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Résumé

Interventions auprès des aidantes naturelles dispensant des soins aux personnes atteintes de démence : une évaluation systématique

Shelley C. Peacock et Dorothy A. Forbes

Le taux de démence chez les personnes âgées est à la hausse. En raison d'une diminution du financement attribué aux institutions de soutien formel, de nombreuses familles se voient obligées de prendre en charge un être cher atteint de démence. Cette évaluation systématique a relevé et synthétisé de l'information sur les interventions conçues pour améliorer le bien-être des aidantes naturelles qui prennent soin de personnes souffrant de démence. Une recherche documentaire a identifié 36 études pertinentes, dont 11 études de valeur sûre, 11 de valeur moyenne, 13 de valeur faible et 1 de valeur médiocre. Cet article se penche sur les études de valeur sûre. Aucune des interventions évaluées n'avait un impact global important sur le bien-être des aidantes naturelles. L'évaluation a démontré que plusieurs interventions étaient bénéfiques aux aidantes naturelles mais que les interventions produisant peu d'impact étaient plus nombreuses. Il est important de pousser davantage les recherches dans le domaine. La réalisation d'évaluations systématiques constitue un important outil qui peut aider les consommateurs et les praticiens à prendre des décisions fondées sur des résultats.

Mots clés : révision systématique, intervention, bien-être, aidantes naturelles

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Interventions for Caregivers of Persons with Dementia: A Systematic Review

Shelley C. Peacock and Dorothy A. Forbes

The prevalence of dementia in older adults is increasing. Due to cuts in funding for formal support, many families are having to provide care for a loved one with dementia at home. This systematic review gathered and synthesized information on interventions designed to enhance the well-being of caregivers of people with dementia. A search of the literature resulted in 36 relevant studies. Of these, 11 were rated as strong, 11 as moderate, 13 as weak, and 1 as poor. This paper focuses on the strong studies. No one intervention had an overall significant impact on the well-being of caregivers. Although several interventions have been shown to be of benefit to caregivers, non-significant findings were more common. Further investigation is greatly needed. Systematic reviews are an important means of guiding consumers and practitioners in making evidence-based decisions.

Keywords: systematic review, informal caregiver, intervention, Alzheimer disease, well-being

With people living longer, the increasing prevalence of dementia in the older population is cause for concern (Hill, Forbes, Berthelot, Lindsay, & McDowell, 1996). In Canada, 8% of those 65 years and older and 35% of those 85 years and older are diagnosed with dementia, and half of all cases live in the community with a spouse, other family members, or friends (Canadian Study of Health and Aging Working Group [CSHAWG], 1994). Alzheimer disease (AD) is the most common form of dementia, affecting 5% of persons 65 and older and up to 26% of those 85 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, affecting 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). Caregiving results in both negative and positive responses. The literature includes an abundance of interventions to assist unpaid caregivers, particularly in coping with the negative consequences of caregiving.

Caregivers experience negative consequences in relation to their physical health, mental heath, social network, and finances (George &

Gwyther, 1986). Their physical health may be compromised by disruptions in sleep. Their mental health can be affected in a number of ways, including depression and strain. Caregivers may have to limit their contacts in social networks even though these play a vital role in sustaining caregivers (Hibbard, Neufeld, & Harrison, 1996). Often caregivers must sacrifice financially in order to fill their caregiving role, such as by limiting career or employment choices and paying out of pocket for formal caregiving services.

