

**A SYSTEMATIC REVIEW OF  
INTERVENTIONS FOR UNPAID CAREGIVERS  
OF PERSONS WITH DEMENTIA**

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### Abstract

The prevalence of dementia is increasing as seniors are living longer than ever before. Due to cuts in funding for formal support such as home care and the decreased number of long-term care beds many families are having to provide care for a loved one with dementia in the community. The results of caregiving lead to both positive and negative consequences. There is an abundance of literature regarding interventions to support and maintain caregivers in the community, many with conflicting results. This study utilized a systematic review to gather and synthesize information about interventions that have an effect on the well-being of caregivers of people with dementia. The steps in a systematic review include: (a) developing a research question, (b) developing relevance and validity tools, (c) conducting a thorough literature search of published and unpublished studies, (d) using relevance and validity tools to assess the studies, (e) completing data extraction for each study, (f) synthesizing the findings and, (g) writing the report. A search of published and some unpublished articles resulted in the retrieval of 92 studies, with 36 meeting the relevance criteria. Utilizing the validity criteria, 11 studies were rated as *strong*, 11 *moderate*, 13 *weak*, and 1 *poor*. The strong and moderate studies are the focus of the review. No one intervention demonstrated an overall significant impact on the well-being of caregivers. Several interventions have been shown to be of benefit to caregivers, however, further investigation is greatly needed. Institutionalization was delayed by the psychotherapy intervention for caregivers and in one of the case management models. Caregiver depression and strain were reduced during in-hospital respite. Two educational interventions demonstrated an increase in knowledge about dementia for caregivers. Interventions individualized to the caregiver or care receiver

were successful in some outcome areas. Non-significant findings were more common. The results of this study will be disseminated to interested researchers, consumers, practitioners and policy makers in a variety of formats. Systematic reviews are an important means to guide consumers and practitioners as they make evidence-based decisions.

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### Dedication

I dedicate this work to my grandparents,  
David (1907-1982) and May (1905-1993) Anderson.  
Their loving influence remains with me to this day.

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## 1. Introduction

Seniors are living longer than ever, and many are at an increased risk for or already have a chronic condition (Pearlin, Mullan, Semple, & Skaff, 1990). The increasing prevalence of dementia in the older population (Hill, Forbes, Berthlot, Lindsay, & McDowell, 1996) is cause for concern. In Canada, 8% of those 65 years of age and older and 35% of those 85 years and older are diagnosed with dementia; half of all cases live in the community with a spouse, other family, or friends (Canadian Study of Health and Aging Working Group [CSHAWG], 1994). Alzheimer Disease (AD) is the most common form of dementia, which affects over 5% of persons 65 years of age and older, and affects up to 26% for those 85 years and older (CSHAWG). The Canadian Study of Health and Aging Working Group estimates from data collected in 1991 that the number of cases of dementia in Canada will nearly triple by the year 2031, reaching approximately 778,000 individuals.

Persons with AD and related dementias suffer a number of consequences, as do their carers. As dementia progresses caregivers must take on more and more responsibilities to sustain their loved-one at home (Kuhn, 2001). Carers exert both physical and psychological energy throughout their caregiving experience. Caregiving results in both negative and positive responses. The literature has an abundance of information regarding interventions that attempt to meet the needs of unpaid caregivers, most of which focus on alleviating the negative consequences of caregiving.

### 1.1 *Statement of Problem*

Many families and friends are caring for a family member with dementia at home with little or no formal support. This unsupported care has the potential to result in a

decreased sense of well-being. The literature reveals many interventions to aid caregivers, however the results vary in relation to their effectiveness (Knight, Lutzky, & Macofsky-Urban, 1993). This may be due to the type and exposure of the intervention, the characteristics of the caregiver and the stage of the disease in the care receiver.

Practitioners require assistance in assessing the multitude of information about caregiver interventions and deciding which interventions are effective for a variety of caregivers and care receivers.

### *1.2 Purpose of the Study*

The goal of this review was to determine the effectiveness of a variety of interventions on the well-being of caregivers who care for elderly persons with dementia in the community. The results will be useful to guide consumers and practitioners in their decision-making about effective interventions for carers.

### *1.3 Need for Study*

In recent years there has been a decrease in the funding of formal home care support services (Armstrong & Kits, 2001). Also, placement in long-term care has become more and more difficult with fewer resources (e.g., beds) (Dyck, 2001). These issues impact caregivers immensely. Families are having to take up and maintain the care of a senior with dementia in the community. Burnout can result and families are left feeling helpless when support is unavailable or not accessed.

Other systematic reviews of effectiveness of caregiver interventions have been completed. For example, Cuijpers (1999) completed a meta-analysis of the effects of family interventions on carers of people with psychiatric conditions. Knight et al. (1993) also completed a meta-analysis of the effects on caregiver distress focusing on

psychosocial and respite interventions for a variety of family caregivers. McNally, Ben-Shlomo, and Newman (1999) completed a systematic review of the effectiveness of respite interventions on carers of people with a chronic disability or illness. Reviews that address solely the issues of caregivers of persons with dementia have not been located. Dementia is a progressive disease while other conditions, such as cerebrovascular accident or cardiovascular disease tend to stabilize. Thus, individuals who care for someone with dementia have unique needs and issues compared to other caregivers (Mignor, 2000). There was sufficient literature regarding the experiences of individuals who care for someone with dementia to support a review of interventions that impact their well-being.

## 2. Literature Review

### 2.1 *Caregiving*

Caregiving is a complex concept (Cantor, 1983). Caregiving implies unpaid, non-professional support provided by individuals who feel close to or a sense of responsibility toward the care receiver; commonly referred to as informal caregiving in the literature. To date, much of the caregiving research has focused on women (Armstrong & Kits, 2001; Bull, 2001; Horowitz, 1985; Houde, 2001). Carers of the elderly include not only family members, but friends and neighbours as well (Hibbard, Neufeld, & Harrison, 1996; Swanson et al., 1997). The tasks involved with caregiving include meal preparation, housework, personal hygiene, shopping, transportation, and financial management (Fast, Forbes, & Keating, 1999; Keating, Fast, Frederick, Cranswick, & Perrier, 1999; Pepin, 1992). This assistance has been conceptualized by researchers as tasks that are unpleasant or difficult (Roberto, Richter, Bottenberg, & Campbell, 1998) as well as an extension of traditional or normative family activity (Biegel & Schulz, 1999; Bull, 2001). Inevitably caregiving affects the well-being of the caregiver, either positively or negatively.

Researchers often discuss caregiving in a purely negative sense and do not consider its positive consequences. Positive consequences can include the reward from a reciprocal relationship (Carruth, 1996; Lo & Brown, 2000), or a strengthened bond to the care receiver (Fast et al., 1999). Farran (2001) suggests that as a result of descriptive studies in the 1990's there is an increased recognition of the positive aspects of caregiving. These positive reactions may be what sustains a caregiver in his or her role longer than would be expected.

The literature reveals that males and females have differing responsibilities in the tasks of caregiving. Women tend to participate and be expected to do hands-on activities such as personal care, meal preparation, and housekeeping (Horowitz, 1985; Keating et al., 1999). Men on the other hand are most likely to engage in household maintenance and financial planning assistance (Horowitz; Houde, 2001; Keating et al.). However, husbands who are the primary caregiver tend to complete all levels of care (Keating et al.). There is increasing pressure on family caregivers, particularly women, to fill the gap left from decreased funding for formal home support services (Armstrong & Kits, 2001). Fast et al. (1999) determined that in 1996 caregivers saved the public system in Canada over five billion dollars in that year alone.

Caregivers are not a homogeneous group. Subgroups exist among those that care for seniors in the community. Not only is gender of the caregiver and relation to the care receiver a consideration; proximity, the type and amount of care, and their relationship with other caregivers are also important in determining types of subgroups. Thus the distinction between primary and secondary caregivers is imperative (Bedard et al., 2001). Each group will have differing issues and needs. The increasing responsibility as a result of funding cuts and the complex situations surrounding caregiving make it even more imperative and more of a challenge to address the needs of carers.

## *2.2 Consequences of Caregiving*

*2.2.1 Caregiver well-being.* Maintaining caregiver well-being is complex at best. Well-being can be considered an umbrella term and has many dimensions, for example physical health, mental health, social network, and finances (George & Gwyther, 1986). Physical health of caregivers may be compromised by disruptions in sleep or alterations



in their own health (Fast et al., 1999). Mental health can be affected in a number of ways. Caregivers' reaction to caregiving, such as anger or guilt, can affect their mental well-being (Fast et al.). The most widely studied aspect of mental health is depression, and will subsequently be discussed separately. Strain may be considered a negative aspect of well-being, and will also be discussed separately.

Pratt, Schmall, Wright, and Cleland (1985) found social support to be a significant factor for those caregivers who managed their situation adequately. The size and positive influence of the social support network are important to assist caregivers at home (Robinson & Austin, 1998). Those caregivers with a smaller support network may be at higher risk for strain (Hibbard et al., 1996). Mastrian, Ritter, and Deimling (1996) suggest that the size of the social support network is not as significant as the perception of support available. Support networks play a vital role in sustaining caregivers (Hibbard et al.).

Often families must sacrifice financially to perform their caregiving role. This may be in the form of alterations in career or employment choices and paying out of pocket for formal caregiving. Fast et al. (1999) found that daughters were more likely to report a negative impact on employment decisions than sons, wives and other female non-kin. An alteration in well-being for a caregiver may be a result of challenges to all or only one of the dimensions. For example, a caregiver may have adequate finances to continue caring at home, but suffer emotionally as the care receiver deteriorates as a result of his or her dementia, thus well-being is negatively affected. There are conflicting results in the literature as to which caregivers exhibit lower levels of well-being (George & Gwyther,

1986). When well-being is compromised caregivers can succumb to the negative consequences of caregiving.

*2.2.2 Caregiver depression.* Depression is a commonly experienced consequence of caregiving (Canadian Study of Health and Aging, 1994; Given & Given, 1998). Although depression is an element of well-being it is commonly studied individually. Depression may be a result of caregiving and range from mild depressive symptoms to a major depressive disorder. Grieving for the care receiver may also illicit depressive symptoms. Symptoms that are present in depression include: depressed mood lasting most of the day, lack of interest or pleasure in activities, weight loss or gain, insomnia or sleeping excessively, feelings of restlessness, loss of energy, feelings of worthlessness, lack of ability to concentrate, and/or thoughts of death or suicide (American Psychiatric Association [APA], 2000). Symptoms that last longer than a two week period, and at least include either depressed mood or lack of interest may signal a major depressive episode (APA). Mignor (2000) suggests caregiver depression manifests as sleep disturbances, loss of appetite, and feelings of loneliness and worthlessness.

Caregivers have been found to be more depressed than the general population (Gallagher, Rose, Rivera, Lovett, & Thompson, 1989) and female caregivers are more likely to experience depression than their male counterparts (Fast et al., 1999). The Canadian Study of Health and Aging found that depression was nearly twice as common in caregivers of people with dementia compared to caregivers of people without dementia. Caregivers may feel trapped and helpless in their situation (Ruppert, 1996). In the case of older adults, the already stressful issues that the elderly face are compounded

further when having to take on the caregiver role with little support. Grieving for the care receiver with dementia may begin well before death (Kuhn, 2001).

*2.2.3 Caregiver strain.* A recurrent and common theme in the literature is caregiver strain, also known as burden. Caregiver strain is always negative, while caregiver well-being may imply both positive and negative responses. Feelings of strain may be a result of manifestations of care receiver disruptive behaviours and the caregiver's difficulty coping with these behaviours (Zarit, Todd, & Zarit, 1986). However, severity of care receiver behaviours is not the only factor that may impact the experience of strain for the caregiver (Zarit et al.). For example, Morgan and Laing (1991) found that the quality of past relationships had an impact on the amount of strain spouses experienced. Spouses that reported feeling strained tended to have a difficult past relationship with the care receiver (Morgan & Laing).

Caregiver strain may be considered as either objective or subjective in nature (Montgomery, Gonyea, & Hooyma, 1985). Each form of strain has its own consequences and may affect carers in complex ways. Families may be very high in objective strain and experience little subjective strain, and the reverse may be true.

Objective strain is the measurable disruption that results from caregiving, for example, sleep deprivation or disruption of planned activities. Bull (1990) suggests that measures of objective strain relate to the significant demand for assistance with tasks and the amount of time spent. Montgomery et al. (1985) report that objective strain is specifically related to the tasks of nursing care, bathing, walking, and transportation. Fast et al. (1999) found women experienced the most disruption to their lives as a result of caregiving. Primary caregivers are faced with the continuous, day to day demands of

caregiving, therefore they may experience a higher level of distress compared to secondary carers (Martin-Matthews, 1993). Thus, the primary caregiver may experience objective strain to a greater degree than a secondary caregiver. This was found to be the case in Bedard et al.'s (2001) study which examined the experience of primary and secondary caregivers who cared for the same adult with AD.

Fortunately, subjective strain is now beginning to be acknowledged (Rose, 1998; Ruppert, 1996). It is far more complex and individual than objective strain. It is defined as "the psychological consequences for the family [and non-kin] and includes...mental health, subjective distress, and burnout" (Cuijpers & Stam, 2000, p. 376). Subjective strain involves varied and complex reactions to the caregiving experience. These reactions may include grief, guilt, family conflict, resentment, role strain, and may be exacerbated by difficulties in past relationship. Practitioners have a difficult challenge in intervening appropriately and researchers have a difficult challenge in measuring the complex nature of caregiver strain.

*2.2.4 Institutionalization.* Often the goal of assisting family caregivers is to delay placing a loved one in a long-term care facility for as long as possible. Although it has been demonstrated that it is cost effective to maintain seniors with AD in their homes rather than be institutionalized (Hollander & Tessaro, 2001), there are both monetary and personal costs to caring for persons with AD. Predictors of institutionalization for those older than 65 years of age include an increased age, those that live alone, those that have functional disabilities, and previous use of home care services (Finlayson, 1999; Miller & Weissert, 2000). In the case of caregivers of people with dementia, the caregiver's feelings of strain related to the challenging behaviours of the care receiver are associated

with the decision to institutionalize the care receiver (Lieberman & Kramer, 1991; Zarit et al., 1986). At some point it may be necessary and a better use of resources to institutionalize an elderly person with AD (Montgomery & Borgatta, 1989).

### 2.3 *Caregiver Interventions*

Interventions to increase caregiver well-being are available in many forms. Common interventions found in the literature are educational groups, support or psychotherapy groups, and home care support or respite (Pasacreta & McCorkle, 2000). As well, there is an emergence of technological interventions that utilize computers and telephones to deliver the intervention. Biegel and Schulz (1999) state there is no "silver bullet" that can relieve strain.

Interventions to date have done little to reduce the subjective experience of caregiver strain. Ostwald, Hepburn, Caron, Burns, and Mantell (1999) suggest a multiple approach to achieve positive outcomes. Yet, it is difficult for families to accept even minimal assistance, let alone multiple interventions (Miller, 1998). Families may see formal support as an invasion of privacy, loss of control in their situation, or that some how they are failing in their role. Often it is not until a crisis that families seek formal support (Montgomery & Borgatta, 1989), which may be well into the caregiving experience. Practitioners should be sensitive to the issues families face when having to access formal support and, if possible, attempt to approach carers early on in their experience and support them throughout their journey, not just when carers become strained and their well-being is compromised. A systematic review of the interventions that are effective in supporting caregivers will assist practitioners and consumers in making decisions about which intervention to use.

#### 2.4 Review Question

A systematic review of an effectiveness question will be undertaken. The research question is: What interventions are effective in supporting unpaid caregivers' well-being when caring for elderly persons with dementia in the community?

### 3. Method

To assess the effectiveness of interventions for caregivers of persons with dementia a systematic review was utilized. The systematic review began in April 2002 and was completed in December, 2002. Systematic reviews can aid in demonstrating the effectiveness of health care interventions (Forbes, 2003; Hunt & McKibbin, 1998) for practitioners and consumers. Carrying out a systematic review is comparable to conducting a research study (Forbes). The unit of analysis is the primary difference (Moher, Jadad, & Klassen, 1998); research reports or articles are the unit of analysis instead of participants or subjects (Forbes). The method of appraisal and synthesis in a systematic review are explicitly described for readers, unlike other reviews (e.g., narrative reviews) (Klassen, Jadad, & Moher, 1998). In light of the enormous amount of literature available and the barriers to accessing journals (e.g., lack of time, resources or appraisal skills) systematic reviews are invaluable to aid with recommendations for policy-makers, clinicians and others (Ciliska, Hayward, Dobbins, Brunton, & Underwood, 1999).

