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# Dementia Caregiver Intervention Research: In Search of Clinical Significance

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## Abstract

**Purpose—**We reviewed intervention studies that reported dementia caregiver outcomes published since 1996, including psychosocial interventions for caregivers and environmental and pharmacological interventions for care recipients. Our goal was to focus on issues of clinical significance in caregiver intervention research in order to move the field toward a greater emphasis on achieving reliable and clinically meaningful outcomes.

**Design and Methods—**MEDLINE, PsycINFO, and Cumulative Index to Nursing & Allied Health databases from 1996 through 2001 were searched to identify articles and book chapters mapping to two medical subject headings: *caregivers* and either *dementia* or *Alzheimer's disease.* Articles were evaluated on two dimensions, outcomes in four domains thought to be important to the individual or society and the magnitude of reported effects for these outcomes in order to determine if they were large enough to be clinically meaningful.

**Results—**Although many studies have reported small to moderate statistically significant effects on a broad range of outcomes, only a small proportion of these studies achieved clinically meaningful outcomes. Nevertheless, caregiving intervention studies have increasingly shown promise of affecting important public health outcomes in areas such as service utilization, including delayed

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institutionalization; psychiatric symptomatology, including the successful treatment of major and minor depression; and providing services that are highly valued by caregivers.

**Implications—**Assessment of clinical significance in addition to statistical significance is needed in this research area. Specific recommendations on design, measurement, and conceptual issues are made to enhance the clinical significance of future research.

## Keywords

Alzheimer’s disease; Randomized clinical trials; Intervention research

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The personal, social, and health impacts of dementia caregiving have been well documented in recent years (Ory, Hoffman, Yee, Tennstedt, & Schulz, 1999; Schulz, 2000; Schulz, O’Brien, Bookwala, & Fleissner, 1995). These findings have in turn generated intervention studies aimed at addressing the burden and distress associated with dementia caregiving, along with a wide-ranging literature that reports the results of this work. We are aware of at least nine reviews and one commentary on two recent reviews (Charlesworth, 2001) that summarized and described the dementia caregiver intervention literature, and each of them provided insightful assessments of the strengths and weaknesses of this work throughout the past decade (Bourgeois, Schulz, & Burgio, 1996; Cooke, McNally, Mulligan, Harrison, & Newman, 2001; Dunkin and Anderson-Hanley, 1998; Kennet, Burgio, & Schulz, 2000; Knight, Lutzky, & Macofsky-Urban, 1993; Pusey & Richards, 2001; Roberts, Browne, Gafni, Varieur, Loney, & de Ruijter, 2000; Toseland & Rossiter, 1989; Zarit & Teri, 1992). Although it may be premature to add another literature review to this growing list, we believe it is important to do so for the following reasons.

First, even though some of these reviews were published only recently, the literature cited tends to be outdated; for example, the majority of studies included in the two 2001 reviews were published before 1995. Because the sheer number of intervention studies has increased dramatically since 1995 and because the scope and quality of this research have significantly improved (see Sorensen, Pinquart, & Duberstein, 2002), we felt it appropriate to take stock of the recent literature with the aim of summarizing what has been achieved in this area and providing direction for its future development. Thus, this review focuses on studies published after 1995.

Second, we include a broader range of intervention studies than previous reviews, focusing on not only psychosocial interventions for caregivers but also environmental and behavioral interventions, as well as pharmacologic interventions for the care recipient. Thus, we included all studies that reported caregiver outcomes regardless of how and to whom the intervention was delivered.

Finally, and most important, we structured our review around issues of clinical significance. We aimed to extend our understanding of the current status of intervention research by examining the practical importance of reported intervention effects. We identify multiple criteria for clinical significance and then assess each study in terms of its success in meeting these criteria.

## The Meaning and Assessment of Clinical Significance

Clinical significance generally refers to the practical value of the effects of an intervention, or the extent to which an intervention makes a “real” difference in the everyday life of an individual (Kazdin, 1999). To date, the discussion of clinical significance has largely occurred within the realms of psychotherapy or clinical medicine. However, this topic is receiving more attention in the broader intervention literature given the increased emphasis on achieving practically relevant outcomes. With increasing frequency, researchers are being asked to address not only issues of treatment efficacy but also the practical importance of treatment outcomes (Kendall, 1999).

Judging the clinical significance of an outcome requires that we answer two questions. The first concerns the nature of the assessed outcome: Is it important to the individual or to society? Psychotherapeutic or medical interventions that target specific conditions such as major depression or other diseases and measure outcomes via clinical assessments of these conditions lend themselves relatively easily to this interpretation. In contrast, caregiver interventions are often designed to address multiple problems, thereby affording the opportunity to achieve outcomes in multiple domains, some of which may be judged more clinically meaningful than others. Because there is considerable debate about the types of measures that can be used to assess clinical significance (Kazdin, 1999; Kendall, 1999), we adopted a broad inclusive approach that encompassed multiple indicators: (a) *symptomatology*—the extent to which individuals return to normal functioning or experience a change in symptoms; (b) *quality of life*—the extent to which interventions broadly improve an individual’s quality of life; (c) *social significance*—the extent to which outcomes are important to society (e.g., impact of intervention on service utilization); and (d) *social validity*—the extent to which treatment goals, procedures, and outcomes are acceptable as assessed by client or expert ratings of the interventions and their impact on participants’ lives. It should be noted that the research and service communities may have very different perspectives on the relative importance of one type of indicator over another, although clearly some overlap exists across these categories.

