

**Caregiving Revisited:
Old and New Perspectives on Families Assisting Elders**

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It is a great honor to receive this award, particularly since it is named for M. Powell Lawton. Powell was a creative and eminent scholar. Those of us fortunate to have worked with him know that he was a kind, caring and positive man. Despite all his accomplishments, he was totally without pretensions. He always had time to talk to everyone, whether it was the President of the Gerontological Society seeking his advice or the greenest graduate student who just wanted to say hello. Powell is a model for all of us, not just for his outstanding scholarship, but for his decency and kindness.

I also want to acknowledge colleagues and graduate students with whom I have worked over the years, and who have added richness to the research I will describe. I want especially to note Shannon Jarrott of Virginia Tech University and Elia Femia of Penn State University who nominated me for this award. Much of the research I will describe has been supported by the National Institute of Aging, National Institute of Mental Health and the Administration on Aging.

Introduction

Anyone who has been at the GSA meetings anytime in the last 25 years knows that there has been tremendous attention to family caregiving. The enduring interest in this topic has to do with the central role the family plays in our lives. There is a timeless feel to the issues of intergenerational relationships and support, and to the struggles of families to do the best they can for their older relatives, while being tugged in many different directions.

With all that has been written and said about caregiving, it is easy to conclude that almost every aspect has been probed, that there is nothing left to say, or that there are no new research directions. What I hope to accomplish is to take a fresh look at some issues and to suggest there are still important questions that need to be explored. My comments are organized around 3 issues:

- The social context of caregiving;
- Main findings on the stress process in caregiving; and
- Promising strategies for intervention research.

While much of my emphasis is on the last point, an appreciation of the social context and stress process of caregiving is a necessary foundation for the next generation of research.

The Social Context of Caregiving

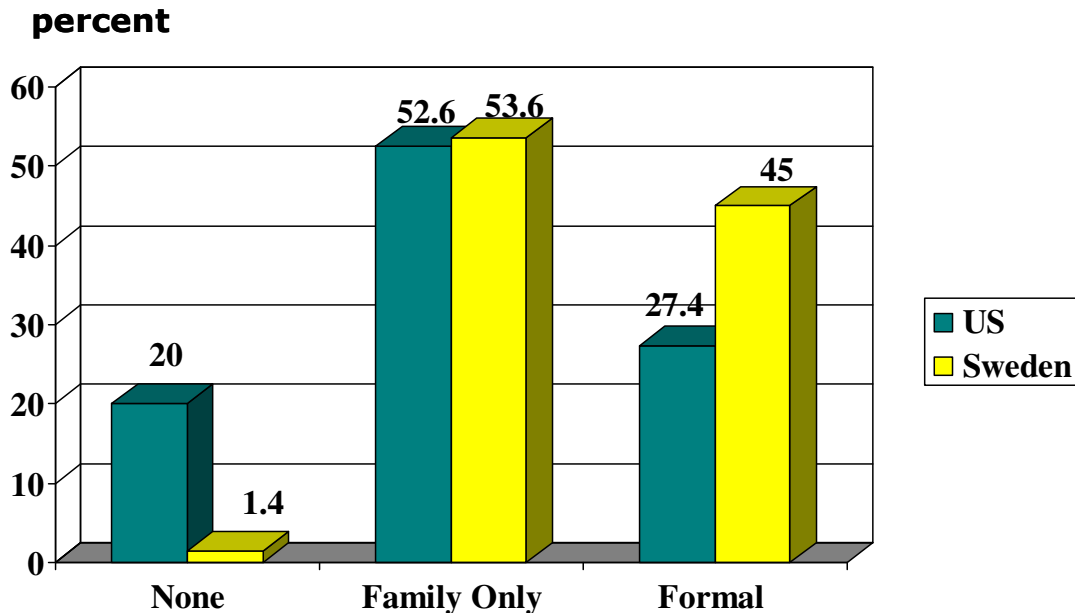
While caregiver receives considerable attention today, it has not always been that way. In one of the early papers on caregiving, published in 1978, Bernice Neugarten, in her inimitable way, pointed out that there was more interest in the topic at her beauty parlor than among her colleagues, for whom caregiving was not an interesting question. Much of the focus of social science research on families at that time was on the nuclear family. Some sociologists even considered the extended family a thing of the past, and it was expected that elderly would largely be left on their own. Certainly, much of the research in the 1960s and 1970s, such as the groundbreaking *Old People in Three Industrial Societies* (Shanas, 1968) focused to a considerable extent on whether older people were alone and lonely, not on the complexity and richness of family life.

