# Innovative Interventions
## to Reduce
## Dementia Caregiver Distress

### A Clinical Guide

**David W. Coon**
**Dolores Gallagher-Thompson**
**Larry W. Thompson**

**Editors**

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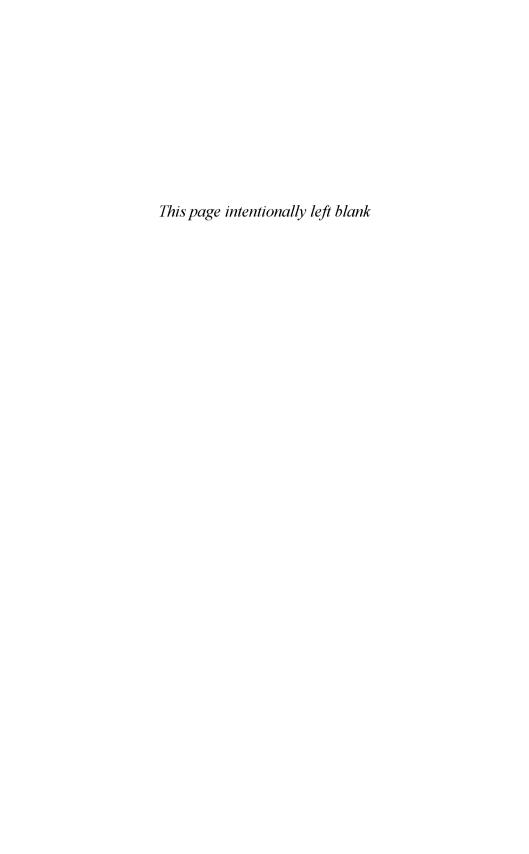John XXIII Multi-Service Center
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# Preface

Evidence is continuing to accumulate that family caregivers who experience increased stress and strain due to their participation in care activities are more likely to have higher morbidity and mortality than caregivers who report little or no difficulty (e.g., Schulz & Beach, 1999). It also is becoming increasingly clear that a pivotal factor in making the decision to place a relative in an institutional setting is the caregiver's appraisal of his or her incapability to continue to provide high-quality care for a loved one in the family setting. As concerned caregivers continue periodically to wrestle with the dilemma of placement, they invariably must consider the delicate balance between their capabilities versus the ever-changing requirements for maintaining high-quality care. The decision to place comes when the balance between these two is eroded. It is clearly understood by researchers, practitioners, and policy makers alike that at the point in caregiving when this occurs, there is a monumental economic impact on both family and societal resources. Perhaps the two most important factors in this equation are perceived decline in their own health status along with increasingly demanding and complex health care and behavioral management requirements with regard to their care-receiver. Because stress and strain are proving to be important determinants of health status, efforts to alleviate these not only may improve quality of life in the family unit, but also may be extremely cost-effective in terms of economic resources by delaying or permanently avoiding institutionalization.

Against this backdrop, it is reasonable to consider any and all assistance programs that might serve this end. However, without careful scrutiny the end-point of such reasoning could be wasteful "shotgun" intervention programs. It behooves interested professionals to expand their notions of what might be considered potential interventions and begin to implement evaluations of their efficacy and effectiveness in alleviating caregiver stress. Furthermore, as one considers the magnitude of factors that potentially aggravate the tasks of caregiving, one could ask if intervention programs at multiple levels (from the individual to the family system and even to the larger community) may operate symbiotically to enhance quality of life for caregivers or antagonistically to increase the burden and stresses confronting them. At the present time we have limited empirical data to address such questions, and even fewer models that

have been developed to guide us in our efforts to evaluate the interaction of multilevel, multifaceted intervention programs.

As our thinking along these lines took shape, we learned that the editorial staff at Springer Publishing Company also perceived a need to publish a volume on intervention programs for dementia caregivers. We were encouraged by Springer to address these issues in an edited book that would include contributions from prominent researchers, practitioners, and policy makers who are focusing on the challenges of developing cost-effective interventions with a variety of different caregiving populations.

