
Issues in assessment and intervention for distress in Alzheimer caregivers

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Current estimates indicate that 4.5 million people in the United States suffer from Alzheimer's disease and that the prevalence doubles every five years beyond the age of 65. It is also estimated that by 2050 the number of cases of Alzheimer's disease will increase to over 13.2 million (Hebert *et al.*, 2003). The vast majority of individuals with Alzheimer's disease are cared for at home by family members. Although caregivers' tasks and associated stress and burden vary by stage of the disease, as a group, caregivers of individuals with Alzheimer's disease have elevated depression and anxiety, increased physical morbidity, and shortened life (Schulz *et al.*, 2005). In short, Alzheimer's caregiving presents a significant public health problem and consequently requires the development of interventions that ameliorate its negative impact.

Researchers have been investigating the effects of various interventions for Alzheimer's caregivers for over 20 years, and a number of excellent reviews of the literature have been published (e.g., Ducharme *et al.*, 2005; Roberts *et al.*, 2000; Schulz *et al.*, 2005). Rather than providing yet another review of the literature, we will refer the reader to those reviews, attempt to synthesize the conclusions of these various reviews, and discuss our own views of the major challenges facing assessment and intervention.

Overview of caregiver intervention research

Although anecdotal reports of early intervention efforts were generally positive, the first critical reviews of the literature were considerably more sobering. Toseland and Rossiter's (1989) early review of 29 studies concluded that

time-limited psychoeducational interventions have only modest therapeutic benefits as measured by global ratings of well-being, mood, stress, psychological status, and caregiving burden. Focusing exclusively on interventions aimed at alleviating caregiver distress, Knight *et al.* (1993) concluded that individual psychosocial interventions and respite programmes are moderately effective, though psychosocial interventions with groups are less effective. Zarit and Teri (1992), in describing the available intervention literature as the 'first generation' of studies, pointed out that expectations had been overly optimistic; conversely, some intervention effects may have been underestimated because of methodological limitations of the studies (Zarit & Toseland, 1989).

Focusing on specific treatment components, Bourgeois *et al.* (1996) organized their critical review of the literature around six broad categories: support groups, individual and/or family counseling, case management, respite and day care services, skills training, and various combinations of these strategies. Several general conclusions were derived from their synopsis of the literature. First, the complexity and rigor of intervention studies continues to improve with an increasing emphasis on randomized designs. Secondly, the literature on the whole supports the conclusion that more is better: multiple-component interventions that blanket caregivers with a diversity of services and supports, hoping that a combination of components will have impact on a caregiver's unique needs, tend to generate larger effects than narrowly focused interventions (Mittelman *et al.*, 2004). Similarly, single-component interventions with higher intensity (frequency and duration) also have a greater positive impact on the caregiver than similar interventions with lower intensity.

Given the complexity of the caregiving experience, the variability in caregivers' cultural context and resources, and the variety of outcomes examined, we should not be surprised to find that more recent reviews of the caregiving intervention literature also have been unable to identify a 'silver bullet' solution to alleviating caregiver distress (Dunkin & Anderson-Hanley, 1998; Kennet *et al.*, 2000; Roberts *et al.*, 2000; Schulz *et al.*, 2000). There is no single easily implemented and consistently effective method for ameliorating the stresses of caregiving. This is particularly true when considering racial and ethnic diversity. It is overly simplistic to think that interventions that are successful with caregivers of one particular ethnic or cultural background will be equally effective with those from very different circumstances, as medical anthropologists such as Kleinman (1980) and Hinton *et al.* (1999) have noted. Thus, the literature suggests the need to develop a high-intensity intervention with multiple components that is targeted to individuals who might benefit most from such an intervention, with appropriate modifications to maximize its relevance to subgroups of racial/ethnic minority caregivers (Gallagher-Thompson *et al.*, 2000).

In a review of 41 randomized clinical trials published between 1999 and 2005, Schulz *et al.* (2005) noted that, generally, studies included a mix of generations (e.g., spouses and adult children) and used multiple-component interventions. Most of these studies focused on caregiver outcomes, but they often excluded or had very limited care recipient outcome measures. Other limitations noted by the authors include unequal attrition rates among treatment groups, inadequate information on treatment implementation, and not adhering to randomized clinical trial standards regarding blinding. Studies often lacked power to detect low to medium effect sizes; however, consistently significant outcomes included decreased caregiver depression, burden, and anxiety, and decreased care recipient behavioural problems.