Rather than withering away, however, the extended family persisted—in changed, but nonetheless vital forms. Families are involved not just in care of children, but in continuing, complex, sometimes difficult, sometimes rewarding relationships with older generations. And they are involved in their care.

Let me illustrate with findings from a cross national study that looks at family involvement with older people in the United States and Sweden (Shea, et al., 2003). The study used national samples of people aged 75 and older from each country. The US data were drawn from the Medicare Current Beneficiary Survey (1992 wave) and the Swedish data from the Aging at Home study (1994). Identical and nearly identical questions were asked in both surveys about performance of personal and instrumental activities of daily living (PADL, IADL). If the respondent needed help with any of the ADLs, they were asked about who provided that help. One of the reasons my colleagues and I conducted this comparison is that care is organized very differently in the Scandinavian countries than in the US. The Swedish system of old age care was established with the specific goals of relieving younger generations of burden, and to make it possible for women to participate fully in the workplace. We therefore expected that formal care would be higher in Sweden and family help would be greater in the US.

Figure 1 shows the sources of help for people who had disabilities in one or more PADL or IADL. Respondents were grouped into three categories: (1) receiving no help (despite having ADL disabilities); (2) receiving family help only; and (3) receiving formal help. Most people in the latter category also received some family help, with the proportion receiving family help the same in each country. Three important findings emerge in Figure 1. First, family involvement is high in both countries. Over half of respondents get help only from their family in each country. The family is very much involved in providing care, even in the Swedish welfare state. Second, as expected, people were more likely to use formal services in Sweden. And third, a finding we did not anticipate, more people in the US received no help from anyone, despite having ADL dependencies. They were not helped by family, by friends, or by the aging service system. This vulnerable group was comprised mainly of people who had no close relatives.

Figure 1. Sources of Assistance Provided in the US and Sweden



Source: Shea et al., 2003.

These data show the continuing involvement of the family—over half of elders get all their care from their family, *even* in a welfare state. AND in our system, those people without sufficient help do not have close family members to give them assistance and/or help them navigate our complex service system. The family remains, to use Christopher Lasch’s (1977) words, a haven in a heartless world.

The family today is different from what people meant in the past. Families come in all shapes and sizes, with great variability in size, structure and in the relationships among family members. From small families with a few people in each generation—called “beanpole” families by Burton and Bengtson (1985), to large extended families. The bigger the family, the more potential resources to help with caregiving. Factors such as divorce, remarriage, step relationships and other family forms, and the ways these arrangements are worked out also affect how and how much help is given.

Probably the biggest change in the potential for families to respond to caregiving needs is the revolution that brought women in large numbers into the workplace. With increased participation in work outside the home, women have less time available to assist aging relatives. This trend holds not only in Western societies, but increasingly in Eastern cultures with strong Confucian traditions, where daughters-in-law traditionally provided care. In Japan, for example, low marriage rates and daughters-in-law who are working

outside the home means that the most likely person to take on the caregiving role today is a spouse (Arai, 2000). This is a ground-breaking change.

In response to this new reality, Japan has created a universal program of long term care insurance that is designed to help with caregiving no longer done by daughters-in-law (Arai, 2001). This program pays both for community services that help maintain someone at home as well as institutional care. Perhaps this is an idea we could import from Japan along with Toyotas and Sonys.

One other contextual factor that has sometimes been overlooked in research is the relationship between caregiver and care receiver. This relationship shapes the commitment the person has to caregiving and even if it is likely to happen in the first place. The work done almost 20 years ago by Robyn Stone and her colleagues (Stone, Cafferata & Sangl, 1987) still is the most informative on who takes on the caregiving role. Looking at primary caregivers, those people with the main responsibility for the care of their relative, spouses form the largest group--48 percent of caregivers (30% wives; 18% husbands). Daughters and daughters-in-law make up the next largest group, 29 percent, followed by a small number of sons (6%). Finally, there is a heterogeneous group of "other" caregivers that make up 17 percent of the total. This group includes grandchildren, siblings, nieces and nephews, cousins and non-kin.

