevant for inclusion, 18 did not use random assignment, seven were not underpinned by psychological models, and the primary outcome measure of three of the studies was not a measure of carer wellbeing. This resulted in 17 quantitative studies and three qualitative studies meeting the relevant inclusion criteria (Figure 1). Thus, 20 studies were included in this review, doubling the

Table 5: Search terms

(1) Caregiver or caregiving or care or caring
<i>and</i>
(2) Dementia or Alzheimer's or cognitively impaired or cognitive impairment or mild cognitive impairment or MCI
<i>and</i>
(3) Intervention study or evaluation study or experimental design or quasi-experimental design or memory clinic or counselling or psychoeducation or technology or support group or psychotherapy or case management or care management or multicomponent or environmental or environmental or cognitive behavioural therapy or CBT or family or systemic

number examined and synthesised into review literature since the review by Gallagher-Thompson and Coon (2007) (Table 6).

Quantitative studies

Data were extracted by SJL and RE. Following the reading of each study by these two authors, data extraction sheets were used to produce an agreed understanding of each study (Appendix 1). Following extraction of data, criteria were developed in order to evaluate the quality of each of the selected studies (Appendix 2). The criteria were developed by the authors so as to be meaningful and appropriate (D Lee, personal communication, 30 March 2007), but were informed by relevant literature (CONSORT, 2010; STROBE, 2007). Initially, a maximum score of two was assigned to each criterion. Following this, the authors agreed a number of criteria that were felt to be of particular importance; these were assigned a maximum score of four (Appendix 2). The guidance checklists were used by the team to give each study a score; ratings were then compared and agreement reached to give a final score for each study (Appendix 4). An example of this process is outlined below using the study by Hepburn et al (2005) (Table 7).

Qualitative studies

Data were extracted by JJ and RE. Following the reading of each study by these two authors, data extraction sheets were used to produce an agreed understanding of each study (Appendix 1). Following extraction of data, criteria were developed in order to evaluate the quality of each of the selected studies (Appendix 3). The criteria were developed by the authors so as to be meaningful and appropriate (D Lee, personal communication, 30 March 2007), but were informed by relevant literature (CASP, 2006). A maximum score of three was assigned to each criterion. The guidance checklists were used by the team to give each study a score; ratings were then compared and agreement reached to give a final score for each study (Appendix 5). An example of this process is outlined below for the study by Mackenzie (2006) (Table 8).

Consistent with Gallagher-Thompson and Coon (2007) and with other previous works (eg Bourgeois, Schulz and Burgio, 1996; Gatz et al, 1998; Sørensen et al, 2002), studies were identified that fell within the following three categories of type of intervention: i) psycho-educational skill-building; ii) psychotherapy-counselling; and iii) multicomponent. In addition, studies were grouped into a fourth intervention category named iv) technology-based.

1. Psycho-educational skill-building studies

To be included within this category, it was necessary for an intervention to aim to increase knowledge of dementia and

Figure 1: Flow diagram of the literature search and retrieval

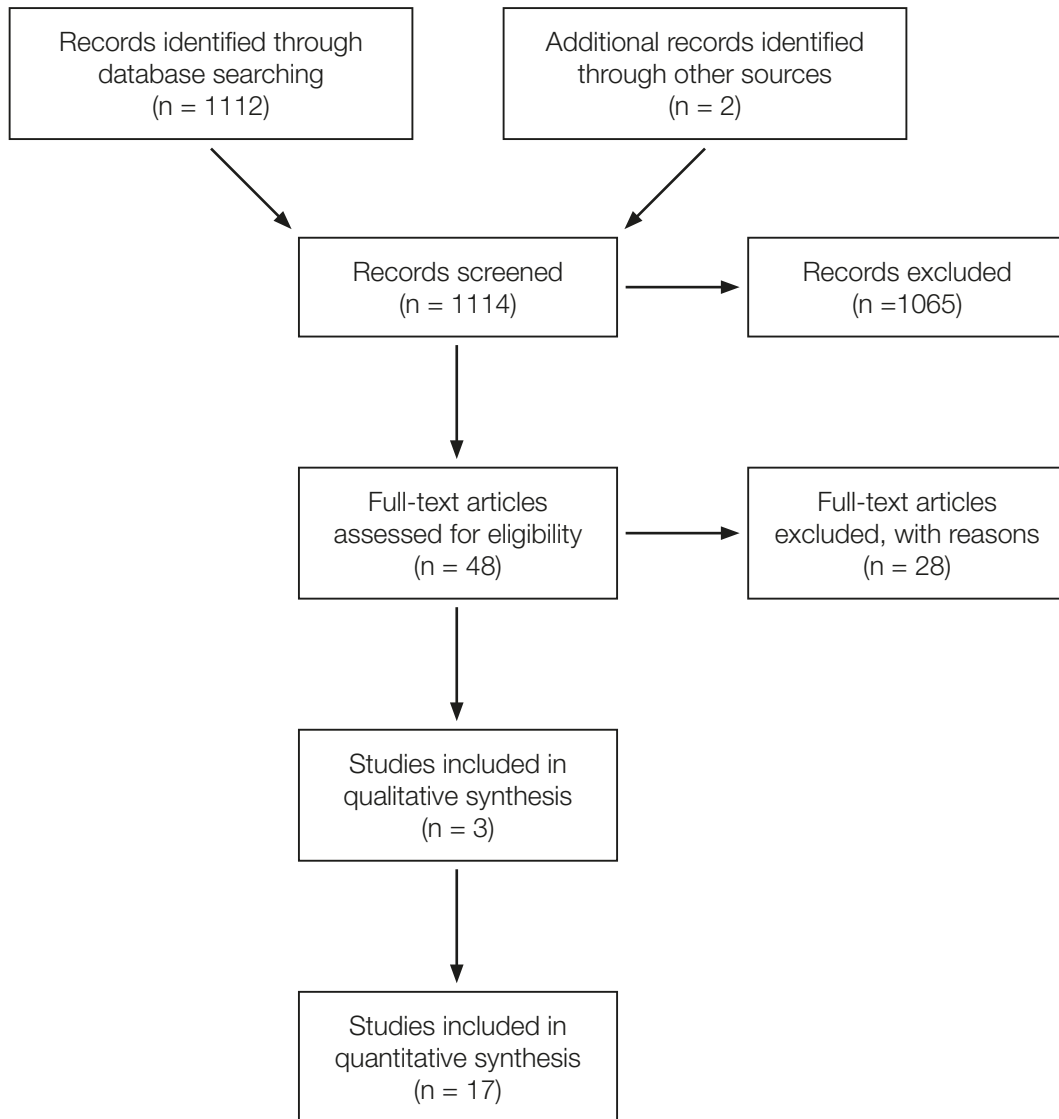


Table 6: Numbers of studies

	Psycho-educational skill building studies	Psychotherapy-counselling studies	Multicomponent studies	Technology-based studies	Total
Gallagher-Thompson and Coon (2007)	14	3	2	N/A	19
Present review	8	1	6	5	20

explore coping skills for managing emotional difficulties arising as a primary consequence of a person's dementia. These interventions would aim to provide information about dementia and strategies for dealing with its impact, as well as information on local services. They would also explore the relationship between the carer and the person with dementia, discuss social networks, and address the managing of emotions.

2. Psychotherapy-counselling studies

To be included in this category, it was necessary for psychotherapy or counselling to be undertaken in an individual or group format. In keeping with the distinction

made by Gallagher-Thompson and Coon (2007), studies with interventions that emphasised the therapeutic relationship would be included in this category rather than the psycho-educational skill-building category.

3. Multicomponent studies

To be included in this category, it was necessary for an intervention to combine two or more conceptually different approaches into one programme. Approaches within this category might include, for example, combinations of individual counselling, family counselling, support group work and telephone support.

Table 7: Example of the quality evaluation process (quantitative studies)

	Maximum score possible	Score obtained
Background		
Does the cited literature clearly explain the field of research?	2	2
Are there clearly defined research questions?	2	2
Is there an argument/rationale for the importance of these research questions?	2	2
Does the study discuss the theory which underpins its intervention?	4	4
Methods		
Are the outcome measures appropriate for the research question? Have they been justified?	4	4
Is the background of those delivering the interventions stated?	2	0
Does the paper state that those delivering the interventions were trained?	2	0
Does the paper state that those delivering the interventions received supervision?	2	0
Was a manual provided for the intervention?	2	0
Does the paper mention treatment fidelity? Was treatment adherence monitored adequately?	2	0
Does the paper discuss the intervention in enough detail for replication?	2	2
Does the paper discuss 'mode of delivery' in sufficient detail?	2	2
Has measurement bias been accounted for by blinding?	2	0
Have the inclusion and exclusion criteria of participants been well described?	2	2
Has sufficient detail been provided about where the sample was recruited from?	2	2
Have power calculations been conducted?	4	0
Was the control group an intervention group?	2	0
Results/Analysis		
Were all groups similar at the beginning of the study?	2	2
Was the sample size sufficient?	4	4
Is power reported?	2	0
Has sufficient detail of statistics been reported?	2	2
Has effect size been reported?	4	4
Is clinical significance discussed as well as statistical significance?	4	4
Are the data presented clearly?	2	2
Conclusions		
Are the conclusions of the study related to clinical practice?	4	4
Does the study adequately answer the research questions?	2	2
Have future avenues for further research been opened up?	4	4
Limitations		
Has the study acknowledged/discussed its limitations?	2	2
TOTAL	76	52

4. Technology-based studies

To be included in this category, it was necessary for an intervention to use the telephone, or another mode of technology, as a significant vehicle for delivery of the intervention. Whilst it could be argued that the criterion for this category is based upon the mode of delivery rather than the theory/content of the therapeutic approach, the researchers felt that defining this category was helpful as the dementia care field is presently in new territory as regards understanding

how technology can influence the delivery of interventions and outcomes.

During the last decade, technology has influenced the ways in which psychological interventions are delivered in a striking and significant way (Drigas, Koukianakis and Papagerasimou, 2011). However, as highlighted by Schulz, Lustig, Handler and Martire (2002), whilst it has been demonstrated that technology-based interventions can be effective in enhancing social support and promoting emotional wellbeing in family caregivers

Table 8: Example of the quality evaluation process (qualitative studies)

	Maximum score possible	Score obtained
Was the research design appropriate to address the aims of the research?	3	3
Was the recruitment strategy appropriate to the aims of the research?	3	3
Were the data collected in a way that addressed the research issue?	3	3
Has the relationship between researcher and participants been adequately considered?	3	0
Have ethical issues been taken into consideration?	3	3
Was the data analysis sufficiently rigorous?	3	3
Is there a clear statement of findings?	3	2
How valuable is the research?	3	3

of people with a chronic illness or disability, it has not been demonstrated that changes are attributable to technology *per se*. Thus, we still have much to explore in order to gain a better understanding of the processes of change within technology-based interventions. What is more, exploration in this area may well further understanding of the way our current interventions work. For example, if the therapeutic relationship is taken as illustrative and representational, there is some evidence that relationship factors drive outcome (eg Luborsky, Singer and Luborsky, 1975). It is therefore important to separately assess interventions that are delivered in a 'non-traditional' manner in order to monitor how the therapeutic relationship is affected by technological advances. Conversely, despite some helpful research findings (eg Horvarth and Symonds, 1991; Martin, Garske and Davis, 2000), there are still many conflicting debates in this area; for instance, about how the therapeutic relationship influences outcomes, and what components constitute the therapeutic relationship. By examining the outcomes of

interventions based on the mode of their delivery, it may well be possible to gain further insight into the processes of change that occur during therapeutic encounters.

Technology-based interventions also offer potential benefits to carers who do not use services for logistical reasons; for example, not being able to find support for the person with dementia to enable the use of a service by the carer (Bank, Argüelles, Rubert, Eisdorfer and Czaja, 2006), being based in a rural area (Glueckauf et al, 2005), and having other appointments to attend (Bank et al, 2006).