The framework that guides this research is based on the work of Forbes and Strang (1997) and Forbes (1998). Their tool is nursing based, user-friendly and relevant to the content of the present review. It is well-described and provided information on how to interpret the validity tool and its ratings by including a validity tool rating scale and dictionary. Forbes and Strang's tools have been utilized by other researchers in the area of dementia care for disruptive behaviours (Opie, Rosewarne, & O'Connor, 1999) and a modified version in assessing the effectiveness of reminiscing with older adults (Buchanan et al., 2002). Other tools, commonly used in systematic reviews included in the Cochrane Library (e.g., Jadad et al., 1996; van Tulder, Assendelft, Koes, & Bouter,

1997), were found to be too restrictive (i.e., inclusion of randomized control trials only) and not nursing based. As well, a search of the Database of Abstracts of Reviews of Effectiveness (available in the Cochrane Library) in the area of dementia and caregiving demonstrated that most studies do not identify the tool used to assess the quality of the included studies. Buchanan et al. was the only review located that included a reference to the tool used, it was the tool developed by Forbes and Strang.

Conclusions about evidence are attained by assessing studies using defined steps. Forbes (2003) identifies the steps of a systematic review as follows: (a) developing a research question, (b) developing relevance and validity tools, (c) conducting a thorough literature search to include both published and unpublished studies, (d) using relevance and validity tools to assess the studies, (e) extracting the data, (f) synthesizing the findings, and (g) writing the report. The following is a discussion of the steps applied to the present study.

### *3.1 Developing a Research Question*

Ideally, for systematic reviews to be of benefit to consumers and practitioners, focus groups comprised of family and paid caregivers and surveys completed by these individuals can be used to identify questions important to them (Forbes & Phillipchuk, 2001). For sake of brevity, the question for review in this study is a result of personal clinical experience. Prior study and literature searches in the areas of family caregivers and dementia have resulted in refinement of the research question.

Forbes (2003) suggests three major components for a good research question related to effectiveness. They are the population, the intervention, and the outcome. The research question for the present study is 'What interventions are effective in supporting



unpaid caregivers' well-being when caring for elderly persons with dementia in the community?' The population is identified as caregivers of elderly individuals with dementia in the community, the interventions may include any means to support carers, and the outcomes are attributes of well-being. The question is broad in order to gather a sufficient amount of information. The population is limited to those who care for someone with dementia in the community and does not include caregivers of persons with other conditions or diseases. This will decrease the heterogeneity of caregivers studied and may enable grouping of outcomes according to the intervention.

### 3.2 *Developing Relevance and Validity Tools*

Previously developed tools by Forbes and Strang (1997) have been modified for use in this systematic review. Further discussion will follow as to how the tools were modified and applied to the studies in this systematic review.

3.2.1 *Relevance tool.* The relevance tool is essential to screen for studies that will ultimately be included in the review. All potentially eligible studies should be assessed (Clarke & Oxman, 2000). The criteria included in the relevance tool should evolve from the research question and include the population, the interventions, and outcomes as well as the study designs that will best answer the question (Forbes, 2003). What is located in the literature may influence the relevance criteria. Clarke and Oxman suggest that two reviewers assess studies for relevance as some reviewers may have pre-formed opinions in the area under consideration. Thus, two reviewers assessed the studies for relevance in the present review.

The relevance criteria for the present review were used to determine if the study:  
(a) was conducted or published in 1992 or later; (b) evaluated an intervention directed at

caregivers of an elderly individual with dementia living in the community; (c) measured one of the following caregiver outcomes: well-being (includes: physical, mental, social, and financial consequences), depression, strain, and/or other (e.g., institutionalization, health care expenditures); and (d) incorporated a control group or a pretest-posttest design with a sample size greater than one. When all four of the inclusion criteria were met the study was then included in the validity appraisal.

The first criteria included both published and unpublished studies to reduce publication bias. A literature search back to 1992 revealed a sufficient number of studies for consideration. Also, a similar systematic review by McKnight et al. (1993) was completed of studies previous to 1992. The second criteria identified if the study assessed an intervention for caregivers of persons with dementia. This eliminated studies that included a variety of caregivers of persons with differing conditions and did not report data specific to caregivers of persons with dementia.

The third criteria identified the outcomes of the studies to be included in the review. The outcome of institutionalization was subsequently added as it was commonly studied and not considered prior to beginning the review. This criteria was broad so as to include as many studies as possible that addressed the salient outcomes for caregivers of persons with dementia. The fourth and final criteria addressed the types of studies that were to be included. Descriptive case studies were not considered, rather studies needed to compare and assess the effectiveness of the intervention under examination. The review was not limited to randomized control trials, as this may have excluded studies that may assess effectiveness utilizing an alternate research design, for example a pretest-posttest design.

The relevance tool was guided by the work of Forbes and Strang (1997). They focused on including studies related to strategies to manage disruptive behaviours of individuals with AD. The present study is concerned with interventions for caregivers of individuals with AD thus the tools were modified accordingly. A summary of the differences between the two relevance tools can be found in Table 3.1 (see p. 17). The relevance tool was pre-tested and revised to meet the purposes of the present review (Appendix A).

3.2.2 *Validity tool*. The validity tool is necessary to assess the quality of included studies, limit bias in the systematic review, and guide interpretation of findings (Clarke & Oxman, 2000). Validity is assessed by considering potential sources of bias and error within a study (Forbes, 2003). Potential sources of bias in healthcare studies include: selection bias, performance bias, attrition bias, and detection bias (Clarke & Oxman). Selection bias may be avoided with randomization of participants or controlling for relevant confounders; performance bias is reduced by blinding both participants and data collectors, when possible, to group allocation; attrition bias is a result of withdrawal of subjects from a study; and finally detection bias again may be avoided by blinding of data collectors completing outcome measures (Forbes, Clarke & Oxman).

The five validity criteria included in this review were: (a) design and allocation to intervention: random (pass), before/after or matched cohort (moderate), and can't tell (fail); (b) attrition: <10% (pass), 11-20% (moderate), >20%, not applicable, and can't tell (fail); (c) confounders controlled (e.g., age or sex of caregiver, cognitive impairment of care receiver): at least four controlled (pass), at least two to four controlled (moderate), one or less of confounders controlled (fail); (d) measures/data collection: methods

Table 3.1

*Summary of Differences in Relevance Tool*

Forbes and Strang relevance rating tool	Unpaid Caregiver relevance rating tool
1. Is the unpublished or publication date of the article 1985 or later?	1. Is the unpublished or publication date of the article 1992 or later?
2. Does the article evaluate a nonpharmacological intervention directed to an elderly individual with SDAT or their informal caregiver?	2. Does the article evaluate an intervention directed at caregivers of an elderly individual with dementia living in the community?
3. Is the intervention within the scope of nursing practice?	3. Not included.
4. Does the study measure at least one of the following care recipient outcomes? Wandering; agitated behaviour; physical violence; vocally disruptive behaviour; eating behaviours; sundowning; withdrawal; self-care ability.	4. Does the study measure one of the following caregiver outcomes? Well-being (includes physical, mental, social, and financial consequences); depression; strain; other (e.g., institutionalization).
5. Does the study incorporate a control group or pretest-posttest design with a sample size greater than one?	5. Does the study incorporate a control group or pretest-posttest design with a sample size greater than one?
Include in critical appraisal. Yes=Y to 1, 2, 3, 4, 5	Include in critical appraisal? (must answer yes to all above questions)

well-described, piloting or pre-testing data collection instruments, and blinding of data collectors (at least two of the three categories rated yes, pass), one of the categories rated yes (moderate), none of the categories rated yes (fail); (e) types of statistical analysis: multivariate (pass), bivariate (moderate), descriptive or can't tell (fail). A study was rated strong if there were no fail ratings and no more than one moderate rating; a moderate study could have no fail ratings and more than one moderate rating; a study rated as weak had two or less fail ratings; and a poor study had more than two fail ratings.

The rating associated with design and allocation to intervention was designed to address selection bias with randomization being the most effective means to achieve that. Attrition rate selection was set to control for attrition bias and had to reflect studies that included a control group and those that employed a pretest-posttest design. The cut off level of 20% was discussed and agreed upon by the thesis advisory committee.

Controlling for as many relevant confounders as possible is essential to limit potential selection bias, particularly for pretest-posttest designs. Potential bias from detection bias was addressed by considering how data was measured and collected by pre-testing instruments and blinding data collectors. Lastly, by using multivariate statistics a study could account for controlling of confounders thus reducing bias from selection of participants. The validity tool then rated studies on how each source of systematic bias was addressed. To limit rater bias two reviewers assessed the relevant studies for validity.

The criteria for the validity tool, validity tool dictionary, and rating scale were modified from the tools of Forbes and Strang (1997). Forbes and Strang included validity criteria with regard to obtaining consent to participate. The participants in Forbes and Strang's review were individuals with dementia, a vulnerable population. In the present

review the participants were able to give consent and some studies may have been excluded because the authors did not report that consent was in fact obtained. Thus including this criterion was not considered necessary and was removed after discussion between the two raters. As well, Forbes and Strang rated a study as strong when no fail ratings were found and no more than two moderate ratings were assessed. Because of the exclusion of one of the criteria in the present review a strong study was one that had no more than one moderate rating and no fail ratings. See Table 3.2 (p. 20) for a summary of the differences between the tools. The validity tool, rating scale and dictionary were pre-tested and revised as necessary (Appendix B).

### 3.3 Literature Search Strategies

The search strategies for this review included on-line computer searches, hand searches of selected relevant journals, and searches of individual reference lists of all retrieved studies. Independent on-line searches were completed for the years 1997 to 2002 of CINAHL, MEDLINE, HealthStar, and PsychINFO. On-line searches of CINAHL and PubMed were conducted for the years between 1992 to April 2002 with the assistance of an experienced librarian. The key words that were utilized included caregiver or carer, dementia or Alzheimer, burden, depression, strain, stress, support, respite, education, intervention, effective, assess, evaluate, and measure. All inter-library loan requests were received. On-line CISTI Source was used to aid in hand searching the table of contents for the *Gerontologist*, *Journal of Gerontological Nursing*, and *Journal of the American Geriatrics Society*. Retrieved studies' reference lists were also searched for relevant studies, which were retrieved and subsequently reviewed.

Table 3.2

*Summary of Differences in Validity Tool*

Forbes and Strang Validity Rating Tool	Unpaid Caregiver Validity Rating Tool
Design - pass moderate fail	Design - pass moderate fail
Inclusion/Consent - pass moderate fail	Not included
Attrition - pass moderate fail	Attrition - pass moderate fail
Confounders controlled - pass moderate fail	Confounders controlled - pass moderate fail
Data Collection - pass moderate fail	Measures/Data Collection - pass moderate fail
Types of Statistical Analysis - pass moderate fail	Types of Statistical Analysis - pass moderate fail
<b>Overall Assessment</b>	<b>Overall Assessment</b>
<i>Strong</i> - no fail rating and no more than two moderate ratings	<i>Strong</i> - no fail rating and no more than one moderate rating
<i>Moderate</i> - no fail rating and more than two moderate ratings	<i>Moderate</i> - no fail rating and more than one moderate rating
<i>Weak</i> - two or less fail ratings	<i>Weak</i> - two or less fail ratings
<i>Poor</i> - more than two fail ratings	<i>Poor</i> - more than two fail ratings

Unpublished dissertations were included in the librarian searches; none were relevant to the present review. Searches completed by the librarian were catalogued using the reference management program of EndNote. A total of 92 studies were retrieved and assessed for relevance. The primary authors of some articles were contacted for

clarification of their studies and for additional information. Two studies were not included because of insufficient reporting, the researchers were contacted via e-mail; however, they did not return requests for additional information. The results of a review may be flawed if not all primary studies in a particular area are located and subsequently included.

#### *3.4 Assessment of Studies Utilizing Relevance and Validity Tools*

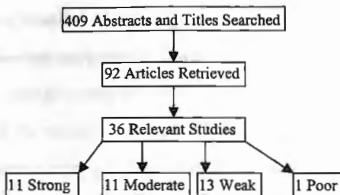
*3.4.1 Relevance tool.* Of the 92 retrieved studies, 36 met all four relevance criteria. The first 19 studies were reviewed by two readers. A high level of agreement ( $\kappa=0.8$ ) of the two readers was reached, thus the remaining studies were assessed independently by the author, with any subsequent concerns discussed and a consensus reached between the two raters.

*3.4.2 Validity tool.* The next phase of the review involved rating the 36 relevant studies for validity. The first 12 relevant studies were rated independently again by two readers and 100% agreement was reached. Subsequent studies were rated by one reader, with any concerns discussed and consensus reached. Of the 36 studies reviewed 11 were judged to be strong, 11 were moderate, 13 were weak, and only 1 was judged poor (Figure 3.1). Descriptive analyses were completed for the 11 strong and 11 moderate studies in the areas of: methodological weaknesses, country in which study was conducted, interventions, outcomes, study design, and common measures for cognitive status of care receivers and caregiver strain, depression, health, and stress.

#### *3.5 Data Extraction*

Consistent, uniform data extraction is required to obtain essential information from studies (Forbes, 2003). To minimize bias in extracting information from studies a





*Figure 3.1: Overview of the Systematic Review*

data extraction tool was developed to include general information and specific study characteristics as reported by the researcher (e.g., the country the study was conducted in; methods employed; participant characteristics; type, intensity, and duration of the intervention; and outcomes measured). A data extraction tool for the present review was modified from the one developed by Forbes and Strang (1997) (Appendix C). It was pre-tested and revised appropriately to reflect the changes in the validity tool. The tool was used to extract significant data from the strong and moderate studies. It was completed independently by the author, with concerns discussed with the second reader.

### 3.6 *Synthesizing the Findings*

A brief discussion of the overall findings is followed by a narrative for each strong and moderate study and summarized in Table A.1 (Appendix D). The findings (please see next chapter) are discussed according to type of intervention. The weak and poor studies are not described in detail; a brief summary of those studies may be found in the discussion chapter. A bibliography of all relevant studies can be found in Appendix E. If level of significance was found to be less than 0.05 then findings were considered to be statistically significant.

### 3.7 Dissemination of Findings

Prior to disseminating the findings, documentation will be reviewed by a consumer to ensure that the findings are relevant and written in language appropriate for the target audience. The findings of this study will be disseminated in a variety of ways. In addition to potential publication in a peer-reviewed journal, publishing the findings in newsletters and developing fact sheets for interested consumers, practitioners, and policy makers may be undertaken. Where possible findings may also be presented at local and national conferences, either as a poster or oral presentation.

## 4. Findings

The findings in this review are based on the 11 strong and 11 moderate rated studies. A brief overall summary of the studies is followed by an individual summary of each study.

### 4.1 Overall Summary of the Strong and Moderate Studies Combined

#### 4.1.1 Methodological Weaknesses

The most common methodological weaknesses of the strong and moderate studies combined include: (a) no random allocation of participants to experimental or control groups ( $n=7$ ); (b) greater than 10% attrition of participants ( $n=5$ ); (c) not controlling for all potentially relevant confounders ( $n=1$ ); (d) data collection strategies did not include piloting of tools and blinding of data collectors ( $n=14$ ); and (e) multivariate analysis not utilized ( $n=9$ ). Figure 4.1 displays these findings.

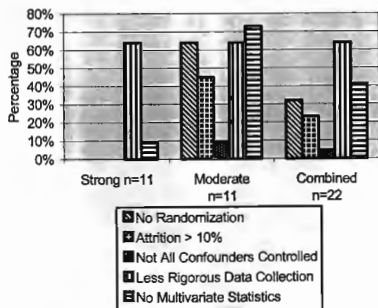


Figure 4.1. Methodological weaknesses of strong, moderate, and combined studies.

#### 4.1.2 General Characteristics

The majority of studies were conducted in the United States ( $n=15$ ), one in Finland, while the remaining were in Canada, United Kingdom/Ireland and Australia (each  $n=2$ ) (Figure 4.2). The studies were categorized according to type of intervention. The most common intervention was education ( $n=8$ ), followed by case management ( $n=4$ ), psychotherapy ( $n=3$ ), respite ( $n=3$ ), technology ( $n=2$ ), assessment clinic ( $n=1$ ), and home care ( $n=1$ ) (Figure 4.3). The most common measured outcomes were found to be depression in caregivers ( $n=9$ ), institutionalization of care receivers ( $n=8$ ), caregiver strain ( $n=7$ ), caregiver coping or appraisal of situation ( $n=7$ ), stress or anxiety ( $n=6$ ), quality of life or health of caregiver ( $n=6$ ), death of care receiver ( $n=4$ ), use of formal services ( $n=4$ ), and caregiver knowledge of dementia ( $n=3$ ) (Figure 4.4).