As the excellent work of Baila Miller (1990) and others have shown, husbands and wives differ considerably in how they approach caregiving. In turn, spouses probably differ from adult children in their commitment and involvement, including such policy relevant dimensions as nursing home placement. Finally, there is this relatively large, yet poorly understood "other" group. We know very little about this diverse collection of caregivers, their motivation, commitment or staying power, yet without their involvement the pressure on formal services would increase markedly.

We have been looking so far at how family structure shapes caregiving issues. Another important perspective is that caregiving in later life emerges in the context long-standing patterns of exchanges in the family. As work by Eggebeen (1992) and others has shown, parents continue to help their adult children throughout the adult years. They usually do not cut children off when they leave the home, but instead help with money and many different types of assistance from baby-sitting to emotional support, or even taking their grown children back into their home in times of need, such as following a divorce or loss of a job. This describes the normative pattern; there are many exceptions, where the flow of help and resources is mainly in the opposite direction. Parents sometimes can make excessive demands for contact, involvement, assistance, and even financial support. There are also families with weak or no relationships between generations, where one generation or the other has broken ties completely.

In later life, of course, the direction of support can change, so that children are providing more help. Even then, however, parents may continue to provide some help to their children, for example, giving financial support to a child who helps them with everyday tasks.

We know relatively little about how earlier patterns of exchange influence caregiving, either the willingness to take it on in the first place, or how the role is enacted. The theories that we have for why children help a parent--exchange theory (repaying a debt), solidarity theory (based on emotion), and contingency or altruism theories (based on need), are probably too simple and mechanistic to capture the complex psychological underpinnings of family relationships, or how helping patterns emerge.

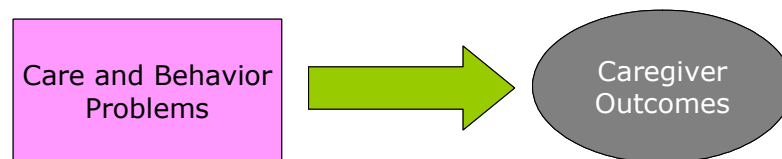
Beyond the specific amount of help given, the emotional climate of giving and receiving may be important. For example, giving in one family may always come with strings attached, while in another family, giving defines the recipient as needy or helpless. In an increasingly narcissistic age, at least some children probably learn to receive but not to give. Think about the wonderfully dysfunctional Bluth family of *Arrested Development*. We laugh because they are not that different from real families. How past exchanges and relationships play out in later life remains a fertile area for research.

Main Findings on the Stress Process of Caregiving

I will now turn to the main findings on the process by which the stresses of caregiving unfold and change over time. This information should be very familiar and so I will provide a brief, conceptual overview.

Early on when caregiving was first being studied and still today—many people believed in what might be called a simple model of the relation of stress and outcomes. This model, which is shown in Figure 2, assumes that there is a strong and direct association between the occurrence of particular stressors such as behavior problems and outcomes such as depression and poor health. Although there is a certain common sense appeal to this idea, it has not been supported by most research. In fact, probably the most central and enduring finding in caregiving research is that stressors have a surprising modest association with outcomes.