Caregivers are primarily adult children or spouses and are predominantly female (Hibbard et al., 1996). The literature indicates that women and men take on different types of caregiving responsibilities. Women tend to engage in more hands-on activities such as personal care, meal preparation, and housekeeping, although when the primary caregiver is a husband he takes on these tasks (Keating, Fast, Frederick, Cranswick, & Perrier, 1999). Men are more likely to provide household maintenance and financial planning assistance (Keating et al.). Most of the assistance given to persons with dementia in their homes is provided with little or no formal support. In recent years there has been a decrease in the funding of formal home-care support services (Armstrong & Kits, 2001), while placement in long-term care has become more and more difficult because of the shortage of beds (Dyck, 2001). The effectiveness of interventions for caregivers varies, however (e.g., Acton & Kang, 2001; Knight, Lutzky, & Macofsky-Urban, 1993), which may be due to the type of and exposure to the intervention, the characteristics of the caregiver, and the stage of the dementia. Practitioners need assistance in assessing the abundance of information about caregiver interventions and deciding which interventions are most effective for particular types of caregivers and care recipients.

There are no recent reviews of the overall well-being of caregivers of persons with dementia. The goal of this review was to determine the effectiveness of a range of interventions to enhance the well-being of caregivers of elderly persons with dementia living in the community.

Method

To assess the effectiveness of interventions for caregivers of persons with dementia, a systematic review was conducted using a framework based on the work of Forbes (1998) and Forbes and Strang (1997). Forbes and Strang conducted a review of the effectiveness of interventions for individuals with AD. Their tool was nursing-based, user-friendly, and relevant to the content of the present review. The relevance, validity, and data-extraction tools developed for their review were modified to reflect the caregiver population in the present review.

In light of the enormous amount of literature available and the barriers to accessing journals (e.g., lack of time, resources, and appraisal skills), systematic reviews can serve to demonstrate to practitioners and consumers the effectiveness of health-care interventions (Forbes, 2003). Conclusions about the evidence are reached using defined assessment steps. Forbes (2003) identifies the steps of a systematic review as: (a) developing a research question, (b) developing relevance and validity tools, (c) conducting a thorough literature search (including both published and unpublished studies), (d) assessing the studies using relevance and validity tools, (e) extracting the data, (f) synthesizing the findings, and (g) writing the report. Steps (a) through (f) apply to the present review.

Developing the Research Question

The question to be addressed in this study is a result of personal clinical experience. It is *What interventions are effective in supporting the well-being of unpaid caregivers of elderly persons with dementia residing in the community?* Such interventions could include any means that support carers and contribute to their well-being. The question is broad in order to allow for the inclusion of a significant number of studies, all of which must meet the relevance and validity criteria.

Developing Relevance and Validity Tools

Relevance tool. To screen for studies that might be included in the review, we developed a relevance tool. In order to be included in the review, a study had to have: (a) been 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 (physical, mental, social, or financial), 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 criteria were met, the study was included in the validity appraisal. The relevance tool was pre-tested by both authors using studies that appeared appropriate to the review and then revised accordingly.

Validity tool. To assess the quality of the studies, limit bias in the systematic review, and guide interpretation of findings (Clarke & Oxman, 2000), we developed a validity tool. The criteria for the validity tool, validity tool dictionary, and rating scale were modified versions of those used for the tools developed by Forbes and Strang (1997). The five validity criteria for this review were: design and allocation to intervention: random (pass), before/after or matched cohort (moderate), or other (fail); attrition: < 10% (pass), 11–20% (moderate), > 20%, not applicable, or not reported (fail); confounders controlled (e.g., age or sex of caregiver, cognitive impairment of care recipient: at least four controlled (pass), at least two to four controlled (moderate), one or less of confounders controlled (fail); measures/data collection: methods well-described, piloting or pretesting 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); types of statistical analysis: multivariate (pass), bivariate (moderate), descriptive or not reported (fail). A study was rated as *strong* if it had no fail ratings and no more than one moderate rating; *moderate* if it had no fail ratings and more than one moderate rating; *weak* if it had one or two fail ratings; and *poor* if it had more than two fail ratings. The strong studies are identified with an asterisk in the reference list.