The three chapters in part 1 outline emerging themes and pose challenges that require continued theoretical exploration and development. In contrast, in part 2 we have included seven chapters that present a broad array of practical intervention strategies developed by individuals from different professional disciplines (including, for example, medicine, social work, occupational therapy, nursing, psychology, and geropsychiatry). Several novel approaches are presented, such as the use of technological advances to help distressed caregivers and the value of partnering with primary care physicians to improve quality of life for both patient and caregiver.

Part 3 presents innovative interventions with specific populations that have received relatively little attention in the caregiving literature to date. These are racial and ethnic minority caregivers, male caregivers, and caregivers who self-identify as lesbian, gay, bisexual, or transgender. Finally, we conclude by recommending several directions for future research.

In this volume, we have sought to provide an overview of the current state of the art with respect to dementia caregiving intervention research. We have also included theoretical developments that we hope will be beneficial to all professionals interested in working with caregivers, whether they be researchers, clinicians, or policy makers. We anticipate that casual readers will find this information useful as well as they pursue their professional careers; perhaps they will even be encouraged to join us in addressing the future challenges of developing and refining multilevel, multifaceted interventions.

We are grateful to the authors for the breadth and depth of their contributions, and for their remarkable cooperation in the editing process. We would like to thank especially Helvi Gold, our section editor, for her patience and encouragement in the development of this book. Without her support and the support of others in Springer Publishing Company, the final completion of this work would never have been realized.

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LARRY W. THOMPSON,
DOLORES GALLAGHER-THOMPSON,
AND DAVID W. COON

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## REFERENCE

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# Background Issues

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# 1

# Family Caregivers: Enduring and Emergent Themes

*David W. Coon, Marcia G. Ory, and Richard Schulz*

The dramatic aging of the American population has focused attention on chronic illnesses and their societal impact (Administration on Aging, 2000a; Federal Interagency Forum, 2000; Robert Wood Johnson Foundation, 2001). The realities of chronic illness not only impact the older persons themselves, but also drive the need for informal care from families and friends. However, this growing need is emerging just as societal shifts such as smaller family sizes, rising divorce rates, and growing numbers of dual income families are attenuating the number of informal caregivers readily available to assist current and future cohorts of impaired older adults (National Health Council, 2001; Schulz, O'Brien, Bookwala, & Fleissner, 1995). Yet caregiving currently remains very much a "family affair," with the majority of informal care being shouldered by family and friends. A recent national telephone survey found that nearly one in four U.S. households included at least one caregiver who provided unpaid care to help someone at least 50 years of age take care of himself or herself. Overall, these findings translate into approximately 22 million caregiving households nationwide (National Alliance for Caregiving and the American Association of Retired Persons [NAC/AARP, 1997]). Caregiving tasks and burdens are often numerous and varied and frequently change across the course of an illness. They can range from the simple running of errands and provision of emotional support to assisting with bathing, feeding, or other activities of daily living and the management of disruptive behaviors. Family and friends typically have to juggle their lives to encompass these care responsibilities and their related

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stressors while at the same time trying to fulfill other substantive familial and social roles (e.g., spouse, parent, and friend, employee, volunteer, and community member). These caregiving responsibilities and the need to balance roles often come with a price—a substantial amount of caregiver stress and distress. As a result, many family caregivers become our "hidden patients" struggling with their own mental and physical health concerns (Administration on Aging, 2000b; Bookwala, Yee, & Schulz, 2000; Coon, Schulz, & Ory, 1999; Fengler & Goodrich, 1979; Schulz & Quittner, 1998).