Since the review by Schulz *et al.* (2005), a few randomized clinical trial studies have been published. Beauchamp *et al.* (2005) conducted an innovative technology-based study using an internet-based interactive multimedia intervention for family caregivers in the workforce (76 per cent adult child caregivers). Participants in the treatment group reported decreased levels of depression, anxiety, stress, and strain, as well as increased self-efficacy, intent to seek support, and caregiver gain. Similar outcomes were reported in a study in which healthcare professionals (e.g., Master's-level counselors, social workers) currently working with community-dwelling older adults were trained to educate caregivers about dealing with mood and behavioural problems (Teri *et al.*, 2005). Caregivers reported decreases in depression, burden, and reactivity to behaviour problems, while care recipients had a decrease in severity and frequency of behaviour problems (as measured by caregiver reports and clinician ratings) and an increase in quality of life (as measured by care recipient and caregiver reports). Teri and colleagues note that this is one of the few studies that has successfully incorporated evidence-based caregiver interventions in a community setting. Both of these studies tracked treatment delivery by noting the amount of participant exposure to the intervention (e.g., amount of time or number of sessions).

In another study, Roth *et al.* (2005) explored the effects of an intervention that targeted social support resources, a topic in need of more study. As a result of a counseling intervention (two individual sessions, four family sessions, a support group, and *ad hoc* phone counseling), spousal caregivers made better use of existing support systems, resulting in increases in objective and subjective measures of support. Treatment implementation was not addressed in this study.

In 1995 in the United States, the National Institute on Aging and the National Institute of Nursing Research funded a multi-site cooperative agreement to develop caregiver interventions. This cooperative agreement is known

as Resources for Enhancing Alzheimer's Caregiver Health (REACH). These studies focused on the development of skill-training interventions to help family caregivers of Alzheimer's patients reduce the burden and distress associated with caregiving. They addressed methodological issues and racial/ethnic and gender differences in treatment outcome. Detailed treatment manuals were created for interventions, and interventionists were certified on the procedures to ensure consistency of treatment delivery. The REACH projects included procedures and measures to track treatment implementation, including delivery, receipt, and enactment. REACH involved six intervention sites (Birmingham, Boston, Memphis, Miami, Palo Alto, and Philadelphia) and a coordinating centre in Pittsburgh.

Detailed analyses of these data suggested that specific components of the REACH interventions might be efficacious in improving caregiver outcomes. The interventions included:

- 1 Individual information and support strategies
- 2 Group support and family systems therapy
- 3 Psychoeducational and skill-based training approaches
- 4 Home-based environmental interventions
- 5 Enhanced technology support systems (telephone-linked computer or TLC).

Because different interventions were used at each site, specific outcomes differed by site. However, a meta-analysis allowed some general conclusions (Schulz *et al.*, 2000). The project concluded that active interventions were superior to control conditions in reducing caregiver burden. Interventions consisting of active engagement of caregivers had a greater impact on reducing caregiver burden. Women and people with a high-school education or lower who were in active interventions reported reduced burden, and Hispanic/Latino caregivers, non-spouse caregivers, and caregivers with less than a high-school education reported lower depression than their counterparts in the control conditions (Schulz *et al.*, 2003).

Built upon the findings of the original REACH project (REACH I), REACH II was funded in 2001 to refine and test a multiple-component psychosocial behavioural intervention to reduce burden and depression among family caregivers of individuals with Alzheimer's disease or related disorders. REACH II was a multi-site clinical trial, with five sites (Birmingham, Memphis, Miami, Palo Alto, and Philadelphia) testing the same intervention. The overall objectives of REACH II were to identify and reduce modifiable risk factors among diverse family caregivers of patients with Alzheimer's disease or a related disorder, enhance the quality of care of the care recipients, and enhance the well-being of the caregivers. The REACH II intervention sought to increase caregiver knowledge, skills, and well-being while enhancing support to the caregiver. The intervention process involved administering a risk appraisal,

prioritizing the risk areas, and then using a stepped intervention approach that addressed risk in multiple domains. Interventions included:

- 1 Risk assessment
- 2 Education (information on Alzheimer's disease and dementia, caregiving, home safety, and caregiver health)
- 3 A caregiver network (computer telephone integration system or CTIS; this system provided access to resources, social support, information and educational materials, and respite)
- 4 Social support (support groups reached via CTIS)
- 5 Behaviour management skills training (e.g., behavioural prescriptions)
- 6 Physical and emotional well-being (stress reduction and relaxation techniques such as signal breath, soothing music, and stretching, as well as strategies for managing mood and increasing pleasant events).

Results from the clinical trial showed significantly greater improvements in quality of life and depression in the intervention group. These results were true for African American, Caucasian, and Hispanic sample (Bells, S., Burgio, L., and the REACH investigators. (November 2006). Enhancing the quality of life of Hispanic/Latino, Black/African American, and White/Caucasian dementia caregivers: The REACH II randomized controlled trial. *Annals of Internal Medicine*, 145(9), 727-738.)

Current issues in Alzheimer's disease caregiving research

The Alzheimer's disease caregiving literature has reached a level of maturity wherein special issues, complications, and needs in future research can be identified. Moreover, because the literature is no longer in its infancy, the bar has been raised for caregiver intervention studies to be considered methodologically adequate. The following sections outline the current issues in caregiver intervention research.