Once a relevant outcome measure has been identified, the second question needs to be addressed: How *large* should an effect be to meet criteria for clinical significance? Traditionally, tests of statistical significance have been used to evaluate the effects of an intervention in terms of the magnitude of effect sizes (cf. Sorensen et al., 2002). However, these metrics do not necessarily reflect the extent to which the treatment is practically meaningful to the individual or society. Statistical significance indicates that the probability of an effect differing from 0 is less than some predetermined value (Type I error). It is possible to identify a clinically unimportant effect as statistically significant by having sufficiently large samples or greatly restricting the variability in a sample (e.g., by selecting homogenous groups of participants; Jacobson & Truax, 1991). Therefore, it is important to apply an additional criterion to statistically significant results to address clinical significance: namely, to make judgments about the clinical meaning of the effect size achieved in the context of the problem being studied. This is all the more important for caregiving intervention studies where many different types of outcomes are measured and small to moderate effect sizes are frequently found (cf. Sorensen et al., 2002).

In reviewing the dementia caregiving intervention literature, we examined each study in two stages. First, we identified and grouped all clinically relevant outcomes reported for each study, using the four categories of clinical significance described above. We adopted liberal criteria in assigning outcomes to each of these categories as follows: Indicators of symptomatology included measures of depression or anxiety, such as major depressive disorder and generalized anxiety. Quality of life includes a broad range of indicators such as burden, life satisfaction, mood and affect, stress and morale, social support, and marital satisfaction; measures of social significance included residential care placement, patient longevity, patient functional status, service utilization, and time spent on caregiving tasks; and social validity was captured by intervention evaluation ratings provided by caregivers.

During the second stage of the analysis, we examined the magnitude of effects reported for these outcomes. To be considered clinically significant, an outcome had to have first achieved statistical significance according to the published report. Once this criterion was met, we then examined the magnitude of the effect using, where possible, a common metric of percentile change attributable to the intervention in order to enable the reader to make informed judgments about the meaningfulness of a given effect. Thus, to meet our criteria of clinical significance, a study had to include clinically relevant and statistically significant outcomes. In addition, the treatment effects had to be large enough to be practically meaningful. Assessing the practical value of an outcome is necessarily a subjective judgment and will likely vary by discipline and occupation.

It is important to note that the majority of studies reviewed were not necessarily designed to meet criteria of clinical significance as traditionally defined in the intervention literature. Instead, they were constructed to achieve statistical significance on one or more specific outcome measures. Thus, it could be argued that we applied an unfair standard in our evaluation of existing literature. Nevertheless, we think it useful to take stock of where we stand on these criteria for several reasons: (a) The demands of dementia caregiving contribute to public health problems that require effective treatment for large numbers of individuals; (b) the intervention literature is now more than a decade old and should be moving in the direction of demonstrating clinically significant outcomes; and (c) focusing our attention on issues of clinical significance is essential for shaping the future research agenda in this area.

## Methods

To optimize identification of intervention articles reporting clinically significant outcomes, we implemented a broad, multicomponent search strategy. First, Medline, PsycINFO, and Cumulative Index to Nursing and Applied Health (CINAHL) databases were searched to identify articles and book chapters mapping to two medical subject headings: *Caregivers* and either *dementia* or *Alzheimer's disease*. Citations yielded from this search written in the English language and published between 1996 and 2001 were evaluated for inclusion in this review. Dissertation abstracts were excluded, as were citations mapping to the medical subject headings *acquired immune deficiency syndrome*, *child care*, *infant care*, and *neoplasms*. Second, MEDLINE, PsycINFO, and CINAHL searches identified additional papers authored by prominent caregiving investigators. Finally, the tables of contents of widely circulated aging and gerontology journals were reviewed for the years 1996–2001.

Articles selected for review met the following criteria: (a) the population of interest was family caregivers for noninstitutionalized persons with dementia; (b) the focus of the investigation was on the implementation of an intervention with caregivers and/or care recipients; (c) quantitative data were reported for at least one clinically relevant outcome; and (d) comparative statistics evaluating between- and/or within-group differences were used. Papers documenting pharmacological interventions with care recipients were included only when they reported caregiver outcomes such as depression or burden. Excluded from this review were case studies and reports of purely qualitative or descriptive data. More than 50 articles reporting the results of 43 distinct studies were ultimately identified for this review, 27 of which discussed interventions using random assignment of participants to treatment conditions.

Although most studies targeted caregivers as the primary beneficiary of interventions, five studies intervened with care recipients to improve caregiver outcomes and one manipulated the physical environment. Great variability in dose and intensity was represented across the interventions, ranging from two visits to a specialty clinic to a full year of 24-hr access to clinicians. Modalities of treatment delivery included telephone calls, computer networks, videotapes, and new cognition-enhancing medications, in addition to more traditional methods such as home visits, support groups, individual and group psychotherapy, day care, and respite care.

For the purposes of this article, we operationalized outcome data primarily as between- or within-group postintervention comparisons. Adopting a liberal approach to identifying outcome data allowed exploration of a broad range of assessment methods addressing the four domains of clinical significance. Consider, for example, the construct of mood, a facet of quality of life. The assessment of mood takes many forms in the papers reviewed here, including single-item Likert scales and standardized instruments evaluating both single mood states (e.g., Anger Expression Scale) and multiple mood states (e.g., Profile of Mood States). Comparison data for each of these approaches are reported here, noting statistical significance while also evaluating magnitude of differences and consequent impact on caregivers. Where quantitative data were available and the range of a scale was known, we report a percentage difference, using as the denominator the scale's maximal value. Also noted are data demonstrating changes in diagnosis, such as an improvement from major depression to subsyndromal depression, or shifts from high- to-low risk status on a standardized instrument such as the Center for Epidemiologic Studies–Depression (CES-D) scale. Institutionalization and mortality outcomes are reported where available, as are participant satisfaction data.