Caring for a family member or friend with Alzheimer's disease or a related progressive dementia appears to come with a special set of challenges. Numerous studies illustrate the deleterious personal, health, and social impacts of dementia care including its astounding economic costs (e.g., Harrow et al., 2002; Leon, Cheng, & Neumann, 1998; Ory, Hoffman, Lee, Tennstedt, & Schulz, 1999; Schulz et al., 1995). Today's caregivers of people with dementia provide care for longer than ever before and more frequently experience greater emotional distress, higher use of psychotropic medications, poorer self-reported physical health, and compromised immune function than their noncaregiving counterparts (e.g., Schulz et al., 1995; Zarit, Johansson, & Jarrott, 1998). Moreover, caregivers of persons with dementia in comparison to caregivers of nondementia persons spend more time providing care, report more physical and mental health problems and caregiver strain, and describe additional employment complications, greater family conflict, and more family and leisure time constraints (Ory et al., 1999). These points not only illustrate the importance of acknowledging the needs of both these types of caregivers relative to noncaregivers, but also stress that service providers, program developers, researchers, and policy makers learn to identify the best ways to assist caregivers in each group, because the two groups may differ with regard to their stressors, perceived stress, and need for informal and formal support to help maintain their physical and mental health (Coon et al., 1999; Ory et al., 1999).

This chapter extends our own prior work by presenting a key set of ongoing and emergent themes in family caregiving of persons with dementia that we find particularly relevant for the development of interventions designed to address the needs of these caregivers (e.g., Coon & Thompson, 2002; Ory et al., 1999; Schulz, 2000; Schulz et al., in press). Many of these themes are pertinent to other types of caregivers and may be extended or modified in consideration of their particular needs and situations. In addition, a number of our themes are interwoven among the remaining chapters of this book, exemplifying the significant strides made in recent years in interventions designed to address the needs of diverse groups of family caregivers of persons with dementia.

## BUILDING AND TRANSPORTING FRAMEWORKS
## FOR CAREGIVER INTERVENTIONS

Although the stressors and strains associated with dementia care are well documented, the majority of interventions described in caregiver intervention research are still not explicitly theory-based or theory-driven. This practice often generates intervention methods, designs, and measurement strategies that are disconnected from one another and leads to results that are in conflict with one another (Bourgeois, Schulz, & Burgio, 1996). Even for those interventions that are unequivocally theory-driven, descriptions of their theoretical frameworks and their relationship to intervention components is frequently lacking, leaving service providers and policy makers without frameworks that help translate significant findings into viable programs and services at local levels. Effective frameworks and their relevant intervention protocols that are easily transportable into service settings are needed for the overall caregiving process as well as for caregiving interventions themselves. Involving service providers, program administrators, and policy makers in the development or refinement of models can help maximize their utility in the service or practice arena. This is a critical step for translating research-based programs into intervention strategies, programs, and services that can reach large numbers of people in real-world settings. The chapters in this book describe a variety of steps taken to develop theory-based innovative interventions that are transferable to numerous organizations and community settings that serve today's family caregivers.

## Expanding Models to Capture the Dynamics of Caregiving

Most current caregiving research is built on stress and coping or stress-process models (e.g., Haley, Levine, Brown, & Bartolucci, 1987; Lazarus & Folkman, 1984; Pearlin, Mullan, Semple, & Skaff, 1990); however, ongoing investigations into dementia caregiving continue to uncover its multidimensional nature. These complexities of dementia caregiving suggest that new models or modifications to existing models are needed to help us better understand the dynamic relationships among caregiver, care recipient, and social and physical environmental variables, as well as the critical linkages between these relationships and caregiver outcomes. It is particularly important that clinical researchers, service providers, and policy makers have useful frameworks to conceptualize effectively the caregiving needs of tomorrow's diverse caregiving families. We need to understand how caregiving processes and outcomes are influenced by the growing numbers of caregivers from blended and other nontraditional families, long-distance family caregivers,

and families with divergent cultural views of the definitions and meanings of dementia, caregiver stress, and family caregiving itself. Different causes of stress and distress among distinct populations of caregivers may require new models or building flexibility into current models to incorporate some uniquely tailored prevention or treatment components. However, both approaches will require increasing our understanding of caregiving dynamics, especially with regard to the unique patterns of care among caregivers from different populations, such as different ethnic and racial minority caregivers, gay and lesbian caregivers who are navigating discriminatory care arenas, and rural families providing care in service-poor regions (Coon et al., 1999; Fredriksen-Goldsen & Scharlach, 2001; Gallagher-Thompson, Solano, Coon, & Árean, in press; Gallagher-Thompson, Haley, et al., 2002).