Figure 2. A Simple Model of Caregiving Stress



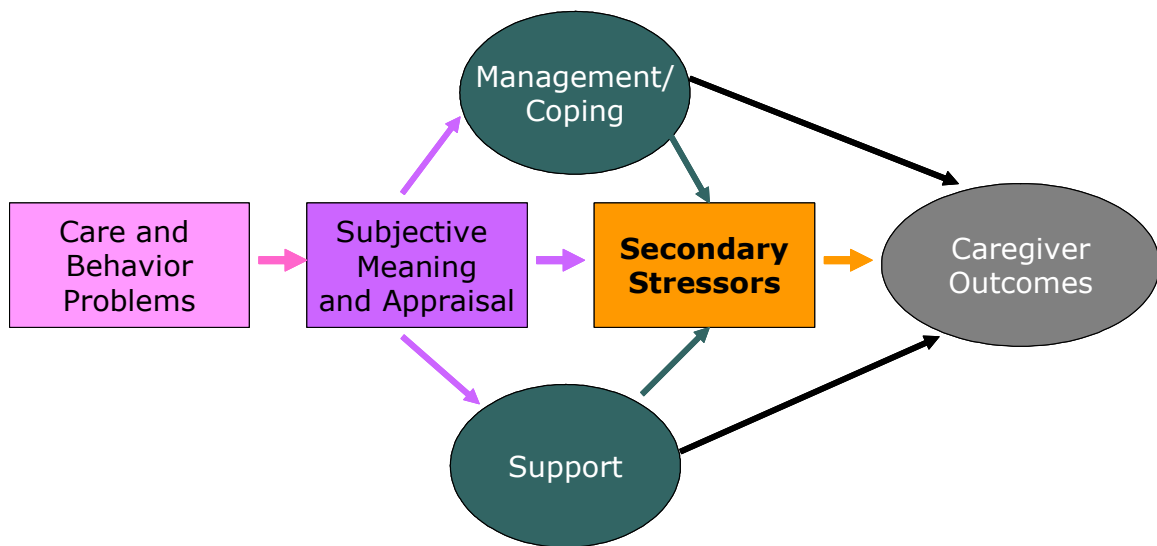
The possibility that caregivers could have very different kinds of adaptation to the same stressors is what got me interested in the field in the first place. In the late 1970s, I was running a small clinic that was part of the training and outreach activities of the Andrus Gerontology Center. Many of the clients were caregivers, in part because we were one of

the few places at the time who were interested in their problems. My students and I were struck by the fact that the caregivers we saw had quite varied reactions to stressors. Some people did very well, despite facing challenging circumstances. Others did poorly, even though their situations seemed quite manageable.

Intrigued by these observations, two of my students, Karen Reeve and Julie Bach, and I conducted a study, and found that stressors such as ADL deficits and behavior problems had only a weak association with subjective burden (Zarit, Reeve & Bach-Peterson, 1980). Instead, it appeared that the meanings that people gave to stressors and how much support they received mediated the impact on outcomes.

This finding has been replicated in many different studies, often to continuing surprise of researchers and clinicians who still believe that all they need to know is what stressors are present in the situation. The most elegant and most thorough examination of the stress process was a study headed Leonard Pearlin that I was fortunate to be part of (e.g., Anshensel, Pearlin, Mullan, Zarit, & Whitlatch, 1995; Pearlin, Mullen, Semple & Skaff, 1990). This study examined the effects of caregiving stressors both in a cross-sectional analysis and also over time using a large, representative sample. The findings from that study shows that stress is an unfolding process. As illustrated in Figure 3, the disease and disabilities create a context in which caregivers may experience distress, but the extent to which they do depends on other risk factors and resources in the situation.

Figure 3. The Stress Process of Caregiving



Adapted from Aneshensel et al., 1995.

Stressors have an immediate subjective impact, which Pearlin (Pearlin et al., 1990) calls primary subjective stressors and Lazarus and Folkman (1984) refer to as primary

appraisal. This subjective impact has to do with the meanings people give to events, the amount of perceived threat the events have, and how disruptive the events are in their lives. People look at the same stressor differently, which is why there can be such different outcomes. How people appraise stressful events in turn can lead to a spillover or proliferation into other areas of life. Caregiving activities may begin to have adverse effects on work, other family relationships, the family's economic well-being, or even the caregiver's sense of self. Pearlin refers to these processes as "secondary" stressors, not because they are less important in the stress process, but because they are not a primary component of the disease or disability that sets off this process in the first place. Even here, the presence of a role conflict is less important in affecting outcomes than the meaning a caregiver gives to these roles. As an example, some caregivers who are employed may find that the multiple demands of work and caregiving are more than they can manage, but others will report that they get a sense of accomplishment while at work that is missing when caring for a relative with dementia. Work for these caregivers provides a type of respite (Aneshensel et al., 1995). Primary and secondary stressors give rise to coping efforts to manage these events, including seeking support. The availability of coping and support resources serve to contain the impact of stressors on the caregiver's life and well-being.

Finally, it is the sum of this process, not just the occurrence of stressors that leads to critical outcomes: the impact on the health and well-being of caregivers or nursing home placement of the care receiver. I also want to note that different combinations of risks and resources can lead to the same outcome, a point that I will return to later.