## Results

The discussion below and the accompanying tables (see Tables 1–4) summarize outcomes reported for measures that fell into each of the four categories of clinical significance. For each outcome category, we report the number of studies that achieved statistically significant outcomes. From these, we selected the subset of studies that we considered to be examples of clinically meaningful outcomes. Because there does not exist a strong consensus on what constitutes a clinically meaningful effect in the caregiver intervention literature, our choices are likely to stimulate debate. This foreshadows an important conclusion of this article: namely, that a consensus panel be convened to define clinical significance in caregiver intervention research.

### Symptomatology

We included in this category indicators associated with clinical psychiatric and physical illness such as major depression and cardiovascular disease. Published studies have examined both symptomatology and caseness, the extent to which an individual falls into a particular diagnostic category before and after treatment. There is strong consensus that helping a caregiver with a clinical diagnosis of major depression progress to a state where he or she no longer meets criteria for this condition is a clinically significant outcome. However, judgments of clinical significance are more difficult to make when symptom counts are the only measure of success or when the measure itself has no clear standards for what represents meaningful change, as might be the case for indicators such as hostility.

Depressive symptoms are the most frequently studied outcomes in caregiver intervention studies. Twenty-four studies included evaluation of depressive symptomatology as an outcome measure. The majority of these ($N = 17$) reported small to modest improvements in depression symptoms for intervention relative to control conditions (see Table 1). The magnitude of changes reported ranged from 0.75% to 10.5%. A change of 10% is equivalent to a reduction of 6 points on the CES-D (scored from 0 to 60). On average, caregivers of persons with dementia reported CES-D scores of approximately 15 (Schulz et al., 1995), placing them at risk for clinical depression. Thus, a reduction of 6 points could be interpreted as movement from the at-risk category (e.g., 16) to the normative range (e.g., 10).

Two studies explored outcomes demonstrating movement across clinical risk categories. Teri, Logsdon, Uamoto, and McCurry (1997) reported that, among caregivers who met pretreatment criteria for either major or minor depression, 52% and 68%, respectively, in the two active treatment conditions no longer met criteria for depression after treatment. Only 20% of caregivers in the two control conditions showed this level of improvement. Similarly, in a secondary analysis of data reported by Gallagher-Thompson and colleagues (2000), Steffen, Futterman, and Gallagher-Thompson (1998) reported that intervention group means decreased from high risk to nearly normative levels in one study and from severe/moderate depression to mild depression in another.

Self-report anxiety inventories are also frequently used in caregiver intervention studies, but the benefits of interventions for anxiety appear to be more equivocal. Four of seven studies collecting anxiety data reported benefits attributable to treatment. One study found stable anxiety levels in the intervention group while those in the control group increased by 7% (King & Brassington, 1997). Another (Millán-Calenti et al., 2000) reported a reduction in the number of individuals reporting clinical levels of anxiety in the active treatment group.

Several studies assessed general levels of psychological distress by using standardized instruments such as the General Health Questionnaire or the Hopkins Symptom Checklist. However, findings supporting a beneficial impact of intervention on distress are limited. Fewer than half of the studies using these measures reported statistically significant treatment effects, although two of these claimed relatively large positive effects. Marriot, Donaldson, Tarrier, and Burns (2000) and Moniz-Cook, Agar, Gibson, Win, and Wang (1998) documented substantial benefit by reducing the number of individuals in high-risk distress categories.

Five of six studies that included anger or hostility as an outcome variable reported improvements attributed to intervention. Although differences between treated and control participants ranged between 6% and 19% in two studies, it is difficult to know how to interpret these findings in terms of their clinical significance, as we have no established clear standards by which they may be evaluated.

Physical health symptoms assessed in caregiver intervention studies included both self-report health assessments ($n$ = 5) and clinical assessments ($n$ = 2) of health status, such as blood pressure and T-cell proliferation. Few studies reported changes in self-assessed health. However, one study found a small reduction in mean blood pressure and greater exercise endurance.

On the whole, caregiver intervention studies showed promise for achieving clinically significant outcomes in improving depressive symptoms and reducing anxiety, and possibly anger and hostility. This is all the more impressive because study participants are typically not selected for levels of symptomatology that would characterize them as meeting criteria for clinical diagnosis. As a result, the magnitude of positive change observed for participants may be inherently limited. Targeting subgroups of individuals high in depressive symptoms, for example, may be one particularly effective strategy in achieving clinically significant outcomes in this domain.

The intervention methods used to achieve these effects varied widely. They included a variety of educational and psychotherapeutic interventions, such as problem solving, coping skills training, behavior management training, support groups, cognitive–behavioral therapy, and other types of counseling. Other approaches incorporated adult day care activities, physical exercise, and teaching caregivers how to provide memory training for care recipients. Because virtually all of these intervention approaches are multifaceted, it is difficult to attribute the observed outcomes to any one component of active treatment conditions.

## Quality of Life

We included a broad range of both general (e.g., life satisfaction, quality of life, marital satisfaction, social support) and caregiving-specific (e.g., caregiver burden) outcomes under this category (see Table 2). Along with depression, caregiver burden is a widely explored outcome in caregiver intervention studies. Thirty-three studies in this review included a measure of burden, and 16 of these reported positive impacts. The magnitude of effects ranged from 1.5% to 14% improvement in burden in treatment versus control conditions. A 14% reduction in burden on a scale such as the Revised Memory and Behavior Problem Checklist (24 items scaled 1–4, range = 24–96) is equivalent to the elimination of three highly bothersome behaviors (Cox, 1997,1998).