To summarise, on the one hand it could be argued that a 'technology-based' category is not a consistent conceptual distinction when viewed alongside the other categories. On the other hand, by defining and applying such a category, it can help to contextualise current activity in this relatively new terrain, thus supporting future research work, clinical practice and, ultimately, the development and reporting of theory.

Results

As identified by Gallagher-Thompson and Coon (2007), the researchers found that studies could be categorised within psycho-educational skill-building, psychotherapy/counselling, and multicomponent studies. As highlighted earlier, a relatively large number of technology-based studies were identified. All studies that met the inclusion criteria are considered under the following four headings.

1. Psycho-educational skill-building studies

As Table 9 reveals, eight studies met the criteria for this category (including one qualitative). The backgrounds of those delivering these interventions included a master's degree mental health nursing student (Chu et al, 2011), master's level research associates (Stern et al, 2008), nurses (Ulstein, Sandvik, Wyller and Engedal, 2007; Villareal-Reyna, Salazar-González, Cruz-Quevedo, Carrillo-Cervantes and Champion, 2010), group leaders with extensive experience and training in group counselling and support work (Chu et al, 2011), bachelor's level staff with experience in gerontology, psychology/social work graduate students, and professional psychologists and social workers (Rabinowitz, Mausbach, Coon, Depp, Thompson and Gallagher-Thompson, 2006).

The quality of the quantitative studies in this category is mixed. Some of the studies talk specifically about some or all of the following: training, treatment protocols, manuals, and adhering to treatment fidelity (Chu et al, 2011; Rabinowitz et al, 2006; Ulstein et al, 2007; Villareal-Reyna et al, 2010). However, others do not mention specific training (Stern et al, 2008), adherence to treatment fidelity (Hepburn et al, 2005; Perren, Schmid and Wettstein, 2006; Stern et al, 2008; Ulstein et al, 2007), use of a manual (Hepburn et al, 2005; Perren et al, 2006; Ulstein et al, 2007), or do not specify who delivered the intervention (Hepburn et al, 2005; Perren et al, 2006). None of the studies in this category addresses the issue of data collection being undertaken by 'blinded' researchers, only two report power calculations (Ulstein et al, 2007; Villareal-Reyna et al, 2010), and only two discuss clinical significance as well as statistical significance (Hepburn et al, 2005; Villareal-Reyna et al, 2010).

About half of the studies in this category make it clear for the reader to see which psychological models have informed the study intervention, and to understand the ways in which the models underpin the work (Hepburn et al, 2005; Rabinowitz et al, 2006; Villareal-Reyna et al, 2010). All the studies discuss their work in relation to clinical practice, some in particular detail (Chu et al, 2011; Hepburn et al, 2005; Stern et al, 2008; Villareal-Reyna et al, 2010), and all studies discuss the populations from which participants were drawn, which helps the reader to make inferences and plan future studies. All these points are important not only for the merit of the individual studies, but they also lend particular weight to the overall evidence base for the use of psychological interventions within clinical practice.

Following evaluation of the studies against the checklists, the highest score obtained within this category was from the work by Villareal-Reyna et al (2010) (Appendix 4). The comprehensive nature of this study ensured, in our opinion, that it was useful for both clinicians and academic researchers. The paper contains a detailed explanation of the intervention and explains the ways in which the programme was built on psychological models. Clear explanation of the clinical significance of the results, alongside the statistical significance, allows clinicians to draw ideas for practice, as well as informing future research.

Seven of the eight quantitative studies in this category produced significant results. These studies demonstrated impacts upon depression, emotional wellbeing, quality of life, attitudes towards

caregiving, and anxiety. It appears that these interventions helped carers to maintain levels of wellbeing over time; those who did not receive interventions were more likely to experience declines in wellbeing over time.

In a UK-based study of diverse ethnic populations that identified the support needs of family carers from Eastern European and South Asian communities living in a northern England city, Mackenzie (2006) reported on a three-stage study using qualitative reporting methods. Stage one of the project used semi-structured interviews to explore: i) carers' experiences of caregiving; ii) the nature and availability of family, community, and mainstream service support; and iii) knowledge of dementia and what the carers would want from a support group programme. Stage two involved the project team in generating and delivering three 10-week support group programmes all tailored to reflect the needs of carers (identified in stage one). The groups were delivered in a range of preferred community languages: one programme for Pakistani carers, one for Eastern European carers, and a third for an ethnically mixed group of South Asian carers. Each programme ran consecutively over a 12-month period. Advocacy support for carers also began in stage two and continued for as long as the carers wished. Field note data were collected during the support group meetings. Stage three of the project involved a follow-up interview with each of the family carers six weeks after the completion of their support group programme. Data gathered in the first and third stages were content analysed and organised into themes. Field notes from the second stage of the project were thematically analysed and cross-referenced with the interview data on completion of the third stage of the project. This comprehensive design provided a rich source of data analysis and reporting that demonstrated, firstly, the need for more culturally sensitive and aware services at the point of diagnosis and, secondly, provided context-specific insights as to why the seeking of a diagnosis may be delayed. These are issues that are important for the NDS (Department of Health, 2009), especially Objective 2 'Good-quality early diagnosis and intervention for all'.

2. Psychotherapy-counselling studies

As Table 10 reveals, there was one qualitative study that fell within this category. Of note, this study contained a mixed-methods design. The quantitative strand of the study, to the best of our knowledge (as at February 2012), is still awaiting publication.

Those delivering the intervention in this study were clinicians with an interest in counselling older couples confronting Alzheimer's disease. Supervision for clinicians was undertaken with team colleagues, an approach that provided a space for exploration of feelings expressed by clients and personal clinician responses. The approach focused on the marital couple as a unit, targeting the relationship, the diagnosis of Alzheimer's disease, and current conflicts as areas for therapeutic work. Those undertaking the interventions had backgrounds in psychodynamic and Gestalt therapies, and they drew ideas in particular from transactional analysis (eg Harris, 1969; Winnicott, 1971).

The study in this category reported case vignettes and clinician reflections, and did not collect additional qualitative data from participants (Auclair et al, 2009). This is probably both a strength and a weakness of the study. For instance, clinician reflections about content and process of therapeutic interventions are a valuable means of developing knowledge. Conversely, additional data collected from participants following counselling sessions may have strengthened the study. Unfortunately, the study by Auclair et al (2009) did not discuss the way in which data analysis was undertaken, which fundamentally undermined confidence in the results.

Table 9: Psychoeducational-skill building carer intervention studies

Quantitative Studies

Author	Country	Sample	Condition	Manual protocol	Length of treatment	Outcome measure	Finding	Quality score
Hepburn et al. (2005)	USA	N = 430 (215 dyads of caregivers (CGs) and people with dementia (PWD)). Majority female carers, majority spouses. Mean CG age = 67.	Condition 1 – The Partners in Caregiving program (PIC). Psychoeducation group approach aimed at developing strategies for dealing with impact of dementia, management techniques, and options made around caregiving decisions. Condition 2 – no attention, wait-list control (WLC).	Programme based on stress-mediation framework (Lazarus & Folkman, 1984; Pearlin et al., 1990).	Condition 1 (PIC) – Six weekly two hour sessions held over consecutive weeks. Condition 2 – Wait-list.	Scale reporting on physical self-maintenance and instrumental abilities (Lawton & Brody, 1969). Revised Memory and Behavior Problems Checklist (Teri et al., 1992). Scales reporting on perceptions of relational deprivation, role captivity, loss of self, caregiving competence, management of meaning, and caregiving mastery (Pearlin et al., 1990). Burden scale (Zarit et al. 1985). Depressive symptoms scale (Radloff, 1977). Affect scale (Bradburn, 1969). Anxiety scale (Spielberger et al., 1970). Beliefs about caregiving scale (Phillips et al., 1989). Decisional conflict scale (O'Connor, 1995).	At 6 month post-test, PIC > WLC; less distress and improved attitude about the need to control and scrutinize care recipients. Changes in carers' understanding, outlook, and confidence allows carers to manage situations in a less controlling fashion, thus mediating the effects of stressors, leading to less overall distress.	52/76
Chu et al. (2011)	Taiwan	N = 60. Spouses = 32%. Children or a daughter-in-law = 64%.	Condition 1 – Structured support group. Topics covered included emotions of carers, problematic behaviours, self-care, communication, and information on local services. Condition 2 – treatment as usual.		Condition 1 – Twelve week programme.	Beck Depression Inventory (BDI-II) (Beck, Steer, & Brown, 1996). Caregiver Burden Inventory (Novak & Guest, 1989).	At 12-week and 16-week follow-up, intervention group > control group on measure of depression. No significant difference on measure of carer burden.	45/76
Rabinowitz et al. (2006)	USA	N = 190. Mean age = 57.	Condition 1 – coping with caregiving class (CWC) - cognitive behavioural mood management skills, including relaxation techniques and engaging in pleasant activities. Condition 2 – enhanced support group (ESG).	Condition 1 – Intervention primarily derived from the works of Beck (1979) and Lewinsohn (1974, 1975) which focus on the role of cognition and behaviour in negative affective states. Condition 2 – Patterned after community carer support groups and based on principles outlined in a support group manual published by the Alzheimer's Association.	Condition 1 – weekly two-hour sessions for ten weeks, monthly sessions for eight months. Condition 2 – weekly two-hour sessions for ten weeks, monthly sessions for eight months.	The self-efficacy scale (available on request from the authors). 10-item modified version of the 20-item STAIS-A.D. (Teri et al., 1992). 20-item Centers for Epidemiological Studies - Depression Scale (Radloff, 1977). The Ways of Coping Checklist (Vitaliano et al., 1985). 11 questions from The Inventory of Socially Supportive Behaviours (Stokes & Wilson, 1984). Evaluation questionnaire reporting satisfaction with the amount of tangible, emotional, and informational support carers had received over the previous month.	Low baseline self-efficacy for obtaining respite predicted significantly > improvement on outcomes in the CWC than in the ESG. Low baseline self-efficacy for obtaining respite predicted significantly greater improvement on all outcomes in the CWC than in the ESG. Participants in the CWC improved significantly more than participants in the ESG condition when baseline self-efficacy for controlling upsetting thoughts was low.	49/76

Author	Country	Sample	Condition	Manual protocol	Length of treatment	Outcome measure	Finding	Quality score
Perren et al. (2005)	Switzerland	N = 256 (128 dyads of CGs and PWD). Mean age of CGs = 68. Spouses = 90%.	Condition 1 – Carer education sessions. Designed as a psycho-educational group. Aimed at imparting knowledge regarding symptoms of dementia and the course of the disease, strengthening of self-perception to improve self care, optimising the relationship dynamics between care recipient and carer, and increasing social competence to enable carers to solicit social support and formal help. Condition 2 – Instruction for memory training. Participants receive a booklet with memory training units and instructed to practice the exercises once a week.		Condition 1 – Eight weekly sessions. Condition 2 – Eight weeks.	'Emotional wellbeing' questionnaire (Weiss et al., 1990). Short version of the Schedule for the Evaluation of Individualised Quality of life (SEIQoL) (Meier et al., 1999). Due to high correlation of the above measures, scores were combined to give an 'overall subjective well-being' measure.	Carers' well-being in the intervention group remained stable over time, whereas carers in the control group reported a significant decrease in their well-being. After 12 months, for participants in the control group an increase in behavioural problems was associated with a decrease in carer well-being, but this was not the case for participants in the intervention group. After 12 and 24 months, increases in functional impairment were significantly associated with carer well-being in the control group, but not in the intervention group. After 12 and 24 months, the greater the increase in cognitive impairment, the lower carer well-being for participants in the control group but not the intervention group.	30/76
Stern et al. (2008)	USA	N = 66. Mean age = 64. Female = 89%. Spouses = 66%.	Condition 1 – Psycho-education groups. Provided carers with the knowledge and tools needed for planning, addressing, and taking action regarding driving cessation for their loved one. Condition 2 – Written materials only. Condition 3 – Treatment as usual, followed by written materials after post-test assessment.	Sessions included information on dementia, discussion on CGs circles of support, video case-study, summary.	Four two-hour group sessions (four to ten CGs per session).	7-item questionnaire on self-efficacy modelled on Self-Efficacy Questionnaire (Fortinsky et al., 2002). The Brief COPE scale (Carver, 1997). 2-item scale created based on the construct of preparation as one of the stages of behaviour change described by Prochaska and Velicer (1997). Three questions about concern about relationship and communication with loved one about driving. Two questions asking if participants were aware of the "Agreement with My Family about Driving" and, if so, whether they had used the agreement.	Post-test participants in active intervention group > on measures of self-efficacy, communication, and preparedness.	45/76