Models of caregiver service utilization as part of the caregiving process are also warranted, including those that help identify and overcome barriers to service utilization such as lack of awareness, lack of recognition that services are needed, time and cost constraints, and language or cultural barriers, as well as concerns about discrimination by groups of minority caregivers. Such models are particularly timely given the recent allocation of family caregiving monies to state area agencies on aging through the National Family Caregiver Support Program (Administration on Aging, 2000b). The development and investigation of service utilization models in turn could be expanded with explorations of social marketing principles (e.g., Nichols, Malone, Tarlowe, & Loewenstein, 2000) or other strategies that help service providers, program developers and policy makers to design and disseminate more effectively available intervention programs and services to caregiving families.

In response to these issues, new models are emerging in the caregiving literature that attempt to address the dynamics of caregiving and service utilization. For example, Montgomery and Kosloski's marker framework looks at the developmental phases of caregiving process as determined by the needs of different types of caregivers (Montgomery & Kosloski, 1999), and rests on two premises: (a) there is no single, generic caregiver role, but rather caregiving emerges from prior role relationships and is integrated with other roles; and (b) caregiving is a dynamic process that unfolds over time with variable durations for different caregivers. The process encompasses seven key "markers" or important points in the caregiving trajectory that mark significant shifts in the caregiving process (e.g., defining oneself as a caregiver, seeking assistance and formal service use, and placement). Moreover, distinct groups of caregivers (e.g., spouses versus adult children) are assumed to experience markers differently and at different intervals, leading to alternate caregiving trajectories that require unique types of services. Similarly, Caron's model (Caron, Pattee, & Otteson, 2000) emphasizes phases of caregiving, rather than stage of disease, whereby caregiving is defined in terms of tasks and challenges faced by families along a continuum of caregiving,

which ranges from prediagnosis, diagnosis, role change, and chronic caregiving to the transition to alternative care and end-of-life issues. The use of the framework by the Chronic Care Network for Alzheimer's Disease project (a national demonstration project described in chapter 8; and Maslow & Selstad, 2001) led to the development of a grid that lists objectives for each caregiving phase and specific local information, programs, and services available to reach those objectives. However, whatever the models and theories used to guide our understanding of the caregiver process including caregiver service utilization, it will be very important to consider how effectively these frameworks characterize the needs of diverse caregivers at different points along their caregiving careers.

## Differentiating and Characterizing Intervention Models

In addition to the theories of caregiving process, service providers and clinical researchers alike would benefit from more explicit descriptions of the theories and models that guide the development and implementation of successful caregiver interventions. For example, is the intervention framed within an environmental-press theory that emphasizes alterations or modifications of the living environment? Or is it driven by psychologically oriented theories of behavior change from cognitive or behavioral traditions that focus on reducing caregiver emotional distress or care recipient problem behaviors? or is it derived from a family systems tradition that extends beyond the caregiver-care recipient dyad? In addition, descriptions of theory-based interventions and their outcome data need to identify more clearly the underlying pathways through which positive change is proposed to occur. Such information will help lead to a greater understanding of which caregiver interventions work for whom. The diverse sociocultural histories and other individual differences of caregivers including the particular points when interventions are accessed suggest that a combination of theoretical frameworks may be necessary to explain how positive change unfolds (Coon et al., 1999; Gitlan et al., 2000).