Promising Strategies for Intervention Research

This brings us to the third topic I want to address, promising strategies for intervention. As research on the stress process has shown, adverse outcomes are not a fixed or intrinsic component of care-related stressors. Rather, outcomes such as depressive symptoms or poor health are the result of the dynamic interplay of risk factors and resources. It follows, then, that intervention strategies that strengthen resources and reduce risks might improve outcomes for caregivers. This assumption has guided the approach that my research group has taken, and that other groups have followed as well.

The first intervention study that my colleagues and I conducted (Whitlatch, Zarit & von Eye, 1991) grew out of a synergistic interplay of research and clinical work. We were, in many ways, working in an ideal situation in which research could inform practice and practice could inform research. Our work focused on people with dementia and their caregivers. We based the development of intervention strategies on findings about variability of outcomes--and why some caregivers did better or worse than others.

Three key points were identified where we thought interventions would be helpful. The first was appraisals. Some caregivers misunderstand or misinterpret common situations that arise in dementia, such as when the patient asks the same question over and over again. They may, for example, believe that the patient does this to annoy them, or because he is not paying attention, or that he is not trying to remember. We thought that

providing information about why patients behave this way would help them re-frame the situation. Instead of trying to reason or argue with patients who have impaired cognitive abilities to process information, caregivers would gain an understanding of how these problems emerged from the damage caused by their relative's brain illness. This understanding would allow them to ignore or distract the person with dementia or to use other appropriate strategies, rather than to get upset.

Second, our observations suggested that many caregivers did not know how to deal with more severe and stressful problems that typically occur with dementia, for example, agitated behavior, wandering, not sleeping at night. These are problems that caregivers report are the most upsetting to them. Here we taught caregivers to use a version of applied behavior management called problem solving. Problem solving involves a systematic examination of a behavior problem. Possible antecedents and consequences are identified, and then interventions developed to change these contingencies. Problem solving differs from the usual approach to management of behavior problems, which matches solutions to problem in a formulistic way (e.g., if a patient is behaving in an agitated way, lower the amount of stimulation in the environment). Although the ultimate solution might be the same, in problem solving it emerges from an understanding of the specific context in which the behavior occurs. In that way, unique features of the situation or the person that might be contributing to the problem can be identified and targeted in the intervention (Zarit, Orr & Zarit, 1985; Zarit & Zarit, 2006).

Third, we looked at social support. One day in our offices, Karen Reeve and my wife, Judy Zarit, were discussing the finding from our earlier study of caregiver burden that people who received more family support has lower subjective burden. They speculated that if family support was a good thing, perhaps it was possible to intervene directly with the family to increase the amount of assistance and emotional support that the caregiver received. To build support, they proposed holding a family meeting to which all involved relatives and friends would be invited. They tried it out, and found that it was a powerful and effective strategy. Not only did family meetings seem capable of building support, but also of diffusing conflict and misunderstandings over diagnosis, treatment and other issues.

As we gained experience with these interventions, we put them together into a treatment protocol and were able to obtain funding from NIMH for a trial. Caregivers of people with dementia were assigned to one of three conditions, (1) Individual and Family Counseling (IFC), which combined the three treatments described above; (2) Support Groups (SG), which were designed to reduce distress through group interactions; and (3) a Wait List (WL) control group. The results showed that people receiving IFC had better outcomes for subjective burden and emotional distress than the other two conditions (Whitlatch et al., 1991).

Similar approaches have been found to be effective by Mittelman and her group (Mittelman et al., 1995; 1996; 2004) and by Marriott & her colleagues (Marriott, Donaldson, Tarrier, & Burns, 2000) in the United Kingdom. Mittelman's group, in particular, expanded and refined the intervention and probably has gotten the best results