Author	Country	Sample	Condition	Manual protocol	Length of treatment	Outcome measure	Finding	Quality score
Villreal-Reyna et al. (2010)	Mexico	N = 46. Mean age = 53. Majority of CGs were daughters.	Condition 1 – Cognitive-conduct (CC) - focus on developing skills to change dysfunctional or negative thoughts, and thoughts to improve one's state of mind. Condition 2 – Laughter (L) - develop skills to increase ability to use humour and increase number of situations in which this occurs. Condition 3 – Cognitive-conduct and laughter (CCL) Condition 4 – Group sessions which provided information about home safety and accident prevention (C).	Condition 1 – CC - Taught cognitive-behavioural skills (Gallagher-Thompson et al., 2001, 2003). Condition 2 – Based on previous work of Elizondo (Proyecto RISA, 2002).	Condition 1 – Eight weekly sessions. Condition 2 – Eight weekly sessions. Condition 3 – Eight weekly sessions. Condition 4 – Eight weekly sessions.	Finding Significance Through Care: Attitudes Towards Care Scale (Farran, Miller, Kaufman, Donner, & Fogg, 1999). Inventory of State Anxiety (Spielberg & Diaz-Guerrero, 2002).	On attitude scale, CCL > L, but not CC. CC group > L and C groups. On anxiety scale, CCL and L and CC > C.	66/76
Ulstain et al. (2007)		N = 342 (171 dyads of CGs and PWD). Female CG = 64%. Spouses = 70%.	Condition 1 – An educational programme about dementia, plus psycho-educational groups. The groups covered issues including communication, problem-solving, and understanding behavioural changes. Condition 2 – Treatment as usual.	Cognitive techniques used within the groups based on work by James, Powell, & Reichelt (2001).	Condition 1 – One three-hour educational programme. Six two-hour group sessions. Ad hoc counselling available. Condition 2 – Ad hoc counselling available.	Norwegian version of the Relatives' Stress Scale (Ulstain, Wyller, & Engedal, 2007)	No significant difference between intervention and control group.	51/76

Qualitative Studies

Author	Country	Sample	Condition	Manual protocol	Length of treatment	Methodology	Finding	Quality score
Mackenzie (2006)	UK	N = 21. 76% = South Asian. 24% = Eastern European.	Condition 1: Support group programme combined with advocacy support.	Group theoretical approach based on ideas of stigma (e.g. Goffman, 1963; Scheff, 1990), culture specific experiences of the second world war (Lukas & Davis, 2001), and culture about mental illness (Ahmad, 2000).	Condition 1: Three ten week support group programmes: one for Pakistani carers, one for Eastern European carers, one for ethnically mixed group of South Asian carers. Advocacy support provided for as long as required by participants.	Semi-structured interviews, content and thematic analysis. Scheff's (1990) work provided an analytical framework through which the experiences carers shared in the project about managing stigma could be obtained. Analysis/interpretation undertaken by approaching stigma from its source as an exterior influence, analysing how this exerted control over the way CGs managed their care- giving role, determining where the roots of stigma are located, and gaining an insight into the ways that shame and inner pride are managed in the face of two cultural frameworks.	The management of stigma and the ways of understanding dementia were common themes which influenced experiences and responses to the intervention. For Eastern European CGs, war and persecution were factors in the stigma process. Loss of social networks due to beliefs about how others would view the person with dementia and their family meant that the intervention provided a valuable support network. For South Asian CGs, religious beliefs, particularly causes of mental illness, were significant factors in the stigma process. Concealment of the person with dementia resulted in isolation, thus the intervention acted as a source of validation and social support.	20/24

Table 10: Psychotherapy-counselling carer intervention studies

Qualitative studies

Author	Country	Sample	Condition	Manual protocol	Length of treatment	Methodology	Finding	Quality score
Auclair et al. (2009)	USA	N = 84 (42 dyads of CGs and PWD). All spousal relationships.	Condition 1: Couple counselling aimed at examining the impact of Alzheimer's disease on the marital relationship and communication.	Condition 1: A present-oriented approach, addressing long-standing dynamics if relevant to presenting problems. Approach based on cognitive-behavioural approaches, psychodynamic theory, Gestalt therapies, and Transactional Analysis (e.g. Harris, 1969; Winnicott, 1971).	Condition 1: Six couple counselling sessions undertaken over a period of two months. Brief ad hoc telephone counselling provided for duration of participation in the study.	Qualitative analysis of transcripts of counselling sessions.	Shifts demonstrated in participants towards a more accepting, non-judgemental, non-blaming attitude. Shifts made towards a more optimistic and collaborative view of the future.	14/24

3. Multicomponent studies

Table 11 shows that six studies met the inclusion criteria for this category (one qualitative). All comprised a mixture of counselling sessions, group work, and telephone counselling. Of note, three out of the seven studies (Drentea, Clay, Roth and Mittelman, 2006; Gaugler, Roth, Haley and Mittelman, 2008; Roth, Mittelman, Clay, Madan and Haley, 2005) were based on the same data set from a large study undertaken at the New York University Aging and Dementia Research Center (NYU-ADRC). Beginning in 1987, this study is a randomised trial of a psychosocial intervention for spousal carers of people with Alzheimer's disease (eg Gaugler et al, 2008; Mittelman, Epstein and Pierzchala, 2003). It was designed to provide counselling and enhance social support throughout the entire journey of supporting a person with Alzheimer's disease. Two other studies within this category were developments from the original NYU-ADRC study (Burns et al, 2010; Mittelman, Brodaty, Wallen and Burns, 2008), and thus the multicomponent intervention of five studies in this category was based on the same treatment protocol. The qualitative study (Sørensen, Waldorff and Waldemar, 2008) was undertaken with a small sample of participants from a large national study carried out in Denmark, the Danish Alzheimer Disease Intervention Study (DAISY) (Waldemar et al, 2010). This study aimed to explore the clinical and health economic impact of a semi-tailored intervention programme for people with dementia and carers.

Those delivering these interventions included specialist nurses with experience in the field of dementia care (Sørensen et al, 2008), and professionals with advanced degrees in social work, psychology, counselling or gerontology (Drentea et al, 2006; Gaugler et al, 2008; Roth et al, 2005).

Only one study in this category explicitly discussed training and supervision of those delivering the interventions (Sørensen et al, 2008), one discussed the use of a manual (Gaugler et al, 2008), and none of the studies addressed treatment fidelity.

One study (with two published papers) used blinded assessors for data collection (Burns et al, 2010; Mittelman et al, 2008). This study also undertook power calculations and discussed effect sizes. The other studies within this category did not address these issues.

The qualitative study in this category (Sørensen et al, 2008) collected data by semi-structured in-depth interviews. These were conducted separately with each person in 10 couples before the counselling-based intervention, and one following completion of the intervention. For the analysis, a template organising style of interpretation was used which appeared appropriate for the design. In this study, the initial codes were refined and modified during the analytic process using iterative cycles between organising, connecting and corroborating

codes. Information was then collected into abstract concepts, as reported in the study findings.

All the quantitative studies in this category found significant results. The outcome measures focused predominantly on depression and social support. Our impression is that these studies demonstrated improvements in wellbeing in carers who were in the treatment conditions.

4. Technology-based studies

Five quantitative studies meet the criteria for this category (Table 12). Two of the papers are based on the same data set (Belle et al, 2006; Lee, Czaja and Schulz, 2010), and a further paper uses the same protocol (Nichols, Martindale-Adams, Burns, Graney and Zuber, 2011). These three papers have been undertaken as part of the 'Resources for Enhancing Alzheimer's Caregiver Health' (REACH) programme.

All studies in this category used either computer-assisted screen telephones (Belle et al, 2006; Finkel et al, 2007; Lee et al, 2010), or ordinary telephones (Farran et al, 2007; Nichols et al, 2011), as a significant vehicle for delivering the intervention. All studies used a mixture of individual sessions and group support sessions. The individual sessions undertaken within the three studies based on the REACH programme (Belle et al, 2006; Lee et al, 2010; Nichols et al, 2011) can be defined as counselling sessions. The individual sessions within the studies by Finkel et al (2007) and Farran et al (2007) are more in keeping with psycho-educational approaches. Thus, the technology category contains a combination of the approaches used within other categories.

Those delivering these interventions included clinical social workers (Farran et al, 2007; Finkel et al, 2007; Nichols et al, 2011), psychologists or nurses (Farran et al, 2007; Nichols et al, 2011), and people with at least a bachelor's degree (Belle et al, 2006; Lee et al, 2010).

All the studies in this category talked about using certified interventionists, or provided specific training for those implementing the intervention. The majority of studies provided supervision, monitored adherence to treatment fidelity, and used assessors who were blinded to treatment condition (Belle et al, 2006; Farran et al, 2007; Finkel et al, 2007; Lee et al, 2010). Two studies provided a manual (Farran et al, 2007; Nichols et al, 2011). Whilst only two papers (from the same study) address the use of power calculations (Belle et al, 2006; Lee et al, 2010), all the studies apart from one (Farran et al, 2007) discuss clinical significance as well as statistical significance.

All the studies in this category found significant results on the outcome measures of depression, burden, and social support. The technology-based interventions appear to demonstrate improvements in wellbeing for those in the treatment groups.

Table 11: Multicomponent carer intervention studies

Quantitative Studies

Author	Country	Sample	Condition	Manual protocol	Length of treatment	Outcome measure	Finding	Quality score
Gaugler et al. (2008)	USA	N=406 (303 dyads of CGs and PWD). All spousal pairs.	Condition 1 – The New York University Caregiver Intervention (NYUCI). Three components: individual and family counselling, support group participation, ad hoc counselling. Condition 2 – Treatment as usual.	Condition 1: Based on the NYU-ADRC psychosocial intervention (e.g. Mittelman et al., 1995).	Condition 1 (NYUCI) – Six counselling sessions undertaken over four month period (two with the carer only, and four with the carer and at least one other family member - not the person with AD). Following counselling, weekly support groups. Ad-hoc counselling - throughout the duration of participation, the carer was free to contact their study counsellor by telephone. Participants attended support groups until their participation in the study had ended.	Dates of nursing home admission were derived from follow-up interviews, records or ad hoc telephone contacts. Zarit Burden Interview (Zarit et al., 1980). 30-item version of the Geriatric Depression Scale (GDS-30) (Yesavage et al., 1982).	Intervention group burden < usual care group at each point after nursing home admission (NHA). Intervention group depression scores < usual care group at all points before NHA with the exception of baseline. These differences were maintained after NHA for approximately four months. This significance was lost due to more rapid decreases in depression in the usual care group following NHA.	43/76
Drentea et al. (2006)	USA	N=183. Mean age CG = 72. Female = 32%.	Condition 1 – Individual and family counselling, participating in a support group, and ad hoc counselling (as requested). Condition 2 – Treatment as usual.	Condition 1: Based on the NYU-ADRC psychosocial intervention (e.g. Mittelman et al., 1995).	Condition 1 – Two individual counselling sessions, one before and one after a series of family sessions undertaken over a four month period. Followed by weekly support groups. Ad hoc counselling was available for as long as participants remained in the study. Assessments undertaken for maximum period of five years.	Stokes Social Network List (Stokes, 1983). Additional items developed at the NYU-ADRC included questions about the amount and adequacy of support received, and whether the carer would use their supports in an emergency. Questions also about whether carer wanted more or less contact. Helpfulness of support rated in five key areas: emotional, physical, socializing, financial and advice.	Treatment group reported > levels of satisfaction with social support from within four months of being in the study, which then remained consistently higher over the five year period. Closer relationships, greater frequency of seeing family and friends, and more emotional support were all associated with greater average support satisfaction.	31/76