Care recipient outcome measures

More comprehensive care recipient outcome measures need to be included. Specifically, in addition to the typical care recipient measures of activities of daily living and instrumental activities of daily living (ADL/IADL), memory and behavioural problems, and rates of institutionalization, researchers should include measures of mood and quality of life. Researchers have avoided measures requiring care recipient self-report because of an assumption that self-reports from cognitively impaired individuals are rarely valid. However, researchers have found that individuals with Alzheimer's disease can give valid and reliable self-reports with mini-mental state evaluation (MMSE) scores as low as 15 (Fisher *et al.*, 2006, reports of pain; Logsdon *et al.*, 2002, quality of life). Simmons *et al.*, (1997)

provide an objective method for identifying nursing home residents capable of accurate report, who would be candidates for satisfaction interviews based on information in the Minimum Data Set, which is readily available in nursing homes. Although a sizable proportion of Alzheimer's disease patients have moderate to severe impairment (e.g., MMSE scores lower than 15), investigators are able to obtain usable care recipient self-report data on a proportion of these individuals.

A fine example of using care recipient self-report can be found in Teri *et al.* (2005). These investigators used the Quality of Life in Alzheimer's Disease measure (QOL-AD) as a major care recipient outcome variable. The QOL-AD is a 13-item measure designed for individuals with memory loss that focuses on quality of life domains identified as important for memory-impaired older adults. The results of the study showed that care recipients in the intervention group (consultant training) reported improved quality of life after training, compared with a routine medical care control.

Racial and ethnic considerations

Caregiving researchers have become more sensitive to possible racial and ethnic differences in Alzheimer's caregiving and a substantial body of literature has catalogued these differences (Schulz *et al.*, 2005). Caregiver intervention studies have begun to investigate race, with some of the REACH I sites focusing on African American/Caucasian (Burgio *et al.*, 2003a) and Hispanic/Caucasian differences (Gallagher-Thompson *et al.*, 2003). REACH II included equal numbers of Hispanic, African American, and Caucasian caregivers in this multi-site clinical trial. Nevertheless, we have found only one published report showing differential responsiveness to intervention by caregiver race (Burgio *et al.*, 2003a). In this study, African American caregivers appeared to respond better to an interventionist visiting their home and teaching caregiving skills in a one-to-one interaction. Conversely, Caucasian caregivers had better outcomes when the materials were posted to them and intervention contacts were made over the phone.

An important issue frequently discussed among caregiver intervention researchers, but never examined systematically, is that of 'race matching'. Specifically, are there differences in attrition or treatment outcome depending on whether the interventionist is of the same or different race as the participant? We are aware of no data addressing this question in the Alzheimer's disease caregiving literature. However, there are data in the psychotherapy literature that address race matching. Unfortunately, the study findings are mixed on the variables of drop-out and attendance at sessions. Although some research indicates that race matching is related to less premature drop-out and

attendance at more sessions (Maramba & Hall, 2002; Sue, 1998; Sue *et al.*, 1991), other studies did not find these relations (Murphy *et al.*, 2004; Sterling *et al.*, 1998). Although the findings are still somewhat mixed, there appears to be a growing consensus that there is no relation between race matching and treatment outcome in psychotherapy (see Maramba & Hall, 2002, for a review; Sue, 1998).

It is unknown whether or not the findings from the psychotherapy literature can be applied to interventionists working with Alzheimer's caregivers. It would appear to us that the nature of the relationship between therapist and client is often different from that between interventionist and caregiver. Whereas many caregiver interventions involve an interventionist teaching various skills to the caregiver, the typical therapist–client relationship is more 'intimate'.

Until this issue can be examined empirically, there are available strategies to address race matching in caregiver intervention research. One possibility is to use intervention teams that include individuals of different racial or ethnic backgrounds (e.g., an African American and a Caucasian). Another option is to allow caregivers to choose between equally trained therapists of different racial or ethnic backgrounds, although these strategies can be difficult to use logistically and may not be feasible. The latter option could also be questioned on methodological grounds. To summarize, in our review of the caregiving literature, race matching has not been used formally. However, it is our opinion that this issue can affect outcome, particularly in geographical areas with a history of racial conflict. At the very least, we suggest that data be gathered on race of interventionist and caregiver. If the study is adequately powered to detect any difference, these data should be examined in a secondary analysis. Most preferable would be to conduct a study focusing on the possible influence of interventionist and caregiver race/ethnicity on outcome.