Recent discussions of stepped care models in the psychological literature (e.g., Davison, 2000; Haaga, 2000) are pertinent to the exploration of individual difference variables as well as to the tailoring of interventions to meet the unique needs of divergent groups of caregivers. If applied to family caregivers, stepped care models would be built on the assumption that not all caregivers would need the same type and intensity of intervention. Moreover, interventionists would want to begin with the most minimally intensive and intrusive intervention that a given group of caregivers (e.g., wives or daughters) would most likely respond to favorably. In stepped care models, treatment monitoring provides an essential guide to intervention continuation or alteration and ultimately serves as a tool to minimize costs. Interventionists only begin to implement more intensive, and

potentially more intrusive, interventions when the less intensive interventions have failed or when those interventions are not in the best interest of the caregiver. For example, ongoing failure to respond to a lower level of care could ultimately discourage future help-seeking by the caregiver or undermine positive treatment response to other levels or types of interventions. Ideally, screens or initial assessments ultimately would be developed to match caregivers with appropriate intervention type and intensity based on empirically supported linkages among initial and ongoing assessments, treatment steps, and outcomes. Still, even with such tools, clinical judgment will often be required to implement these general principles with specific cases of caregivers (Davison, 2000; Haaga, 2000).

Finally, Schulz and his colleagues recently developed a conceptual model with utility for both providers and researchers that helps characterize caregiver interventions, their content, process, and goals. The framework uses the following intervention components in its classification scheme:

1. *the primary entity targeted* (e.g., the caregiver, the care recipient, or the social or physical environment)
2. *the primary domain targeted* (such as one's knowledge, behavior, or affect)
3. the *intensity* of the intervention, including the amount and frequency of interventionist contact with the intervention participant
4. *personalization*, or the extent to which the intervention is tailored to the individual needs of the participant (Czaja, Schulz, Lee, & Belle, 2001; Schulz, Gallagher-Thompson, Haley, & Czaja, 2000).

This taxonomy can be used as a tool where interventions can be classified and identified as fitting the parameters needed by the caregivers served within particular programs or by identifying areas where additional caregiver intervention research is needed. Thus, it may prove useful in the development, description, and translation of models and their interventions into service arenas.

## IN PURSUIT OF INTERVENTION OUTCOMES

Caregiving intervention studies to date have included (with varying degrees of success) a myriad of outcomes ranging from caregiver mental health and distress to care-recipient behavior problems and institutionalization. The appropriate identification of outcomes rests in the clear identification of both the proximal and distal outcomes of the intervention (Kennet, Burgio, & Schulz, 2000). The taxonomy described in the previous section can help researchers and program evaluators link relevant primary and secondary outcomes to the parameters of their particular interventions. Too often, interventions fail to assess their proximal goals, focusing

instead on the big-ticket distal outcomes like service utilization, time to institution-alization, or reduction of depression. However, proximal outcomes are essential in helping us understand how interventions work. For example, an intervention designed to reduce caregiver depression by increasing their engagement in pleas-ant activities needs to measure both the distal outcome of depression as well as the proximal outcome of caregiver pleasant activities. Without a measure of pleasant activities, we muddy our understanding of how or why the intervention does or doesn't work. This also raises the issue of targeting interventions to appropriate groups of caregivers. Caregivers who are not reporting depressive symptoms and a constriction of pleasant activities, but rather are struggling with anger as a result of care-recipient problem behaviors, are unlikely to benefit from this intervention or be able to report even fewer depressive symptoms.

Intervention researchers also need to consider incorporating outcome measures that can easily be adopted by service providers and program staff in the transfer of interventions to the community for ongoing monitoring and evaluation. How-ever, a tension exists between the various stakeholders interested in caregiver interventions. Policy makers and other researchers often want to see outcome measures commonly used with other populations to facilitate comparisons be-tween caregivers and noncaregivers. Yet those outcomes do not always reflect the desired outcomes of intervention participants themselves or their service providers, which suggests the need for explorations beyond traditional outcome measures. This exploration may prove particularly important for nonmajority caregivers. Gottlieb and his colleagues in chapter 2 expand upon this debate and raise important issues regarding the development and application of measures to assess the extent to which interventions are implemented as intended, because problems with implementation erode confidence in both the intervention and its outcomes.