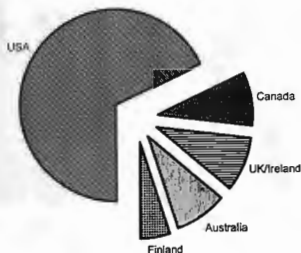


Figure 4.2. Countries where studies were conducted.

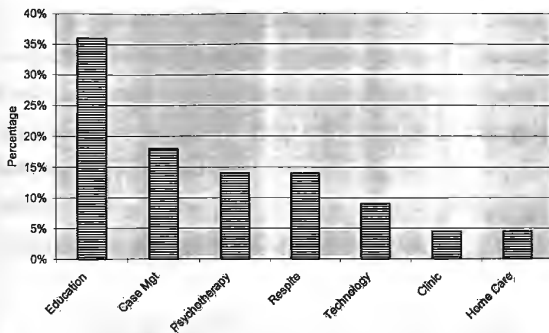


Figure 4.3. Types of interventions.

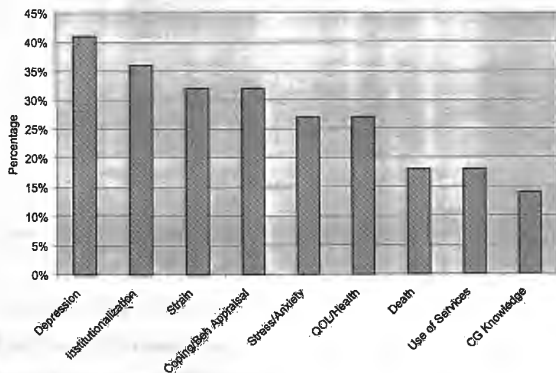


Figure 4.4. Most commonly measured outcomes.

### 4.1.3 Instruments

4.1.3.1 *Care receivers.* The most common measurement tools used to assess care receivers (Figure 4.5) were examined. Many of the studies utilized the Mini-Mental State Examination (MMSE) ( $n=9$ ) (Folstein, Folstein, & McHugh, 1975) to assess level of cognitive impairment or severity of dementia in the participating care receivers; followed by the Diagnostic and Statistical Manual of Mental Disorders (DSM-III-R) ( $n=3$ ) (APA, 1987), Global Deterioration Scale (GD Scale) ( $n=3$ ) (Reisberg, Ferris, De Leon, & Crook, 1982), and the Clinical Dementia Rating (CDR) ( $n=3$ ) (Berg, 1988).

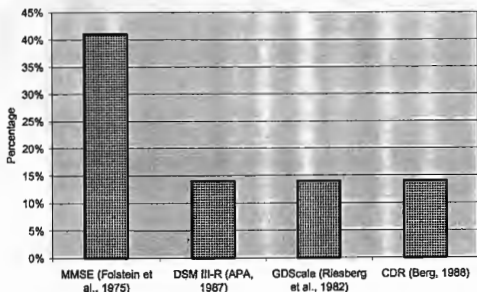


Figure 4.5. Most common measurement tools used to assess care receivers.

4.1.3.2 *Caregivers.* The most common instruments utilized to assess caregivers are displayed in Figure 4.6. Caregiver characteristics most commonly measured included: strain measured with a version of the Zarit Burden Interview (ZBI) ( $n=6$ ) (e.g., Zarit, Reever, & Bach Paterson, 1980), health measured with General Health Questionnaire (GHQ) ( $n=3$ ) (Goldberg, 1978), and depression measured with two instruments, the

Geriatric Depression Scale (GDS) ( $n=4$ ) (Yesavage et al., 1983) and the Centre for Epidemiological Studies-Depression Scale (CESDS) ( $n=3$ ) (Radloff, 1977). Caregiver perception of care receiver problem-behaviours was measured with either the Memory and Problem Behavior Checklist (MPBC) (Zarit & Zarit, 1990) or its revised version (MPBC-R) (Teri et al., 1992) (combined  $n=4$ ). There were a handful of studies that utilized investigator developed tools ( $n=4$ ).

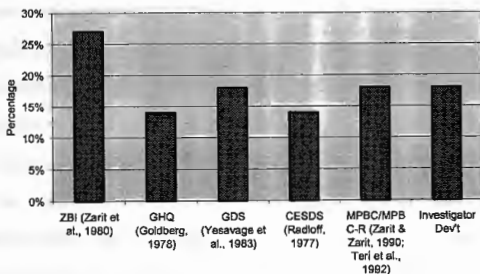


Figure 4.6. Most common measurement tools used to assess caregivers.

#### 4.2 Individual Study Summaries

The following is a discussion of each included study. The results are categorized according to type of intervention. Please see Table A.1 (Appendix D) for summaries of the strong and moderate studies.

##### 4.2.1 Assessment Clinic

One study's intervention was unique and not comparable to others collected for this review. It was rated as moderate.

4.2.1.1 *Moderate*. A randomized pilot trial was conducted by Logiudice et al. (1999) to assess the impact that a memory clinic for individuals with mild to moderate dementia would have on the quality of life of caregivers. Participants were randomized to either the intervention group ( $n=25$ ) or the control ( $n=25$ ). Those in the intervention group attended the memory clinic on two separate occasions. In the first visit the care receivers in the intervention group had a thorough medical and cognitive assessment while the caregivers were provided with advice and counseling. The second visit consisted of a neuropsychological assessment by a neuropsychologist or speech pathologist, followed by a family conference to discuss the results of the assessments. A plan of assistance and referral to services were then provided. Control group participants were interviewed for data collection only, in their home.

Measurements were obtained for both groups at baseline, and at 6 and 12 months follow-up. Significant findings at six months revealed that overall quality of life related to psychosocial health of caregivers improved for the intervention group, including the subgroups of alertness behaviours and social interaction. At 12 months, however, only social interaction remained significant. A number of nonsignificant findings of the intervention include number of deaths or institutionalization of the care receiver, impact on psychological morbidity, strain, tolerance of disruptive behaviors, and caregiver knowledge of dementia. It appears that the quality of life associated with psychosocial health, as measured by social interaction, was improved as a result of this intervention. Strengths of this study include randomization and low attrition, however, data collectors were not blinded, the instruments were not pre-tested and multivariate statistics were not conducted.



#### 4.2.2 Case Management

Four studies, rated as strong, examined the effect of intensive case management on caregivers. Three of the four studies utilized the data obtained in the Medicare Alzheimer's Disease Demonstration and Evaluation (MADDE), with each study focusing on different caregiver outcomes.

4.2.2.1 *Strong*. Eloneimi-Sulkava et al. (2001) examined whether seniors with dementia could be supported to stay in the community longer with the assistance of a nurse case manager. A randomized control design with a two-year follow-up was utilized. Intervention caregivers ( $n=53$ ) received coordinated care, services and support for the caregivers. The nurse case manager provided: (a) advocacy for caregivers and care receivers; (b) comprehensive support; (c) continuous counseling; (d) annual training courses for both caregiver and care receiver; (e) follow-up calls; (e) in home visits; (f) assistance with obtaining formal support services; and (g) 24 hour availability by mobile telephone. The control group ( $n=47$ ) received the usual services provided in that region. Measures were obtained at baseline upon entering the study and at two endpoints, when the care receiver was institutionalized and when death occurred.

The main outcome measure for this study was the time to institutionalization. Using the Kaplan-Meier survival method there was a significantly lower rate of institutionalization for the intervention group compared to the control in the first six months of the study; the benefit of the intervention, however, decreased with time. The authors also examined care receivers at different stages of dementia. Interestingly, they found that those more severely impaired in the intervention group remained in the community longer. The impact of the intervention was less for those mildly impaired. By

the end of the two-year follow-up the number of care receivers institutionalized was similar in both the control and intervention groups. Thus there was not a sustained effect in this case of nurse case management. Confidence in these findings are supported by use of randomization, and use of multivariate survival analyses. Although attrition may be considered high (51% in the intervention group and 53% in the control group), this is related to the outcome measures of institutionalization or death and thus is not considered a weakness in this case. Attrition usually reflects participants wishing to leave the study because of dissatisfaction with the intervention. A limitation of the study is the data collection. Although common tools were utilized, the measures were not pre-tested on a similar population to those participants in the study and data collectors were not blinded to group membership.

The next three strong studies utilized the same data, but reported different outcome measures. The MADDE was developed in December, 1989 to address the ongoing needs of both caregivers and care receivers with dementia, with the goal to improve well-being of the participants. The program ran until November, 1994. The demonstration's intervention consisted of two program models, with four sites in each model. Model A sites had a case manager to client ratio of 1:100, with a reimbursement cap for community services of \$290-\$489 per month for each client. Model B sites had a smaller ratio of 1:30 case managers to clients and a maximum benefit of \$430-\$600 per month. Case managers were social workers, with one site utilizing nurses. The intervention was available to individuals diagnosed with an irreversible dementia and their caregiver who resided in the demonstration site's catchment area. Subjects ( $n=8,387$  at baseline) were randomly assigned to intervention or control status after volunteering to

participate. The intervention was available for up to three years as long as the care receiver remained at home. Upon death or institutionalization the caregivers were disenrolled 60 days later. All participants received baseline and semi-annual assessment interviews until death or institutionalization of the care receiver or up to three years after enrollment in the program.

The first of the three studies, Miller, Newcomer and Fox (1999), examined the effects of MADDE on institutionalization. The sample included in this study (intervention  $n=4151$ , control  $n=3944$ ) had no significant difference in mortality rates with either univariate or multivariate analyses. A Cox proportional hazards regression was utilized to estimate the effect of the intervention on institutionalization. When intervention groups, all sites and models A and B combined, were compared to controls the intervention did not affect the rate of institutionalization. One exception was with one site having an increased rate of institutionalization compared to controls. This may have been a result of advocacy on part of the case managers and the lack of restriction on nursing home entry. Overall, the MADDE had little effect on institutionalization rates for all intervention participants combined or for individual subgroups.

Newcomer, Spitalny, Fox, and Yordi (1999) examined MADDE's effect on use of community based services. Utilizing logistic regression the proportion of intervention participants ( $n=2,682$ ) using home care services more than doubled, while controls ( $n=2,527$ ) increased by 50%. The results are similar for adult day care use. Within 12 months the intervention group doubled their previous use of day care services, while the control group increased their use by 50%. Membership in the intervention group significantly increased the likelihood of day care use compared to the control.

Intervention participants who used home care services used about 45 hours more than the control group participants. These results indicate that the MADDE intervention participants had an overall higher likelihood of using community services compared to the control group. This was consistent with the purpose of the demonstration to identify needs of families and assist them to obtain appropriate services.

Newcomer, Yordi, DuNah, Fox, and Wilkinson (1999) examined the effects of MADDE on caregiver strain and depression. A two-stage hierarchical linear model was used to detect differences between groups and site location. Although at the six month period the intervention group ( $n=2,728$ ) experienced a significant reduction in strain compared to the control group ( $n=2,576$ ) no significant differences were found at any of the other semi-annual interview periods. Caregiver depression was not significantly different between groups at any time period. Overall the MADDE had little effect on decreasing strain and depression for caregivers, despite having greater exposure to case management and a greater likelihood of using community services.

A limitation of the MADDE studies' design is in the data collection process. The studies do not report if the data collectors were blinded to participants' group membership, nor were the common tools pre-tested on a similar population. However, there are a number of strengths: the use of a large data set, relatively low attrition (especially in light of the sample), and use of multivariate statistics.

In summary, the findings of these studies reveal conflicting results with respect to the effectiveness of case management in decreasing the rate of institutionalization. Eloneimi-Sulkava et al., (2001) found a decrease in rate of institutionalization in the first year of their study, while the MADDE study (Miller et al., 1999) found no impact from

case management on reducing rates of institutionalization. Differences may be attributed to the fact that Eloneimi-Sulkava et al.'s study was conducted in Finland and MADDE was based in the United States. Case management did double the likelihood of the intervention group using community services while the control group's use increased by 50% in the MADDE study (Newcomer, Spitalny et al., 1999). Case managers appropriately advocated for caregivers to obtain increased formal support. Overall, case management on the whole did not impact levels of strain or depression for caregivers despite support from the case manager and access to community services (Newcomer, Yordi et al., 1999).

#### 4.2.3 Education

A total of eight studies were categorized as educational interventions. Four studies met the rating of strong, the remaining four were rated as moderate. For this review education as an intervention is defined as researchers/clinicians providing education about a subject and/or teaching the participants a new skill. A variety of educational interventions were included.

4.2.3.1 *Strong*. The first strong study by Brodaty, Gresham, and Luscombe (1997) examined the effects of a caregiver training program on the rates of institutionalization and time to death of care receivers with dementia. A prospective, randomized control trial with approximately eight years of follow-up was conducted. Caregivers and care receivers over the age of 80 with mild to moderate dementia ( $n=96$  dyads) were randomly assigned to an immediate intervention group, a waitlist group or a memory re-training only group. Caregivers in the intervention groups received training and education on a variety of topics (e.g. distress, guilt, assertiveness training) while the care receivers participated in a

memory clinic. The training for both caregivers and care receivers was delivered over the same ten days; waitlist participants received training approximately six months after application to the program. The memory re-training group caregivers received ten days of respite. Data collection was the same for all three groups; telephone conferences were conducted at 3, 6, and 12 months post-program, then annually until institutionalization or death of the care receiver.

Kaplan-Meier survival analysis revealed no statistical difference between the two intervention groups (immediate training and waitlist groups) in regard to time to institutionalization or death of the care receiver, thus groups were combined for further analyses. The subsequent analyses showed caregiver training to have a significant effect on delaying institutionalization and only a trend towards delaying care receiver death as compared to the memory re-training (respite) only group. This demonstrates that caregiver training programs have potential benefits to delay both institutionalization and death of the care receiver.

A unique and strong approach used by Brodaty et al. (1997) was the provision of an intervention for care receivers concurrently with caregivers. This addresses the issue of access for some caregivers who are unable to leave their loved one alone to attend a function. As well, randomization, low attrition, use of three groups, and multivariate statistics added to the rigor of this study. The utilization of a waitlist control group ensured all participants received care, which may be an incentive to participate for strained caregivers. A limitation of the study is that data collectors were not blinded to participants' group assignment and instruments were not pre-tested.

The second strong study examines the effects of a stress-adaptation model on improving caregiver interaction with care receivers with dementia conducted by Corbeil, Quayhagen, and Quayhagen (1999). Participants were randomized to an active cognitive-stimulation group ( $n=28$ ), a passive cognitive-stimulation (placebo) group ( $n=28$ ), or a control group ( $n=31$ ) that received no intervention. All participants received assessments at baseline, post-intervention (at 12 weeks), and at nine months follow-up.

Although the intervention had no impact on caregivers' stress when interacting with care receivers, it did have a significant impact on caregivers' positive reappraisal at nine months follow-up. A repeated measures design revealed that those in the intervention group remained positive in their appraisal of their interactions with care receivers, while the placebo and control groups became negative in their re-appraisal. A caregiver coping approach was provided to the caregivers in the problem-focused strategies of the intervention that enhanced the caregiver-care receiver interaction. Thus the caregiving situation was perceived in a more positive light. Randomization and use of three groups were strengths in this study.

The third strong education intervention study was conducted by Marriott, Donaldson, Tarrier, and Burns (2000). Their educational intervention was aimed at reducing the strain of caregivers of individuals with AD. A prospective randomized control trial with two control groups was utilized. The intervention group ( $n=14$ ) received a modified family intervention initially developed in the treatment of schizophrenia. Over 14 sessions, members were provided with education, stress management, and coping skills training, in addition to an in-depth family interview. The control groups (both  $n=14$ ) did not receive any training, however one of the two controls received the in-depth

family interview to determine if it independently could be perceived as a source of support to caregivers. All assessments and data collection were conducted at baseline, post-intervention (nine months after entry into study), and at three months follow-up (12 months after entry).

The results of the study revealed no impact from the in-depth family interview as evidenced by no significant differences between control groups. Significant findings include a decrease in depression at follow-up and a decrease in behavioural disturbances by the care receivers at post-intervention only for the intervention group compared to the control groups. As well, the intervention caregivers had fewer psychiatric cases (as measured by the General Health Questionnaire; Goldberg, 1978) at post-treatment and follow-up compared to the control groups. The use of three groups and the randomization process strengthened this study, in addition to low attrition, blinded data collectors, and use of multivariate statistics, such as stepwise multiple regression, to analyze results.

The fourth strong study by Wright, Litaker, Laraia, and DeAndrade (2001) evaluated a 12 month education program for caregivers of individuals with AD that included counseling provided by a nurse. People were recruited while the care receiver was being treated on an inpatient unit for agitation related to AD. Participants were randomized to either intervention or control groups. Individual education and counseling were provided to intervention participants ( $n=68$ ) in their home at 2, 6, and 12 weeks after discharge from the hospital. Additional support was provided by phone contact at 6 and 12 months post discharge. Control group subjects ( $n=25$ ) were contacted at the same five time periods by telephone for data collection purposes only.