Although 17 studies found no evidence of overall effectiveness of interventions, 4 did demonstrate benefit for specific subgroups and 1 showed benefit for a particular subtype of caregiver burden. For example, Bass, McClendon, Brennan, and McCartley (1998) found that a computer-based intervention had beneficial effects, but only for spouse caregivers with higher levels of informal support. Ripich, Ziol, and Lee (1998) reported a decrease in hassles associated with communication but not with caregiver hassles in general. Overall, these studies suggest that statistically significant reductions in burden can be achieved at least with some populations of caregivers. However, the practical significance of these outcomes is debatable.

Evidence for the impact of intervention on general quality of life or life satisfaction is mixed. Two of four studies reported positive effects. One study (Zanetti, Metitieri, Bianchetti, & Trabucchi, 1998) indicated approximately 13% improvement in life satisfaction among individuals in the treatment condition when compared with the controls. A number of studies included outcomes closely related to quality of life, such as morale ($n = 1$) or stress-related outcomes ($n = 5$). The majority of these studies reported modest positive effects; one study (Mitchell, 2000) reported a relatively large effect consisting of a 29% increase in stress management self-efficacy, a measure related to but not directly indicative of quality of life.

Mood and affect are frequently included as elements of quality of life, and interventionists have generally been successful in improving the affective state of caregivers. Four of six (see Table 2) studies reported positive effects of intervention, including increased positive mood and decreased negative mood. However, gauging the clinical significance of these effects is difficult because there are no normative standards for evaluating meaningful change.

We also included under quality of life several outcomes often viewed as mediators or moderators of individual response to chronic stress exposure. These include coping strategies used by caregivers ($n = 4$), social support ($n = 6$), and marital satisfaction ($n = 3$). Conceptually, these outcomes are believed to play an important role in the occurrence of other clinically significant outcomes, such as symptomatology and service use, but they can also be viewed as outcomes on their own merit. All four studies that used coping strategies as an outcome reported positive effects, but the findings for social support and marital satisfaction were at best mixed.

In sum, although the ability to improve the general quality of life of caregivers appears to be limited, there is evidence that specific components of quality of life, such as burden, mood, and perceived stress, are responsive to caregiver interventions. Small to moderate positive effects have been reported with a wide range of interventions, including psychoeducational interventions, behavior management training, stress management, support programs, and relaxation training.

Three medication studies were also included in this group. In several studies where care recipients were given donepezil, tacrine, or metrifonate, caregivers reported enhanced quality of life. Finally, effective service-based interventions included respite care, adult day care, geriatric evaluation and case management, and an environmentally focused occupational therapy intervention. With the exception of the medication trials, such as the randomized trial of metrifonate for the care recipient, virtually all interventions were multidimensional, with caregivers receiving combinations of treatment that might include education and training, support, and formal services. Thus, attributing outcomes to specific causes is difficult.

The broad range of measures included in this category raises questions about their relative importance in comparison to one another. Clearly, a focused outcome indicator such as mood would be less compelling as representative of overall quality of life than information gleaned from a multidimensional quality-of-life scale. To the extent that the goal of an intervention study is to affect quality of life, we may need to develop comprehensive outcome instruments that capture multiple elements of the caregiving experience. Researchers and clinicians may also have reservations about the importance of achieving outcomes on indicators such as enhanced coping strategies, social support, and marital satisfaction, in part because there is no consensus about what constitutes meaningful levels of change on these variables.

## Social Significance

Measures of social significance included residential care placement, patient longevity, patient functional status, service utilization, and time spent on caregiving tasks. Of these, the most frequently examined outcome was residential care placement. As shown in Table 3, seven studies addressed the impact of intervention on residential care placement, and six of these suggested a beneficial effect on placement outcomes. Four studies reported differential rates of institutionalization between treatment and control groups ranging from 12% to 50%. Caregivers in treatment conditions were less likely to institutionalize their care recipient 12–18 months after enrollment than caregivers in control conditions; however, three studies demonstrated delays in placement for the treatment condition ranging from 166 days to more than 300 days. Consistent with the findings on institutionalization, researchers have also demonstrated positive impact on the care recipient’s functional status, with three of four studies providing evidence of a beneficial impact on activity of daily living and instrumental activity of daily living dependence.

A variety of other service utilization outcomes yielded a mixed pattern of results. Researchers reported both increases and decreases in formal service use, such as home care, adult day care, and respite services, as a result of intervention. A similar pattern of results was found for utilization of informal support, such as obtaining assistance from other family members. Finally, two investigations reported results on the impact of intervention on time spent caregiving, and both showed reductions; one study (Cox, 1998) reported a decrease of 30 hr per week in time spent caregiving, and another (Shikiar et al., 2000) reported a reduction of 30 min per day.

Delaying institutionalization of the care recipient has been heralded as an important and clinically significant outcome because of the high costs of institutional care. Individuals with Alzheimer’s disease typically prefer receiving care at home for as long as possible; this approach often saves public resources, although some debate exists about whether this is necessarily beneficial for the caregiver. Nevertheless, some impressive effects have been demonstrated in this regard. Achieving such effects typically requires very intense, multidimensional interventions that include heavy doses of counseling, support, and education.