Strength-based interventions

The majority of caregiver intervention research has been influenced by the stress process model (Lazarus & Folkman, 1984). Most outcome measures have focused on appraisal of problem situations (e.g., behavioural burden, depression, anxiety) and coping styles (e.g., problem-focused coping, emotion-focused coping). Susan Folkman has published a revised stress process model (Folkman, 1997) that incorporates 'meaning-based coping'. In this model, Folkman acknowledges that caregiving can result in positive emotions. Moreover, caregiver acknowledgement of positive aspects of caregiving, positive reappraisal, and spiritual beliefs can serve as moderators of the impact of negative event outcome. This new conceptualization presents two issues very

relevant to caregiving research. First, most dementia caregiving studies have failed to measure such constructs as positive aspects of caregiving (Tarlow *et al.*, 2004), caregiver 'powerfulness' (Hagen *et al.*, 2003), or positive affect (Watson *et al.*, 1988); thus, they measure the effects of interventions as only half of the picture. In other words, interventions in which efficacy has been measured only by decreases in depression, burden, and anxiety might conceivably have detected strong effects on positive emotions or powerfulness. Secondly, except for multiple-component studies that include pleasant events training, no interventions for dementia caregivers at this time have employed treatment components targeted directly at increasing positive emotions, such as psychotherapy focused on meaning (Greenstein & Breitbart, 2000), dignity therapy (Chochinov *et al.*, 2005), or legacy training (Allen *et al.*, 2005).

Researchers and clinicians are beginning to add strength-based components such as those listed in Folkman's revised stress and coping model (e.g., meaning-based coping strategies of positive reappraisal, revised goals, and spiritual beliefs) to interventions in other areas of research. For example, Greenstein and Breitbart (2000) have used 'meaning-centred' group psychotherapy for palliative care inpatients with advanced cancer. Therapy sessions focus on topics such as generating meaning, reframing daily experience from that of dying to that of living, and life review. This intervention has also been shown to decrease depression among palliative care recipients (Nelson *et al.*, 2002). A second therapeutic approach incorporating strength-based components and used more broadly is 'dignity therapy', developed by Chochinov and colleagues (2004, 2005). The treatment is delivered individually to terminally ill inpatients and those receiving home-based palliative care services with a variety of medical aetiologies. Treatment consists of an audiotaped semi-structured interview involving life review. Interviews are transcribed and then given to the patient to share with family members. Results have shown that dignity therapy is effective in reducing physical suffering and depressive symptoms and increasing the will to live. Moreover, patients' beliefs that the interviews would be helpful to their family members were associated with perceptions that life was more meaningful. We recommend that future studies include strength-based treatment components and a mix of measures assessing both negative and positive emotions.

Clinical significance

Although it is necessary for investigators to show a statistically significant change due to their intervention, there is a growing consensus that it is no longer sufficient for interventions to show statistical significance alone. With adequate statistical power, significance can be achieved by a change of only a

few points on a scale encompassing a large range of scores. Although it might be statistically significant, the improvement might not and often does not change the caregiver's day-to-day life in any meaningful way. Clinical significance means that the intervention has made a meaningful change in the caregiver's life (Schulz *et al.*, 2002). There are several methods of addressing clinical significance. One strategy is to measure symptomology on a scale such as the Center for Epidemiologic Studies Depression Scale (CES-D). There is a cut-off of 16 on the CES-D that suggests clinical depression. An intervention that results in reduced symptomology, such that a majority of the scores move from over 16 to 16 or below, can be considered clinically significant because it moved a majority of the caregivers out of the clinical depression category.

Another method is to assess social validity. For example, a caregiver can be videotaped interacting with a care recipient before and after treatment. If a panel of mental health professionals and caregivers agree that the post-treatment videotapes show that the caregiver's interactions are 'calmer' or display less anxiety or anger, it can be argued that the intervention brought about a socially validated change.

A promising and easy-to-understand measure of clinical significance is termed 'number needed to treat' (NNT; Kraemer & Kupfer, 2005). This measure is frequently used in clinical medicine research, but to our knowledge has not been used in psychosocial intervention research, despite its clear relevance. Basically, NNT determines the number of clients that would need to be treated before the occurrence of one treatment success. This is best understood from an example. Consider a trial comparing psychoeducation to a control condition for reducing depression in Alzheimer's disease caregivers. A dichotomous criterion is then set to define a success. For example, a success could be a CES-D score that is one-half of a standard deviation lower after intervention (or at a Time 2 assessment in the control group). Another possible outcome could be placement in a nursing home. The researcher then counts the number who reached the criterion in the intervention and control groups. If, say, 8.6 per cent of the participants in the intervention group and 7 per cent of the control group participants reduced their CES-D score at least one-half of a standard deviation, then NNT would be:

$$1/(0.086 - 0.07) = 63$$

This tells the reader that one would need to treat 63 caregivers in order to successfully reduce one caregiver's depression, as defined, in a clinically significant way.

This is an extreme example showing the results of a less than potent intervention. There are many factors to consider when using NNT: the definition

of a success, the possible side effects of the intervention, and so on. For example, what if the data gave $NNT = 5$ (in other words, one would need to treat five caregivers before one success was found)? Normally, this would be considered a good NNT. However, what if the intervention were skills training plus an anxiolytic? Anxiolytics can result in falls and confusion in older caregivers; they can also be addictive. In this situation $NNT = 5$ might be considered inadequate, but perhaps $NNT = 2$ would be considered worth the risk when one considers the potential gain.