Chi-square analysis demonstrated that the intervention did not have a significant impact on rates of institutionalization or death. Further, mixed model ANOVA's revealed no significant effect of the intervention on reducing care receiver agitation, improving depression, stress, and health for the caregiver. The study did not reveal any significant long-lasting effects of the intervention.

A major benefit of this study was the implementation of the intervention in the caregiver's own home. When caring for someone with AD it is often difficult to participate in research that is conducted outside of the home. Also, researchers obtain a different perspective from observing individuals in their home as opposed to an experimental setting. Strengths of the study included randomization, low attrition for those wishing to leave the study because of dissatisfaction with the intervention, and pre-testing of instruments. Use of multivariate statistics and collection of five data points per subject also strengthened the study. All categories were rated as strong.

*4.2.3.2 Moderate.* The first moderate study by Coen, O'Boyle, Coakley, and Lawlor (1999) examined the impact of an education program on caregiver quality of life, strain and well-being. The present study is based on results from two previous pilot runs. A pretest-posttest design was utilized and participants were subdivided post-program by perceived status. The result of the subdivision included caregivers who reported their situations to be better ( $n=12$ ), worse ( $n=12$ ), and no change ( $n=4$ ). Results of those caregivers in the no change group were pooled with the results of the caregivers who reported their situation as better (thus  $n=16$ ). The intervention consisted of eight weekly sessions, each two hours in length. The sessions covered a variety of topics, including information on dementia, management of everyday problems, reality orientation,

communication techniques, coping, management of stress, hospitalization, and legal issues. Participants were interviewed prior to starting the program by an experienced psychologist. Measures were obtained from the pre-program interview and six to seven months post-program.

For all participants, there was an increase from pre-program to post-program in caregiver knowledge regarding dementia using t-test analysis. With respect to the subdivisions (better/no change and worse groups) logistic regressions revealed the only significant difference between the subgroups was the change in scores on care receiver behaviour disturbance. The remaining differences in scores from pre-program to post-program were not significant for quality of life, strain, well-being, care receiver functioning, behavioural status, or appraisal of social support.

There is no evidence to suggest this intervention has any impact on quality of life, caregiver strain and well-being. The sole significant result, for both subgroups, was increased dementia knowledge. Education alone appears limited in improving overall psychological well-being for caregivers, thus the researchers felt it necessary to discontinue the program altogether. A strength of the study is utilization of pilot runs prior to conducting the present study. Limitations include small sample size and lack of randomization of participants to an intervention or waitlist group.

The second moderate study by Fisher and Laschinger (2001) investigated the effectiveness of relaxation training on increasing caregivers' self-efficacy. It was theorized that an increase in self-efficacy would aid in controlling the anxiety that results from the disruptive behaviours manifested by individuals with AD. A pretest-posttest design involved a total of 36 participants in six separate intervention groups delivered

over six months. The six week intervention provided participants with six training sessions on relaxation. Participants also received manuals to supplement learning and were asked to keep logs of their use of the individual relaxation techniques. Measures were obtained in the initial and final sessions by graduate nursing students.

Following the intervention, a t-test revealed a significant change in caregivers' overall self-efficacy for controlling anxiety related to disruptive behaviours of the care receivers. At pretest, researchers discovered that male caregivers had significantly higher self-efficacy scores compared to female caregivers; this difference between genders did not remain at post intervention. An additional pretest difference in caregivers' self-efficacy was in regard to the number of years since diagnosis of AD; again this difference did not remain significant at post intervention. The difference in incidence of problems with disruptive behaviours of the care receivers was found to be less at post intervention, but not to a significant degree.

Strengths of this study include a low attrition, which may be a result of the positive and social nature of the intervention; as well, the study had strong validity as data collectors were trained and instruments were pre-tested. Generalizability of the findings in this study is limited because the participants were recruited from existing programs in one facility, thus including individuals already open to and accessing formal support. Interestingly, anxiety was not measured in this study, thus its impact on the results is unknown.

For the third moderate educational intervention study McCurry, Logsdon, Vitiello, and Teri (1998) conducted a randomized control trial with three groups to investigate the benefits of an intervention to improve the quality of sleep for caregivers. The two

intervention groups differed as those participants in phase one ( $n=7$ ) received the intervention in a group format and the second phase participants ( $n=14$ ) received the intervention on an individual basis, as per the suggestion of the group participants. The second phase was shortened from six weeks to four, also at the suggestion of the group participants. The third group, the waitlist control ( $n=15$ ), was offered the intervention at the three month follow-up. The intervention included information about age-related sleep changes, development of individualized sleep schedules and treatments, discussion about difficulty complying with the recommended treatment, techniques on coping and stress, relaxation exercises, and a final session that summarized the intervention. Participants also kept a daily diary of their sleep patterns. Measures for all participants occurred pre and post-intervention and a three month follow-up.

Analyses did not reveal any differences that may have resulted from the two interventions. Thus group and individualized intervention participants were combined for further comparisons with the waitlist control. Utilizing analysis of variance (ANOVA) the intervention did significantly improve overall sleep quality for intervention caregivers compared to the waitlist group at both post-intervention and at three months follow-up. However, no significant differences between groups were detected for caregiver mood, patient behaviours, or caregiver depression at either post-treatment or follow-up.

The researchers further examined the differences between individuals that responded well to the intervention versus those individuals that did not. T-test results indicated that well-responders were younger than poor-responders. A significant number of well-responders complied with the compressed sleep schedules compared to poor-

responders indicating that compliance with the recommendations (intervention) was in part responsible for the improvement in sleep.

Despite the small sample size and short follow-up period, this study was rated as moderate. Participants were randomly assigned and three groups were utilized, including a waitlist control. This ensured that although participants did not immediately receive the intervention, in three months it would be available to them if they wished. The small sample size did, however, limit the power of statistical analyses that could be completed. The intervention did in fact impact sleep quality, but had little effect on caregiver mood or depression, and care receiver problem behaviours.

The fourth moderate study examined the effects of a communication training intervention conducted by Ripich, Ziolo, and Lee (1998). The intervention was offered to a number of caregivers from one center. Those that were free and able to participate ( $n=19$ ) made up the intervention group, while those who were at a distance, had no time or had other commitments made up the control group ( $n=18$ ). Although, the groups differed in that the intervention group had a higher socioeconomic status, this was controlled for in all analyses.

The intervention consisted of two hour weekly sessions, over four weeks. The content of the intervention included information on AD, communication issues with people who have AD, and techniques to enhance communication and was delivered by a speech-language pathologist. Intervention participants completed questionnaires prior to training, within three weeks post-training, and at 6 and 12 months follow-up. The control group completed questionnaires at baseline, and the 6 and 12 months follow-up. Data analyses of ANOVA's indicated that intervention caregivers had a significant decrease in

"communication hassles" compared to the control group, this was maintained at the 12 month follow-up. In addition, the intervention caregivers showed a significant increase in knowledge about AD and communication issues compared to the control caregivers, again consistent to 12 months follow-up. No significant changes were noted in positive or negative affect, depression, health or general hassles for the intervention caregivers compared to control group members following training.

The strengths of this study are the use of a 12 month follow-up, and the low attrition level. Although a control group was utilized it was self-selected, thus weakening the generalizability of the study as there may have been factors that differed between the groups that were not tested by the researchers. The study demonstrated that the intervention does have an long-lasting impact on communication hassles and increases knowledge for the intervention participants, although it has no impact on affect, health, depression or overall hassles experienced by caregivers.

In summary, education interventions are not sufficient to improve overall caregiver psychological well-being, such as decreasing strain and depression or reducing care receiver disruptive behaviours (Coen et al., 1999; Corbeil et al., 1999; McCurry et al., 1998; Ripich et al., 1998; Wright et al., 2001). There is an exception with Marriott et al.'s (2000) family intervention as it demonstrated a decrease in depression for caregivers through to follow-up. Coen et al. in fact decided to halt their intervention because of lack of improvement in elements of psychological well-being.

There are, however, a number of significant findings. Brodaty et al. (1997) was able to demonstrate that institutionalization and death of the care receiver are delayed with a caregiver training program. Educational interventions can increase caregiver

knowledge of dementia (Coen et al., 1999; Ripich et al., 1998), thus preparing caregivers for how their role may evolve or what they may expect. Researchers/clinicians should be sensitive as to how caregivers perceive that education. Caregivers should be informed about symptoms of dementia, but should also be provided information on how they may handle the changes that result from dementia. Interventions that provide caregiver coping methods can enhance positive re-appraisal (Corbeil et al., 1999) and demonstrate a decrease in communication hassles (Ripich et al.), thus improving interactions between caregivers and care receivers. Fisher and Laschinger's (2001) relaxation training intervention improved overall self-efficacy of intervention caregivers enabling them to handle the anxiety associated with caring for someone with AD. In addition, McCurry et al. (1998) were able to improve general sleep quality for caregivers with their individualized intervention.

#### 4.2.4 Home Care

Only one study, rated as moderate, consisted of examining the effects of formal support, namely Home Care, on three areas of stress for caregivers. These three areas were: yielding of role (institutionalization of care receiver), anxiety, and physical health.

4.2.4.1 *Moderate*. Winslow (1997) conducted a secondary analysis of data from a longitudinal study of stress and coping to examine the effects of formal support on the stresses that can result when caring for someone with AD. A pretest-posttest design was utilized with a convenience sample ( $n=452$ ). The first two of four interview periods are included in this analysis. Use of 11 formal support services (not listed) was measured.

Analysis of the three areas of stress were completed with a series of multiple regressions. Results demonstrated that caregiver anxiety after one year was explained by

caregiver overload, the level of anxiety measured at baseline, and lower levels of care receiver dependence; this accounted for 36% of the explained variance in caregiver anxiety. There were no significant findings between formal support and level of anxiety and physical health of the caregiver. There were no separate analyses reported on the 11 individual services included in this study. It would be of value to know what differences there were (if any) between types and amount of services used by the caregivers. The limitations of this study were reflected in the lack of a control group for comparison and an attrition rate greater than 10 percent. However, the tools used for data collection were well-described and unlike many of the other studies researchers reported that the interviewers were trained. Use of multivariate statistics, such as multiple regression, also added to the rigor of this study.

#### *4.2.5 Psychotherapy*

One study regarding psychotherapy was rated as moderate, the remaining two were rated as strong. All three studies utilized the same data with different outcomes reported for each.

The New York University Aging and Development Research Center (NYU-ADRC) in 1987 initiated a longitudinal study to evaluate the benefit of a complex intervention for spouse caregivers of individuals with AD. Volunteer subjects were randomly assigned to intervention ( $n=103$ ) or control ( $n=103$ ) groups. The intervention consisted of two individual sessions and four family sessions of counseling with a graduate-prepared counselor over a four month period. Subsequent to the counseling participants were expected to join a support group of their choosing. Intervention caregivers also received comprehensive support from counselors who assisted them with



locating additional resources if necessary. The control group caregivers received the standard assistance provided by the NYU-ADRC, and were not prohibited from joining a support group. All participants completed questionnaires every four months in the first year of the study, then every six months for up to eight years of follow-up.

4.2.5.1 *Strong*. Mittelman et al. (1993) examined the NYU-ADRC study data from the first year and this study was rated as strong. The outcome measure was the delay in institutionalization of the care receiver. Logistic regression was utilized to examine the effectiveness of the intervention and assess other predictors of institutionalization. The intervention group had less than half as many institutionalized care receivers as the control group after 12 months. Significant predictors of institutionalization were lower care receiver income, greater severity of dementia, dependence in activities of daily living, and caregivers not involved in a support group. In steps two and three of the regression caregiver and care receiver age were entered. This revealed that the younger the caregiver and the older the care receiver the more likely the care receiver would be institutionalized. Nonsignificant findings as predictors of institutionalization were gender of the caregiver, number of caregiving years, level of depression, family cohesion, informal and formal support, number of services used, and physical health of caregivers and care receivers.

The second strong study using this data, Mittelman, Ferris, Shulman, Steinberg, and Levin (1996), also examined institutionalization, but over a three and half year time period instead. Kaplan-Meier survival analysis revealed a significant delay in institutionalization for the intervention group. It was estimated that care receivers in the intervention group remained at home 329 days longer than those in the control group. A

Cox proportional hazard model indicated that intervention caregivers were less likely to institutionalize the care receiver at any given time compared to the control group. The care receivers that benefit the most from this intervention had mild to moderate dementia. Contrary to the above study from 1993, female caregivers were more likely to institutionalize their spouse when the study is extended over a longer time period. As well, caregiver age was not significant in explaining institutionalization unlike the previous study.

4.2.5.2 *Moderate*. The third Mittelman et al. (1995) study was rated as moderate. The moderate rating reflected the level of attrition. The attrition in this examination did not include the outcomes of death or institutionalization and as a result those participants who left the intervention group did not have further measures taken to assess how they might be different from those who remained in the study, unlike the above studies. The main outcome of focus in this examination was the effect of the intervention on level of caregiver depression. Results of 12 months follow-up revealed that control group caregivers became increasingly depressed, while the intervention group caregivers remained stable. A multivariate analysis of covariance revealed that gender of the caregiver, and amount of formal and informal support were found to be nonsignificant in relation to level of depression.

In summary, the NYU-ARDC benefited caregivers the most in delaying institutionalization (Mittelman et al., 1993; 1996). Predictors of institutionalization after 12 months in the program were: lower care receiver income, increased dependence in activities of daily living, not being involved in a support group, and care receivers with greater levels of dementia (Mittelman et al., 1993). After three and half years of follow-

up, the level of dementia remained significant in predicting institutionalization similar to the findings after the first 12 months (Mittelman et al., 1996). Contradictions were found between the studies in regard to gender and age as predictors of institutionalization. Intervention caregivers appeared to remain stable as control group caregivers increased in their level of depression (Mittelman et al., 1995). A strength of these studies was the inclusion of spouse caregivers only, however this limits the generalizability of the findings to other types of caregivers. The long follow-up time period is a strength, as well as use of randomization, an adequate sample size, and the use of multivariate statistics. However, data collectors were not blinded and instruments were not pre-tested by the researchers.

#### 4.2.6 Respite

Three studies examined the intervention of respite care. All were rated as moderate. The following is a discussion of each.

4.2.6.1 *Moderate*. Adler, Ott, Jelinski, Mortimer, and Christensen (1993) conducted a study of the effects of a two-week in-hospital respite stay. A pretest-posttest design was utilized. The respite care of the 37 subjects consisted of a pre-arranged hospital admission to a veterans affairs medical center. Inclusion for this study was limited to veterans who were suffering from a progressive dementia and were being provided ongoing medical care at the center's memory loss clinic. Families were offered two-weeks of respite every six months; respite was initiated by the caregiver.

Caregivers were administered instruments to measure levels of stress and depression. As well, the functional ability of the care receiver was measured. Caregiver measures were obtained 14 days pre-respite, day of discharge of care receiver, and 14

days post-respite. Care receiver measures were taken 14 and seven days pre-respite, day of admission, and 14 days post-respite.

No significant findings resulted between families who had used respite previously compared to those families using respite for the first time. Care receivers were categorized according to type of dementia, which allowed comparison between those with AD and those with a non-AD type dementia. T-test results demonstrated a significant difference in level of cognitive impairment, as measured by the Mini-Mental State Examination (Folstein et al, 1975), with the AD care receivers being more impaired than non-AD care receivers. Comparison of AD caregivers and non-AD caregivers was completed using a repeated-measures ANOVA which revealed the groups did not differ significantly at any measure times with respect to strain or depression. Both sets of caregivers experienced a decrease in mean strain scores and improvement in mood between 14 days pre-respite and time of discharge; this decrease in strain and improvement of mood were only statistically significant for the non-AD caregivers when using a Wilcoxon test. By 14 days post-respite neither group of caregivers had a significant decrease in strain or improvement in mood. Thus, this study demonstrated that respite care impacts caregivers during the respite period only and levels of strain and depression return to pre-respite levels. This study could have been strengthened with the use of a comparison group and blinding in data collection.

The second respite intervention study also examined the effects of in-hospital respite conducted by Larkin and Hopcroft (1993). Care receivers ( $n=21$ ) were outpatients at a veteran's hospital dementia unit whose families were offered two-weeks respite once every three months. Recognizing the short-lived benefit of respite to caregivers this study

focused on the lasting effects of possible functional and cognitive decline of the care receiver. Caregivers initiated the use of respite and were asked to participate in the study.