Literature Search Strategies

We conducted online searches of CINAHL, PubMed, and PsychINFO for the period 1992 to April 2002 in consultation with an experienced librarian. The keywords were caregiver, carer, dementia, Alzheimer, burden, depression, strain, stress, support, respite, education, intervention, effective, assess, evaluate, and measure. In order to access as many studies as possible, we also used the thesaurus for each of the keywords in the individual databases. All inter-library loan requests were received. We used the online CISTI Source to aid in hand searching the table of contents of the *The Gerontologist, Journal of Gerontological Nursing,* and *Journal of the American Geriatrics Society.* The reference lists of retrieved studies were also searched for relevant studies, which were then retrieved and reviewed. The primary authors of some articles were contacted for clarification and additional information.

Assessment of Studies Utilizing Relevance and Validity Tools

Of the 92 studies retrieved, 36 met all four relevance criteria. The first 19 of these were reviewed by both authors. A high level of agreement (kappa = 0.8) was reached by the authors. Therefore, the remaining studies were assessed independently by one author, with any subsequent concerns discussed and consensus reached.

In the next phase of the review, the 36 relevant studies were rated for validity. The first 12 of these were rated independently by both authors and 100% agreement was reached. The remaining studies were rated by one author, with any concerns discussed and consensus reached. Of the 36 studies reviewed, 11 were rated as strong, 11 as moderate, 13 as weak, and 1 as poor. Descriptive analyses were completed for the 11 strong studies in the areas of methodological weaknesses, country in which the study was conducted, interventions, outcomes, and study design.

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 data-extraction tool was developed, to include general information and specific study characteristics as reported by the primary researcher. The data-extraction tool was pre-tested and revised accordingly to reflect the criteria for the validity tool. This process was undertaken independently by the primary author, with any concerns discussed with the second author.

Data Synthesis

Based on the information in the data-extraction tool, descriptive synthesis was used to summarize the characteristics of the participants, interventions, outcomes, and quality of the studies. Descriptive synthesis enables readers to survey the pattern of characteristics found in the studies and helps them to make decisions about applying the findings to their population of caregivers (Moher, Jadad, & Klassen, 1998). The findings of the strong studies are discussed according to type of intervention. Due to the diversity of interventions, statistical analysis (i.e., meta-analysis) was not possible. If the level of significance was found to be equal to or less than $p = 0.05$, the findings were considered statistically significant.

Findings

A brief summary of the strong studies is followed by a summary of their findings, by type of intervention. Please see Appendix 1 for individual summaries. A more detailed description of the strong studies and moderate studies can be found elsewhere (Peacock, 2003).

The most common methodological weakness of the strong studies related to data collection. For 7 of the 11 strong studies, data-collection strategies did not include piloting of tools and blinding of data collectors. Although these studies utilized well-known tools, the authors did not test the tool on a population similar to that used in the study, nor did they blind the data collectors. The majority of studies were conducted in the United States ($n = 8$), with one each conducted in Australia, Finland, and the United Kingdom. No studies conducted in Canada received a strong rating. All studies employed randomization of participants to an intervention or control group. The studies were categorized according to type of intervention: education ($n = 4$), case management ($n = 4$), psychotherapy ($n = 2$), and computer networking ($n = 1$). The most commonly measured outcome was institutionalization of the care recipient ($n = 6$), followed by death of the care recipient ($n = 3$), perceived behaviour disturbances in the care recipient ($n = 3$), caregiver depression ($n = 3$), caregiver strain (*n* = 2), caregiver stress (*n* = 2), and use of formal services (*n* = 2).

Case-Management Interventions

Four studies rated as strong examined the effect of intensive case management on caregivers. Three of the four utilized data obtained from the Medicare Alzheimer's Disease Demonstration and Evaluation (MADDE), with each study focusing on different caregiver outcomes. The MADDE was developed to address the ongoing needs of both care recipients with dementia and their caregivers, with the goal of improving the well-being of participants. The MADDE intervention consisted of two program models with four sites in each. The two program models differed in the amount of reimbursement and in the case manager-client ratio.

The fourth case-management study (Eloniemi-Sulkava et al., 2001) examined whether seniors with dementia could remain in the community longer with the assistance of a nurse case manager. The case manager provided coordinated care, including services and support for caregivers. The control-group caregivers received the usual services provided in the area.