Although NNT carries with it its own set of complications, we believe that it is the most informative and intuitive measure of clinical significance. We recommend that researchers conducting psychosocial intervention research consider using NNT.

Use of attention control groups

Over the past 20 years, caregiver interventions have become increasingly complex and treatment sessions have increased in duration (e.g., from a simple 3-hour group session in earlier studies to twelve 1-hour in-home sessions in the REACH II project). Various control or comparison groups have been used; however, the least used but most informative control group is an attention control group. A number of dementia experts and an increasing number of National Institutes of Health initial review groups (IRGs) have posited a simple and obvious question. Considering that Alzheimer's caregivers are often isolated from human companionship, how can researchers know that it is their intervention that is responsible for therapeutic change and not the mere presence of another individual providing one-to-one attention? We could find only one study that compared a multi-component intervention to an attention control group (Bourgeois *et al.*, 2002). This study found therapeutic changes in the intervention group that went beyond any effects due to attention.

There are both logistical and ethical issues involved with attention control. Most problematic is devising sessions that offer face validity. In the Bourgeois *et al.*, study (2002), the researchers conducted 'friendly visits', in which research staff would visit the home and talk with the caregiver about their week using 'empathic listening'. Empathic listening involves responding to the caregivers in a sympathetic manner while providing no directions for solving problems. However, this procedure obviously can present ethical dilemmas. If the caregiver reports a behaviour that places either the caregiver or care recipient in danger (e.g., wandering or access to a loaded handgun), these events cannot be ignored. One procedure used in the Bourgeois *et al.* study (2002) was to hand the caregiver brief, non-tailored, written protocols that provided suggestions

for a specific emergent problem. It is our recommendation that whenever possible, future intervention studies should compare their intervention with attention control conditions.

Treatment implementation

The *sine qua non* of caregiver intervention research—in fact, of any intervention research—is the measurement of treatment implementation (TI; Burgio *et al.*, 2001). The term 'treatment implementation' refers to a class of strategies used to document and assess the induction of individual treatment components. TI strategies can be classified according to three aspects of intervention: delivery, receipt, and enactment. Treatment delivery involves the activity of the interventionist, and specifically his or her ability to present the intervention to the client as intended. The focus is on the interventionist's therapeutic skills. Did the interventionist deliver all the components described in the treatment manual? Of equal importance, did the interventionist exclude therapeutic components associated with other forms of intervention? For example, did elements of reality therapy creep into a protocol intended to deliver reminiscence therapy? One method for assessing treatment delivery is to audio- or videotape treatment sessions and obtain independent checklist ratings of whether critical components were observed and, conversely, whether any 'extraneous' treatment components were observed.

Treatment receipt refers to the extent to which a client actually received the intended treatment. This is often defined as the client's mastery of concepts and/or skill development. Treatment receipt can be assessed by paper-and-pen surveys or questionnaires measuring skill level. Depending on the intervention used, the client might be asked to demonstrate skills so that they can be evaluated for inclusion of the correct components and accuracy of skill application. For example, a client receiving treatment in dealing with distressing situations could be asked to use problem-solving steps to solve a sample problem.

Treatment enactment is the degree to which a client demonstrates changes and therapeutic behaviours related to the intervention in the natural environment. Do the clients use the knowledge and skills that define the intervention in their daily lives? For example, if memory training is used for memory problems, do the clients use the components (e.g., mnemonic techniques) throughout the day to improve their memory performance? Sometimes this type of data can be gathered automatically through the use of technology. For instance, a specialized telephone with direct links to therapeutic information and social support resources can be programmed to record the number of times it is used by participants to access information and support. Typically, however, assessment of enactment is more difficult. In the memory

training example, the clinician/researcher would need to rely on verbal or written self-reports by clients of the various mnemonics used during the day. It should be noted that, although enactment should be closely associated with desired treatment outcomes, enactment indicators are distinct from the primary outcomes of the study. For example, mnemonic use during the day is an enactment indicator, but performance on a memory task after mnemonic training would be the outcome of a memory training study.

When one considers the caregiver intervention literature in total, the majority of researchers have neglected to measure TI in any form. One of the aims of REACH I and REACH II was to demonstrate how TI can be measured in caregiver intervention research and to convince researchers of its importance in clinical research. Considering that TI measurement was an aim of REACH I and REACH II, these two outcome papers are the only publications that we are aware of wherein all three types of TI were measured (Belle, Burgeo, *et al.*, 2006; Schulz *et al.*, 2003). More recent studies include sections in their papers describing their TI efforts (Teri *et al.*, 2005). A discussion of these efforts can be found in Burgio *et al.* (2003b).