Caregivers were surveyed by telephone three days pre-respite, three days before discharge, and 14 days post-respite. Psychological stress measures for the caregivers were obtained at all three time periods while care receiver functional measures were obtained at pre and post-respite. There were no differences found between caregivers who had used respite previously compared to those using it for the first time. ANOVA analysis showed that during respite care most caregivers experienced a significant reduction in psychological distress. The subgroups of hostility, anxiety, depression, and obsessive-compulsiveness were all significantly reduced for the period of respite only. Overall caregiver stress was not impacted over the long-term by the use of respite. The lack of a comparison group, data collectors not being blinded to participants, and no pre-testing of instruments are weaknesses in this study.

A third respite intervention article involved a pilot study of a visiting/walking program for cognitively impaired elderly living in their own homes (Wishart et al. (2000). A computer-generated randomized design ( $n=24$ ), with a waitlist control was utilized in the study. Prior to implementing the intervention, volunteers received two three-hour training sessions. As well, volunteers were provided with on-going support and information from the Victorian Order of Nurses should any concerns arise. The volunteer was expected to make a commitment of two hours per week for six weeks after being matched with a client. Activities were tailored to the interests of the client.

Questionnaires were completed at baseline (prior to randomization) and six weeks after the intervention. The waitlist control group was offered the intervention in six weeks

time. The groups differed with the control group having a higher level of education, thus education was used as a covariate. Utilizing analysis of covariance, the intervention caregivers were found to be significantly less strained than the waitlist control group. No significant differences were detected between the groups in change in social support and health expenditures. Caregivers expressed satisfaction with the program and would recommend it to others. This pilot study demonstrated that caregivers of individuals with dementia can benefit from a regular walking program delivered by volunteers, by feeling less strained. A strength of this study is the use of computer-generated randomization of participants. Limitations are an attrition rate greater than 10% and a short follow-up period. As well, data collectors were not blinded and instruments were not pre-tested.

In summary, these respite programs provided a significant reduction in strain and depression for caregivers, although these results were not long-lasting in the two in-hospital respite programs (Adler et al., 1993; Larkin & Hopcroft, 1993). Even though the visiting/walking program did not reduce the use of formal services by caregivers, it may be a useful program to provide meaningful relief to caregivers while benefiting care receivers with activities that interest them (Wishart et al., 2000). All of the studies had relatively small sample sizes (less than 40 participants) which limited the use of multivariate statistics. There appears to be great potential for respite to benefit caregivers. How quality of life for both caregiver and care receiver is impacted is an important consideration when examining the effectiveness of respite services.

Both Adler et al. (1993) and Larkin and Hopcroft (1993) considered how respite would impact the care receiver (although not a focus of this review) and found contradictory results. Larkin and Hopcroft suggest that care receivers deteriorate further

as a result of removing them from their home environment, while Adler et al. stated the deterioration did not exceed what would occur from the natural progression of AD. In-hospital respite should also consider the effects it may impose on care receivers.

#### 4.2.7 Technology

Two studies were included under the technological category. One involved utilizing computers, rated as strong, the other telephone support, rated as moderate.

4.2.7.1 *Strong*. Brennan, Moore, and Smyth (1995) examined the effects of a special computer network on caregivers of people with AD. Of the 102 participants originally recruited, 96 completed the study. Upon meeting the inclusion criteria, participants were randomly assigned to receive the computer intervention ( $n=51$ ) or to the comparison group ( $n=51$ ). The intervention group received a computer installed in their home with 90 minutes of training on its function. Through the computer network participants could receive information, decision-making support, communication, and an opportunity for questions and answers. Private e-mails to the network and questions were responded to by the nurse moderator. The comparison group did not have a computer installed, but did receive a placebo training session.

ANOVA analysis revealed that the intervention group experienced a significant increase in decision-making confidence, however no significant differences between the groups were found in relation to decision-making skills and social isolation. There was no difference in the number of health services used between the intervention and comparison groups. Multiple regression analysis supported the results of the repeated measures ANOVA. This study utilized a strong study design (randomized control trial), had low

attrition, pre-tested instruments, and conducted multivariate statistics, contributing to its strength. All categories were rated as strong.

4.2.7.2 *Moderate*. The second study (Davis, 1998) utilized a pretest/posttest design to examine the effects of a telephone-based intervention on caregivers of people with dementia. Experienced dementia caregivers helped develop the program. Seventeen (85%) participants completed the intervention from baseline to the end of 12 weeks of intervention. Prior to initiating the telephone intervention participants were visited in their home for an intensive two hour training session with the interventionist. The training focused on general problem-solving techniques, guidance on how to use the problem tip sheets, and how to complete the caregiving log. Participants were instructed to mail the completed log and any questions that arose in the previous seven days. The interventionist then telephoned the participant weekly to address the caregiving problems identified in the log and to provide encouragement for a total of 12 weeks. Telephone contacts generally lasted 45 to 60 minutes.

Measures were completed at baseline and at the end of the 12 weeks by a research assistant who was blinded to the study's purpose. T-tests revealed that at 12 weeks caregivers displayed a significant increase in use of social support, decrease in depressive symptoms, and an increase in life satisfaction, even though care receiver's behaviour problems and caregivers' reaction to them did not change. Problem-solving styles were not significantly different using t-test comparisons of pre and posttest scores. These results suggest the intervention has a positive impact on caregiver affect. A strength of this study was in the pre-testing of instruments and blinding of the data collector to the purpose of the study. However, no comparison group was utilized, attrition was greater



than 10% , not all relevant confounders were measured, and multivariate statistics were not conducted. This may be related to this study being a pilot study for the feasibility of implementing a telephone intervention.

In summary, both these studies brought the intervention to the caregiver's home in an attempt to reduce the isolation experienced by some caregivers who may be homebound as a result of their caregiving responsibilities. Positive results of these studies include improved decision-making (Brennan et al., 1995) and an impact on caregiver affect (Davis, 1998). As more people become comfortable with the use of computers or a new generation of caregivers emerge Brennan et al.'s intervention may have different outcomes in the future. Telephone interventions may be of particular relevance to supporting caregivers in rural communities.

## 5. Discussion

The results of this systematic review reveal few significant effects of the interventions on caregiver outcomes. Positive findings include the following: the assessment clinic had an impact on psychological well-being, but only for the subgroup of social interaction (Logiudice et al., 1999); case management increased the likelihood of using formal support services (Newcomer, Spitalny et al., 1999), and demonstrated conflicting results for delaying institutionalization (Eloneimi-Sulkava et al., 2001; Miller et al., 1999); educational interventions demonstrated an increase in caregiver knowledge about dementia (Coen et al., 1999; Ripich et al., 1998), and one educational intervention was able to impact a decrease in depression for caregivers to three months follow-up (Marriott et al., 2000); Mittelman et al.'s (1993; 1996) studies demonstrated a delay in institutionalization with the use of psychotherapy for caregivers.

In-hospital respite interventions were effective in reducing caregivers' strain and depression, but only during the time the care receiver attended respite and not for an extended period (Adler et al., 1993; Larkin & Hopcroft, 1993). The finding of no enduring effect of the respite intervention to follow-up was similar to McNally et al.'s (1998) systematic review of respite for care receivers with a variety of conditions. Wishart et al.'s (2000) walking program for cognitively impaired care receivers also provided relief to the caregiver. As well, the technological interventions improved decision-making confidence (Brennan et al., 1995) and improved caregiver affect (Davis, 1998).

Non-significant findings were more common. Logiudice et al.'s (1999) memory clinic had no impact on death or institutionalization of the care receiver, strain or

knowledge of the caregiver, and tolerance of disruptive behaviours. Case management had no significant effect on strain or caregiver depression (Newcomer, Yordi et al., 1999). As a whole, educational interventions had no effect on overall psychological well-being, including depression and strain (Coen et al., 1999; Corbeil et al., 1999; McCurry et al., 1998; Ripich et al., 1998; Wright et al., 2001) with the exception of Marriott et al.'s (2000) study. The investigation of home care services by Winslow (1997) revealed no significant findings except to explain caregiver anxiety. Lastly, the technological intervention using a home computer had no impact on decreasing social isolation, improving decision-making skills and did not increase use of formal supports (Brennan et al., 1995), and the telephone intervention did not increase problem-solving skills, and caregivers' reaction to problem behaviours.

### 5.1 *Limitations*

Overall methodological weaknesses of the included studies can be found in Figure 4.1 (p. 24). The most common weakness is in the area of data collection, 14 of the 22 included studies did not report pre-testing the tools they used and blinding of the data collectors regarding participants' membership in either control or intervention groups. Although many used well-known tools (e.g., MMSE; Folstein et al., 1975) and may have described the tool well, the fact remains that the tool was not pre-tested by the current researcher on a sample similar to the one included in the study.

A second common area of weakness is the lack of utilizing multivariate statistics ( $n=9$ ). This was not possible in some studies due to the small sample size. The caregiving situation is complex and many variables may influence the outcomes of caregiving. Moving beyond description and comparison of two variables (descriptive and bivariate

analysis), to explaining and predicting relationships (multivariate statistics) will strengthen our understanding of the caregiving experience. Incorporating as many relevant variables as possible may provide further direction in decisions regarding which interventions to use and when. Multivariate statistics provide more sophisticated analyses of these complex situations.

Randomization and the use of a control group would have strengthened the design of many of the studies. Furthermore, how randomization was achieved was often not adequately described for the reader. Almost a quarter of the studies had attrition rates greater than 10%. Participants who leave a study may have an impact because they may be significantly different than those who remain, a problem that may be more pronounced in studies with small sample sizes. A potential explanation for these apparent weaknesses may be related to lack of reporting as opposed to not incorporating the strategy in the study. Often a sentence or two is all that is needed to adequately explain the steps taken by a researcher, yet for whatever reason (e.g., journal space limitations) reports of studies often lack detail that aid the reader in having a full understanding of what transpired.

Several of the studies had small sample sizes (less than 50 participants) and did not report if a power analysis was completed. If a study fails to detect a difference between groups, it may in fact be due to the size of the sample and not that the hypothesis was incorrect (Burns & Grove, 2001). An insufficient sample size may result in non-significant results.

The review is limited by the articles retrieved. Due to cost, the European database of Embase was not searched. This database may have provided abstracts of additional foreign articles other than the ones included in the review. The databases that were

searched, however, are considered thorough and reliable. As well, research may have been performed in this area but not published, limiting access to those findings; no researchers that were contacted shared information of other possible work in progress. Publication bias (i.e., not publishing studies that revealed only non-significant results) may also skew the availability of completed research.

The validity criteria pertaining to level of attrition (i.e., >20% attrition) that resulted in a fail score and a weak rating may have excluded studies that would otherwise been rated as strong. For those studies that utilized a randomized control design, considering differential attrition between the treatment and control groups would have been appropriate. However, many of the studies did not incorporate a randomized control design. Often studies were not specific about why participants left a study, and even less specific about the rate per group (if applicable). It is important to know if participants withdraw from a study as a result of the intervention or for other valid reasons (e.g., death of the care receiver).

Carrying out this systematic review has been complex due to the heterogeneous nature of the interventions. Yet, to single out a particular intervention, with the exception of education which had sufficient variety in its own right, would have resulted in a limited review. The variety of interventions and use of multiple instruments for measuring similar variables made it impossible to pool findings in order to conduct a meta-analysis. The findings of this review must be considered in light of the methodological limitations found in the included studies and in the conduct of the review.

### *5.2 Implications for Practice*

Several interventions show promise in supporting caregivers. Respite interventions demonstrated a reduction in strain during the intervention. Clinicians need to find ways to carry on the support when care receivers return to their homes. Follow-up is vitally important in the community. Interventions that were individualized to the caregiver or care receiver were more successful, for example, the sleep quality intervention (McCurry et al., 1998) or the walking program (Wishart et al., 2000). Technological interventions warrant further consideration as a new generation of caregivers emerge. The use of computers or telephone interventions would particularly benefit individuals in rural communities. The MADDE case management intervention succeeded in supporting caregivers to access formal support services. When there are resources available to assist with the strain of caregiving, case managers would be invaluable in referring caregivers to those reliable resources.

Educational interventions that included coping skills training in addition to information regarding dementia had better success than education alone (e.g., Coen et al., 1999; Marriott et al., 2000). Content in the educational interventions should be relevant to participants (e.g., spouse caregivers may have different needs than daughters, or grandchildren). Researchers and clinicians should recognize that living with the care receiver or not imposes different caregiver consequences. Children may have role adjustment issues and male and female caregivers have different issues and consequences as well.

For clinicians wishing to advise caregivers, particular attention must be paid to the type of strain, either objective or subjective, the caregiver may be experiencing. For

example McCurry et al. (1998) were successful in improving sleep quality of caregivers, an element of objective strain. Their sleep intervention however, did not impact subjective elements of strain, such as mood or perception of care receiver problem behaviours. In turn, caregivers should be as explicit as possible as to what they need from the formal system. Many of the studies ( $n=8$ ) examined how to delay institutionalization, as if it were always a positive outcome. There may come a time when keeping a loved one at home means delaying relief from some types of strain.

Interventions cannot solely focus on the caregiver. Providing concurrent interventions for the care receiver may further provide relief to the caregiver. An excellent example of this was the walking program (Wishart et al., 2000). A reason for caregivers not accessing certain interventions may be due to not being able to leave the care receiver.

A huge challenge is to provide the right intervention, at the right time in the caregiving journey, to the right caregiver. Supporting caregivers before they are in crisis should be the goal. Further research is required to determine which interventions are most effective for which type of caregivers and when. A needs assessment is essential to target interventions to appropriate caregivers. Several interventions have been shown to be of benefit to caregivers, however, further investigation is greatly needed.

### *5.3 Implications for Research*

All studies rated as strong employed randomization of participants (Figure 4.1, p.19). However, considering the population under study, randomizing individuals to an intervention or control group may not always be possible. An alternative is the use of waitlist control groups to ensure that all participants will eventually receive the

intervention. Potential participants may then be more willing to participate in the study since most individuals volunteer with the expectation that they will receive help to manage their caregiving. This approach would also increase the sample size which was often small in the studies included in the review.

Not surprisingly most of the studies in this review recruited individuals already accessing help in the formal system. It may be of value to aggressively recruit less available participants in order to increase the generalizability of findings. Researchers and clinicians could advertise for participants in more public formats, for example, local newspapers or in senior's complexes. How do caregivers who do not ask for assistance and manage their loved ones independently differ from those participants who receive formal assistance? Frequently, different types of caregivers are included in one study instead of focusing an intervention on a single type of caregiver, for example female spouses only. Clinicians and consumers require direction in determining what type of intervention to provide and who will benefit the most.

Replication of published studies would be of benefit in the future to aid in the accumulation of knowledge about particularly successful interventions for a variety of caregivers. Furthermore, combining samples may be possible with the use of meta-analysis. A meta-analysis was not possible in this review due to the heterogeneity of the interventions and the reported results. Researchers and editors of journals should be encouraged to fully report the research process and findings, both significant and non-significant, to enhance the ability of others to replicate a study.

There also exists the challenge of developing instruments that can adequately measure small changes in well-being that may result as a consequence of an intervention



(Farran, 2001). Instruments that are specific to different caregivers and disease processes should be developed to capture the unique experience of each population (Bell, Araki, & Neumann, 2001). In light of the complexity of caregiving, there is a challenge to develop reliable and valid measurement tools that are meaningful to researchers and clinicians in addition to caregivers themselves. Results in many studies may be obscured due to lack of sensitivity of tools. In some instances qualitative results differed from the quantitative findings. For example, Brennan et al.'s (1995) study revealed that qualitative responses from participants suggested that the computer network was perceived as a social support service, yet quantitative measures failed to detect a change in social isolation after the computer network intervention. A common set of reliable and valid outcome measures used in studies would make comparison of outcomes between studies more meaningful and consistent. Researchers and clinicians have a long road to travel in developing these tools. The common tools used in the included studies can be found in Figures 4.5 and 4.6 (p. 27 and p. 28 respectively).

An outcome not often measured is quality of life. Despite some level of strain some caregivers are able to experience a positive quality of life, regardless of their caregiving situation. Possibly the focus should be less on strain and depression and more on the quality one experiences in their caregiving.

The heterogeneity and small sample sizes of many of the studies impact the ability of the design to detect a difference if one exists between the intervention and control groups. Conducting a power analysis to determine the appropriate sample size is recommended in future studies. It is difficult to assess the quality of a complex, multiple approach to providing interventions. Duration and intensity of the intervention may also

be an issue. The common length of follow-up in the included studies was usually 12 months or less. Considering the progression of AD and that the average length of the illness is between 8 to 10 years (Geldmacher & Whitehouse, 1996), researchers must bear in mind the length of time in the caregiving experience.

Finally, both researchers and journal editors have an obligation to publish readable and complete reports of studies. Clinicians and caregivers would benefit from studies that are appropriate to their level of understanding. Systematic reviews are valuable forms of research that combine studies and disseminate their information in an unbiased rigorous manner.