## Social Validity

Social validity refers to the acceptability of an intervention to the targeted individual. Interventions will have little chance of succeeding if the caregiver finds them onerous or is unwilling to implement them. Intervention researchers frequently ask study participants to rate interventions as a whole in terms of their overall value. They also inquire about the extent to which the intervention was helpful or beneficial and whether participants would recommend the intervention to others in similar circumstances. The 14 studies that collected social validity data all reported positive outcomes, despite the variable content, intensity, and duration of interventions evaluated. A typical finding was that 80%–100% of participants rated the intervention as helpful, beneficial, or valuable (see Table 4). These resounding positive findings should be viewed cautiously for several reasons. First, these conclusions can only be generalized to individuals who chose to participate in the study and remained long enough to provide these ratings. Second, respondents may feel obligated to report positive results so as not to disappoint interventionists who have worked hard on their behalf. Third, having suffered through a challenging intervention, respondents may have a need to reduce dissonance by enhancing the value of the experience. From a public health perspective, these types of outcomes are necessary—but probably not sufficient—to meet a clinical significance criterion.

## Discussion

Our goal was to review a broad range of intervention studies aimed at improving the lives of caregivers of persons with dementia. Compared with previous reviews of this literature, the studies included here were broader in scope and more representative of recently published work. Moreover, we attempted to broaden the discussion of outcomes by raising issues of clinical significance in caregiver intervention research. Work in this area must ultimately meet this standard if our goal is to improve the lives of caregivers in meaningful ways.

Overall, the data suggest that there is evidence of clinically significant outcomes in the caregiver intervention literature. Most studies met criteria for social validity; study participants consistently rated the interventions as beneficial, helpful, or valuable. Researchers and policymakers would likely agree that social validity is important but is probably not the most valued indicator of clinical significance.

Interventions show promise of achieving clinically significant outcomes in improving depressive symptoms, and, to a lesser degree, in reducing anxiety, anger, and hostility. Although our ability thus far to improve overall quality of life for caregivers appears to be limited, there is evidence that specific components of quality of life, such as caregiver burden, mood, and perceived stress, are responsive to interventions. Finally, some impressive and clinically meaningful effects have been demonstrated for delayed institutionalization of the care recipient.

These findings are consistent with a recent meta-analysis of the intervention literature (Sorensen et al., 2002) that showed that caregiver interventions produce statistically significant improvement of .14 to .41 standard deviation units, on average, for outcomes such as depression, caregiver burden, subjective well-being, and caregiver satisfaction. Our analysis of the literature augments these findings by showing how these effect sizes may be viewed in a public health context. We demonstrated that, across several studies, researchers were able to achieve outcomes with strong implications for public health goals and objectives. Interventions that result, for example, in delayed institutionalization or in significant improvements for crippling depression represent just two effects that serve critical interests in both the personal and the public health domains. Such outcomes have potentially far-reaching consequences for promoting health and wellness for all those affected by chronic disablement.

Our review further shows that there is no single, easily implemented, and consistently effective method for achieving clinically significant effects across caregivers. Most intervention studies examined in this review reported some level of success, and as a group, they provided valuable insights about different methods for achieving caregiver impact. There exists strong consensus that all caregivers are likely to benefit from enhanced knowledge about the disease, the caregiving role, and resources available to caregivers. Once the informational needs have been met, caregivers might additionally benefit from training in general problem-solving skills, as well as from interventions that target managing care recipient behaviors or caregivers' own emotional response to caregiving. Some studies have taught the caregiver rudimentary behavior management skills, including behavioral assessment techniques and methods for changing antecedents and consequences of disruptive behaviors. Recent intervention studies have also suggested that there may be important synergies achieved by simultaneously treating care recipients (e.g., giving medications or memory retraining) and caregivers, and by altering the social and physical environments via multicomponent interventions.

The existing literature also contains a rich array of methods for delivering interventions to caregivers. Among these are traditional approaches, such as individual and group therapy sessions, as well as newer technologies involving enhanced telephone systems, computers, and the World Wide Web. As sophisticated communication technologies become easier to use and more readily available, treatment delivery options will increase.

When compared with previous dementia caregiver intervention reviews, our conclusions are decidedly more positive (cf. Charlesworth, 2001; Cooke et al., 2001; Pusey & Richards, 2001). However, our conclusions need to be qualified by a host of methodological problems that still characterize much of this literature. First, sample sizes are often too small to detect even large effects (cf. Cooke et al., 2001). For example, of the 43 distinct studies included in this review, only 1 would have been able to detect as statistically significant a small effect size, 14 a medium effect size, and 13 a large effect size (α set at .05 with 80% power). For the remaining studies, the samples were too small to detect even a large effect. Second, randomized controlled clinical trial methods have been used infrequently and are often implemented incompletely. For example, only 1 study reported intention to treat analysis to assess treatment effectiveness (Mittelman, Ferris, Shulman, Steinberg, & Levin, 1996), and only 6 studies clearly indicated that outcome assessors were masked with respect to treatment assignment. Third, interventions were typically not well described, and treatment implementation data were infrequently collected or reported (Burgio et al., 2001). Finally, the proportion of studies reporting clinically significant outcomes for important public health indicators was relatively small. Nevertheless, this work is instructive and provides important insights for the future development of this research area.

Clearly, there is room for increased methodological rigor in caregiver intervention research, and we have available good models and clear standards for enhancing the quality of research in this area (e.g., randomized controlled clinical trials methodology). These standards are being increasingly met by studies reported in the literature, and we strongly support continued improvement along these lines.

We have already made a number of methodological recommendations for future research. This list should be expanded to include a number of conceptual enhancements, such as the development of a standardized taxonomy for characterizing and measuring multicomponent psychosocial interventions (cf. Czaja, Schulz, Lee, & Belle, 2002). The application of a clearly articulated and useful taxonomy would enable us to better describe and compare interventions across studies as well as link intervention components to specific outcomes. Closer attention paid to the assumed links between an intervention and the proposed outcomes would also be useful. For example, we should not expect that interventions aimed at reducing caregiver anger or hostility will also delay institutionalization for the care recipient. Furthermore, and this speaks directly to the issue of clinical significance, we need to be more careful in our choice of study participants. If we target caregivers who are at or near the normal range of depressive symptomatology, we are unlikely to achieve meaningful improvements with an intervention designed to decrease depression. In other words, we should be sure that the study participants display the problems targeted by the intervention.