The findings of these studies conflict with respect to the effectiveness of case management in decreasing the rate of institutionalization. Eloneimi-Sulkava et al. (2001) found a decrease in the rate of institutionalization in the first year of their study, while the MADDE study (Miller, Newcomer, & Fox, 1999) found that case management did not reduce the rate of institutionalization. Case management did double the likelihood of the intervention group's using community services, while the control group's use of community services increased by 50%, in the MADDE study (Newcomer, Spitalny, Fox, & Yordi, 1999). However, 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, DuNah, Fox, & Wilkinson, 1999).

Education Interventions

Four studies utilizing an education intervention were rated as strong. For this review, education as an intervention was defined as researchers/clinicians providing education about a subject and/or teaching the participants a new skill, either in a group setting or individually. The first study (Brodaty, Gresham, & Luscombe, 1997) provided caregivers in the intervention groups with training and education in a variety of topics (e.g., distress, guilt, assertiveness training) while care recipients participated in a memory clinic. The control-group caregivers were provided with respite while care recipients participated in the memory clinic. The second study examined the effects of a stress-adaptation model on improving interaction between care recipients with dementia and their caregivers (Corbeil, Quayhagen, & Quayhagen, 1999). The third education intervention study (Marriott, Donaldson, Tarrier, & Burns, 2000) aimed at reducing the strain experienced by caregivers of individuals with AD. The intervention group received a modified family intervention initially developed in the treatment of schizophrenia while control groups received no training. Finally, the fourth study (Wright, Litaker, Laraia, & DeAndrade, 2001) evaluated an education program for individual caregivers that included counselling by a nurse. The control group received no education or counselling.

The results indicate that education interventions are insufficient to improve overall caregiver psychological well-being, such as decreasing strain and depression or reducing disruptive behaviours by the care recipient (Corbeil et al., 1999; Wright et al., 2001); Marriott et al.'s (2000) education intervention is an exception in that it resulted in decreased depression for caregivers through to follow-up. There are, however, a few significant findings. Brodaty et al. (1997) were able to demonstrate that institutionalization and death of the care recipient were delayed with a caregiver training program. As well, interventions that provided the caregivers with coping methods were shown to enhance positive reappraisal (Corbeil et al.), thus improving interactions between caregivers and care recipients.

Psychotherapy Interventions

Two studies utilizing psychotherapy were rated as strong. They used the same data but reported different outcomes. An intervention at the New York University-Aging and Dementia Research Center (NYU-ADRC) consisted of six sessions of individual and family counselling that focused on communication and problem-solving in relation to caring for someone with AD. Intervention caregivers were required to join a support group and had access to further counselling at any time, while control-group caregivers received the standard assistance provided by the NYU-ADRC. The intervention benefited caregivers most by delaying institutionalization of the care recipient (Mittelman et al., 1993; Mittelman, Ferris, Shulman, Steinberg, & Levin, 1996). Predictors of institutionalization after 12 months in the program included: not being involved in a support group and care recipients with greater levels of dementia (Mittelman et al., 1993). After 3½ years of follow-up, the level of dementia remained significant in predicting institutionalization (Mittelman et al., 1996). Contradictions were found between the studies with regard to gender and age as predictors of institutionalization.

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.

Computer-Networking Intervention

Brennan, Moore, and Smyth (1995) examined the effects of a special computer network on caregivers of people with AD. Participants were randomly assigned to have a computer installed in their home or to the comparison group. Through the computer network, caregivers could receive information, decision-making support, communication, and an opportunity for questions and answers. 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, social isolation, or use of health services.