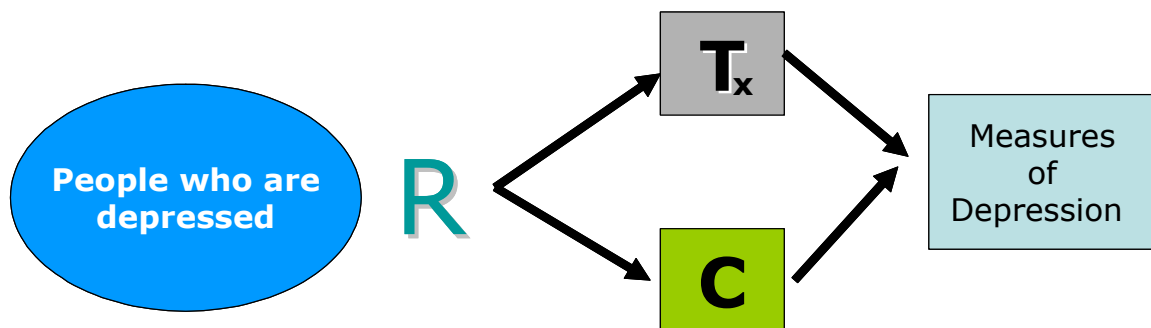
of any intervention with family caregivers. They have reported that caregivers in the treatment condition, which included individual counseling, several family meetings and a maintenance support group, had reductions in depression and subjective burden compared to controls. The treatment group also kept their relative at home for a longer period. In a recent analysis, Mittelman and colleagues (2004) showed that benefits of the treatment were sustained 3 years after baseline. Given the chronic stress caregivers experience and the downward course of their relative's illness, this is a remarkable finding.

Many interventions, however, have not had positive outcomes, or only very modest success. I want to focus the rest of my comments on some possible reasons why trials may not have been successful. One possibility, of course, is that there may be little leverage for change. Caregivers may be too embedded in the relationship to make changes, or their reactions may be too much a part of their personality to be modified in a substantial way. Or the stressors may just be too demanding or too painful for all but a small handful of caregivers to manage?

An alternative interpretation is that caregiver interventions in an optimal way. A review of the literature suggests several problems in design and measurement may have contributed to modest or nil findings.

Turning first to design, randomized trials are considered the "gold standard" for evaluating the efficacy of a treatment, but they have been applied to caregiver interventions without considering if modifications might be needed to address unique characteristics of the population or the questions being posed. At the risk of committing heresy, I would like to suggest that issues of internal and external validity that make a particular design optimal depend on the specific research context, and that what is a gold standard for one problem might be a cross of gold for another. Let me explain

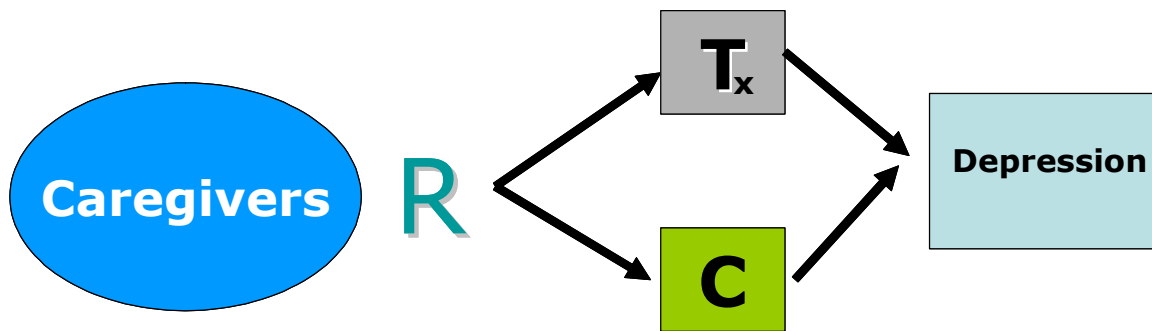
Figure 4a. Randomized Trial for Treatment of Depression



Consider first the design shown in Figure 4a. This is a typical design for a randomized trial for treatment of people suffering from depression. People who meet certain

eligibility criteria, such as a diagnosis of major depressive disorder are randomly assigned to one or more treatment and one or more control conditions. Improvement is assessed in terms of reductions in depressive symptoms.