Translational research agency

Our ultimate goal is to transfer our research knowledge of caregiver interventions into the community, where agency staff could use the intervention in their everyday practice. It is a rare intervention indeed that can be transferred from a research protocol to everyday applications (e.g., a caseworker in the field).

It is preferable that a multi-step approach be used to transfer an intervention to a naturalistic setting. First, a component analysis design is recommended (Jacobson & Truax, 1991; Jacobson *et al.*, 1996) so that the relative strength of each component could be determined. In this way, weak treatment components can be dropped from the multiple-component intervention, yielding a package that is more feasible for use in the community. However, component analysis designs are used rarely in clinical research because they require very large sample sizes. Thus, use of this design in a clinical research study would be prohibitively expensive. It is possible that the relative strength of the components could be explored through TI measures. For example, if the researcher were to have data on how frequently a component is used and relate that to outcome, some sense of strength of treatment component could be derived. Though plausible, we know of no research group that has attempted this procedure.

The next step should be to systematically examine treatment effectiveness in the community. In effectiveness studies, the researcher examines which factors

contribute to actual use of a treatment by indigenous staff (Is a well-designed manual adequate? Are videotaped examples necessary? Is it necessary for a treatment consultant to be made available?).

Conclusions

Some of the following conclusions are empirically based, and some are based on the authors' 15 years of experience researching caregiver interventions. Alzheimer's disease caregiver intervention research has come a long way over the last 20 years (see Schultz *et al.*, 2005 for a review of clinical trials). What can be concluded from this intervention research? Active interventions, such as skills training, are superior to more passive interventions (e.g., group-led psychoeducation); interventions involving 'active engagement' between interventionists and caregivers appear to be superior to interventions that provide less or no active engagement; and multiple-component interventions are superior to treatments that focus on only one area (e.g., behaviour management for behavioural disturbance).

The most important conclusion is that we can help improve caregivers' quality of life. We believe that it is critical that caregiver researchers look for innovative strategies, for example interventions that focus on improving caregivers' strengths (see strength-based interventions, above). We also believe that all studies should pay close attention to measuring treatment implementation (Burgio *et al.*, 2001) so that researchers and clinicians have a better idea of what was done during intervention and so that the intervention can be replicated.

Although there have been tremendous gains in the quality of interventions and research methodology, the overall effect of intervention studies to date has been modest. Particularly in the more recent clinical trials, we cannot conclude that the modest improvements are due to poor designs or ineffective treatments. The literature clearly shows that caregivers' quality of life is determined by multiple factors: depression, lack of respite and social support, poor caregiver health and energy levels, and violation of how they expected to live out their later years. This is only a partial list of factors affecting caregivers' quality of life and perceptions of stress and burden.

One strategy is to develop interventions that are tailored to the caregiver's particular constellation of stressors. The challenge here is to utilize tailored interventions while still conforming to the requirements of clinical trial methodology.

One option we do *not* have is to stop researching interventions to help Alzheimer's caregivers. There may be a cure for Alzheimer's disease in the future, perhaps even the not-so-distant future, or prophylactic treatments to prevent the

disease from occurring. However, demographics dictate that the disease and its effects on caregivers will grow exponentially worldwide before a cure will be found. We as a society cannot ignore or minimize the suffering of so many millions of people until the day when a cure can be found.

