

BEHAVIORAL AND PSYCHOSOCIAL INTERVENTIONS FOR FAMILY CAREGIVERS

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GERONTOLOGIC RESEARCH in the past 40 years has shown that caring for an older, disabled person affects the health and well-being of the caregiver. This important contribution led to a wide range of programs and services designed to buffer caregivers from the effects of stressors. Many of these programs have been quite innovative. Although empirically validated treatments have lagged behind clinical innovation, a growing number of well-conducted studies are providing a solid foundation that guides practice. Several excellent meta-analyses—with excellent summary tables—of this body of work have been published (Gallagher-Thompson & Coon, 2007; Knight et al., 1993; Pinquart & Sorensen, 2006; Zarit & Zarit, 2007). These reviews concluded that although there are many promising approaches, their benefits for caregivers are sometimes modest, and some interventions appear to have little or no effect.

Building on the findings of those meta-analyses and on our own critical reading of the literature, we will focus on three issues:

- What types of treatment are the most promising?
- What methodologic challenges may have reduced the efficacy in past trials?
- What are some promising strategies for the next generation of studies that could lead to improved outcomes for family caregivers?

This review concentrates on interventions for caregivers of people with dementia. Caring for people with dementia is the most challenging and most frequently studied area. Many of the issues that arise in caring for this population apply broadly to other patient groups.

Characteristics of Effective Interventions

Effective treatments for caregivers have four overlapping characteristics: a psychological rather than purely educational approach, multidimensionality, flexibility, and sufficiency in the amount or dosage of treatment.

Psychological Interventions

Interventions that take a psychoeducational or psychotherapeutic approach have a greater effect than do those that use education alone or other types of interventions (Pinquart & Sorensen, 2006; Sorensen et al., 2002). Caregivers who are treated using a psychoeducational or psychotherapeutic approach actively apply the general information they receive to their specific situation. They practice new skills, receive feedback, and develop plans to implement these skills in situations they might encounter. In contrast, educational interventions are based on the assumption that learning new information will lead to new behavior, giving participants little if any opportunity to translate their new knowledge into action by practicing during the intervention.

In a psychoeducational treatment, the therapist uses psychotherapeutic techniques to encourage behavior change and, in particular, to overcome barriers to change (Zarit & Zarit, 2007). In a group treatment, for example, the leader uses group processes, such as commenting on the similarities among the concerns raised by participants, to build cohesion and to facilitate modeling of new behavior. In one-to-one psychotherapeutic interventions, the therapist can use her or his relationship with the caregiver to overcome barriers to change (Whitlatch et al., 1991). In interventions with multiple family members, a family systems perspective may guide the selection of strategies that will build cooperation (Mittelman et al., 2003; Zarit & Zarit, 2007).

Multidimensional Interventions

The most successful interventions are multidimensional; that is, they address multiple stressors and other risk factors that affect caregivers' health and well-being (Gallagher-Thompson & Coon, 2007; Gitlin et al., 2006; Pinquart & Sorensen, 2006; Sorensen et al.; Teri et al., 2003). In contrast, use of a single intervention or service is often less effective at lowering stress or burden.

A caregiver's stress is best described as a multidimensional problem (Aneshensel et al., 1995; Pearlin et al., 1990). Well-being results from the dynamic interplay of multiple stressors and the resources that are available to mediate them. The stressors or risk factors that are present vary considerably from one caregiver to the next and over time. It may be that multidimensional interventions are more effective than one-dimensional programs because they are more likely to touch on a particular caregiver's problems.

The type of help caregivers are most likely to receive is case management, which matches people's needs with available programs. Given the patchwork system of services and funding of U.S. health care, case management makes sense. However, the results of trials using only case management have been disappointing, with caregivers neither improving on measures of well-being or burden nor delaying the use of institutional care as compared with control groups (Fox et al., 2000; Kemper, 1988; Newcomer et al., 2001). We believe this is because case management addresses only one problem for caregivers—a confusing service system—while ignoring other issues, including the difficulty caregivers have in turning over the care of their relative to formal service providers. Multidimensional interventions that address psychological barriers to service use have better

outcomes (Gitlin et al, 2006; Mittelman et al., 1995, 1996; Whitlatch et al., 1991).

Flexible Interventions

Many intervention trials use a scripted protocol that allows little flexibility. This approach ensures fidelity to the treatment plan and makes replication possible. However, such a rigid approach cannot respond to individual treatment needs.

The best example of a flexible intervention for caregivers is the protocol used by Mittelman and colleagues (Mittelman et al., 1995, 1996, 2003, 2004). The counselor drew from a set of approaches, such as addressing behavior problems and increasing family support, but had considerable latitude in allocating time to different problems. The results have consistently been positive, with reduced depression and burden and increased time to institutionalization of the care recipient (Mittelman et al., 1995, 1996, 2004).