The broad range of outcomes reported in this review is indicative of both strengths and weaknesses in the caregiver intervention literature. On the one hand, these outcomes point to the multifaceted impact of caregiving and the diversity of intervention effects that can be achieved. On the other hand, this diversity of outcomes along with the diversity of interventions make it difficult to reach strong conclusions about what has been achieved in this literature. We recommend that a core set of outcomes be included in all intervention studies and that they represent each of the four categories of clinical significance identified here. In making this recommendation, we are not advocating that all studies need to be designed to achieve clinical significance in all domains, but rather that at least some aspects of all domains be measured. Furthermore, it would be useful to develop consensus-based recommendations regarding specific measures to be used within each category of clinical significance. Once specific measures have been identified, the next step would be to reach consensus on what constitutes a clinically meaningful effect size for a given measure, along with recommended statistical procedures for demonstrating those effects (cf. Kendall, Marrs-Garcia, Nath, & Shedrick, 1999).

Finally, and perhaps most important, researchers should set as their goal the achievement of reliable and clinically significant outcomes, preferably in multiple domains. To the extent that we succeed in achieving this goal, we will not only solve a vexing social problem but also advance the field of social/behavioral intervention research.

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*Asterisks indicate articles included in the literature review. A table describing and summarizing outcomes for all studies included in this review is available from R. Schulz.

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## Table 1

Clinical Symptomatology Outcomes: Statistically Significant and Clinically Meaningful Findings

| | Statistically Significant Effects | | |
|---|---|---|---|
| **Symptomatology Measures** | **Positive** | **No Effect** | **Clinically Meaningful Outcomes** |
| Clinical assessment | | | |
| Schedule for Affective Disorders and Schizophrenia (Endicott & Spitzer, 1978) | 2 | 0 | Depression diagnosis improved or remained stable among ~80% of those in a life satisfaction psychoeducational group as compared with 51% in a problem-solving group and 56% in the wait-list controls (Gallagher-Thompson et al., 2000). A secondary analysis found diagnostic improvement among 30% of caregivers with baseline depressive disorders receiving group treatment as compared with individual treatment (Steffen et al., 1998). |
| Hamilton Depression Rating Scale (Hamilton, 1967) | 1 | 0 | Clinically significant improvement in major and minor depression pre- to posttreatment in two active treatment conditions (52% and 68%) as compared with two control conditions (20% each; Teri et al., 1997). |
| Depressive symptoms | 17 | 7 | Small to moderate improvements in depressive symptoms, ranging from 0.75% to 10.5% for active interventions vs controls were reported in seven studies (Bourgeois, Schulz, Burgio, & Beach, in press; Gallagher-Thompson, Arean, Rivera, & Thompson, in press; King & Bassington, 1997; Marriott et al., 2000; Steffen, 2000; Steffen et al., 1998; Zarit et al., 1998). |
| Center for Epidemiologic Studies Depression Scale (Radloff, 1977) | | | |
| Beck Depression Inventory (Beck et al., 1961) | | | |
| Brief Symptom Inventory (Derogatis, 1992) | | | |
| Geriatric Depression Scale (Yesavage et al., 1983) | | | An 8-week video, phone, and bibliotherapy intervention caused depression scores to decrease by 10% in treatment relative to controls (Steffen, 2000). |
| Profile of Mood States (McNair et al., 1971) | | | |
| Hospital Anxiety and Depression Scale (Zigmond & Smith, 1983) | | | Two studies reported changes in clinical risk categories. Mean depression scores changed from high to low risk for a home-based intervention study (Steffen, 2000) and from severe/moderate to mild in both individual psychotherapy and group cognitive– behavioral therapy intervention groups (Steffen et al., 1998). |
| Anxiety | 4 | 3 | An intensive support (12 months biweekly education/ therapy groups and home visits) intervention found the clinical risk for anxiety category to decrease for treatment participants (Millán-Calenti et al., 2000). |
| Beck Anxiety Scale (Beck, Epstein, Brown, & Steer, 1988) | | | |
| Brief Symptom Inventory (Derogatis, 1992) | | | |
| Hospital Anxiety and Depression Scale (Zigmond & Smith, 1983) | | | |
| State–Trait Anxiety Inventory (Spielberger, Gorsuch, & Lushene, 1970) | | | |
| Taylor Manifest Anxiety Scale (Bendig, 1956) | | | |
| Anger and hostility | 5 | 1 | Two studies reported decreases in anger ranging from 5.8% to 18.9% compared with controls (Steffen, 2000; Zarit, Stephens, Townsend, & Greene, 1998). |
| Brief Symptom Inventory (Derogatis, 1992) | | | |
| Caregiver Anger Review (Steffan & Berger, 2000) | | | |
| State–Trait Anger Expression Inventory (Spielberger et al., 1985) | | | |
| Psychological morbidity | 4 | 5 | A 14-week stress management and coping skills intervention for distressed caregivers resulted in a 54%–77% decrease in number of high-risk caregivers as compared to 7%–23% fewer high-risk caregivers in comparison groups (Marriot et al., 2000). |
| Brief Symptom Inventory (Derogatis, 1992) | | | |
| General Health Questionnaire (Goldberg, 1972) | | | |