Author	Country	Sample	Condition	Manual protocol	Length of treatment	Outcome measure	Finding	Quality score
Roth et al. (2005)	USA	N = 312. Mean age = 71. Female = 58%.	Condition 1 – Individual and family counselling, participating in a support group, and ad hoc counselling (as requested). Condition 2: Treatment as usual.	Condition 1: Based on the NYU-ADRC psychosocial intervention (e.g. Mittelman et al., 1995).	Condition 1 – Two individual counselling sessions, one before and one after a series of family sessions undertaken over a four month period. Followed by weekly support groups. Ad hoc counselling was available for as long as participants remained in the study. Assessments undertaken for maximum period of five years.	Stokes Social Network List (Stokes, 1983). Additional items developed at the NYU-ADRC included questions about the amount and adequacy of support received, whether the carer would use their supports in an emergency and if the carer wanted more or less contact. Helpfulness of support rated in 5 key areas: emotional, physical, socializing, financial and advice. Memory and Behaviour Problems Checklist (Zarit et al., 1985). Geriatric depression scale (Yesavage et al., 1983).	Intervention > increase on objective and subjective measures of social support. Improvements in satisfaction with social support were found to be predictive of reductions in stressfulness appraisals and depression.	41/76
Mittelman et al. (2008)	US/UK/ Australia	N = 316 (158 CG and PWD dyads). Female = 56%. Mean age = 71.	Condition 1 – Donepezil and psychosocial intervention. Also received resource information and help in an emergency. Condition 2 – Donepezil only. Also received resource information and help in an emergency.	Condition 1 – Based on the NYU-ADRC psychosocial intervention (eg. Mittelman et al., 1995).	Condition 1 – Undertaken within three months of enrollment into the study. Psychosocial intervention consisted of two individual counselling sessions, one before and one after three family sessions. Ad hoc counselling on demand by telephone (and/or face-to-face in Australia) was available for as long as participants remained in the study. Donepezil was given for 24 months in both conditions one and two.	Beck Depression Inventory (BDI-II) (Beck, Steer, & Brown, 1996). Stokes Social Network List (Stokes, 1983). Revised Memory and Behavior Problems Checklist (Teri et al., 1992).	Treatment group > reduction in depression scores than control group.	51/76
Burns et al. (2010)	US/UK/ Australia	N = 316 (158 CG and PWD dyads). Female = 56%. Mean age = 71.	Condition 1 – Donepezil and psychosocial intervention. Also received resource information and help in an emergency. Condition 2 – Donepezil only. Also received resource information and help in an emergency.	Condition 1 – Based on the NYU-ADRC psychosocial intervention (eg. Mittelman et al., 1995).	Condition 1 – Undertaken within three months of enrollment into the study. Psychosocial intervention consisted of 2 individual counselling sessions, one before and one after three family sessions. Ad hoc counselling on demand by telephone (and/or face-to-face in Australia) was available for as long as participants remained in the study. Donepezil was given for 24 months in both conditions one and two.	Beck Depression Inventory (BDI-II) (Beck, Steer, & Brown, 1996). Stokes Social Network List (Stokes, 1983). Revised Memory and Behavior Problems Checklist (Teri et al., 1992).	Sydney participants in treatment group < likely to be admitted to nursing homes than those in Manchester and New York in treatment group.	43/76

Qualitative Studies

Author	Country	Sample	Condition	Manual protocol	Length of treatment	Methodology	Finding	Quality score
Sørensen et al. (2008)	Denmark	N = 20 (10 dyads of CGs and PWD). All spousal or cohabiting relationships. Mean CG age = 73. Female = 50%.	Condition 1: Condition 1 – The Danish Alzheimer Disease Intervention Study (DAISY). Five key components: Counselling sessions, courses providing information on dementia, information folders, outreach telephone counselling, logbooks to make notes about daily life and prepare for counselling sessions.	Condition 1 – The DAISY programme. Counselling sessions based on constructivist principles (Peavey, 1997) and self-validation processes (Ishima, 1993).	Condition 1 – Eight to twelve month programme overall. Counselling sessions: a) Two sessions with the patient and carer, b) Two sessions with the patient alone, c) Two sessions with the carer alone, d) One optional session with the patient, carer and family network. Courses: separate courses run for PWD and carers. Each contained five sessions. Information folder - provided at single time point. Outreach telephone counselling - approximately five-eight telephone calls with three-four week intervals.	Qualitative interviews, template organising style of interpretation.	Intervention was found to be stimulating and rewarding. CGs better able to cope with everyday life and social relations. Changes in awareness and attitudes demonstrated. There were no apparent negative outcomes of the intervention.	23/24

Table 12: Technology-based carer intervention studies

Quantitative Studies

Author	Country	Sample	Condition	Manual protocol	Length of treatment	Outcome measure	Finding	Quality score
Finkel et al. (2007)	USA	N = 36. Mean CG age = 65. Female = 68%. Spouses = 44%. Children = 53%. White = 92%. Black = 8%.	Condition 1 - Information provided about dementia, community resources, and strategies to enhance safety, communication, self-care, social support, and management of problem behaviours. The customised Computer-Telephone Integration System (CTIS) was the primary vehicle for intervention delivery. Condition 2 - Basic educational materials provided.	Condition 1 - Modelled after the intervention developed at the Florida site of the Resources for Enhancing Alzheimer's Caregiver Health (REACH) programme (Belle et al., 2006).	Condition 1 - The intervention occurred over six months and included two in-home sessions (initial and last session). Twelve sessions were conducted via the CTIS system. Eight sessions were individual and six sessions were group (six carers and a facilitator). Condition 2 - Information provided at baseline. Two brief (<15 minutes) telephone check-in calls at three and five months post-randomisation.	10-item version of the Centers for Epidemiologic Studies Depression Scale (CES-D) (Irwin et al., 1999). Revised Memory and Behavior Problems Checklist (Teri et al., 1992). Carer health and health behaviours scale (nine-item modified version) (Posner et al., 1993). Received social support scale from the Inventory of Socially Supportive Behaviours (Barrera et al., 1981; Krause et al., 1995). Three questions from the primary domains of the Revised Memory and Behavior Problem Checklist (memory, depression, and disruption) (Teri et al., 1992). Project evaluation questionnaire. Questionnaire evaluating the CTIS system (intervention group only).	No significant main effects of treatment group were detected. However, a significant relationship was found between baseline depression and level of depression following the intervention. Specifically, as baseline depression increased, carers in the intervention group demonstrated significantly greater improvements in depression. Similar results were obtained for social support: as baseline support increased, those in the intervention condition were more likely to maintain that support.	44/76
Lee et al. (2010)	USA	N = 642. Hispanic = 33%. White = 34%. Black = 33%. Mean CG age = 62.	Condition 1 - Intervention group involved a range of strategies: provision of information, didactic instruction, role playing, problem solving, skills training, stress management techniques, and telephone support groups. Condition 2 - Information only (provided by mail), and two "check-in" calls.	Condition 1 - Intervention focused on five target areas by providing education, skills to manage troublesome care recipient behaviours, social support, cognitive strategies for reframing negative emotional responses, strategies for enhancing healthy behaviours and managing stress. Analysis guided by the Stress Process Model of caregiving (Pearlin et al., 1990). Moderating variables included age, sex, educational level, CG-CR (care-receiver) relationship, social support, religious coping.	Condition 1 - Twelve 1.5 hour sessions (nine in-home), three 0.5 hour telephone sessions, and five structured telephone support group sessions. Undertaken over six month period. Condition 2 - information only (provided by mail), and two brief (<15 minute) "check-in" calls at three months and five months after randomization. Undertaken over six month period. Workshop on dementia and caregiving also provided at end of study (after 6-month assessment).	10-item version of the Centers for Epidemiologic Studies Depression Scale (CES-D) (Irwin et al., 1999). 12-item version of the Zarit Caregiver Burden Interview (Bedard et al., 2001).	Amongst Black CGs, those with lower religious coping > reduction in depression than those with higher levels of religious coping. Also amongst this group, older CGs > reduction in burden than younger CGs. Older Hispanics > decrease in burden compared to control.	50/76

Author	Country	Sample	Condition	Manual protocol	Length of treatment	Outcome measure	Finding	Quality score
Belle et al. (2006)	USA	N = 642. Hispanic = 33%. White = 34%. Black = 33%. Mean CG age = 62.	Condition 1 - The Resources for Enhancing Alzheimer's Caregiver Health (REACH) programme. Intervention group involved a range of strategies: provision of information, didactic instruction, role playing, problem solving, skills training, stress management techniques, and telephone support groups. Condition 2 - information only (provided by mail), and two "check-in" calls.	Condition 1 (REACH) - Intervention focused on five target areas by providing education, skills to manage troublesome care recipient behaviours, social support, cognitive strategies for reframing negative emotional responses, strategies for enhancing healthy behaviours and managing stress.	Condition 1 - Twelve 1.5 hour sessions (nine in-home), three 0.5 hour telephone sessions, and five structured telephone support group sessions. Undertaken over six month period. Condition 2 - information only (provided by mail), and two brief (<15 minute) "check-in" calls at three months and five months after randomization. Undertaken over six month period. Workshop on dementia and caregiving also provided at end of study (after six month assessment).	10-item version of the Centers for Epidemiologic Studies Depression Scale (CES-D) (Irwin et al., 1999). 12-item version of the Zarit Caregiver Burden Interview (Bédard et al., 2001). 11-item questionnaire exploring self-care. 10-item questionnaire assessing 3 domains of support - received support, satisfaction with support, negative interactions or support (Barrera et al., 1981; Krause, 1995; Krause & Markides, 1990). 3 questions assessing the primary domains of the Revised Memory and Behavior Problem Checklist (Tert et al., 1992). Institutional placement of care-recipients at six month follow-up. Seven questions about how people benefited from participating in the study.	Significantly greater improvements in quality of life among Hispanic or Latino, and White or Caucasian participants, but not Black or African-American participants.	63/76
Nichols, Martindale-Adams, Burns, Graney, & Zuber (2011)	USA	N = 105. Mean age CG = 72. Majority female = 94%. Majority white = 78%.	Condition 1 - REACH VA. Interventionists worked with participants to undertake problem solving and development of behavioural strategies. Education and support also provided on self-care and communication. Condition 2 - No control group as effectiveness of intervention established in earlier study trial (REACH-II).	Condition 1 - Activities were specified to occur at each session, but sessions were individualised using a risk assessment. Education, support, and skills training to address five caregiving risk areas: safety, social support, problem behaviours, depression, and carer health.	Condition 1 - (REACH VA). Nine 1-hour individual home sessions, three 0.5-hour individual telephone sessions, five 1-hour monthly telephone support group sessions. Undertaken over a six month period.	12-item version of the Zarit Caregiver Burden Interview (Bédard et al., 2001). Patient health questionnaire. Medical outcomes Study Short-Form 36. 21 question risk appraisal (adapted from REACH II). 25 problem behaviours linked to carer notebook topics were assessed as occurring or not during the previous month. For each behaviour present, the carer was asked about bother or concern. Caregiver Vigilance Scale (Mahoney et al., 2003). Seven questions about how people benefited from participating in the study.	Following intervention, decrease in burden, reduction in impact of depression on daily lives, and reduction in caregiving frustrations.	51/76

Author	Country	Sample	Condition	Manual protocol	Length of treatment	Outcome measure	Finding	Quality score
Farran et al. (2007)	USA	N=143. Mean CG age = 36. Majority female = 83%. Majority white = 81%.	Condition 1 - Caregiver Skill Building (CSB) Intervention. Content covered five main topics - introduction to the CSB model, potential causes of behavioural symptoms, prevention of behavioural symptoms during personal care (particularly verbal and physical aggression), management of restless behaviours, management of hallucinations, delusions, and paranoid or suspicious behaviours. Condition 2: Brief information and support (ISO). Provides generalized information and support that addresses routine care-related issues, but does not include individualized skill building specifically targeted to behavioural symptoms.	Condition 1 - CSB intervention. Based on work about: dealing with behaviours (Teri et al., 1992), appraising causes of behaviour (Gwyther, 1994; Rabbins, 1994), understanding a person's strengths and weaknesses (Hellen, 1998; Kielhofner, 2002), understanding behaviour as an expression of unmet need (Whall & Kolanowski, 2004), understanding a carer's strengths and weaknesses (Gwyther, 1994; Rabbins, 1994). Manual and slides provided for each session. Condition 2: ISO. Content covers five main topics: understanding the disease, dealing with behavioural symptoms, providing personal care, caring for the carer, and finding and using help (Farran & Keane-Hagerty, 1994; Toseland & Rossiter, 1989).	Condition 1 - Twelve weekly sessions (five group sessions followed by seven individualized telephone sessions), Two group booster sessions at six and twelve months, and 'as needed' telephone contact over the twelve month treatment period. Condition 2 - Twelve weekly sessions (five group sessions followed by seven individualized telephone sessions), Two group booster sessions at six and twelve months, and 'as needed' telephone contact over the twelve month treatment period.	Nine-item behaviour distress subscale representing agitated behavioural symptoms was derived from the Revised Memory and problem behaviors checklist (Roth et al., 2003; Teri et al., 1992). 15-item Behaviour Management Scale-revised (BMS-R) (Farran et al., 2004).	CSB treatment group > reduction in distress in dealing with CR agitated behaviour.	50/76

Discussion

This review of studies published between 2005 and 2011 has updated and adapted previous systematic reviews undertaken by Pinquart and Sørensen (2006), and Gallagher-Thompson and Coon (2007). The present review focuses on psychological interventions for carers of people with dementia, and contains evidence from both quantitative and qualitative studies.