Dosage of Treatment

Interventions that provide more treatment generally have better outcomes. The Mittelman studies (Mittelman et al., 1995, 1996, 2004) are a case in point. After completing the core treatment program (about six sessions), participants were referred to ongoing support groups. Counselors could also engage in additional follow-up sessions by telephone or in person, according to the caregiver's needs. Given the long-term course of dementia care, it is not surprising that an intervention that provided ongoing support was found to have good immediate and long-term outcomes.

Dosage has been a critical issue in studies of respite care. In many studies, the amount of

help caregivers received was low (Fox et al., 2000; Kemper, 1988; Lawton et al., 1984; Montgomery & Borgatta, 1989; Newcomer et al., 2001; Zank & Schacke, 2002). Although the findings of these studies may be interpreted as demonstrating a failure of respite care (Callahan, 1989), a more likely explanation is that small amounts of relief don't lower the caregiver's feelings of burden or emotional distress.

To address this problem, our research group studied adult day services by first considering what might constitute a "therapeutic dosage"; in other words, how often adult day services would need to be used to make a difference for caregivers (Zarit et al., 1998). We found that caregivers whose relative attended adult day services at least twice a week for three months had lower care-related strain levels than did a control group. The caregivers who received this intervention were also less angry and had fewer symptoms of depression.

Unlike research on new medications, research on psychosocial treatment rarely considers how much exposure to the intervention is needed to make a difference. Just as a new medication wouldn't be effective at a subtherapeutic dosage, neither would a psychosocial treatment. Dosage should not be left to guesswork, nor should it be determined, as has sometimes happened, by economic considerations that limit treatment without regard to the amount of help that could actually make a difference (Carcagno & Kemper, 1988). Instead, the amount of treatment needed to make a therapeutic difference should be determined as part of the treatment development process.

Caregiver Intervention Research Design Problems

In addition to the issues cited above, other problems in the design of caregiver intervention studies have contributed to the modest or negative outcomes seen in many studies. More details can be found in Zarit and Femia (Zarit & Femia, 2008). Four main points follow.

Mismatched Research Design and Treatment Goals

An example of a study design matched to treatment goals is a randomized trial for the treatment of depression in which enrollees meet the operational criteria for depression set out by the *Diagnostic and Statistical Manual of Mental Disorders*. The participants have the problem—depression—that is treated in the study.

But consider a typical study of caregivers that intends to reduce their depressive symptoms. Eligibility for participation is likely based solely on being a caregiver. Although depression is a common problem for family caregivers (Coon et al., 2003; Schulz et al., 1995), it is not universal, and many caregivers in the sample will not be depressed. Therefore, they will not show any improvement in their level of depression. In fact, treating them for a problem they don't have may even worsen their situation (Collins et al., 2005).

A few caregiver studies have used a matched design (Belle et al., 2006; Coon et al., 2003; Smith & Toseland, 2006), with caregivers having to meet a minimum threshold for emotional distress to be included. As a result, the entire sample had the potential to show

improvement on the outcome measures. It is probably not a coincidence that the findings in these studies were positive.

Mismatched Treatment and Caregivers' Needs or Risk Factors

Most interventions for caregivers seek to improve an outcome, such as depression or burden, by addressing risk factors for that outcome. Risk factors have included a lack of information about dementia and about community services; difficulty managing the memory and behavior problems of a person with dementia; inadequate support or assistance; misunderstandings and conflicts between the caregiver and other family members; and the inability of the caregiver to carry out other activities, such as work.

The problem with this approach is that it assumes these risks will be present for all caregivers. However, studies indicate that the extent to which any particular risk factor is present or problematic varies among caregivers (Aneshensel et al., 1995). Behavior problems, for example, are common in people with dementia and are a major risk factor for burden and depression in their caregivers. Yet some caregivers report that their relative has few behavior problems (Femia et al., 2007; Teri et al., 1992) or that they can manage these problems and don't need skill-building or other interventions in this area (Zarit et al., 1986). A trial that enrolls caregivers who don't need help in a specific area provides treatment for a problem that doesn't exist.

The risk factors targeted should be related to the outcome measures. Many studies have assumed that improving caregivers' knowledge about dementia and care-related prob-

lems will lower their depression and burden. Although the information is undoubtedly useful to caregivers, a lack of information is not a risk factor for depression. A few studies have systematically addressed risk factors that are known to be related to depression, such as the patient's behavior problems (Teri et al., 1997) or cognitive distortions (for example, insisting that a deceased parent is alive) (Whitlatch et al., 1991). These studies showed reductions in caregivers' emotional distress, just as those studies with designs matched to their treatment goals did.