| | Statistically Significant Effects | | |
|---|---|---|---|
| **Symptomatology Measures** | **Positive** | **No Effect** | **Clinically Meaningful Outcomes** |
| Hopkins Symptoms Checklist (Derogatis, Lipman, Rickels, Uhlenhuth, & Covi, 1974) | | | A counseling/memory training intervention resulted in 20% fewer high- risk caregivers as compared with a 50% increase in high-risk caregivers among controls (Moniz-Cook et al., 1998). |
| Medical Outcomes Study Short Form | | | |
| Physical health symptoms | 1 | 4 | A 12-month intensive support intervention resulted in a 15% increase in the number of caregivers reporting their health as good or better; the percentage of caregivers able to visit a physician increased from |
| Brook's Caregiver Health Index (Brook et al., 1979) | | | |
| Health and Social Utilization Questionnaire (Browne, Arpin, Corey, Fitch, & Gafni, 1990) | | | 8% to 39% (Millán-Calenti et al., 2000). |
| Health Assessment Scale (Rosencranz & Pihlblad, 1970) | | | |
| Self-report health data (Hodgson, Higginson, & Jefferys, 1998) | | | |
| Clinical health assessments | 2 | 0 | An exercise-based intervention resulted in a reduction of 7.4 mmHg/4.7 mmHg in mean blood pressure relative to controls, and a 1.0-minute greater increase in stress-test duration compared with controls (King & Brassington, 1997). |
| Ambulatory blood pressure monitoring | | | |
| Exercise stress test | | | |
| T-cell proliferation | | | |

## Table 2

Quality of Life: Statistically Significant and Clinically Meaningful Findings

| | Statistically Significant Effects | | |
|---|---|---|---|
| **Quality of Life Measures** | **Positive** | **No Effect** | **Clinically Meaningful Outcomes** |
| Caregiver burden | 16 | 17 | Six-month respite care for low-income families resulted in a 14% decrease in burden (Cox, 1997, 1998). |
| Caregiver Appraisal (Lawton, Kleban, Moss, Rovine, & Glickman, 1989) | | | Burden risk decreased from moderate to mild among caregivers in a 3-week small-group educational program (Belmin et al., 1999).<br>Caregivers in a life satisfaction psychoeducational intervention reported a decrease in burden equivalent to two fewer upsetting or difficult caregiving tasks (Gallagher-Thompson et al., 2000) |
| Caregiver Hassles Scale | | | |
| Given Burden Scale (Given, Given, Stommel, Collins, & King, 1990) | | | |
| Caregiver Task Checklist (Poulshock & Deimling, 1984) | | | |
| Consequences of Caregiving | | | An intensive support intervention resulted in a 29% decrease in the number of caregivers who felt trapped by their role, as well as a 23% decrease in the number of caregivers who curtailed their social lives as a result of their duties (Millán-Calenti et al., 2000). |
| Memory and Behavior Problem Checklist (Zarit, Reever, & Bach-Peterson, 1980) | | | |
| Caregiver Burden Scale (Carey, Oberst, McCubbin, & Hughes, 1991; Oberst, Thomas, Gass, & Ward, 1989) | | | |
| Caregiver Distress Scale | | | |
| Screen for Caregiver Burden (Vitaliano, Russo, Young, Becker, & Maiuro, 1991) | | | |
| Zarit Burden Interview (Zarit et al., 1980) | | | |
| Objective and Subjective Burden (Montgomery, Gonyea, & Hooyman, 1985) | | | |
| Revised Burden Interview (Zarit, Orr, & Zarit, 1987) | | | |
| Life satisfaction/quality of life | 2 | 3 | Life satisfaction improved 12.8% among caregivers in a 6-week educational and support intervention but was unchanged among controls (Zanetti et al., 1998). |
| Life Satisfaction Index (Wood, Wylie, & Sheafer, 1969) | | | |
| Schedule of the Evaluation of Individual Quality of Life (O'Boyle, Browne, Hickey, McGee, & Jouce, 1996) | | | |
| LEIPAD Quality of Life Assessment | | | |
| Quality of Life Scale (DeLeo et al., 1994; modified from Teri & Logsdon, 1991) | | | |
| Philadelphia Geriatric Center Moral Scale | | | |
| Mood and affect | 4 | 2 | Mood improvements of 5%–7% and 12%–20% were found among groups (patient behavior modification, caregiver stress reduction) compared with control participants (Bourgeois et al., in press). |
| Positive and Negative Affect Schedule (Watson, Clark, & Tellegan, 1988) | | | |
| Profile of Mood States (McNair et al., 1971) | | | |
| Visual Analogue Scale | | | |
| Single-item Likert scale | | | |
| Perceived stress and stress management | 3 | 2 | A stress management intervention resulted in a 29.6% increase in stress management self-efficacy (Mitchell, 2000). |
| Perceived Stress Scale (Cohen, Kamarck, & Mermelstein, 1983) | | | |
| Stress management efficacy | | | |
| Coping strategies | 4 | 0 | |
| Coping Response Inventory (Moos, 1992) | | | |
| Revised Coping Strategies Inventory (Quayhagen & Quayhagen, 1988) | | | |
| Ways of Coping Questionnaire (Folkman, Lazarus, Dunkel- Schetter, DeLongis, & Gruen 1986) | | | |

| Quality of Life Measures | Statistically Significant Effects | | Clinically Meaningful Outcomes |
|---|---|---|---|
| | Positive | No Effect | |
| Social support | 2 | 4 | A state-subsidized respite program reported a 12% increase in satisfaction with support among Caucasian, but not African American, participants (Cox, 1998). |
| Duke–UNC Social Support Questionnaire (Broadhead, Gehlbach, de Gruy, & Kaplan, 1988) | | | |
| Interpersonal Support Evaluation List (Cohen, Mermelstein, Kamarck, & Hoberman, 1985) | | | |
| Satisfaction with support | | | |
| Social Support Appraisal Questionnaire (Vaux et al., 1986) | | | |
| Social Support Questionnaire | | | |
| Marital satisfaction | 1 | 2[a] | |
| Dyadic Adjustment Scale (Spanier, 1976) | | | |
| Marital Needs Satisfaction Scale (Stinnett, Collins, & Montgomery, 1970) | | | |

[a] One study reported worsened marital satisfaction in active treatment group (Gendron, Poitras, Dastoor, & Pérodeau, 1996).