Gallagher-Thompson and Coon (2007) identified three categories of evidence-based interventions: psycho-educational skill-building programmes, psychotherapy-counselling interventions, and multicomponent interventions. The researchers have identified a further group of studies that warranted definition as a separate category: interventions that are technology based.

The number of studies within each category is fairly even, with the exception of the psychotherapy-counselling category, which contains just one study. Having said this, when one takes into account the use of the same data set for multiple publications, there are a higher number of 'separate' studies in the psycho-educational skill-building category. Nonetheless, it is probably fair to say that the recent evidence base is fairly evenly split across the three categories of psycho-educational skill-building, multicomponent interventions and technology interventions. The literature on counselling-psychotherapy has been updated with one qualitative study. However, the recent evidence base for this category remains poor in relation to the other categories, although it should be noted that all multicomponent studies included counselling as a component.

The majority of studies examine the constructs of depression, burden, social support, and wellbeing. Two studies (Farran et al, 2007; Stern et al, 2008) use more specific measures because their intervention focus is more specific. Stern et al (2008) measures self-efficacy, preparedness and communication in relation to cessation of driving for the person with dementia. Farran et al (2007) measures carer distress in dealing with agitated behaviour. Indeed, these two studies, alongside some of the multicomponent studies that are tailored to an individual's problems, demonstrate growth in the evidence base for interventions targeted at specific issues for carers of people with dementia. This is a positive finding as the nature of the issues that arise for carers of people with dementia are complex and vary between individuals. The development of focused interventions for carers, whether individually tailored interventions or group interventions around a common issue, is therefore a significant and important addition to practice and the dementia care literature.

The psycho-educational skill-building studies suggest that these interventions can impact upon depression, emotional wellbeing, quality of life, attitudes towards caregiving and anxiety. The study by Hepburn et al (2005) focused on distress, which was defined as a broad range of outcomes including depression, anxiety and caregiving competence. Within certain studies, the reason for significant findings is because the intervention group has remained stable and the control group has declined (eg Perren et al, 2005). However, other studies have suggested improvement in the intervention group (eg Hepburn et al, 2005; Villareal-Reyna et al, 2010). At this point in time the researchers would suggest that, at the very least, the interventions in this category help to maintain levels of wellbeing over time, whilst those who do not receive interventions are more likely to experience deterioration on the outcome measures described. Consistent with previous reviews (eg Gallagher-Thompson and Coon, 2007), the majority of interventions within this category draw from cognitive-behavioural theory and principles (eg Beck et al, 1979), and also stress and coping theoretical models (eg Lazarus and Folkman, 1984).

In the main, the multicomponent studies focus predominantly on the outcomes of depression and social support, whilst the technology-based category impacts particularly upon depression, burden and social support. These studies appear to demonstrate improvements in wellbeing, rather than maintenance of it. The studies in this category generally comprise a mix of individual and family therapy sessions, and psycho-educational support group sessions.

The qualitative studies add valuable process and outcome data to this review, and provide an important contrast to the constructs measured by the quantitative studies. Post-intervention, these studies highlight changes within awareness (Sørensen et al, 2008), attitudes (Auclair et al, 2009; Sørensen et al, 2008), and more collaborative views of the future between partners (Auclair et al, 2009). On this latter point, this collaboration is underpinned by more accepting, non-judgemental and non-blaming attitudes (Auclair et al, 2009). An increase in the number of studies, perhaps a multi-centre study, to further explore the impact of psychotherapy and counselling on carers of people with dementia, would develop the literature in this area. Whilst many of the multicomponent studies within this review include a therapy/counselling component, studies that focus specifically on this type of intervention are greatly needed. As discussed, current findings point to the changes that can occur in roles and relationships following a diagnosis of dementia, thus future studies that explore the impact of therapy within these areas will be of great value. In addition to clinician reflections, psychotherapy-counselling studies using interviews as a mode of data collection, for example, would enhance current work.

Reflecting on the quality of the studies overall, the technology-based interventions category probably contains studies of the highest quality. Most of these address important research issues: for example, supervision, adherence to treatment fidelity, and use of blinded assessors. In addition, the majority of these studies address clinical significance as well as statistical significance. The researchers would suggest that clinical significance is a particularly valid concept within psychological research, but appears to receive little attention in many of the studies in the other three categories. It would be helpful if future studies addressed this issue. At the present time, it is not easy to tease apart the nature and extent of the impact of mode of delivery within interventions for carers of people with dementia. Thus, future technology-based studies could be strengthened by comparing groups that deliver interventions using face-to-face delivery or screen telephone, for example. Furthermore, future studies using a psycho-educational skill-building approach could be particularly strengthened by reporting power calculations and effect sizes. Prospective multicomponent studies could also be strengthened by addressing treatment fidelity and training/supervision of those delivering the interventions. The importance of supervision to facilitate client care and self-care when undertaking clinical work within research studies is of paramount importance, but can be overlooked. Thus future studies in all categories should continue to embed supervision arrangements within their psychological intervention protocols.

The majority of studies include control groups, which are not 'treatment as usual'; these groups range from participants being provided with written information, to receiving a comprehensive treatment alternative. This is very helpful for adding to the limited knowledge of the mechanisms of change within interventions. Further, one of the studies within this review states that it is the first translation of a large randomised-controlled trial of a psychological intervention for carers of people with dementia into a routine clinical setting (Nichols et al, 2011). The results of the studies are promising, suggesting that the efficacy trials that are being undertaken

(ie studies that are controlled and not undertaken in real-world settings) are of real-world value, and are at the same time adding to theoretical understanding and the evidence base of practice interventions.

The use of technology in the delivery of psychological interventions

It is interesting to reflect on the possible reasons for the increase in the number of interventions using technology as a significant vehicle for intervention. Work by Glueckauf et al (2005) identifies that, despite research findings on the effectiveness of psychological interventions, there is a gap between these findings and the implementation of interventions in clinical practice. Some of the reasons for this include financial barriers precluding attendance, difficulties with public transport for older people, and difficulty for primary carers in leaving a person with dementia in order to attend a support session. The use of technology-based interventions is perhaps one way to attempt to overcome some of these barriers and improve access for carers who are isolated. Glueckauf et al (2005) argue that initial studies examining 'telehealth' interventions for family carers have been promising, and the present review supports this opinion. On the other hand, Wade and Wolfe (2005) remind us that many of the current older adult population do not have access or ability to use some technologies, such as computers, thus highlighting the continued flexibility needed to access a population with a wide range of 'technology capacity'. In summary, reasons for practice to keep up to date with the development of technology-based interventions include:

- the current economic climate
- the forthcoming 'older' generations for whom technology is an integral part of communication
- widening geographical distances between family networks
- the growing gap between services provided in urban communities and rural communities (Glueckauf et al, 2005).

Social support: a key mechanism of change?

Previous work has not been able to discuss in detail the mechanisms of change within psychological treatments for carers of people with dementia (Gallagher-Thompson and Coon, 2007). This is highlighted by Roth et al (2005) who state that:

... we know very little about why certain caregiver interventions are effective, and what mediating processes may account for the effects of interventions on key outcome variables ... our review of the published literature on controlled interventions for dementia caregivers did not reveal a single report in which a mediation analysis had been conducted to examine the mechanisms responsible for any treatment effects (pp634–635).

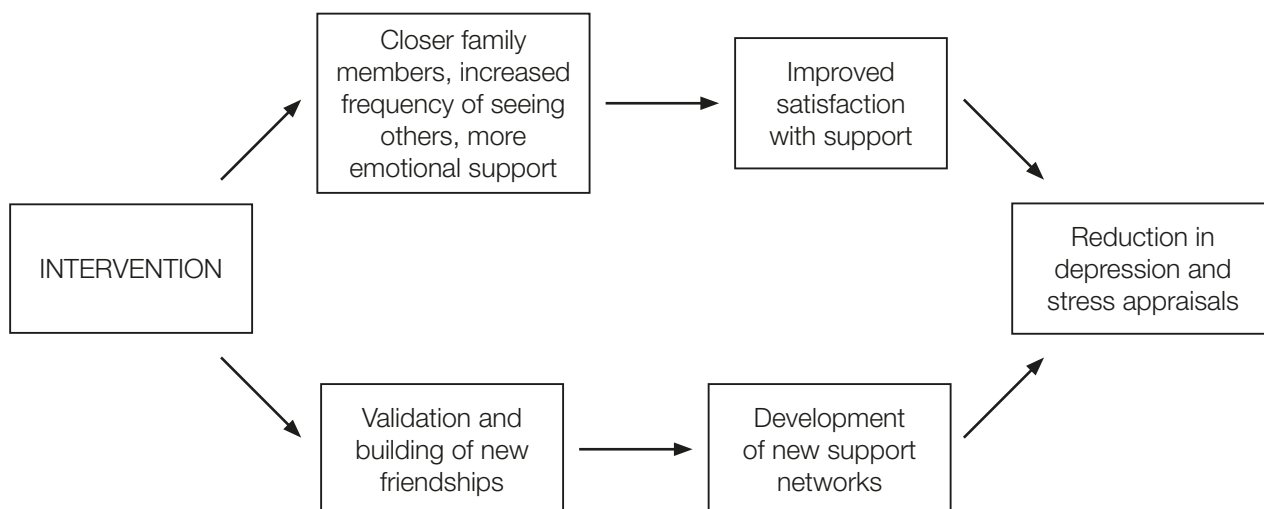
The last few years have seen some encouraging developments in this area. Within the present review, two quantitative papers specifically address mechanisms of change (Drentea et al, 2006; Roth et al, 2005), and their findings are concerned with social support. In addition, the qualitative study by Mackenzie (2006) provides theoretical grounding for understanding the processes underpinning the importance of social support. The following is a summary of these findings:

- Roth et al (2005) found that improvements in satisfaction with social support led to a reduction in stress appraisals and depression.
- Drentea et al (2006) found that closer relationships, greater frequency of seeing others, and more emotional support were all associated with increases in satisfaction with social support.
- Mackenzie's work (2006) with people from Eastern European and South Asian backgrounds suggests that stigma from within communities can lead to concealment of the person with dementia, estrangement from social supports/family networks, and isolation. One of the significant outcomes of Mackenzie's (2006) findings is that group intervention can provide a much needed space for validation and social support following loss through stigma.