#### *5.4 Summary of Weak and Poor Studies*

The other relevant studies not included in this review were rated as weak (13 studies) and poor (1 study) according to the validity criteria. The most common fail rating for these studies was in regard to attrition. Of the weak and poor studies 13 had attrition rates of participants greater than 20%. One of the weak studies and the poor study did not incorporate, at least, bivariate statistics, limiting the findings to descriptive in nature. In addition to high attrition rates and lack of sophisticated statistical analysis, the poor study also had fail ratings relating to not controlling for all potentially significant confounders and data collection strategies were less than optimal. Please see Appendix E for the bibliography of all relevant studies.

## 6. Conclusion

An abundance of literature was available that examined the effectiveness of interventions for caregivers of people with dementia. Of the 92 articles retrieved, 36 met the relevance criteria and subsequently the 22 studies rated either strong or moderate were included in the review. Several of the interventions were shown to be of benefit to caregivers. Individualized approaches may address the uniqueness of caregivers or care receivers more readily than a single intervention delivered to a group of caregivers. Respite offered relief from caregiver strain and depression, however not after the care receiver returned home. Technological interventions are of interest especially for rural caregivers and as technology becomes more advanced. Case management was effective in increasing the use of formal services. Educational interventions increase knowledge of dementia for caregivers. Generally, non-significant findings were more common and implies that the interventions are not effective. These results indicate that researchers need to target caregivers and their needs more effectively. Clearly further research and replication of studies are essential; particularly in determining which intervention(s) best fit the needs of particular types of caregivers and at different stages of dementia.

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Gerontology Reprints.

## Appendix A

## Relevance Tool

Reference ID: \_\_\_\_\_

Reviewer: \_\_\_\_\_

Date: \_\_\_\_\_

## Instructions for Completion:

1. Circle Y or N for each relevance criterion.
2. Record inclusion decision: article must satisfy all 5 criteria.
3. Record if additional references are to be retrieved.

## RELEVANCE CRITERIA

- |   |   |   |
|---|---|---|
| 1. Is the unpublished or publication date of the article 1992 or later?   | Y | N |
| 2. Does the article evaluate an intervention directed at caregivers of an elderly individual with dementia living in the community? | Y | N |
| 3. Does the study measure one of the following caregiver outcomes?  | Y | N |
| Well-being (includes: physical, mental, social, and financial consequences)   | Y | N |
| Depression  | Y | N |
| Strain  | Y | N |
| Other (e.g., institutionalization, health care expenditures)  | Y | N |
| 4. Does the study incorporate a control group or pretest-posttest design with a sample size greater than one?                       | Y | N |

## REVIEWER DECISION

- |  |   |   |
|--|---|---|
| 1. Include in critical appraisal? (must answer yes to all above questions) | Y | N |
| 2. Additional references: if Y mark items on reference list of article.    | Y | N |

## IF DISCREPANCY IN INCLUSION DECISION

- |                         |   |   |   |
|-------------------------|---|---|---|
| Reason for discrepancy? | Oversight                                 | Y | N |
|                         | Differences in interpretation of criteria | Y | N |
|                         | Differences in interpretation of study    | Y | N |

## FINAL DECISION

- |                   |   |   |
|-------------------|---|---|
| Include in study? | Y | N |
|-------------------|---|---|

(adapted from Forbes &amp; Strang, 1997, p. 45)

## Appendix B

## Validity Tool

Reference ID: \_\_\_\_\_

Reviewer: \_\_\_\_\_

Date: \_\_\_\_\_

## A) Design and allocation to intervention:

1. Random
2. Before/After
3. Matched Cohort
4. Can't tell

## Sample:

## B) Attrition (when rate differs by group, record highest attrition rate):

1. < 10%
2. 11-20%
3. > 20%
4. Not applicable
5. Can't tell

## C) Confounders controlled:

1. Age of caregiver
  2. Sex of caregiver
  3. Education of caregiver
  4. Income of caregiver
  5. Cognitive impairment of care receiver
  6. Physical impairment of care receiver (ADL's)
  7. Other
  8. Can't tell
  9. Differences between groups:
- 

## D) Measures/Data Collection:

- |                   |   |   |   |
|-------------------|---|---|---|
| 1. Well described | Y | N | U |
| 2. Pre-tested     | Y | N | U |
| 3. Blinded        | Y | N | U |

## E) Types of statistical analysis:

1. Multivariate
2. Bivariate
3. Descriptive
4. Other
5. Can't tell



**F) OVERALL ASSESSMENT OF STUDY:**

	<b>PASS</b>	<b>MOD</b>	<b>FAIL</b>
1. Design and allocation to intervention	1	2	3
2. Attrition	1	2	3
3. Confounders	1	2	3
4. Measures/Data collection	1	2	3
5. Statistical analysis	1	2	3

**REVIEWER RATING:**

**STRONG**                      **MODERATE**                      **WEAK**                      **POOR**

**IF DISCREPANCY IN VALIDITY DECISION:**

Reason for discrepancy:	Oversight	Y	N
	Difference in interpretation of criteria	Y	N
	Difference in interpretation of study	Y	N

**FINAL DECISION:**

**STRONG**                      **MODERATE**                      **WEAK**                      **POOR**

(adapted from Forbes, 1998; Forbes & Strang, 1997, p. 46)

### Validity Tool Dictionary

A) Design and allocation to intervention/control group:

1. Random:

Randomly assigned process utilized and described.

2. Before/After:

Subjects evaluated pre-post intervention.

3. Matched cohort:

Site/group selected that has comparable characteristics.

B) Attrition:

Percentage of subjects remaining in the study at the final data collection period in all groups. When deaths or LTC placements are measured as an outcome they will not be considered as variables related to attrition.

C) Confounders controlled:

Confounders 1 to 6 are considered the most significant.

D) Measures/Data collection:

1. Well described: the questionnaire/tool is described, including the reliability and validity, and/or is cited.

2. Pre-tested: questionnaire/tool has been pre-tested with a similar/same population.

3. Blinded: the investigator collecting the data is not aware which subjects are in the experimental or control groups.

E) Types of Statistical Analysis

Refers to the type of statistical procedures used to determine significance.

(adapted from Forbes & Strang, 1997, p. 48)

### Rating Scale

#### A) Design and allocation to intervention

1. Random - *pass*
2. Before/after and matched cohort - *moderate*
3. No control and can't tell - *fail*

#### B) Attrition

1. <10% - *pass*
2. 11-20% - *moderate*
3. >20% or did not state level of attrition - *fail*

#### C) Confounders Controlled

1. Most of the confounders (at least 4 of 1-6) controlled - *pass*
2. At least two-four of the confounders (1-7) controlled and other relevant, but not listed, confounders controlled or when subjects act as their own control (as in pretest/posttest design) all relevant confounders addressed - *moderate*
3. One or less of the confounders (1-7) controlled - *fail*

#### D) Measures/Data Collection

1. At least two of the three categories rated as Y - *pass*
2. One of the three categories rated Y - *moderate*
3. None of the categories rated Y - *fail*

#### E) Types of Statistical Analysis

1. Multivariate - *pass*
2. Bivariate - *moderate*
3. Descriptive or can't tell - *fail*

#### F) Overall Rating

1. No fail ratings and no more than one moderate rating - *strong*
2. No fail ratings and more than one moderate rating - *moderate*
3. Two or less fail ratings - *weak*
4. More than two fail ratings - *poor*

(adapted from Forbes & Strang, 1997, p. 49)

Appendix C  
Data Extraction Tool

Reference ID: \_\_\_\_\_  
 Reviewer: \_\_\_\_\_  
 Date: \_\_\_\_\_  
 Year article published: \_\_\_\_\_  
 Years data collected: \_\_\_\_\_

**Country in which study was conducted:**

1. Canada
2. USA
3. U.K.
4. Sweden/Norway
5. Australia
6. Japan
7. Italy
8. Other: \_\_\_\_\_
- 9.

**Theoretical basis for intervention:** \_\_\_\_\_

**Research Design:**

1. Random
2. Control group
3. Pretest/posttest
4. Matched cohorts
5. Survey
6. Other

**Sample size:**

Sample size at baseline \_\_\_\_\_  
 Number of groups \_\_\_\_\_  
     Size of control \_\_\_\_\_  
     Size of experimental 1 \_\_\_\_\_  
     Size of experimental 2 \_\_\_\_\_  
 Sample size at completion of study \_\_\_\_\_

**Study population: Control**

Caregiver:  
 Gender: Male \_\_\_ % Female \_\_\_ %  
 Age: Mean \_\_\_ Range \_\_\_  
 Education: Mean \_\_\_ Range \_\_\_  
 Relationship to care receiver:  
 Spouse \_\_\_ Child \_\_\_ Other \_\_\_

Outcome Measures:

**Treatment Group**

Male \_\_\_ % Female \_\_\_ %  
 Mean \_\_\_ Range \_\_\_  
 Mean \_\_\_ Range \_\_\_  
 Spouse \_\_\_ Child \_\_\_ Other \_\_\_

Strain Instrument(s) used:  
 Depression Instrument(s) used:  
 QOL Instrument(s) used:  
 OTHER Instrument(s) used:

*Care Receiver:*

Gender: Male \_\_\_% Female \_\_\_% Male \_\_\_% Female \_\_\_%  
 Age: Mean \_\_\_ Range \_\_\_ Mean \_\_\_ Range \_\_\_  
 Probable Alzheimer's disease: Instrument(s) used \_\_\_\_\_  
 Cognitive impairment: Instrument(s) used \_\_\_\_\_  
 Physical impairment: Instrument(s) used \_\_\_\_\_

**Setting of Intervention:**

1. In caregiver's home
2. Public facility

**Intervention provider**

1. RN
2. RN with advanced preparation
3. Other professional: Psychologist  
Social Worker
4. Informal caregiver
5. Volunteer  
Training \_\_\_\_\_
6. Unknown
7. Other

**Type of Intervention:**

1. Educational Group
2. Psychotherapy (support) Group
3. Combined - Psychoeducational Group
4. Respite: In home Daycare (outside home) Overnight stay
5. Technological intervention: Telephone Computer

**Intervention intensity**

1. Frequency \_\_\_\_\_
2. Intensity of intervention \_\_\_\_\_
3. Duration of intervention \_\_\_\_\_

**Co-Intervention**

1. Accessing other formal services
2. Care for care receiver provided so caregiver may attend intervention

**Compliance with intervention:**

(When rate differs between groups record lowest level)

1. At least 90%
2. 80-90%
3. <80%
4. Not applicable
5. Can't tell

**Types of Analysis:**

1. Multivariate
2. ANOVA
3. T-test
4. Chi-square
5. Correlational
6. Other
7. Can't Tell

(adapted from Forbes & Strang, 1997, p. 50)

Summaries of Strong and Moderate Studies

Study	Design (Weaknesses)	Participants	Intervention & Provider	Outcomes
<b>Assessment Clinic</b>				
Logiudice et al. (1999) Australia	Randomly Assigned Moderate (d, e)	<p><i>Caregivers:</i></p> <p>n=50 at baseline n=45 at completion <i>Intervention:</i> n=25 Male: 24% Age: mean 61.4yrs (SD 14.0) Spouse: 60% Child: 32% <i>Control:</i> n=25 Male: 20% Age: mean 60.7yrs (SD 12.6) Spouse: 48% Child: 40%</p> <p><i>Care Receivers:</i></p> <p><i>Intervention:</i> Male: 47.8% Age: mean 72.9yrs (SD 7.9) <i>Control:</i> Male: 39.1% Age: mean 77.5yrs (SD 8.6) (At baseline control participants were older, and more dependent and cognitively impaired) Dementia diagnosis ICD-10 Classification of Mental and Behavioral Disorders (WHO, 1992) and severity (Clinical Dementia Rating [CDR; Hughes et al., 1982]).</p>	<p>Intervention group participants attended a memory clinic on two occasions. The first visit consisted of a medical assessment and interview. The second visit consisted of assessment by a neuropsychologist or a speech pathologist and family conference to reveal findings of the assessments.</p> <p>The control group was visited in their home by the same individuals who administered the measurement tools to the intervention group. No assessment was made by the neuropsychologist or speech pathologist and no family conference took place.</p> <p>All tools were administered at baseline, 6 and 12 months.</p>	<p><i>Significant:</i> At 6 months overall psychosocial health status (<math>p &lt; .01</math>) (Functional Limitations Profile [FLP; Patrick &amp; Peach, 1989]) including the subgroups of alertness behaviors (<math>p &lt; .05</math>) and social interaction (<math>p &lt; .01</math>) improved for the intervention group (after age and baseline FLP score were adjusted). Only the subgroup of social interaction remained significant at 12 months (<math>p &lt; .05</math>).</p> <p><i>Nonsignificant:</i> No difference in the number of deaths between groups at 6 (<math>p = .07</math>) or 12 months (<math>p = .14</math>); nor with institutionalization at 6 (<math>p = .15</math>) or 12 months (<math>p = .30</math>).</p> <p>No difference between groups for psychological morbidity (General Health Questionnaire [GHQ; Goldberg, 1972]), strain (Family Burden Interview [Zarit &amp; Zarit, 1990]), tolerance of care receiver's disruptive behaviors (Memory and Problem Behavior Checklist [MBPC; Zarit &amp; Zarit, 1990]), and caregiver knowledge of dementia (Dementia Knowledge Test [Diekmann, Zarit, Zarit, et al., 1988]).</p>
<b>Case Management</b>				
Eloniemi-Sulkava et al. (2001)	Randomly Assigned Strong	<p><i>Caregivers:</i></p> <p><i>Intervention:</i> n=53 Male: 25%</p>	<p>Intervention group provided with systematic comprehensive support for two years by a</p>	<p><i>Significant:</i> In the first months significantly less intervention participants were institutionalized</p>

Table A.1

continued

Finland	(d)	<p>Age: mean 64.8yrs (range 34-83)            Spouse: 60%            Child: 27%            Control: n=47            Male: 38%            Age: mean 63.3yrs (range 40-86)            Spouse: 51%            Child: 43%</p> <p style="text-align: center;"><i>Care Receivers:</i></p> <p>Intervention:            Male: 51%            Age: mean 78.8yrs (range 65-97)            Control:            Male: 43%            Age: mean 80.1yrs (range 67-91)            Dementia diagnosis: Diagnostic and Statistical Manual of Mental disorders (DSM-III-R [American Psychological Association, 1987]) criteria and Mini-mental State Examination (MMSE [Folstein, Folstein, &amp; McHugh, 1975]).</p>	<p>dementia family coordinator (nurse case manager). The coordinator provided: support for clients; advocacy; counseling; annual training courses for clients; follow-up calls; in-home visits; assistance to arrange for additional services; and 24 hour/day availability by mobile phone. Coordinator had access to physician referrals. Control group received the usual services provided by the health care system. Study participants were followed for two years and the occurrence of institutionalization or death at home was recorded.</p>	<p>compared to the control group (<math>p=.04</math>). The participants who were more severely demented benefited the most from the intervention by remaining in the community longer compared to the control group.</p> <p><i>Nonsignificant:</i> By the end of the first year there was no difference in the number of deaths between groups (<math>p=.49</math>).</p> <p>By end of the second year there was no difference between groups in rate of institutionalization (<math>p=.80</math>) and equal number of participants died.</p>
Miller et al. (1999) USA	Randomly Assigned Strong (d)	<p style="text-align: center;"><i>Caregivers:</i></p> <p>Intervention: n=4151            Male: 31.7%            Age: 58% &lt; 70yrs            Spouse: 46.9%            Child: 40.5%            Control: n=3944            Male: 30.9%            Age: 59% &lt; 70yrs            Spouse: 46.4%            Child: 39.9%</p> <p style="text-align: center;"><i>Care Receiver:</i></p> <p>Intervention:            Male: 38.7%            Age: 42% are 70-79yrs            Control:</p>	<p>Intervention group received intensive case management in addition to a set amount of reimbursement per month towards community services. Four Model A sites had case manager to client ratio of 1:100 and community service reimbursement cap of \$290-\$489 per client. Four Model B sites had ratio of 1:30 manager to clients and an amount of \$430-\$699 per client. Control group received usual care. All participants received</p>	<p><i>Significant:</i> No significant findings found.</p> <p><i>Nonsignificant:</i> Institutionalization rates did not differ between intervention and control groups, either for individual sites or all combined.</p> <p>The aim of this intervention was to reduce strain (Zarit Burden Scale [ZBI; Zarit et al., 1980; Zarit, Todd, et al., 1986]) and stress (Zarit Stress Scale [Zarit, Orr, &amp; Zarit, 1985]) among caregivers and no constraints were put on to decrease the likelihood of institutionalization; thus case managers may have inadvertently assisted caregivers to institutionalize their loved</p>