Figure 4b. Randomized Trial for Treatment of Caregivers



But now consider the design shown in Figure 4b. This is the design that has most often been used in caregiver treatment studies. In this situation, people are enrolled into the study because they are caregivers. They are then treated for a problem (usually for subjective burden or some aspect of well-being), but without consideration of whether they have that problem in the first place. Let's focus on depression, which is the most widely used outcome in caregiver interventions. Most studies of the rate of depression among caregivers show that between 20 percent and 50 percent have clinically significant symptoms. That is a high prevalence of depressive symptoms, but it also means that between 50 and 80 percent do not have the problem that the treatment addresses. Since people in the sample who are not depressed cannot show improvement, the result is a loss of statistical power to detect change. It is also possible that treating people for a problem they do not have may actually worsen their outcomes.

This problem can be addressed in different ways. If the focus of an intervention is treatment of depressive symptoms, one straightforward approach would be to enroll caregivers who are depressed into the study. In other words, eligibility for the study would be that a person is a caregiver *and* meets a minimal threshold for depressive symptoms. If the focus is on an outcome other than depression, a similar strategy could be used to select caregivers who have that problem in the first place. An alternative approach would be to reconceptualize the study as prevention research, and to enroll caregivers who are not depressed. In that situation, the goal of treatment would be to prevent caregivers from becoming depressed. In either case, the study would need to have an adequate sample size to detect treatment effects. These approaches stand in contrast to how much researchers have handled the issue, which has been to include participants in the study because they are caregivers, but who may be quite heterogeneous with respect to the outcomes targeted by the intervention.

A related problem has to do with the risks and protective factors or resources targeted by the intervention. Caregiver treatment studies have tended to use interventions that target

one or two risk factors, for example, how caregivers appraise problem behaviors or lack of social support. Just as it is inappropriate to treat people for a problem such as depression which many in the sample may not have, it is also not a useful strategy to target people as having a particular risk factor *unless they actually have it*. Consider behavior problems, which are experienced very frequently by people with dementia and are often stressful for their caregivers. Yet some people with dementia experience few or no disruptive behaviors, and not all caregivers are bothered by these behaviors or have difficulty managing them. If people are included in a study that targets behavior problems solely on the basis of their incumbency in the caregiving role, the result is that some of them will not be able to benefit from the treatment being offered, with a corresponding loss of statistical power to detect treatment effects.

This problem could be viewed in another way. Interventions for caregivers have generally failed to take into account the extent of individual differences that are found at every step in the stress process. Caregivers vary in their exposure to stressors, in their subjective responses to those stressors, in the resources they have for managing or containing stressors, and in the outcomes they experience. The “one size fits all” approach does not generally work for clothing, and it does not work for caregiver interventions.

It should not be surprising, then, that the outcomes reported by the more flexible interventions (interventions like those done by Mittelman’s group) have generally been positive. In contrast to “one size fits all,” these approaches tailor the components of treatment and the dosage of those components to the needs of the individual caregiver.

A new type of treatment design called “adaptive intervention,” has been developed to deal with situations that are similar to caregiving where when there are multiple risks that can lead to the same outcome (Collins, Murphy, & Bierman, (in press). In an adaptive intervention, participants are assessed for the specific risk and protective factors that contribute to the targeted outcome (e.g., relief of depressive symptoms). They then receive treatment modules that address their specific risks. Adaptive treatment, in effect, captures the art of good clinical practice, where interventions are modified to fit the person and his/her needs. Despite the fact that each person would receive a somewhat different mix of treatment components and dosage, it is possible to test the efficacy of an adaptive trial with the same scientific rigor as any other intervention. This is a promising strategy –one that my colleagues and I have begun testing with caregivers.

Other problems in caregiver interventions have been due to the measurement strategies that have been used. In some studies, the dependent or outcome measures have not had an obvious or direct relationship to what was being done in the treatment. Consider, for example, support groups. Despite their enduring popularity, relatively few studies have found that support groups have positive benefits. One possible reason for these results is that there has been a disconnect between the things that support groups do well, such as sharing information and providing a special kind of support that comes from people who are experiencing the same problem, and the outcomes that have been typically used, such as depression or burden. Giving information to caregivers is undoubtedly helpful, but it

is not a treatment for depression. To cite another example, care management can improve access to services, but it does not directly address depressive symptoms or well-being. There are many other factors likely to affect a caregiver's well-being.