The theme of social support appears to be significant in more than two-thirds of studies in this review. As Figure 2 reveals, the researchers therefore felt that it was relevant to draw together the findings from the work of Roth et al (2005), Drentea et al (2006), and Mackenzie (2006) (which use multicomponent and psycho-educational skill-building interventions), to develop the following heuristic to explain the data:

This model can be linked with other recent work within the field which identifies the mediators of 'building connections' and 'feeling connected' within psychosocial interventions (Elvish, Gardner, Keady and Lever, 2011). Cognisance of this process-oriented, evidence-based direction may be very helpful for clinicians as they develop psychosocial interventions within

Figure 2: Processes of change/mediating factors



healthcare settings. However, additional research to explore the processes of change within psychological interventions would help to develop and apply initial theoretical models.

Which interventions, and who benefits?

Pinquart and Sörensen (2006), and Gallagher-Thompson and Coon (2007), suggested that further studies are needed to investigate the acceptability and efficacy of interventions for people from various cultural and ethnic backgrounds. Moderator analyses undertaken by Belle et al (2006) and Lee et al (2010) have furthered understanding since the previous reviews were undertaken. Initial analysis by Belle et al (2006) found that their intervention led to improvements in quality of life for White or Caucasian, and Hispanic or Latino, carers, but not for Black or African-American carers. However, further exploration by Chu et al (2010) identified that sub-groups of Black carers did benefit from the intervention. Specifically, spousal carers reported changes in quality of life, and older carers reported a decrease in burden.

People with lower self-efficacy for obtaining respite care improved more on measures of depression following a psycho-educational group intervention (Rabinowitz et al, 2006). The authors of this study suggest that one reason for this finding is because those with a reduced sense of agency in managing stress and negative cognitions are taught a much needed skill set for managing caregiving.

Gallagher-Thompson and Coon (2007) identified a need for more research to explore which interventions are most effective for carers supporting people at different 'stages' of illness. Farran et al (2007) go some way to addressing this as they found that their intervention reduced distress for participants caring for people with high levels of agitation. These authors (Farran et al, 2007) used a specific intervention that combines a needs-led understanding of behaviour with cognitive and behavioural principles.

It is not easy to draw conclusions about whom to target our resources at, as studies have adopted different designs and eligibility criteria. For example, some studies have explored the impact of their intervention on depressed participants (eg Finkel et al, 2007), whilst others have excluded people based on a cut-off score indicative of depression (Villareal-Reyna et al, 2010). However, we are able to draw stronger inferences about the types of intervention that are beneficial. The results of this review suggest that interventions underpinned by cognitive/cognitive-behavioural models produce meaningful change. It is more difficult to draw conclusions about the use of theoretical standpoints that are not primarily driven by cognitive-behavioural theory, not because of the quality of the studies but because there are fewer of them. The researchers would suggest that clinicians who particularly wish to make use of these studies, should access the relevant section(s) within this review to gain further information about particular studies. Future studies within the psychotherapy-counselling category, together with further research on the processes of change, will strengthen our knowledge of the relative impact of different theoretical approaches. The evidence from this review also supports the use of interventions that aim to increase knowledge of dementia and address communication. Regarding the ways in which interventions are delivered, consistent with some previous findings (Schulz et al, 2005), multicomponent and technology-based interventions that combine individual and group sessions appear to be most beneficial.

Within the UK, work by Mackenzie (2006) highlights the importance of awareness and understanding about how ethnic minorities understand dementia, and how this impacts upon use of services. When thinking about delivery of services, it is helpful

to draw from broader literature on memory clinics (eg Banerjee, Willis, Matthews, Contell, Chan and Murray, 2007), which suggests that memory clinic models can effectively engage ethnic minority populations. Whilst psychological interventions are currently provided through a variety of service models (for example, primary care teams/community mental health teams), there may be an argument for providing them through memory services.

Geographical location of studies

It is important to note that only three papers within this review included participants from the UK (Mackenzie, 2006; Mittelman et al, 2008; Burns et al, 2010). Twelve papers were conducted in the USA, and one each in Mexico, Switzerland, Denmark, Norway and Taiwan.

The study undertaken by Mittelman et al (2008) was the first multinational psychosocial intervention study in the field of dementia caregiving. Subtle differences identified between participants at baseline suggested that Americans felt less satisfied with their levels of social support, and reported higher levels of depression. People in the UK tended to feel more supported by their social networks, reported less family conflict, and reported slightly lower levels of depression (Burns et al, 2010). Whilst main outcome measures in this study suggested that benefits were independent of country, these baseline differences do fall within areas of target for interventions. In addition to this, many of the USA-based studies explore variables that are not so easily transferable to the UK context. For example, some of the ethnic minority classifications are not transferable to the UK, and discussion about the impact of factors such as social class system and sexuality are missing. The researchers would therefore suggest that more UK-based studies are needed in order to tailor and generalise the results of this review. Future UK-based studies should focus on cultures that are representative of Britain, and include an exploration of the impact of background and sexuality on responses to intervention.

Study findings and recommendations

Research and training

- Further research is necessary to explore the processes of change within psychological interventions. Additional exploration of mediators, such as social support, would help to develop initial theoretical models based on change processes.
- Studies that explore and evaluate the impact that the mode of delivery has on process and outcome are called for, particularly in the use of technology.
- An increase in the number of studies, perhaps clustered around a programmatic multi-centre study, measuring the impact of psychotherapy and counselling on carers of people with dementia, is required.
- The number of UK-based studies in this field should be increased, together with the cost-effectiveness of delivering various types of carer-focused interventions. Additional research exploring the impact of factors such as social background and sexuality would strengthen the applicability of the current literature to the UK.
- The qualifications of those delivering psychological interventions within this review are varied. Standardisation of training/qualifications would be beneficial for clients and clinicians, and would help to harmonise future comparative studies.

Practice and policy

- Consistent with previous work (Gallagher-Thompson and Coon, 2007), the results of this review suggest that interventions underpinned by cognitive/cognitive-behavioural models can produce meaningful change. Evidence also supports the use of interventions which aim to increase knowledge of dementia and address communication. It is more difficult to draw conclusions about the use of theoretical standpoints that are not primarily driven by cognitive-behavioural theory, not because of the quality of the studies, but because there are fewer of them. The researchers would suggest that clinicians who particularly wish to make use of these studies should access the relevant section(s) within this review to gain further information about particular studies. Future studies within the psychotherapy-counselling category, together with further research on the processes of change, will strengthen our knowledge of the relative impact of different theoretical approaches.
- Based on the findings of this review, it is suggested that multicomponent and technology-based interventions that are a combination of individual and group sessions are most effective.
- Various recent policy documents within the field of mental health, for example 'New Horizons' (Department of Health, 2009) and the National Dementia Strategy (Department of Health, 2009), have addressed the issue of stigma. This review highlights the continued need for future policies to particularly focus on stigma within ethnic minority cultures, and its impact on people's use of services.
- In England, the commissioning strategy attached to the National Dementia Strategy (Department of Health, 2009) should consider technology-based interventions as a support for family carers of people with dementia.
- The updated findings for carer interventions from this review should be considered for inclusion in any revised national dementia guideline.

References

References marked with an asterisk denote studies which met the inclusion criteria for the present review.

Acton, G. J., & Kang, J. (2001). Interventions to reduce the burden of caregiving for an adult with dementia: a meta-analysis. *Research in Nursing and Health, 24*, 349–360.

Ahmad, W. I. U. (2000). *Ethnicity, disability and chronic illness*. Buckingham: Open University Press.

Alzheimer's Society (2007). *Dementia UK: A report into the prevalence and cost of Dementia, prepared by the Personal Social Services Research Unit (PSSRU) at the London School of Economics and the Institute of Psychiatry at Kings College London for the Alzheimer's Society*. London: Alzheimer's Society.

Aneshensel, C.S., Pearlin, L.I., Mullan, J.T., Zarit, S.H. & Whitlatch, C.J. (1995). *Profiles in caregiving: the unexpected career*. San Diego: Academic Press.

*Auclair, U., Epstein, C., & Mittelman, M. (2009). Couples counselling in Alzheimer's disease: Additional clinical findings from a novel intervention study. *Clinical Gerontologist, 32*(2), 130–146.

Banerjee, S., Willis, R., Matthews, D., Contell, F., Chan, J., & Murray, J. (2007). Improving the quality of care for mild to moderate dementia: An evaluation of the Croydon Memory Service Model. *International Journal of Geriatric Psychiatry, 22*(8), 782–788.

Bank, A. L., Argüelles, S., Rubert, M., Eisdorfer, C., & Czaja, S. J. (2006). The value of telephone support groups among ethnically diverse caregivers of persons with dementia. *The Gerontologist, 46*(1), 134–138.

Barrera, M., Sandler, I., & Ramsay, T. (1981). Preliminary development of a scale of social support: Studies on college students. *American Journal of Community Psychology, 9*, 435–441.

Beck, A. T., Rush, J., Shaw, B., & Emery, G. (1979). *Cognitive theory of depression*. New York: Guilford.

Beck, A. T., Steer, R. A., & Brown, G. (1996). *BDI-II Manual*. San Antonio: The Psychological Corporation.

Bédard, M., Molloy, D. W., Squire, L., Dubois, S., Lever, J. A., & O'Donnel, M. (2001). Zarit burden interview: A new short version and screening version. *The Gerontologist, 41*, 652–657.

*Belle, S. H., Burgio, L., Burns, R., Coon, D., Czaja, S. J., Gallagher-Thompson, D., Zhang, S. (2006). Enhancing the quality of life of dementia caregivers from different ethnic or racial groups: A randomized, controlled trial. *Annals of Internal Medicine, 145*(10), 727–738.

Bourgeois, M. S., Schulz, R., & Burgio, L. (1996). Interventions for caregivers of patients with Alzheimer's disease: A review and analysis of content, process, and outcomes. *International Journal of Aging and Human Development, 43*, 35–92.

Bradburn, N. M. (1969). *The structure of psychological well-being*. Chicago: Aldine Publishing.

Brodsky, H., Green, A., & Koschera, A. (2003). Meta-analysis of psychosocial interventions for people with dementia. *Journal of the American Geriatrics Society, 51*, 657–664.

*Burns, A., Mittelman, M., Cole, C., Morris, J., Winter, J., Page, S., & Brodaty, H. (2010). Transcultural influences in dementia care: Observations from a psychosocial intervention study. *Dementia and Geriatric Cognitive Disorders, 30*, 714–723.

Carver, C. S. (1997). You want to measure coping but your protocol's too long: Consider the brief COPE. *International Journal of Behavioral Medicine, 4*, 92–100.

CASP (2006). *10 questions to help you make sense of qualitative research*. Retrieved 9 January 2012 from <http://www.sph.nhs.uk/sph-files/casp-appraisal-tools/Qualitative%20Appraisal%20Tool.pdf>

*Chu, H., Yang, C. Y., Liao, Y. H., Chang, L. I., Chen, C. H., Lin, C. C., & Chou, K. R. (2011). The effects of a support group on dementia caregivers' burden and depression. *Journal of Aging and Health, 23*(2), 228–241.

CONSORT (2010). *The consort statement*. Retrieved 9 January 2012 from <http://www.consort-statement.org/consort-statement/overview0/>

Department of Health (2009a). *Living well with dementia: A national dementia strategy*. Retrieved 15 June 2010 from http://www.dh.gov.uk/prod_consum_dh/groups/dh_digitalassets/@dh/@en/documents/digitalasset/dh_094051.pdf

Department of Health (2009b). *New horizons. A shared vision for mental health*. London: Crown Copyright.

*Drentea, P., Clay, O. J., Roth, D. L., & Mittelman, S. M. (2006). Predictors of improvement in social support: Five-year effects of a structured intervention for caregivers of spouses with Alzheimer's disease. *Social Science & Medicine, 63*, 957–967.

Drigas, A., Koukianakis, L., & Papagerasimou, Y. (2011). Towards an ICT-based psychology: E-psychology. *Computers in Human Behaviour, 27*, 1416–1423.

Elvish, R., Gardner, P., Keady, J., & Lever, S. J. (2011, November). *Reminiscence groups for people with dementia and their relatives*. Paper presented at the conference 'Social Participation: Knowledge, Policy and practice', Melbourne.