continued

		<p>Male: 40.8%            Age: 41% are 70-79yrs            Diagnosis of dementia: MMSE (Folstein et al., 1975), ADL impairment (Katz et al., 1963), and IADL impairment (Lawton &amp; Brody, 1969).</p>	<p>baseline and semi-annual assessment interviews for up to three years after enrollment in the study.</p>	<p>one with dementia compared to other models of case management.</p>
Newcomer, Spitalny et al. (1999) USA	Randomly Assigned Strong (d)	<p><i>Caregivers:</i>  <i>Intervention:</i> n=2682            Male: 28.3%            Age: mean 63.8yrs (SD 14.3)            Spouse: 51.2%            Child: 40.2%  <i>Control:</i> n=2527            Male: 27.1%            Age: mean 63.6yrs (SD 14.5)            Spouse: 51.3%            Child: 39.1%</p> <p><i>Care Receivers:</i>  <i>Intervention:</i>            Male: 60.6%            Age: mean 78.5yrs (SD 7.8)  <i>Control:</i>            Male: 57.5%            Age: mean 78.7yrs (SD 8.0)            (Control group had significantly more females)            Diagnosis of dementia as above.</p>	As above.	<p><i>Significant:</i> The intervention group was more than twice as likely to use Home Care Services (<math>p &lt; .01</math>) than the control group caregivers.; the same is true for Adult Day Care use (<math>p &lt; .05</math>).  <i>Nonsignificant:</i> Nothing nonsignificant reported.</p>
Newcomer, Yordi et al. (1999) USA	Randomly Assigned Strong (d)	<p><i>Caregivers:</i>  <i>Intervention:</i> n=2731            Male: 41%            Age: mean 63.0yrs (SD 14.2)            Spouse: 49%            Child: 43%  <i>Control:</i> n=2576            Male: 26%            Age: mean 63.0yrs (SD 14.4)            Spouse: 50%            Child: 41%</p>	As above.	<p><i>Significant:</i> Intervention group participants had small reductions in strain (four of eight sites)(adapted ZBI [Zarit et al., 1980]) and depression (three of eight sites)(Geriatric Depression Scale[GDS; Yesavage et al., 1983]) that were statistically significant for some individual sites over the 36 months.  <i>Nonsignificant:</i> Depression (GDS) and strain (ZBI) were not found significantly different at any time period between the</p>

continued

		<i>Care receivers:</i>		groups.
		<p><i>Intervention:</i> Male: 28% Age: mean 78.0yrs (SD 8.1)</p> <p><i>Control:</i> Male: 26% Age: mean 78.0yrs (SD 8.4) Diagnosis of dementia as above.</p>		
<b>Education</b>				
Brodsky et al. (1997) Australia	Randomly Assigned Strong (d)	<p><i>Caregivers:</i> n=96 at baseline n=93 at completion <i>Immediate Intervention</i> (group I): n=33 <i>Waitlist</i> (group II): n=31 <i>Memory retraining only</i> (group III): n=30 (Demographics reported combined) Male: 46.2% Age: mean 67.5yrs (SD 8.0) Spouses: 93% (child not reported)</p> <p><i>Care Receivers:</i> Female: 48.4% Male: 51.6% Age: mean 70.1yrs (SD 6.6) Dementia diagnosis using <i>standard criteria</i>, approximately 70% had AD.</p>	<p>Caregiver Training consisted of an intensive 10-day program with a variety of sessions. Care receivers participated in a program concurrent to caregivers consisting of memory training, reminiscence therapy, relaxation techniques, and outings. Group II waitlist received program 6 months later. Group III caregivers received 10 days respite, during which time the care receivers completed the memory training. All received 12 month booster sessions and interviews were the same for all groups. Groups were followed between 6.5 to 8 years, depending on time to institutionalization or death of care receiver.</p>	<p><i>Significant</i> : Length of follow-up differed significantly (<math>p &lt; .01</math>) between groups; group I and III were followed 7.8 years, while group II was followed 7.4 years. When groups I and II (caregivers received training) were combined (they did not differ significantly) there was a significant (<math>p &lt; .05</math>) impact on delaying institutionalization compared to group III (caregivers received no training). Eight year survival analysis revealed that caregivers who received training (groups I and II) kept care receivers at home longer (<math>p = .037</math>). <i>Nonsignificant</i>: The number of care receivers from each group who were institutionalized was not found to be significant (<math>p = n.s.</math>). There was a nonsignificant finding (<math>p = .08</math>) of the intervention delaying death of the care receiver.</p>
Corbeil et al. (1999) USA	Randomly Assigned Strong	<p><i>Caregivers:</i> n=95 at baseline n=87 at completion <i>Intervention</i>: n=28 Male: 25%</p>	<p>Caregivers in <i>active cognitive-stimulation</i> group attended one hour sessions six days/week for 12 weeks. Caregivers were trained in activities to stimulate</p>	<p><i>Significant</i>: Positive reappraisal of the caregivers' interaction with the care receiver remained positive in the intervention group and became negative for the control groups (<math>p &lt; .05</math>).</p>

Table A.1

continued

		<p>Age: mean 69.0yrs (SD 9.8)            Education: mean 14.3yrs (SD 3.0)            Spouse/child not reported            Placebo: n=28            Male: 11%            Age: mean 63.9yrs (SD 12.3)            Education: mean 14.1yrs (SD 2.4)            Control: n=31            Male: 32%            Age: mean 68.2yrs (SD 10.6)            Education: mean 14.1yrs (SD 2.4)</p> <p>Care Receivers:            (reported groups combined)            Male: 64%            Age: mean 74.2yrs (SD 7.9)            Diagnosis of probable AD: Global Deterioration Scale (GD Scale; Reisberg et al., 1982).</p>	<p>the mind of the care receiver. The <i>passive</i> (placebo) cognitive-stimulation group followed the same timeframe as active intervention group, but were presented with <i>passive activities</i> (watching television). Caregivers in the control group were only contacted for assessments. Assessments occurred pre-intervention, post-intervention (three months) and at 9 months follow-up.</p>	<p><i>Nonsignificant:</i> Intervention had no impact on the level of stress for the caregivers when interacting with the care receiver.</p>
Marriott et al. (2000) United Kingdom	Randomly Assigned Strong	<p>Caregivers:            n=42 at baseline            n=41 at completion            Intervention: n=14            Male: 36%            Age: mean 69.6yrs (SD 15.2)            Spouse: 64%            Child: 21%            Control 1: n=14            Male: 21%            Age: mean 58.1yrs (SD 16.7)            Spouse: 36%            Child: 57%            Control 2: n=14            Male: 36%            Age: 63.0yrs (SD 14.0)            Spouse: 57%            Child: 43%</p> <p>Care Receivers:</p>	<p>Intervention group received the Camberwell Family Interview (CFI) and a modified cognitive-behavioral intervention. Intervention consisted of: education (3 sessions), stress management (6 sessions), and coping skills training (5 sessions); delivered by a clinical psychologist in 14 sessions with two weeks between each session. The group also received written material. Control group 1 received no intervention. Control group 2 received the CFI interview only. Caregivers and care receivers</p>	<p><i>Significant:</i> At 3 months follow-up there was a decrease (<math>p &lt; .001</math>) in depression (Beck depression Inventory [BDI, Beck, 1988]) for the intervention caregivers compared to the control groups. A decrease (<math>p = .024</math>) in behavioral disturbances (MOUSEPAD, Allen et al., 1996) of the care receivers in the intervention group at post-treatment only. Intervention group had fewer psychiatric cases (GHQ [Goldberg &amp; Williams, 1988]) than the control groups at post-treatment (<math>p = .014</math>) and follow-up (<math>p = .001</math>).  <i>Nonsignificant:</i> There were no significant differences between the control groups, thus the CFI alone had no impact on control 2 caregivers.</p>

Table A.1

continued

		<p><i>Intervention:</i>  Male: 29%  Age: mean 76.6yrs (SD 9.3)  <i>Control 1:</i>  Male: 29%  Age: mean 77.7yrs (SD 6.8)  <i>Control 2:</i>  Male: 29%  Age: mean 76.3yrs (SD 10.6)  Diagnosis of AD (DSM-III-R [APA, 1987]);  other measures: Cornell Scale for Depression in  Dementia (CSDD, Alexopoulos et al., 1988),  MOUSEPAD (Allen et al., 1996), and CDR  (Hughes et al., 1982; Morris, 1993).</p>	<p>had assessments completed at  pre-treatment, post-treatment  (nine months after entering  study) and three months follow-  up.</p>	
Coen et al. (1999) Ireland	Pretest/ Posttest Moderate (a, b)	<p><i>Caregivers:</i>  n=32 at baseline  n=28 at completion  Female: 71%  Male: 29%  Age: mean 56.9yrs (range 35-80)  Spouse: 46%  Child: 36%</p> <p><i>Care Receiver:</i>  No demographics reported.  AD diagnosis: MMSE (Folstein et al., 1975);  Baumgarten Dementia Behaviour Disturbance  Scale (DBD Scale; Baumgarten, Becker, &amp;  Gauthier, 1990); and Blessed-Roth Dementia  Scale (Roth, Huppert, Tym, &amp; Mountjoy, 1988).</p>	<p>Education program by a  psychologist consisted of eight  weekly 2h sessions that  included information on a  variety of topics and skills.  Data was collected pre-program  and six months post-program.  Participants were asked to  classify their caregiving  experience (7-point scale, Zarit  et al., 1987) post-program, two  groups emerged: 'better/no  change carers (n=16) and  'worse' carers (n=12).</p>	<p><i>Significant:</i> 'Better/no change' carers  (p=.0004) and 'worse' carers (p=.005)  had a significant increase in knowledge  about dementia. The significant  difference between 'better/no change'  carers and 'worse' carers was in respect  to behaviour disturbance of the care  receiver (p=.05) (DBD Scale  [Baumgarten et al., 1990]; 'worse'  carers reported more behaviour  disturbance than 'better/no change'  carers. 'Worse' carers experienced an  increase in strain (p=.04)(ZBI [Zarit,  Reever, &amp; Bach Peterson, 1980]),  poorer QOL (p=.06)(Schedule for  Evaluation of Individual Quality of  Life-Direct Weighting, SEIQoL-DW  [O'Boyle, Browne, Hickey, McGee, &amp;  Joyce, 1996]), poorer appraisal of social  support (p=.02)(Vaux Social Support  Appraisal Scale, SS-A [Vaux et al.,  1986]), and greater difficulty tolerating</p>

Table A.1

continued

Fisher & Laschinger (2001) Canada Education	Pretest/ Posttest Moderate (a, e)	<p><i>Caregivers:</i>  <math>n=36</math> at completion            Female: 83.3%            Male: 16.7%            Age: mean 61.4yrs (SD 13.2)            Education: High school 53%, some post-sec 42%            Spouses: 64.9%            Child: 21.6%</p> <p><i>Care Receivers:</i>            Female: 44.4%            Male: 55.6%            Age: mean 73.2yrs (SD=13.9)            Diagnosis of AD required.</p>	<p>Six weekly relaxation training sessions offered over six months to six separate groups of caregivers. Relaxation component was developed by one of the researchers. Participants were also given a manual and tracked their use of the relaxation techniques in a diary log.            Data was collected in the initial (pre-test) and the final (posttest) sessions by graduate nursing students.</p>	<p>patient disruptive behaviour (<math>p=.043</math>)(DBD Scale) post-program.  <i>Nonsignificant:</i> 'Better/no change' carers experienced no significant impact on QOL (<math>p=.42</math>) (SEIQoL-DW), well-being (<math>p=.73</math>) (GHQ [Goldberg, 1972]), strain (<math>p=.14</math>) (ZBI), or appraisal of social support (<math>p=.10</math>)(SS-A) post-program.  <i>Significant:</i> Overall self-efficacy for controlling anxiety associated to problem behavior (MBPC [Zarit &amp; Zarit, 1982]) was found to be significantly higher post-intervention (<math>p=.03</math>).  <i>Nonsignificant:</i> The difference between genders regarding self-efficacy did not remain following the intervention (<math>p=.27</math>).            No significant difference was found in the incidence of behavioral problems (MBPC) from pre-test to posttest.</p>
McCurry et al. (1998) USA	Randomly Assigned Moderate (d, e)	<p><i>Caregivers:</i>  <i>Group Intervention: n=7</i>            Male: 29%            Age: mean 68.0yrs (SD 7.5)            Education: mean 14.6yrs (SD 1.9)            Spouse: 100%  <i>Individual Intervention: n=14</i>            Male: 21%            Age: mean 64.9yrs (SD 13.3)            Education: mean 15.3yrs (SD 3.5)            Spouse: 50%            Child: 36%  <i>Waitlist Control: n=15</i></p>	<p>Study conducted in two phases. First phase consisted of group intervention; participants participated in six week intervention consisting of: sleep hygiene, stimulus control, sleep compression, relaxation techniques, and education about dementing illnesses and issues. Second phase lasted four weeks instead of six, consisted of the same intervention delivered on an individual basis.</p>	<p><i>Significant:</i> Overall sleep quality (Pittsburgh Sleep Quality Index (PSQI; Buysse, Reynolds, Monk, Berman, &amp; Kupfer, 1989)) was significantly better for intervention participants compared to the waitlist group at post-treatment (<math>p&lt;.05</math>) and follow-up (<math>p&lt;.05</math>). Individuals that responded well with improved sleep quality (PSQI) tended to be younger (<math>p=.001</math>) and more compliant with treatment recommendations (<math>p=.05</math>).  <i>Nonsignificant:</i> No significant</p>

Table A.1

continued

		<p>Male: 26%            Age: mean 72.6yrs (SD 7.7)            Education: mean 15.4yrs (SD 3.0)            Spouse: 87%            Child: 13%</p> <p><i>Care Receivers:</i>  <i>Group Intervention:</i>            Male: 71%            Age: mean 71.3yrs (SD 5.8)  <i>Individual Intervention:</i>            Male: 43%            Age: mean 81.9yrs (SD 6.9)  <i>Waitlist Control:</i>            Male: 60%            Age: mean 78.3yrs (SD 7.0)            Diagnosis of senile dementia.</p>	<p>Measurements were taken at pre and post-intervention assessments and three months follow-up for both intervention groups and the waitlist.</p>	<p>differences found between group intervention versus individual intervention.            No differences between groups in caregiver mood (Centre for Epidemiological Studies-Depression Scale [CESDS; Radloff, 1977]), strain (Screen for Caregiver Burden [Vitaliano, Russo, Young, Becker, &amp; Maiuro, 1991]), or care receiver behavior problems (Revised MBPC [Teri et al., 1992]).</p>
Ripich et al. (1998) USA Education	Pretest/ Posttest Moderate (a, d, e)	<p><i>Caregivers:</i>  <i>Intervention: n=19</i>            Male: 19%            Age: mean 60.9yrs (SD 14.3)            Education: mean 13.4yrs (SD 2.25)            Spouse: 58%            Other: 42%  <i>Control: n=18</i>            Male: 17%            Age: mean 62.5yrs (SD 13.4)            Education: mean 13.3yrs (SD 2.02)            Spouse: 61%            Other: 39%            (Intervention group had greater socioeconomic status)</p> <p><i>Care Receivers:</i>  <i>Intervention:</i>            Male/female not reported            Age: mean 79.9yrs (SD 6.6)  <i>Control:</i></p>	<p>Intervention participants attended weekly 2 hour educational sessions over 4 weeks delivered by a speech-language pathologist. Control group self-selected because of other commitments, no time, or distance; they had no access to program. Participants completed questionnaires pre-entry, post-program (intervention group only), 6 months and 12 months.</p>	<p><i>Significant:</i> Intervention group had significant decrease in communication hassles (<math>p &lt; .05</math>) (Caregiver Hassles Scale [CHS; Kinney &amp; Stephens, 1989]) and an increase in Knowledge Assessment Measure (<math>p &lt; .001</math>) (10-item measure developed by the authors) over time.  <i>Nonsignificant:</i> The intervention had no significant effect on positive or negative affect (modified version of Positive and Negative Affect Scale [Kercher 1992; Watson, Clark, &amp; Tellegen, 1988]), depression (modified version of CESDS [Radloff, 1977]), health, or general hassles (CHS).</p>