Clarification of Caregivers' Goals

Why would caregivers enroll in a treatment trial if they didn't have major emotional distress or burden or if they weren't struggling with many of the typical risk factors? We don't know. We assume they were seeking help for other concerns that were not addressed by the intervention or were hoping the treatment would prevent their situation from becoming worse.

Instead of determining caregivers' goals, researchers have often imposed their own goals on them. The results of the discrepancy between researchers' goals and those of caregivers can be seen in some studies of caregivers who were assisting relatives with disabilities severe enough to qualify them for institutional care. The caregivers were not told that the goal of the intervention was to delay or prevent nursing home placement by providing community-based services. Furthermore, the caregivers were not asked whether they were currently considering institutional placement or wanted to delay it. Not surprisingly, these studies found the intervention

had no effect on subsequent placement (Carcagno & Kemper, 1988; Miller et al., 1999).

Heterogeneity of Caregivers' Social Roles and Characteristics

Caregivers may be husbands, wives, daughters, daughters-in-law, sons, siblings, grandchildren, or people who are not relatives. The obligations and commitments for providing care that are expected of the person in each of these relationships differ. Caregivers also differ among themselves in their other obligations and in the resources they have for providing care. For example, spouses who are retired may have time to provide care, but they may have health problems of their own that limit their physical capabilities. Daughters are more likely to have competing obligations in their work and family roles (Stephens et al., 2001), and they may be more willing than spouse caregivers to use paid help to supplement care (Zarit et al., 1999). Husbands and wives may approach caregiving very differently (Miller, 1990; Zarit et al., 1986). Other notable differences among caregivers are related to ethnicity and socioeconomic status.

Few intervention studies have taken these differences into account. A major contribution of the multisite Resources for Enhancing Alzheimer's Caregiver Health (REACH) trials is the finding that ethnic and kin relationships significantly interact with treatment. Black caregivers were more likely to respond positively than whites to a behavior management intervention (Burgio et al., 2003), and Cuban American husbands and daughters were more likely than other caregivers to respond to a combined family systems and technology intervention (Eisdorfer et al., 2003).

New Approaches to Caregiver Intervention Research

More research is needed to identify interventions that protect caregivers from the adverse effects of stress and enable them to provide high-quality care. New research approaches and increased clarity about the goals of research and the goals that caregivers have for themselves are necessary. Studies reflecting the practice concerns of social work and of nursing are also needed.

Researchers can begin by matching the goals of treatment with the outcome measures. One option is to focus only on those caregivers who have the problem that the researchers want to treat; for example, a study aimed at improving depression should include only those caregivers who meet the minimum criteria for depressive symptoms or a depressive disorder (Belle et al., 2006; Coon et al., 2003). The treatment would then focus explicitly on characteristics and risk factors associated with depression in caregivers, not on a broader array of issues.

Preventive Interventions

For the many caregivers who are not currently burdened or depressed, the beginning point for researchers would be to more systematically determine why they are seeking treatment. In all likelihood, they have specific concerns based on the stressors they are currently experiencing, or they are worried about how caregiving will affect them in the future. Treatment should be designed to address these concerns, and the success of the preventive intervention would be measured by

improvements in caregivers' management of current stressors and by reductions in the subsequent occurrence of negative outcomes.

A study by Ostwald and colleagues suggests that a resource-building approach might help prevent stress-related symptoms (Ostwald et al., 1999). A multidimensional psychoeducational group provided information, taught management skills, and helped build family support. No immediate posttreatment differences in outcomes were found between the treatment group and a control group, but two months later, burden and depression were significantly lower among caregivers in the treatment group than in the control group.

Adaptive Interventions

A promising research strategy that has been used with other at-risk populations is known as an adaptive, tailored, or stepped intervention (Bierman, 2002; Collins et al., 2004, 2005; Conduct Problems Prevention Group; Sobell & Sobell, 1999; Tinetti et al., 1996). In an adaptive treatment trial, participants are systematically assessed for risk factors and protective factors that affect the targeted outcome (for example, relief of depressive symptoms). Participants are then assigned to specific treatment components based on their own risk factors. This approach has the flexibility of a clinical intervention, where the clinician tailors treatment to the individual's needs. Unlike a clinical intervention, however, an adaptive intervention uses operational rules to determine the type and amount of treatment and can be replicated.

A follow-up study to the original REACH program, REACH II (Belle et al., 2006), used

an adaptive approach that explicitly tailored the intervention based on the caregiver's scores on risk factors in the initial assessment. The results showed improvements in caregivers' quality of life and depressive symptoms.

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