Discussion

This systematic review reveals few significant effects for caregiver interventions. Positive findings include: (a) case management increased the likelihood of using formal support services (Newcomer, Spitalny, et al., 1999) (but the results are conflicting with regard to delaying institutionalization [Eloniemi-Sulkava et al., 2001; Miller et al., 1999]); (b) an education intervention was able to decrease depression among caregivers at 3 months follow-up (Marriott et al., 2000); (c) psychotherapy for caregivers delayed institutionalization of the care recipients (Mittelman et al., 1993, 1996); and (d) the use of computer networking improved decision-making confidence (Brennan et al., 1995).

Non-significant findings were more common. Case management had no significant effect on strain or caregiver depression (Newcomer, Yordi, et al., 1999). On the whole, education interventions had no effect on overall psychological well-being, including depression and strain (Corbeil et al., 1999; Wright et al., 2001), with the exception of Marriott et al.'s (2000) study. Lastly, the networking intervention using a home computer did not decrease social isolation, improve decision-making skills, or increase use of formal supports (Brennan et al., 1995).

Limitations

Overall, the most common weakness is in the area of data collection. Seven of the 11 studies rated as strong did not report pre-testing the tools they used and blinding the data collectors regarding participants' membership in either control or intervention groups. Although many used well-known tools (e.g., Mini-Mental State Examination [Folstein,

Folstein, & McHugh, 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.

Although all the strong studies employed randomization, the authors do not always describe how this was achieved for the benefit of the reader. Often a sentence or two is all that is needed to adequately describe the steps taken by a researcher, yet, for whatever reason (e.g., space limitations), reports often lack the detail necessary for the reader to have a full understanding of the process. Furthermore, all the strong studies used convenience sampling with caregivers who had already accessed the formal system. This limits the generalizability of the findings.

This review is limited by the articles retrieved. Research may have been completed in this area but not published, resulting in limited access to the findings; none of the researchers who were contacted shared information on other work in progress. Publication bias (i.e., not publishing studies that revealed only non-significant results) could also skew the results of this review. The findings of the review must be considered in light of the methodological limitations found in the included studies and in the conduct of the review.

Implications for Practice

Although the variances explained by the interventions were not reported by the authors of the included studies, several of the interventions appear to have clinical significance as well as statistical significance in supporting caregivers. The use of computers for networking would particularly benefit caregivers living in rural communities. The MADDE case-management intervention was successful in helping 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. Education interventions that included training in coping skills, in addition to information on dementia, had more success than those that offered education alone (e.g., Marriott et al., 2000). The content of education interventions should be relevant to participants. The relationship of the caregiver to the care recipient, as well as their living arrangement, and the gender of the caregiver are some of the factors that can affect the caregiving experience. Education programs may have to take these into consideration.

Clinicians wishing to advise caregivers should pay particular attention to the type of strain (i.e., objective or subjective) that the caregiver may be experiencing. In turn, caregivers should be as explicit as possible about what they need from the formal system. Six of the studies examined ways of delaying institutionalization, as if this were always a positive outcome. There may come a time for any caregiver when keeping a loved one at home means delaying relief from various types of strain. Providing the right intervention, at the right time in the caregiving journey, to the right caregiver, represents a huge challenge. Further research is required to determine which intervention is most effective for which type of caregiver, and when.

Implications for Research

All studies rated as strong employed randomization of participants. 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 in managing their caregiving.

Not surprisingly, most of the studies in this review recruited individuals who had already accessed help from the formal system. It may be useful to aggressively recruit less available participants in order to increase the generalizability of findings. How do caregivers who do not ask for assistance and manage their loved one independently differ from those who receive formal assistance? In addition, researchers frequently include different types of caregivers in an intervention instead of focusing on a single type of caregiver — for example, female spouses.

An outcome not often measured is quality of life. Some caregivers are able to enjoy a positive quality of life regardless of their caregiving situation. Perhaps the focus should be less on strain, depression, and rate of institutionalization and more on the quality of caregiving as experienced subjectively.

The majority of research in the area of interventions for caregivers of individuals with dementia is conducted in the United States. In light of Canada's different health-care system, there is a need for research that reflects the services delivered in Canada. In addition, a large proportion of Canada is rural and remote, which may have an impact on 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. The systematic review is a valuable form of research that combines studies and disseminates information in an unbiased, rigorous manner.