These examples raise three issues. First, when planning an outcome study, the starting point is to ask how does this treatment work, that is, what therapeutic processes will be introduced to effect change. Second, we would then ask what specific outcomes would be likely to improve if caregivers are exposed to this treatment. Giving information, for example, is not likely to be an effective treatment for depression, but it may help with other types of problems, such as helping caregivers feel less trapped in their role, or helping them become more active decision-makers for the choices facing them. Third, the evaluation would follow this same logic. We would want to determine that caregivers actually received information and support. If they are not exposed to the therapeutic processes that are supposed to take place in a support group or any other intervention, then it is unrealistic to expect that they will experience positive changes on the outcome variables. If, however, the treatment has its intended effects, we could then reasonably test if those processes had an effect on specific outcomes.

This type of analysis of what might be called proximal and distal treatment processes can also lead to a different conclusion, that the proximal targets of the intervention may be of value by themselves, regardless of whether they affect any other outcomes. It may be a good thing for a caregiver to have more information, whether or not giving information has an effect on public health indicators, such as depression or health.

Beyond issues of measurement, a major point that has not generally been considered is whose goals are being addressed—the caregiver's or the researcher's. In some instances, goals for treatment studies have been formulated in part by policy researchers whose primary concerns are about lowering costs, particularly to Medicaid or other funding programs. The possibility that the caregiver might not share that goal, or that the intervention might not meet the caregiver's needs has not been considered. Another frequent goal has been delay of placement. It is assumed in these studies that caregivers who receive certain kinds of assistance will *want to* delay placement, but the caregivers have never actually been engaged in a discussion of their own preferences and goals. It should be no surprise that it has been very difficult to demonstrate a reduction of placement.

The manualized treatments that have been used in caregiver studies in recent years have assumed that the risks they have targeted and the outcomes they measure are what caregivers want. These interventions have generally not included opportunities to discuss goals with caregivers, to develop a shared agenda, or to vary the treatment if caregivers have different goals. A mismatch between the caregiver's and the researcher's goals is likely to lead to a poor outcome.

One final point is the magnitude or dosage of the intervention. While dosage has long been a central issue in drug trials, the amount of exposure to behavioral and social interventions has rarely received systematic consideration. In the caregiving literature,

we can find examples of studies that expected to produce far-reaching changes while providing fairly minimal exposure to treatment. Some studies, for example, have shown that caregivers receive very little benefit from adult day care and other respite programs, but the amount of service use in these programs has sometimes been quite low. Just as a medication would not be expected to have its intended effects at a minimal dosage, so would respite or other social programs.

After reviewing these unsuccessful respite studies, my colleagues Mary Ann Stephens, Aloen Townsend, Rick Greene and I decided that to test if adult day care might be effective in relieving care-related strain if caregivers received sufficient exposure to the program. Following consultation with day care providers, we decided that a minimum exposure of two days a week for three months or more was needed to achieve therapeutic results. In designing our evaluation, we were also cognizant of the fact that adult day care could not be expected to fix every problem caregivers were facing. Using the stress process model to guide us, we felt that the most immediate impact of day care would be on subjective appraisals, specifically, the caregiver's ratings of the impact that daily routines and care were having on his/her life. We also measured the possible impact on caregivers' well-being, although we did not expect to find an effect, because well-being is determined by many different factors besides the amount and type of care. The results confirmed our hypothesis that appraisals would be affected by day care use (Zarit, Stephens, Townsend, & Greene, 1998). Caregivers whose relative used adult day care regularly for 3 months or more had lower feelings of overload and strain, compared to the controls who had not used day care. To our surprise, however, we also found that caregivers in the day care group had lower depressive symptoms and feelings of anger compared to the controls. In this instance, a powerful intervention had both an immediate impact, as well as a generalized effect on other domains.

Conclusions

There is much work that still needs to be done on family caregiving. Important questions need to be addressed about family structure and relationships, and about how the stress process unfolds in different contexts and setting. We especially need more and better tests of novel treatments that are designed to make the everyday experience of caregiving families a bit more manageable. I hope that as a field, we approach these tasks with respect for the enormous effort that families make, the sacrifices they are willing to make, the courage they have, and their ability to overcome bad advice from friends, family, physicians and other service providers. These families show us everyday how the ties of affection and obligation transcend memory loss and disability. Working with families, we can find the best ways to support their primary goal--helping the disabled elder to preserve dignity and meaning for as long as possible.

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