References

- Allen, R. S., Ege, M. A., & Hilgeman, M. M. (2005). Legacy activities as interventions near the end of life. Poster presented at the meeting of the Gerontological Society of America, Orlando, FL, November.
- Beauchamp, N., Irvine, A. B., Seeley, J., & Johnson, B. (2005). Worksite-based internet multimedia program for family caregivers of persons with dementia, *Gerontologist*, 45, 793–801.
- Bourgeois, M. S., Schulz, R., & Burgio, L. (1996). Interventions for caregivers of patients with Alzheimer's disease: a review and analysis of content, process, and outcomes, *International Journal of Aging and Human Development*, 43, 35–92.
- Bourgeois, M. S., Schulz, R., & Burgio, L. (2002). Skills training for spouses of patients with Alzheimer's disease: outcomes of an intervention study, *Journal of Clinical Geropsychology*, 8, 53–73.
- Burgio, L., Lichstein, K. L., Nichols, L., Czaja, S., Gallagher-Thompson, D., Bourgeois, M., et al. (2001). Judging outcomes in psychosocial interventions for dementia caregivers: the problem of treatment implementation, *Gerontologist*, 41, 481–489.
- Burgio, L., Stevens, A., Guy, D., Roth, D. L., & Haley, W. E. (2003a). Impact of two psychosocial interventions on white and African American family caregivers of individuals with dementia, *Gerontologist*, 43, 568–579.
- Burgio, L. D., Fisher, S. E., Phillips, L. L., & Allen, R. S. (2003b). Establishing treatment implementation in clinical research, *Alzheimer's Care Quarterly*, 4, 204–215.
- Burgio, L. D., & the REACH Investigators. (2006). Enhancing the quality of life of Hispanic/Latino, Black/African American, and White/Caucasian dementia caregivers: the REACH II randomized controlled trial.
- Chochinov, H. M., Hack, T., Hassard, T., Kristjanson, L. J., McClement, S., & Harlos, M. (2004). Dignity and psychotherapeutic considerations in end-of-life care, *Journal of Palliative Care*, 20, 134–142.
- Chochinov, H. M., Hack, T., Hassard, T., Kristjanson, L. J., McClement, S., & Harlos, M. (2005). Dignity therapy: a novel psychotherapeutic intervention for patients near the end of life, *Journal of Clinical Oncology*, 23, 5520–5525.
- Ducharme, F., Levesque, L., Lachance, L., Giroux, F., Legault, A., & Preville, M. (2005). 'Taking care of myself': efficacy of an intervention programme for caregivers of a relative with dementia living in a long-term care setting, *International Journal of Social Research and Practice*, 4, 23–47.
- Dunkin, J. J., & Anderson-Hanley, C. (1998). Dementia caregiver burden: a review of the literature and guidelines for assessment and intervention, *Neurology*, 51, S53–60.
- Fisher, S. E., Burgio, L. D., Thorn, B. E., & Hardin, J. M. (2006). Obtaining self-report data from cognitively impaired elders: methodological issues and clinical implications for nursing home pain assessment, *Gerontologist*, 46, 81–88.

- Folkman, S. (1997). Positive psychological states and coping with severe stress, *Social Science and Medicine*, 45, 1207–1221.
- Gallagher-Thompson, D., Coon, D. W., Solano, N., Ambler, C., Rabinowitz, Y., & Thompson, L. W. (2003). Change in indices of distress among Latino and Anglo female caregivers of elderly relatives with dementia: site-specific results from the REACH national collaborative study, *Gerontologist*, 43, 580–591.
- Gallagher-Thompson, D., Lovett, S., Rose, J., McKibbin, C., Coon, D., Futterman, A., et al. (2000). Impact of psychoeducational interventions on distressed family caregivers, *Journal of Clinical Geropsychology*, 6, 91–110.
- Greenstein, M., & Breitbart, W. (2000). Cancer and the experience of meaning: a group psychotherapy program for people with cancer, *American Journal of Psychotherapy*, 54, 486–500.
- Hagen, B., Gallagher, E., Rutman, D., & Sandilands, M. (2003). The Caregiver Powerfulness Scale: an alternative way to evaluate support group interventions for family caregivers of the frail elderly? *Journal of Mental Health and Aging*, 9, 145–156.
- Hebert, L. E., Scherr, P. A., Bienias, J. L., Bennett, D. A., & Evans, D. A. (2003). Alzheimer disease in the US population: prevalence estimates using the 2000 census, *Archives of Neurology*, 60, 1119–1122.
- Hinton, W. L., Fox, K., & Levkoff, S. (1999). Introduction: exploring the relationships among aging, ethnicity, and family dementia caregiving, *Culture, Medicine and Psychiatry*, 23, 403–413.
- Jacobson, N. S., & Truax, P. (1991). Clinical significance: a statistical approach to defining meaningful change in psychotherapy research, *Journal of Consulting and Clinical Psychology*, 59, 12–19.
- Jacobson, N. S., Dobson, K. S., Truax, P. A., Addis, M. E., Koerner, K., Gollan, J. K., et al. (1996). A component analysis of cognitive-behavioral treatment for depression, *Journal of Consulting and Clinical Psychology*, 64, 295–304.
- Kennet, J., Burgio, L., & Schulz, R. (2000). Interventions for in-home caregivers: a review of research 1990 to present. In R. Schulz (Ed.), *Handbook on Dementia Caregiving: Evidence-Based Interventions for Family Caregivers* (pp. 61–126). New York, Springer.
- Kleinman, A. (1980). *Patients and Healers in the Context of Culture*. Berkeley, CA, University of California Press.
- Knight, B. G., Lutzky, S. M., & Macofsky-Urban, F. (1993). A meta-analytic review of interventions for caregiver distress: recommendations for future research, *Gerontologist*, 33, 240–248.
- Kraemer, H. C., & Kupfer, D. J. (2005). Size of treatment effects and their importance to clinical research and practice, *Biological Psychiatry*. Available online at <<http://dx.doi.org/doi:10.1016/j.biopsych.2005.09.014>>
- Lazarus, R. S., & Folkman, S. (1984). *Stress Appraisal and Coping*. New York, Springer.
- Logsdon, R. G., Gibbons, L. E., McCurry, S. M., & Teri, L. (2002). Assessing quality of life in older adults with cognitive impairment, *Psychosomatic Medicine*, 64, 510–519.
- Maramba, G. G., & Hall, G. C. (2002). Meta-analyses of ethnic match as a predictor of dropout, utilization, and level of functioning, *Cultural Diversity and Ethnic Minority Psychology*, 8, 290–297.