Conclusion

We located an abundance of research examining the effectiveness of interventions for caregivers of people with AD. Of the 92 articles retrieved, 36 met the relevance criteria and the 11 studies rated as strong were described. Several of the interventions were shown to be of benefit to caregivers. Individualized approaches may address the uniqueness of caregivers or care recipients more readily than a single intervention delivered to a group of caregivers. Use of computers in a networking intervention is especially interesting for rural caregivers and may increase in relevance as technology becomes more advanced. Case management was effective in increasing the use of formal services. Generally, non-significant findings were more common. Clearly, further research, particularly in Canada, is essential to determine which intervention(s) best fit the needs of particular types of caregivers and best apply at particular stages in the course of dementia.

Appendix 1 *Summaries of Strong Studies*

Study	Participants	Intervention and Provider	Outcomes
CASE MANAGEMENT			
Eloniemi-Sulkava et al. (2001) Finland RCT	*Caregiver participants:* *Intervention:* $n = 53$ Male 25%/female 75% Age: mean 64.8 (range 34–83) Spouse 60%/child 27% *Control:* $n = 47$ Male 38%/female 62% Age: mean 63.3 (range 40–86) Spouse 51%/child 43%	Intervention group provided with systematic comprehensive support for 2 years by a family coordinator. The coordinator provided: support for clients; advocacy; counselling; annual training courses for clients; follow-up calls; in-home visits; assistance to arrange for additional services and physician referrals; 24-hour/day availability by mobile phone. Control group received the usual services provided by the health-care system. Participants were followed for 2 years; date of institutionalization or death was recorded.	*Significant:* In the first months, significantly fewer intervention participants were institutionalized compared to the control group ($p = .04$). The participants with severe dementia benefited the most from the intervention, by remaining in the community longer compared to the control group. *Nonsignificant:* By the end of the first and second year there were no differences in the number of deaths between groups. By the end of the second year there was no difference between groups in rate of institutionalization.
Miller et al. (1999) USA RCT	*Caregiver participants:* *Intervention:* $n = 4,151$ Male 31.7%/female 67.3% Age: 58% < 70 Spouse 46.9%/child 40.5% *Control:* $n = 3,944$ Male 30.9%/female 69.1% Age: 59% < 70 Spouse 46.4%/child 39.9%	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 manager to client ratio of 1:30 and an amount of $430–$699 per client. Control group received usual care. All participants received baseline and semi-annual assessments for up to 3 years.	*Significant:* No significant findings found. *Nonsignificant:* Institutionalization rates did not differ between intervention and control groups, either for individual sites or all combined. The aim of this intervention was to reduce strain among caregivers and no constraints were imposed to decrease the likelihood of institutionalization (unlike with other case management models).

Newcomer, Spitalny, et al. (1999) USA RCT	*Caregiver participants:* *Intervention: n* = 2,682 Male 28.3%/female 71.7% Age: mean 63.8 (*SD* 14.3) Spouse 51.2%/child 40.2% *Control: n* = 2,527 Male 27.1%/female 72.9% Age: mean 63.6 (*SD* 14.5) Spouse: 51.3%/child: 39.1%	As above.	*Significant:* The intervention group was more than twice as likely to use home-care services ($p < .01$) and adult daycare ($p < .05$) than the control group caregivers. *Nonsignificant:* No nonsignificant findings were reported.
Newcomer, Yordi, et al. (1999) USA RCT	*Caregiver participants:* *Intervention: n* = 2,731 Male 41%/female 59% Age: mean 63.0 (*SD* 14.2) Spouse 49%/child 43% *Control: n* = 2,576 Male 26%/female 74% Age: mean 63.0 (*SD* 14.4) Spouse 50%/child 41%	As above.	*Significant:* The intervention group had small reductions in strain (four of eight sites) and depression (three of eight sites) that were significant for some individual sites over the 36 months. *Nonsignificant:* Depression and strain were not found to be significantly different at any time period between the groups.