## Table 3

Social Significance Outcomes: Statistically Significant and Clinically Meaningful Findings

| | Statistically Significant Effects | | |
|---|---|---|---|
| **Social Significance Measures** | **Positive** | **No Effect** | **Clinically Meaningful Outcomes** |
| Residential care placement | 6 | 1 | Four studies reported differences in the range of 12.6%–50% in rate of institutional placement at 12–18 months between caregivers receiving treatment and controls (Mittelman et al., 1995; Moniz- Cook et al., 1998; Riordan & Bennett, 1998; Roberts et al., 1999). |
| Caregiver Report Health and Social Utilization Questionnaire (Browne et al., 1990) | | | |
| Medical records | | | Three studies demonstrated delays in placement, including a mean of 166 days in one study (Riordan & Bennett, 1998), 19.9 and 8.1 months in a second study (Brodaty, Gresham, & Luscombe, 1997), and a median of 329 days in a third study; overall relative risk (RR) .65 for placement in intervention group. Lower risk observed for patients with moderate (RR = .38) and mild (RR = .18) dementia (Mittelman et al., 1996). |
| Patient longevity | 1 | 1 | Trend ($p = .08$) toward greater longevity (12.0–15.4 months) among patients in treatment groups (immediate and wait-list intensive caregiver and care recipient intervention) as compared with control participants. This difference was significant at 5-year follow-up (Brodaty et al., 1997). |
| Caregiver report | | | |
| Patient functional status | 3 | 1 | A cross-sectional comparison of donepezil users and nonusers found that treated patients had less ADL and IADL dependence (Fillit et al., 2000). |
| Clinical Dementia Rating Scale (Hughes, Berg, Danziger, Coben, & Martin, 1982) | | | Two studies reported better functional outcomes for intervention vs control participants at follow-up (Gitlin, Corcoran, Winter, Boyce, & Hauck, 2001; Marriott et al., 2000). |
| Functional Independence Measure (Granger & Hamilton, 1992) | | | |
| Instrumental Activities of Daily Living (Lawton & Brody, 1969) | | | |
| Physical Self Maintenance Scale (Lawton, 1988) | | | |
| Service utilization | 5 | 1 | A cross-sectional comparison of donepezil users and nonusers found that treated patients were 6.3% less likely to be hospitalized and 8.7% less likely to have gone to the emergency room (Fillit et al., 2000). |
| Awareness of state sponsored services | | | |
| Emergency room use | | | |
| Formal support use | | | A Medicare demonstration project documented odds ratios (OR) of 2.77 for home care services ($M$ = 45 hrs/year) and OR = 2.61 for adult day care utilization ($M$ = 7 days/year; Newcomer, Spitalny, Fox, & Yordi, 1999). |
| Service utilization | | | Caregivers in a cognitive–behavioral group intervention reported a 24% increased use of formal care (Gendron et al., 1996).<br>Intervention participants (counseling and memory training) reported 50% less use of respite care but 30% more adult day care use as compared with controls (Moniz-Cook et al., 1998). |
| Informal support | 2 | 0 | Use of formal support increased and informal support decreased by 12% more among caregivers in an intervention (8-week cognitive– behavioral intervention; Gendron et al., 1996). |
| Assistance from multiple caregivers | | | |
| Hours of informal support | | | |
| Type and frequency of informal supports | | | |
| Time spent on caregiving tasks | 2 | 0 | A state-subsidized respite care program documented a decrease of 30 hr per week in time spent caregiving among Caucasian participants, but not African Americans (Cox, 1998). |
| Caregiver Activity Time Survey (Clipp & Moore, 1995) | | | |
| Hours of caregiving | | | Caregivers of patients treated with metrifonate spent 30 min fewer per day on caregiving tasks than caregivers of patients receiving placebo (Shikiar et al., 2000). |

## Table 4

Social Validity Measure: Statistically Significant and Clinically Meaningful Findings

| | Statistically Significant Effects | | |
|---|---|---|---|
| **Social Validity Measures** | **Positive** | **No Effect** | **Clinically Meaningful Outcomes** |
| Intervention evaluation ratings | 14 | 0 | In studies that used global ratings (*n* = 5), 90%–100% of participants rated the interventions positively (Bourgeois, Burgio, Schulz, Beach, & Palmer, 1997; Gendron et al., 1996; Quayhagen et al., 2000; Roberts et al., 1999; Wilkins, Castle, Heck, Tanzy, & Fahey, 1999). |
| Component ratings | | | |
| Global ratings | | | |
| Recommendation of program to others | | | 85%–96% of participants in two studies would recommend the intervention to others (Pillemer, Suitor, Landreneau, Henderson, & Brangman, 2000; Quayhagen et al., 2000); 75% of participants with improved situations attributed the improvement to the intervention (8-week education and support group; Coen, O’Boyle, Coakley, & Lawlor, 1999).<br>Eighty-one percent of intervention components rated as helpful or very helpful (patient behavior modification and caregiver stress reduction; Bourgeois et al., in press).<br>One-hundred percent of intervention components rated extremely high in one study (Steffen, 2000) and 88% rated extremely high in another study (Riordan & Bennett, 1998). |