Table A.1

continued

Home Care		Age: mean 76.4yrs (SD 8.4) Dementia diagnosis: Criteria from the National Institute on Neurological and Communicative Disorders and the Alzheimer's Disease and related Disorders Association (NINCDS-ADRDA [McKhann et al., 1984]) and MMSE (Folstein et al., 1975).		
Winslow (1997) USA	Pretest/ Posttest; Secondary analysis Moderate (a, b)	<i>Caregiver:</i>  n=555 at baseline n=452 at completion Female: 69% Males: 31% Age: mean 61yrs (range 27-88yrs) Spouses: 58% Child: 42% Education: 35% > High school <i>Care Receivers:</i> Female/Male: not reported Age: mean 75yrs (range 40-90) Reported as having a diagnosis of AD.	<i>Impact of 11 services</i> investigated to determine the mediating effects; services not listed, but included home care, respite, and day care. Data was collected prior to study and 1 year follow-up.	<i>Significant:</i> Caregiver anxiety (Hopkins Symptom Checklist [HSC; Derogatis, Lipman, Covi, & Rickles, 1971; Lipman, Rickles, Covi, Derogatis, & Uhlenhuth, 1969]) was explained by caregiver overload ( $p=.001$ ), less care receiver dependency ( $p=.02$ ), and level of caregiver anxiety at Time 1 ( $p=.004$ ); this model accounted for 36% of the variance for anxiety after 1 year. Institutionalization of care receiver was explained by care receiver problem behavior ( $p=.0001$ ) and use of formal supports ( $p=.002$ ). Analyses of female spouses only revealed 27% of variance for institutionalization explained by caregiver age ( $p=.02$ ), dependency ( $p=.03$ ), problem behaviour ( $p=.003$ ), and formal support ( $p=.001$ ). Tool most frequently used: primary investigator's qualitative tool (Aneshensel, Pearlin, Mullan, Zarit, & Whitlatch, 1995; Pearlin, Mullan, Semple, & Skaff, 1990) unless indicated otherwise. <i>Nonsignificant:</i> Relationship between formal support, coping, and anxiety

Table A.1

continued

				(HSC) were not significant, and had no effect on caregiver physical health. Impact of caregiver age, gender, relationship, and problem behaviour had negligible effect on health.
<b>Psycho-education</b>				
Wright et al. (2001) USA	Randomly Assigned Strong	<p><i>Caregivers:</i>  <i>Intervention: n=68</i>            Male: 24% (average of both groups)            Age: mean 60.4yrs (SD 14.6)            Education: mean 12yrs (average of both groups)            Spouses: 50%            Child: 35% (daughters only)  <i>Control: n=25</i>            Male: 24%            Age: mean 57.2yrs (SD 9.8)            Education: mean 12yrs            Spouse: 32%            Child: 44% (daughters only)            (Groups differed by ethnicity)</p> <p><i>Care Receivers:</i>  <i>Intervention:</i>            Male/female not reported            Age: mean 77.8yrs (SD 7.0)  <i>Control:</i>            Age: mean 76.4yrs (SD 7.2)            Were recent AD patients on inpatient medical unit; tools utilized Blessed Dementia Rating Scale (Blessed, Tomlinson, &amp; Roth, 1968), and MMSE (Folstein et al., 1975).</p>	<p>Intervention group contacted by clinical nurse specialist (CNS) after initial assessment made on the hospital unit. CNS made 3 home visits with caregiver two, six and 12 weeks post-discharge, then phoned six and 12 months after discharge. The CNS provided strategies for troubling behaviour of the care receiver, monitored care receiver medication, and offered supportive counseling. Control group contacted by phone at same times as intervention group, for data collection purposes only. Data collected at baseline while the care receiver was a patient (Time 0), and subsequently two, six, and 12 weeks, six and 12 months post-discharge (Times 1-5 respectively).</p>	<p><i>Significant:</i> The percent of care receivers at home at Time 5 was higher for the intervention group than the control (<math>p&lt;.03</math>).  <i>Nonsignificant:</i> None of the expected outcomes had any lasting effects or reached significance. Particularly the impact of the intervention on: decreasing the rate of institutionalization or death, reducing care receiver agitation (Cohen-Mansfield Agitation Inventory [Cohen-Mansfield, Marx, &amp; Rosenthal, 1989]), caregiver depression (CESDS [Radloff, 1977]), stress (CHS [Cavanaugh &amp; Kinney, 1998; Kinney &amp; Stevens, 1989]), and a positive impact on health (Multilevel Assessment Inventory [Lawton, Moss, Fulcomer, &amp; Kleban, 1982; Weinberger et al., 1986]).</p>
<b>Psychotherapy</b>				
Mittelman et al. (1993) USA	Randomly Assigned Strong (d)	<p><i>Caregivers:</i>  <i>Intervention: n=103</i>            Male: 49.5%            Age: 45% are 70-70yrs</p>	<p>Intervention group caregivers provided with six individual and family counseling sessions by family counselors; they were</p>	<p><i>Significant:</i> After 12 months the intervention group had less than half as many care receivers institutionalized than the control (<math>p&lt;.05</math>).</p>



Table A.1

continued

		<p>Spouse: 100%</p> <p>Control: <math>n=103</math></p> <p>Male: 34%</p> <p>Age: 43% are 70-79yrs (groups had to be controlled for gender)</p> <p style="text-align: center;"><i>Care Receivers:</i></p> <p><i>Intervention:</i></p> <p>Male: 50.5%</p> <p>Age: 47% are 70-79yrs</p> <p><i>Control:</i></p> <p>Male: 66%</p> <p>Had to have a diagnosis of AD; severity of dementia was determined by the GD Scale (Reisberg et al., 1982).</p>	<p>required to attend weekly support group indefinitely; and had further access to counselor. Control group participants had access to services normally provided in their area. They were not required to participate in support groups, but not denied if they wished to attend. All caregivers interviewed and completed questionnaires every four months in the first year, then every six months for up to eight years of follow-up. The present study considered data from baseline to 12 months follow-up.</p>	<p>An increased rate of institutionalization was impacted by lower care receiver: income (<math>p&lt;.05</math>), increased severity of dementia (<math>p&lt;.05</math>)(GD Scale [Reisberg et al., 1982]), and increased dependence in activities of daily living (<math>p&lt;.01</math>) (Caregiver Questionnaire developed for study).</p> <p>The older the care receiver (<math>p&lt;.05</math>) and the younger the caregiver (<math>p&lt;.05</math>) the more likely the care receiver would be institutionalized.</p> <p><i>Nonsignificant:</i> Gender of caregivers did not effect rate of institutionalization (<math>p=n.s.</math>).</p>
Mittelman et al. (1996) USA	Randomly Assigned Strong (d)	As above.	<p>As above.</p> <p>The present study considers data from baseline to three and half year follow-up.</p>	<p><i>Significant:</i> Intervention group care receivers remained at home significantly (<math>p=.02</math>) longer than those in control group. Caregivers found to be two-thirds as likely to institutionalize their spouse at any point in time if they were in intervention group than control group (<math>p=.02</math>).</p> <p>Female caregivers were more likely than male caregivers to institutionalize their spouse (<math>p=.04</math>).</p> <p>Severity of dementia (GD Scale [Reisberg et al., 1982]) in care receiver was a major predictor of institutionalization; the greater the deterioration the more likely they were to be placed in long-term care (<math>p=.001</math>).</p> <p><i>Nonsignificant:</i> Caregiver age was not significant (<math>p=.5</math>) in explaining</p>

Table A.1

continued

Mittelman et al. (1995) USA	Randomly Assigned Moderate (b, d)	As above.  <i>Caregivers:</i> n=203 at baseline n= 173 at 12 month follow-up  <i>Care Receivers:</i> No account for death or institutionalization.	As above. The present study considered the intervention's effect on the outcome of caregiver depression in the first year of the study.	<i>institutionalization of the care receiver.</i>  <i>Significant:</i> After the first year the control group became more depressed (GDS [Yesavage et al., 1983]) while the intervention group remained stable ( $p < .05$ ).  <i>Nonsignificant:</i> Gender was not associated with a change in depression (GDS) over time. Nor was depression related to informal support (Social Network Questionnaire [Stokes, 1983]) of family.
Respite				
Adler et al. (1993) USA	Pretest/ Posttest Moderate (a, d, e)	n=37 Female: 92% Male: 8% Age: mean 64yrs Spouses: 81% Children: 11%  <i>Care Receivers:</i> Male: 100% Age: mean 74.2yrs MMSE score: mean 10.5/(30) All veterans with diagnosis of dementia. Probable AD n=25; non-AD dementia n=12. Non-AD participants had higher mean MMSE (Folstein et al., 1975) scores.	Participants offered two-weeks of respite every six months. Caregivers initiated the use of respite. The intervention consisted of prearranged hospital admission to a non-acute geriatric ward. Caregivers were administered a number of instruments 14 days before respite, day of discharge and 14 days post-respite. Analyses were conducted AD and non-AD caregivers pooled and split.	<i>Significant:</i> AD care receivers experienced an increase in dependence ( $p = .04$ ) (Physical Self-Maintenance Scale [PSMS, Lawton & Brody, 1984]) which is a negative impact. Non-AD caregivers experienced a significant decline in strain ( $p = .001$ ) (ZBI [Zarit, et al., 1980; Zarit & Zarit, 1987]) and in mood ( $p = .02$ ) (GDS [Yesavage et al., 1983]) between two weeks prior to respite and at time of discharge.  <i>Nonsignificant:</i> Caregiver scores on strain ( $p = .22$ ) (ZBI) and depression ( $p = .22$ ) (GDS) for both AD and non-AD caregivers combined at all time measures showed no improvement two weeks post-respite. The decline in strain (ZBI) and depression (GDS) for the non-AD caregivers did not remain significant at two weeks post-respite.
Larkin &	Pretest/	<i>Caregivers:</i>	Two-week inpatient respite	<i>Significant:</i> During respite (T2)

Table A.1

continued

Hopcroft (1993) USA	Posttest Moderate (a, d, e)	<p>n=23 at baseline n=22 at completion Female: 86% Male: 14% Age: mean 63.7yrs (range 44-78) Spouse: 86% Other: 14% Employed: 23%</p> <p style="text-align: center;"><i>Care Receivers:</i></p> <p>n=21 Male: 95% Age: mean 68.5yrs (range 55-85) All were veterans with a diagnosis of AD (DSM III-R [APA, 1987]; NINCDS-ADRDA [McKhann et al., 1984]).</p>	made available to caregivers whose family member was an outpatient at a veteran's hospital Dementia Unit; respite offered once every three months. Families requesting respite were asked to participate in the present study. Measures conducted three days prior to respite (T1), three days prior to discharge from respite (T2) and 14 days post-intervention (T3).	<p>caregivers experienced a decrease in psychological distress (<math>p=.003</math>) (Global Severity Index [GSI], part of the Brief Symptom Inventory [BSI; Derogatis &amp; Melisaratos, 1983]). Also, caregivers experienced decrease in stress scores (GSI) on the symptom dimensions of: obsessive-compulsiveness (<math>p=.001</math>), depression (<math>p=.002</math>), anxiety (<math>p=.009</math>), and hostility (<math>p=.001</math>).</p> <p><i>Nonsignificant:</i> Overall caregiver stress (BSI) was lower two weeks post-respite compared to pre-respite but not significant.</p> <p>No difference in stress levels (BSI) between caregivers who used respite before compared to first time users. Caregivers who accessed other services compared to those who received no other formal support had no difference in levels of stress (BSI).</p> <p>No correlation between care receiver ADL impairment (modified Katz ADL Scale [Katz et al., 1963]) and stress (BSI).</p>
Wishart et al. (2000) Canada	Randomly Assigned Moderate (b, d, e)	<p style="text-align: center;"><i>Caregivers:</i></p> <p>n=24 at baseline n=21 at completion <i>Intervention:</i> n=11 Male: 8% Age: mean 58.2yrs (SD 12.4) Education: mean 12.9yrs (SD 2.4) Spouse: 36% Child: 64% (daughters only) <i>Waitlist control:</i> n=10 Male: 20%</p>	<p>Care receiver intervention group received activities (e.g. walking, crafts tailored to the client) provided by a volunteer two hours per week, over six weeks.</p> <p>Waitlist control group received the same intervention 6 weeks later.</p> <p>Questionnaires were completed at baseline and at 6 weeks.</p>	<p><i>Significant:</i> Intervention group very satisfied with the program. Intervention group experienced significant reduction in strain (ZBI [Zarit et al, 1986; Zarit Orr, &amp; Zarit, 1985]) compared to waitlist control group (<math>p=.02</math>).</p> <p><i>Nonsignificant:</i> No significant difference between groups in social support change (Duke-UC Functional Support Questionnaire [Broadhead, Gehlbach, deGruy, &amp; Kaplan, 1988]).</p>

Table A.1

continued

		<p>Age: mean 56.8yrs (SD 15.5)            Education: mean 15.8yrs (SD 2.7)            Spouse: 30%            Child: 60% (daughters only)            (Control had higher level of education).</p> <p style="text-align: center;"><i>Care Receivers:</i></p> <p><i>Intervention:</i>            Male: 27%            Age: mean 81.4yrs (SD 8.1)  <i>Waitlist control:</i>            Male: 11%            Age: mean 78.7yrs (SD 7.6)            Had to have cognitive impairment.</p>	<p>No significant difference between groups noted for health and social service utilization (inventory developed by Browne, Arpin, Corey, Fitch, &amp; Gafni, 1990).</p>	
<i>Technology</i>				
Brennan et al., 1995, USA	Randomly Assigned Strong	<p><i>Caregiver:</i>            n=102 at baseline            n=96 at completion  <i>Intervention:</i> n=51  <i>Control:</i> n=51            (Demographics reported combined)            Female: 67%            Male: 33%            Age: median 64yrs            Education: &gt;high school 86%            Spouses: 68%            Child: 28%</p> <p style="text-align: center;"><i>Care Receiver:</i>            No demographics reported.            Diagnosis of AD; gross measure of functional status (CDR [Berg, 1988]).</p>	<p>Intervention group received a computer installed in their home, thus having access to computer-link 24h/d, at no charge. Participants received 90 minutes of training. Access to information, decision support, communication, and a question &amp; answer segment provided by a nurse.            Time logged on the computer was tracked.            Control group received no computer and given placebo training session.</p>	<p><i>Significant:</i> Intervention group caregivers had significant increase in decision-making confidence (<math>p &lt; .01</math>) (measured with investigator-developed instrument, 1995).  <i>Non-significant:</i> Caregivers in intervention group experienced no change in decision making skills (<math>p = .20</math>) or social isolation (<math>p = .51</math>) (Instrumental and Expressive Social Support Scale [Ensel &amp; Woelfel, 1986]) compared to control group.            Results of intervention not changed when intervening variables (e.g. strain) controlled.            No difference between study groups in the total number of community and medical services used by caregivers (<math>p = .65</math>).</p>
Davis (1998) USA	Pretest/ Posttest Moderate	<p><i>Caregivers:</i>            n=20 at baseline            n=17 at completion</p>	<p>The telephone intervention was initiated by an <i>interventionist</i> visiting the participant at home.</p>	<p><i>Significant:</i> Caregivers showed a significant increase in use of social support (<math>p = .02</math>) (3 subscales from the</p>

Table A.1

continued

(a, b, c, e)

Female: 75%  
 Male: 25%  
 Age: mean 57.2yrs (range 25-79)  
 Spouses: 35%  
 Child: 65%  
*Care Receivers:*  
 Male/female not reported.  
 Age: mean 79yrs (range 64-92)  
 Diagnosis of dementia: MMSE (Folstein et al., 1975), scores had to be between 3-8.

for two hours of training about the intervention and how to fill out and use the log. For a period of 12 weeks the interventionist phoned the caregiver once a week to provide support and problem-solving.  
 A blinded RA completed measures prior to and after the 12 weeks.

Interpersonal Support Evaluation List [ISEL; Cohen, Mermelstein, Karmack, & Hoberman, 1985]), a decrease in depressive symptoms ( $p=.003$ ) (GDS [Gallagher-Thompson & Steffen, 1994; Yesavage et al., 1983]), and an increase in life satisfaction ( $p=.03$ ) (LSI-Z [Wood, Wylie, & Sheafer, 1969]).  
*Nonsignificant:* No changes occurred for caregivers in problem-solving styles (Rational Problem-Solving Inventory [Subsection of Social Problem-Solving Inventory-Revised; Maydeu-Olivares & D'Zurilla, 1996]), in the number of problem behaviours of the care receivers or caregivers reaction to it (Revised MBPC; Teri et al., 1992).

**Key:**

**Methodological Weaknesses**

- a) No random allocation.
- b) More than 11% attrition.
- c) Did not control for all potentially relevant confounders.
- d) Data collection strategies did not optimize validity.
- e) Multivariate analysis was not conducted.

## Appendix E

## Bibliography of Relevant Studies

*Strong Studies*

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**Key:**

**Fail Ratings**

• Attrition > 20%

δ Not all relevant confounders controlled

∞ Not rigorous data collection

∓ No bivariate or multivariate statistical analyses