Appendix 1 (cont'd)

Study	Participants	Intervention and Provider	Outcomes
EDUCATION			
Brodaty et al. (1997) Australia RCT	*Caregiver participants:* n = 96 at baseline n = 93 at completion Immediate Intervention (group I): n = 33 Waitlist (group II): n = 31 Memory retraining only (group II): n = 30 (Demographics reported combined) Male 46.2%/female 53.8% Age: mean 67.5 (*SD* 8.0) Spouses 93% (child not reported)	Caregiver training consisted of 10-day program with a variety of sessions. Care recipients participated in a program concurrently 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 care recipients completed the memory training. All received 12-month booster sessions, and interviews were the same for all groups. Groups were followed for between 6.5 and 8 years (at the end of which period the care recipient was institutionalized or died).	*Significant:* Length of follow-up differed significantly ($p < .01$) between groups; groups I and III were followed for 7.8 years, while group II was followed for 7.4 years. When groups I and II (caregivers received training) were combined (they did not differ significantly), there was a significant ($p < .05$) impact on delaying institutionalization compared to group III (control). Eight-year survival analysis revealed that caregivers who received training (groups I and II) kept care recipients at home longer ($p = .04$). *Nonsignificant:* Care recipients who were institutionalized or died did not differ between groups.
Corbeil et al. (1999) USA RCT	*Caregiver participants:* *Intervention:* n = 28 Male 25%/female 75% Age: mean 69.0 (*SD* 9.8) Spouse/child not reported Placebo: n = 28 Male 11%/female 89% Age: mean 63.9 (*SD* 12.3) *Control:* n = 31 Male 32%/female 68% Age: mean 68.2 (*SD* 10.6)	Caregivers in *active cognitive-stimulation* group attended 1-hour sessions six days/week for 12 weeks. Caregivers were trained in activities to stimulate the mind of the care recipient. The *passive* (placebo) cognitive-stimulation group were presented with passive activities (watching television). Caregivers in the control group were contacted only for assessments. Assessments occurred pre-intervention and at 9 months and 3 months follow-up.	*Significant:* Positive interaction between caregivers and care recipients remained positive in the intervention group but became negative for the control group ($p < .05$). *Nonsignificant:* Intervention had no impact on the level of stress for the caregivers when interacting with the care recipient.

Marriott et al. (2000) United Kingdom RCT	*Caregiver participants:* *Intervention:* n = 14 Male 36%/female 64% Age: mean 69.6 (*SD* 15.2) Spouse 64%/child 21% *Control 1:* n = 14 Male 21%/female 79% Age: mean 58.1 (*SD* 16.7) Spouse 36%/child 57% *Control 2:* n = 14 Male 36%/female 64% Age: 63.0 (*SD* 14.0) Spouse 57%/child 43%	Intervention group received the Camberwell Family Interview (CFI) and a modified cognitive-behavioural intervention. Intervention consisted of education, stress management, and coping skills training delivered by a clinical psychologist in 14 sessions with 2 weeks between each session. The group also received written material. Control Group 1 received no intervention. Control Group 2 received the CFI interview only. Assessments completed at pre-treatment, post-treatment, and 3 months follow-up.	*Significant:* At 3-month follow-up there was a decrease ($p < .001$) in depression for the intervention caregivers compared to the control groups. A decrease ($p = .024$) in behavioural disturbances of the care recipients in the intervention group at post-treatment only. Intervention group had fewer psychiatric cases than the control groups at post-treatment ($p = .014$) and follow-up ($p = .001$). *Nonsignificant:* There were no significant differences between the control groups, thus the CFI alone had no impact on control 2 caregivers.
Wright et al. (2001) USA RCT	*Caregiver participants:* *Intervention:* n = 68 Male 24%/female 76% (average of both groups) Age: mean 60.4 (*SD* 14.6) Spouse 50%/daughter 35% *Control:* n = 25 Male 24%/female 76% Age: mean 57.2 (*SD* 9.8) Spouse 32%/daughter 44% (groups differed by ethnicity)	Intervention group contacted by clinical nurse specialist (CNS) after initial assessment made on the hospital unit. CNS made three home visits to caregiver 2, 6, and 12 weeks post-discharge, then phoned 6 and 12 months post-discharge. The CNS provided strategies for troubling behaviour by the care recipient, monitored the care recipient's medication, and offered supportive counselling. Control group contacted by phone for data-collection purposes only. Data collected at baseline while in hospital, and subsequently 2, 6, and 12 weeks and 6 and 12 months post-discharge.	*Significant:* The percentage of care recipients at home at 12 months post-discharge was higher for the intervention group than the control group ($p < .03$). *Nonsignificant:* None of the expected outcomes had any lasting effects or reached significance — e.g., reducing care recipient agitation, caregiver depression or stress; no positive impact on health.