- Mittelman, M. S., Roth, D. L., Haley, W. E., & Zarit, S. H. (2004). Effects of a caregiver intervention on negative caregiver appraisals of behavior problems in patients with Alzheimer's disease: results of a randomized trial, *Journals of Gerontology, Series A: Biological Sciences and Medical Sciences*, *59*, 27–34.
- Murphy, M., Faulkner, R., & Behrens, C. (2004). The effect of therapist-client racial similarity on client satisfaction and therapist evaluation of treatment, *Contemporary Family Therapy*, *26*, 279–292.
- Nelson, C. J., Rosenfeld, B., Breitbart, W., & Galietta, M. (2002). Spirituality, religion, and depression in the terminally ill, *Psychosomatics*, *43*, 213–220.
- REACH II Investigators. (submitted for publication). Enhancing the quality of life of Hispanic/Latino, Black/African American, and White/Caucasian dementia caregivers: the REACH II randomized controlled trial.
- Roberts, J., Brown, R., & Gafni, A. (2000). Specialized continuing care models for persons with dementia: a systematic review of the research literature, *Canadian Journal of Aging*, *19*, 106–126.
- Roth, D. L., Mittelman, M. S., Clay, O. J., Madan, A., & Haley, W. E. (2005). Changes in social support as mediators of the impact of a psychosocial intervention for spouse caregivers of persons with Alzheimer's disease, *Psychology and Aging*, *20*, 634–644.
- Schulz, R., Beach, S. R., Ives, D. G., Martire, L. M., Ariyo, A. A., & Kop, W. J. (2000). Association between depression and mortality in older adults: the Cardiovascular Health Study, *Archives of Internal Medicine*, *160*, 1761–1768.
- Schulz, R., Burgio, L., Burns, R., Eisdorfer, C., Gallagher-Thompson, D., Gitlin, L. N., et al. (2003). Resources for Enhancing Alzheimer's Caregiver Health (REACH): overview, site-specific outcomes, and future directions, *Gerontologist*, *43*, 514–520.
- Schulz, R., Martire, L. M., & Klinger, J. N. (2005). Evidence-based caregiver interventions in geriatric psychiatry, *Psychiatric Clinics of North America*, *28*, 1007–1038.
- Schulz, R., O'Brien, A., Czaja, S., Ory, M., Norris, R., Martire, L. M., et al. (2002). Dementia caregiver intervention research: in search of clinical significance, *Gerontologist*, *42*, 589–602.
- Simmons, S. F., Schnelle, J. F., Uman, G. C., Kulvicki, A. D., Lee, K. H., & Ouslander, J. G. (1997). Selecting nursing home residents for satisfaction surveys, *Gerontologist*, *37*, 543–550.
- Sterling, R. C., Gottheil, E., Weinstein, S. P., & Serota, R. (1998). Therapist/patient race and sex matching: treatment retention and 9-month follow-up outcome, *Addiction*, *93*, 1043–1050.
- Sue, S. (1998). In search of cultural competence in psychotherapy and counseling, *American Psychologist*, *53*, 440–448.
- Sue, S., Fujino, D. C., Hu, L. T., Takeuchi, D. T., & Zane, N. W. (1991). Community mental health services for ethnic minority groups: a test of the cultural responsiveness hypothesis, *Journal of Consulting and Clinical Psychology*, *59*, 533–540.
- Tarlow, B. J., Wisniewski, S. R., Belle, S. H., Rubert, M., Ory, M. G., & Gallagher-Thompson, D. (2004). Positive aspects of caregiving: contributions of the REACH project to the development of new measures for Alzheimer's caregiving, *Research on Aging*, *26*, 429–453.
- Teri, L., McCurry, S. M., Logsdon, R., & Gibbons, L. E. (2005). Training community consultants to help family members improve dementia care: a randomized controlled trial, *Gerontologist*, *45*, 802–811.

- Toseland, R. W., & Rossiter, C. M. (1989). Group interventions to support family caregivers: a review and analysis, *Gerontologist*, 29, 438-448.
- Watson, D., Clark, L. A., & Tellegen, A. (1988). Development and validation of brief measures of positive and negative affect: the PANAS scales, *Journal of Personality and Social Psychology*, 54, 1063-1070.
- Zarit, S. H., & Teri, L. (1992). Interventions and services for family caregivers. In K. W. Schaie & M. P. Lawton (Eds), *Annual Review of Gerontology and Geriatrics* (Vol. 11, pp. 287-310). New York, Springer.
- Zarit, S. H., & Toseland, R. W. (1989). Current and future directions in family caregiving research, *Gerontologist*, 29, 481-483.