Farran, C. J., Gilley, D. W., McCann, J. J., Bienias, J. L., Lindeman, D. A., & Evans, D. A. (2004). Psychosocial interventions to reduce depressive symptoms of dementia caregivers: A randomized clinical trial comparing two approaches. *Journal of Mental Health and Aging, 10*(4), 337–350.

*Farran, C. J., Gilley, D. W., McCann, J. J., Bienias, J. L., Lindeman, D. A., & Evans, D. A. (2007). Efficacy of behavioral interventions for dementia caregivers. *Western Journal of Nursing Research, 29*(8), 944–960.

Farran, C. J., & Keane-Hagerty, E. (1994). Multi-modal intervention strategies for caregivers of persons with dementia. In E. Light, G. Niederehe, & B. D. Lebowitz (Eds.), *Stress effects on family caregivers of Alzheimer's patients: Research and interventions* (pp. 242–259). New York: Springer.

Farran, C., Miller, B., Kaufman, J., Donner, E., & Fogg, L. (1999). Finding meaning through caregiving: Development of an instrument for family caregivers of persons with Alzheimer's disease. *Journal of Clinical Psychology, 55*, 1107–1125.

*Finkel, S., Czaja, S. J., Schulz, R., Martinovich, Z., Harris, C., & Pezzuto, D. (2007). E-Care: A telecommunications technology intervention for family caregivers of dementia patients. *American Journal of Geriatric Psychiatry, 15*(5), 443–448.

Fortinsky, R. H., Kercher, K., & Burant, C. J. (2002). Measurement and correlates of family caregiver self-efficacy for managing dementia. *Aging and Mental Health, 6*, 153–160.

Gallagher-Thompson, D. (2007). Exciting advances in caregiver research. *Aging and Mental Health, 11*(6), 613–615.

Gallagher-Thompson, D., Arean, P., Rivera, P., & Thompson, L. W. (2001). A psychoeducational intervention to reduce distress

- in Hispanic family caregivers: Results of a pilot study. *Clinical Gerontologist*, 23, 17–32.
- Gallagher-Thompson, D. & Coon, D. W. (2007). Evidence-based psychological treatments for distress in family caregivers of older adults. *Psychology and Aging*, 22(1), 37–51.
- Gallagher-Thompson, D., Solano, N., Coon, D., & Areal, P. (2003). Recruitment and retention of Latino dementia family caregivers in intervention research: Issues to face, lessons to learn. *The Gerontologist*, 40(3), 45–51.
- Gatz, M., Fiske, A., Fox, L., Kaskie, B., Kasl-Godley, J., McCallum, T., & Wetherell, J. L. (1998). Empirically validated psychological treatments for older adults. *Journal of Mental Health and Aging*, 4, 9–46.
- *Gaugler, J. E., Roth, D. L., Haley, W.E., & Mittelman, M. S. (2008). Can counseling and support reduce burden and depressive symptoms in caregivers of people with Alzheimer's disease during the transition to institutionalization? Results from the New York University Caregiver Intervention Study. *Journal of the American Geriatrics Society*, 56, 421–428.
- Glueckauf, R. L., Stine, C., Bourgeois, M., Pomidor, A., Rom, P., Young, M. E., Massey, A., & Ashley, P. (2005). Alzheimer's rural care healthline: Linking rural caregivers to cognitive-behavioral intervention for depression. *Rehabilitation Psychology*, 50 (4), 346–354.
- Goffman, E. (1963). *Stigma: Notes on the management of a spoiled identity*. London: Penguin.
- Greene, J. G., Smith, R., Gardiner, M., & Timbury, G. C. (1982). Measuring behavioural disturbance of elderly demented patients in the community and its effects on relatives: a factor analytic study. *Age and Ageing*, 11, 121–126.
- Gwyther, L. (1994). Managing challenging behaviors at home. *Alzheimer Disease and Associated Disorders*, 8(3), 110–112.
- Harris, T. A. (1969). *I'm Ok, you're OK*. New York: Harper Collins.
- Harvey, R.J., Skelton-Robinson, M., & Rossor, M.N. (2003). The prevalence and causes of dementia in people under the age of 65 years. *Journal of Neurology, Neurosurgery and Psychiatry*, 74, 1206–1209.
- Hellen, C. (1998). *Alzheimer's disease: Activity-focused care* (2nd ed.). Boston: Butterworth-Heinemann.
- *Hepburn, K. W., Lewis, M., Narayan, S., Center, B., Tornaore, J., Bremer, K. L., & Kirk, L. N. (2005). Partners in caregiving: A psychoeducation program affecting dementia family caregivers' distress and caregiving outlook. *Clinical Gerontologist*, 29(1), 53–69.
- Horvath, A. O., & Symonds, B. D. (1991). Relation between working alliance and outcome in psychotherapy: A meta-analysis. *Journal of Counselling Psychology*, 38(2), 139–149.
- Irwin, M., Artin, K. H., & Oxman, M. N. (1999). Screening for depression in the older adult: Criterion validity of the 10-item center for epidemiological studies depression scale (CES-D). *Archives of Internal Medicine*, 159, 1701–1704.
- Ishima, F. I. (1993). On self-validation. *Trumpeter (online)*, 10, 2–8.
- James, I. A., Powell, I., & Reichelt, K. (2001). Cognitive therapy for carers: distinguishing fact from fiction. *Journal of Dementia Care*, 9, 24–26.
- Kielhofner, G. (2002). *Model of human occupation: Theory and application* (3rd ed.). Baltimore: Lippincott Williams & Wilkins.
- Krause, N. (1995). Negative interaction and satisfaction with social support among older adults. *The Journals of Gerontology, Series B: Psychological Sciences and Social Sciences*, 50, 59–73.
- Krause, N., & Markides, K. (1990). Measuring social support among older adults. *International Journal of Aging and Human Development*, 30, 37–53.
- Lawrence, V., Murray, J., Samsi, K., & Banerjee, S. (2008). Attitudes and support needs of Black Caribbean, south Asian and White British carers of people with dementia in the UK. *The British Journal of Psychiatry*, 193, 240–246.
- Lawton, M. P., & Brody, E. M. (1969). Assessment of older people: Self-maintaining and instrumental activities of daily living. *The Gerontologist*, 9, 179–188.
- Lazarus, R.S. (1966). *Psychological Stress and the Coping Process*. New York: McGraw Hill.
- Lazarus, R. S., & Folkman, S. (1984). Coping and adaptation. In W. D. Gentry (Ed.), *The Handbook of Behavioral Medicine* (pp. 282–235). New York: Guilford.
- *Lee, C. C., Czaja, S. J., & Schulz, R. (2010). The moderating influence of demographic characteristics, social support, and religious coping on the effectiveness of a multicomponent psychosocial caregiver intervention in three racial ethnic groups. *Journal of Gerontology: Psychological Sciences*, 65(2), 185–194.
- Lewinsohn, P. M. (1974). A behavioral approach to depression. In R. J. Friedman & M. M. Katz (Eds.), *The psychology of depression* (pp. 157–178). New York: John Wiley & Sons.
- Lewinsohn, P. M. (1975). Engagement in pleasant activities and depression level. *Journal of Abnormal Psychology*, 84, 729–731.
- Luborsky, L., Singer, B., & Luborsky, L. (1975). Comparative studies of psychotherapies: Is it true that 'everyone has won and all must have prizes'? *Archives of General Psychiatry*, 32, 995–1008.
- Lukas, C., & Davis, N. (2001). *Forgotten holocaust: The Poles under German occupation 1939-1944*. New York: Hippocrene Books.
- *Mackenzie, J. (2006). Stigma and dementia: East European and South Asian family carers negotiating stigma in the UK. *Dementia*, 5(2), 233–247.
- Mahoney, D. F., Jones, R. N., Coon, D. W., Mendelsohn, A. B., Gitlin, L. N., & Ory, M. (2003). The caregiver vigilance scale: Application and validation in the resources for enhancing Alzheimer's caregiver health (REACH) project. *American Journal of Alzheimer's Disease and Other Dementias*, 18(1), 39–48.
- Martin, D. J., Garske, J. P., & Davis, M. K. (2000). Relation of the therapeutic alliance with outcome and other variables: A meta-analytic review. *Journal of Consulting and Clinical Psychology*, 68(3), 438–450.
- Meier, D., Vodoz, V., & Spiegel, R. (1999). Development of a short measurement of individual quality of life (SEIQoL short form). In K. Iqbal, D. F. Swaab, B. Winblad & H. M. Wisniewski (Eds.), *Alzheimer's disease and related disorders* (pp. 817–821). London: John Wiley & Sons Ltd.
- Meshefedjian, G., McCusker, J., Bellavance, F., & Baumgarten, M. (1998). Factors associated with symptoms of depression among informal caregivers of demented elders in the community. *The Gerontologist*, 38(2), 247–253.
- *Mittelman, M. S., Brodaty, H., Wallen, A. S., & Burns, A. (2008). A three-country randomized controlled trial of a psychosocial intervention for caregivers combined with pharmacological treatment for patients with Alzheimer disease: Effects on caregiver depression. *American Journal of Geriatric Psychiatry*, 16(11), 893–904.