Appendix 1 (cont'd)

Study	Participants	Intervention and Provider	Outcomes
PSYCHOTHERAPY			
Mittelman et al. (1993) USA RCT	*Caregiver participants:* *Intervention:* n = 103 Male 49.5%/female 50.5% Age: 45% are 70–75 Spouse 100% *Control:* n = 103 Male 34%/female 66% Age: 43% are 70–79 (groups had to be controlled for gender)	Intervention group caregivers provided with six individual and family counselling sessions by family counsellors; caregivers were required to attend a weekly support group indefinitely and had further access to counsellor. Control group participants had access to services normally provided in their area. They were not required to participate in support groups but were not denied if they wished to attend. All caregivers were interviewed and completed questionnaires every 4 months in the first year, then every 6 months for up to 8 years of follow-up. The present study covers data from baseline to 12 months' follow-up.	*Significant:* At 12 months the intervention group had less than half as many care recipients institutionalized as the control ($p < .05$). Increased rate of institutionalization was impacted by lower care-recipient income ($p < .05$), severity of dementia ($p < .05$), and increased dependence in activities of daily living ($p < .01$). The older the care recipient ($p < .05$) and the younger the caregiver ($p < .05$), the greater the likelihood of the care recipient being institutionalized. *Nonsignificant:* Caregiver gender did not affect rate of institutionalization. Nonsignificant predictors of institutionalization: number of caregiving years, depression, informal and formal support, number of services, and physical health of caregivers/care recipients.

Mittelman et al. (1996) USA RCT	As above.	As above. The present study considers data from baseline to $3\frac{1}{2}$ years' follow-up.	*Significant:* Intervention care recipients remained at home significantly ($p = .02$) longer than those in control group. Intervention caregivers were not as likely to institutionalize the care recipient as control caregivers ($p = .02$). Female caregivers were more likely than male caregivers to institutionalize their spouse ($p = .04$). Severity of dementia in care recipient was a major predictor of institutionalization; the greater the deterioration the greater the likelihood of placement in long-term care ($p = .001$). *Nonsignificant:* Caregiver age was not significant in explaining institutionalization.
COMPUTER NETWORKING			
Brennan et al., 1995 USA RCT	*Caregiver participants:* $n = 102$ at baseline $n = 96$ at completion *Intervention:* $n = 51$ *Control:* $n = 51$ (demographics reported combined) Male 33%/female 67% Age: median 64 Spouse 68%/child 28%	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 and answer segment provided by a nurse. Time logged on the computer was tracked. Control group received no computer and were given placebo training session.	*Significant:* Intervention group caregivers had significant increase in decision-making confidence ($p < .01$). *Nonsignificant:* Intervention caregivers experienced no change in decision-making skills or social isolation compared to control group. Results of intervention not changed when intervening variables (e.g., strain) controlled. No difference between groups in the number of services used by caregivers.

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* Strong study included in the review.

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