- Mittelman, M. S., Epstein, C., & Pierzchala, A. (2003). *Counseling the Alzheimer's Caregiver: A Resource for Health Care Professionals*. Chicago: AMA Press.
- Mittelman, M. S., Ferris, S. H., Shulman, E., Steinberg, G., Ambinder, A., Mackell, J. A., & Cohen, J. (1995). A comprehensive support program: Effect on depression in spouse-caregivers of AD patients. *Gerontologist*, *35*, 792–802.
- Morrissey, E., Becker, J., & Rupert, M.P. (1990). Coping resources and depression in the caregiving spouses of Alzheimer patients. *British Journal of Medical Psychology*, *63*, 161–171.
- National Institute for Health and Clinical Excellence/Social Care Institute for Excellence (2006). *Dementia: supporting people with dementia and their carers in health and social care. NICE clinical practice guideline 42*. London: Author.
- *Nichols, L. O., Martindale-Adams, J., Burns, R., Graney, M. J., & Zuber, J. (2011). Translation of a dementia caregiver support program in a health care system- REACH VA. *Archives of Internal Medicine*, *171*(4), 353–359.
- Novak, M., & Guest, C. (1989). Application of a multidimensional caregiver burden inventory. *The Gerontologist*, *29*, 798–803.
- O'Connor, A. (1995). Validation of a decisional conflict scale. *Medical Decision Making*, *15*(1), 25–30.
- Pearlin, L. I., Mullan, J. T., Semple, S. J., & Scaff, M. M. (1990). Caregiving and the Stress Process: An Overview of Concepts and their Measures. *Gerontologist*, *30*(5), 583–594.
- Peavey, V. R. (1997). *Sociodynamic counselling: A constructivist perspective for the practice of counselling in the 21st century*. Victoria: Trafford Publishing.
- *Perren, S., Schmid, R., & Wettstein, A. (2007). Caregivers' adaptation to change: The impact of increasing impairment of persons suffering from dementia on their caregivers' subjective well-being. *Aging & Mental Health*, *10*(5), 539–548.
- Phillips, L. R., Rempusheski, V. F., & Morrison, E. (1989). Developing and testing the beliefs about caregiving scale. *Research in Nursing and Health*, *12*(4), 207–220.
- Pinquart, M. & Sörensen, S. (2006). Helping caregivers of persons with dementia: which interventions work and how large are their effects? *International Psychogeriatrics*, *18*(4), 577–595.
- Posner, B. M., Jette, A. M., Smith, K. W., & Miller, D. R. (1993). Nutrition and health risks in the elderly: The nutrition screening initiative. *American Journal of Public Health*, *83*, 972–978.
- Prince, M., Bryce, R., & Ferri, C. (2011). *World Alzheimer Report: The benefits of early diagnosis and intervention*. Retrieved 2 November 2011 from <http://www.alz.co.uk/research/WorldAlzheimerReport2011.pdf>
- Prochaska, J. O., & Velicer, W. F. (1997). The transtheoretical model of health behavior change. *American Journal of Health Promotion*, *12*, 38–48.
- Proyecto RISA. (2002). *Yosoypp*. Retrieved from <http://www.yosoypp.com.mx>
- Rabbins, P. V. (1994). The phenomenology of behavior: An overview of behavioral principles. *Alzheimer Disease and Associated Disorders*, *8*(3), 61–66.
- *Rabinowitz, Y. G., Mausbach, B. T., Coon, D. W., Depp, C., Thompson, L. W., & Gallagher-Thompson, D. (2006). The moderating effect of self-efficacy on intervention response in women family caregivers of older adults with dementia. *American Journal of Geriatric Psychiatry*, *14*, 642–649.
- Radloff, L. S. (1977). The CES-D Scale: A self-report depression scale for research in the general population. *Applied Psychological Measurement*, *1*, 385–401.
- Roth, D. L., Gitlin, L. N., Coon, D. W., Stevens, A., Burgio, L. D., Gallagher-Thompson, D., et al. (2003). Psychometric analysis of the revised memory and behaviour problems checklist: Factor structure of occurrence and reaction ratings. *Psychology and Aging*, *18*(4), 906–915.
- *Roth, D. L., Mittelman, M. S., Clay, O. J., Madan, A., & Haley, W. E. (2005). Changes in social support as mediators of the impact of a psychosocial intervention for spouse caregivers of persons with Alzheimer's disease. *Psychology and Aging*, *20*(4), 634–644.
- Royal College of Psychiatrists (2005). *Who cares wins – Improving the outcome for older people admitted to the general hospital: Guidelines for the development of Liaison Mental Health Services for older people*. Report of a Working Group for the Faculty of Old Age Psychiatry. London: Royal College of Psychiatrists.
- Scheff, T. J. (1990). *Microsociology: Discourse, emotion and social structure*. London: University of Chicago Press.
- Schulz, R., Lusting, A., Handler, S., & Martire, L. M. (2002). Technology-based caregiver intervention research: Current status and future directions. *Gerontechnology*, *2*(1), 15–47.
- Schulz, R., Martire, L., & Klinger, J. (2005). Evidence-based caregiver interventions in geriatric psychiatry. *Psychiatry Clinics of North America*, *28*, 1007–1038.
- Speilberger, C. D., Gorusch, R. L., Lushene, R. E. (1970). *Manual for the state-trait anxiety inventory*. Palo Alto: Consulting Psychology Press.
- Spielberg, C. D., & Diaz-Guerrero, R. (2002). IDARE: Inventario de ansiedad: Rasgo-Estado [IDARE: inventory of anxiety]. México City, México: El Manual Moderno.
- *Stern, R. A., D'Ambrosio, L. A., Mohyde, M., Carruth, A., Tracton-Bishop, B., Hunter, J. C., Daneshvar, D. H., & Coughlin, J. F. (2008). At the crossroads: Development and evaluation of a dementia caregiver group intervention to assist in driving cessation. *Gerontology & Geriatrics Education*, *29*(4), 363–382.
- *Sørensen, L. V., Waldorff, F. B., & Waldemar, G. (2008). Early counselling and support for patients with mild Alzheimer's disease and their caregivers: A qualitative study on outcome. *Aging & Mental Health*, *12*(4), 444–450.
- Sörensen, S., Pinquart, M., & Duberstein, P. (2002). How effective are interventions with caregivers? An updated meta-analysis. *The Gerontologist*, *42*, 356–372.
- Stokes, J. P. (1983). Predicting satisfaction with social support from social network structure. *American Journal of Community Psychology*, *11*, 141–152.
- Stokes, J. P., Wilson, D. G. (1984). The inventory of socially supportive behaviors: dimensionality, prediction, and gender differences. *American Journal of Community Psychology*, *12*, 53–69.
- STROBE (2007). *STROBE Statement – Checklist of items that should be included in reports of case-control studies*. Retrieved 9 January 2012 from http://www.strobe-statement.org/fileadmin/Strobe/uploads/checklists/STROBE_checklist_v4_case-control.pdf
- Teri, L., Truax, P., Lagsdon, R., Uomoto, J., Zarit, S., Vitaliano, P. P. (1992). Assessment of behavioral problems in dementia: The revised memory and behavior problems checklist. *Psychology and Aging*, *7*(4), 622–631.

Toseland, R. W., & Rossiter, C. M. (1989). Group interventions to support family caregivers: A review and analysis. *The Gerontologist*, 29(4), 438–448.

The NHS Confederation (2010). *Acute awareness: improving hospital care for people with dementia*. London: The NHS Confederation.

Ulstein, I., Wyller, T. B., & Engedal, K. (2007). The relative stress scale; a useful instrument to identify various aspects of carer burden in dementia. *International Journal of Geriatric Psychiatry*, 22, 61–67.

*Ulstein, I. D., Sandvik, L., Wyller, T. B., & Engedal, K. (2007). A one-year randomized controlled psychosocial intervention study among family carers of dementia patients – effects on patients and carers. *Dementia and Geriatric Cognitive Disorders*, 24, 469–475.

*Villareal-Reyna, M. A., Salazar-González, Cruz-Quevedo, J. E., Carrillo-Cervantes, A. L., & Champion, J. D. (2010). Outcomes of interventions for Alzheimer's family caregivers in Mexico. *Western Journal of Nursing Research*, 1–18. Retrieved 12 August 2011 from <http://wjn.sagepub.com/content/early/2010/11/20/0193945910387283>

Vitaliano, P., Russo, J., Carr, J. E. (1985). The ways of coping checklist: revision and psychometric properties. *Multivariate Behavior Research*, 20, 3–26.

Wade, S. L., & Wolfe, C. R. (2005). Telehealth interventions in rehabilitation psychology: Postcards from the edge. *Rehabilitation Psychology*, 50(4), 323–324.

Waldemar, G., Waldorff, F. B., Buss, D. V., Eckermann, A., Keiding, N., Rishøj, S., Siersma, V., Sørensen, J., Sørensen, L. V., & Vogel, A. (2010). The Danish Alzheimer Intervention Study: Rationale, study design and baseline characteristics of the cohort. *Methods in Neuroepidemiology*, 36, 52–61.

Weiss, W., Spuhler, T., Gruet, F., Guidani, D., & Noack, H. (1990). *Enquête auprès de la population 'La santé et la promotion de la santé'. Etude intercantonale sur les indicateurs*

de santé (IGIP-PROMES) [Population survey on health and health promotion. Swiss study on health indicators]. Rapport final. Lausanne: Institut Suisse de la Santé Publique et des Hôpitaux ISH/SKI.

Whall, A. L., & Kolanowski, A. M. (2004). The need-driven dementia-compromised behavior model: A framework for understanding the behavioral symptoms of dementia. *Aging & Mental Health*, 8(2), 106–108.

Williams, O., Keady, J., & Nolan, M. R. (1995). Younger-onset Alzheimer's disease: learning from the experience of one spouse carer. *Journal of Clinical Nursing*, 4(1), 31–36.

Winnicott, D. W. (1971). *Playing and reality*. New York: Basic Books.

Yesavage, J. A., Brink, T. L., Rose, T. L., & Adey, M. (1983). The geriatric depression rating scale: Comparison with other self-report and psychiatric rating scales. In T. Cook, S. H. Ferris, & R. Bartus (Eds.), *Assessment in geriatric psychopharmacology* (pp. 153–165). New Canaan, CT: Mark Powley Associates.

Yesavage, J. A., Brink, T. L., Rose, T. L., Lum, O., Huang, V., Adey, M., Leirer, V. O. (1982). Development and validation of a geriatric depression screening scale: A preliminary report. *Journal of Psychiatric Research*, 17(1), 37–49.

Yon, A. & Scogin, F. (2007). Procedures for identifying evidence-based psychological treatments for older adults. *Psychology and Aging*, 22(1), 4–7.

Zarit, S. H. & Femia, E. E. (2008). A future for family care and dementia intervention research? Challenges and strategies. *Aging and Mental Health*, 12(1), 5–13

Zarit, S., Orr, N., & Zarit, J. (1985). *The hidden victims of Alzheimer's disease: Families under stress*. New York: University Press.

Zarit, S. H., Reever, K. E., & Bach-Peterson, J. (1980). Relatives of the impaired elderly: Correlates of feelings of burden. *Gerontologist*, 20, 649–655.

Appendices

Appendix 1: Template of data extraction sheets

Template data extraction sheet – Quantitative studies

Author	Sample	Condition	Manual-protocol	Length of treatment	Outcome measure	Finding	Notes	Characteristics of those delivering treatment	Treatment adherence

Template data extraction sheet – Qualitative studies

Author	Sample	Condition	Manual-protocol	Length of treatment	Methodology	Finding	Notes	Characteristics of those delivering treatment	Treatment adherence

Appendix 2: Guidance checklist for critical appraisal (quantitative studies)

<p>Background</p> <p>Does the cited literature clearly explain the field of research? Are there clearly defined research questions? Is there an argument/rationale for the importance of these research questions? Does the study discuss the theory which underpins its intervention?*</p> <p>Methods</p> <p>Are the outcome measures appropriate for the research question? Have they been justified?*</p> <p>Is the background of those delivering the interventions stated? Does the paper state that those delivering the interventions were trained? Does the paper state that those delivering the interventions received supervision? Was a manual provided for the intervention? Does the paper mention treatment fidelity? Was treatment adherence monitored adequately? Does the paper discuss the intervention in enough detail for replication? Does the paper discuss 'mode of delivery' in sufficient detail? Has measurement bias been accounted for by blinding? Have the inclusion and exclusion criteria of participants been well described? Has sufficient detail been provided about where the sample was recruited from? Have power calculations been conducted?*</p> <p>Results/Analysis</p> <p>Were all groups similar at the beginning of the study? Was the sample size sufficient?*</p> <p>Is power reported? Has sufficient detail of statistics been reported? Has effect size been reported?*</p> <p>Is clinical significance discussed as well as statistical significance?*</p> <p>Are the data presented clearly?</p> <p>Conclusions</p> <p>Are the conclusions of the study related to clinical practice?*</p> <p>Does the study adequately answer the research questions? Have future avenues for further research been opened up?*</p> <p>Limitations</p> <p>Has the study acknowledged/discussed its limitations? * = criterion score assigned double weighting</p>
--

Appendix 3: Guidance checklist for critical appraisal (qualitative studies)

Was the research design appropriate to address the aims of the research?
 Was the recruitment strategy appropriate to the aims of the research?
 Were the data collected in a way that addressed the research issue?
 Has the relationship between researcher and participants been adequately considered?
 Have ethical issues been taken into consideration?
 Was the data analysis sufficiently rigorous?
 Is there a clear statement of findings?
 How valuable is the research?

Appendix 4: Final scores for quantitative studies

	Total Score
Psychoeducational-skill building Caregiver Intervention Studies	
Hepburn et al. (2005)	52/76
Chu et al. (2011)	45/76
Rabinowitz et al. (2006)	49/76
Perren et al. (2005)	30/76
Stern et al. (2008)	45/76
Villareal-Reyna et al. (2011)	66/76
Ulstein et al. (2007)	51/76
Multicomponent Caregiver Intervention Studies	
Gaugler et al. (2008)	43/76
Drentea et al. (2006)	31/76
Roth et al. (2005)	41/76
Mittelman et al. (2008)	51/76
Burns et al. (2010)	43/76
Technology Caregiver Intervention Studies	
Finkel et al. (2007)	44/76
Lee et al. (2010)	50/76
Belle et al. (2006)	63/76
Nichols et al. (2011)	51/76
Farran et al. (2007)	50/76

Appendix 5: Final scores for qualitative studies

	Total Score
Psychoeducational-skill building Caregiver Intervention Studies	
Mackenzie (2006)	20/24
Psychotherapy-counselling Caregiver Intervention Studies	
Auclair et al. (2009)	14/24
Multicomponent Caregiver Intervention Studies	
Sørensen et al. (2008)	23/24