## Extending Outcomes

Most outcomes in caregiver intervention research have focused on the mental health or psychosocial consequences of caregiving. However, caregiving can also negatively affect caregivers' physical health and health behaviors (Schulz et al., 1995). For example, recent data from the Caregiver Health Effects Study showed that older adults caring for a disabled spouse who experienced strain as a result of their caregiving role were 63% more likely to die within 4 years than noncare-givers (Schulz & Beach, 1999). Similarly, caregivers also appear less likely than their noncaregiving counterparts to practice preventive health behaviors that are important in chronic disease prevention and control (Burton, Newsom, Schulz, Hirsch, & German, 1997; King & Brassington, 1997; Scharlach, Midanik, Run-kle, & Soghikian, 1997). These findings underscore that health care and other

service providers might need to see caregiver/care-recipient dyads as a unit to assess both the care recipient's and the caregiver's risk for negative physical health outcomes (Schulz & Beach, 1999). The American Medical Association's recent addition to its Web site of a Caregiver Health Assessment section—including a caregiver self-assessment tool, resources for caregivers, and a dementia guide—serves as another indicator of growing interest in caregiver physical-health outcomes. These recent research findings also underscore the importance of developing and testing interventions that help caregivers maintain as many healthy lifestyle behaviors as possible while facing the arduous demands of family caregiving. As an initial step, the first systematic investigation of a physical-activity intervention tailored to caregivers of persons with dementia demonstrated that female caregivers could indeed benefit from a regular moderate-intensity exercise program in terms of reductions in stress-induced cardiovascular reactivity and improvements in sleep quality (King, Baumann, O'Sullivan, Wilcox, & Castro, 2002).

Although the vast majority of research delineates negative effects of caregiving, an expanding literature suggests that caregiver stress and burden may be counterbalanced in part by the positive aspects of caregiving, or caregiver gain, including such aspects as the opportunity to serve as a role model for others or give back to the care recipient, prevention of further care-recipient deterioration, increased self-esteem, an enhanced sense of meaning or purpose, and feeling appreciated or other feelings of pleasure (e.g., Farran, Keane-Hagerty, Salloway, Kupferer, & Wilken, 1991; Kramer, 1997a; Lawton, Rajagopal, Brody, & Kleban, 1992; Miller & Lawton, 1997; NAC/AARP, 1997). This relatively new caregiver literature provides increasing support for the "gains" perspective as a particularly meaningful arena for research and intervention development, especially given several studies suggesting that individual difference variables such as race, ethnicity, gender or education may be related to perceived rewards from caregiving (e.g., Kramer, 1997b; Lawton et al., 1992; Picot, Debanne, Namazi, & Wykle, 1997). These positive aspects may affect the quality of care as well, having beneficial effects for both caregivers and care recipients.

Quality of care as an intervention outcome has received relatively little attention in the caregiving literature (Schulz & Williamson, 1997) but is deserving of future consideration. For example, some research suggests that certain caregivers may be at particular risk for abuse, including caregivers who experience violence from their care recipient, experience a lack of adequate help from their informal or formal supports, or report certain care-recipient behavior problems like verbal or physical aggression, embarrassing public displays, or refusal to eat or take medications (e.g., Anetzberger, 1987; Compton, Flanagan, & Gregg, 1997; Pillemer & Suitor, 1992). These findings suggest not only the need for measures to capture quality of care for use in caregiving intervention programs, but also intervention strategies designed to target various points along the spectrum of

care. These strategies might be designed to support the potential enhancement of exemplary caregiving activities and the maintenance of current satisfactory care activities or to prevent physical, psychological, or financial harm to the care recipient.

Studies that further explore physical health and health behaviors, positive aspects of caregiving, and quality of care within the caregiving process can benefit theories or frameworks of caregiver adaptation that are useful in the development and evaluation of caregiver interventions. Service providers and program developers, in turn, can benefit from intervention studies designed to have an impact on these specific outcomes.

## A Move Toward Clinical Significance

As a complement to the outcome issues presented thus far, a recent review of dementia caregiver interventions extends the traditional discussion of caregiver outcomes beyond statistical significance to include issues of clinical significance or the *practical importance* of the intervention effects (Schulz et al., in press). This recent review echoes our position that researchers, program evaluators, and policy makers need to examine the extent to which an intervention makes a "real" difference in the everyday lives of caregivers, their care recipients, or their families (e.g., Kazdin, 1999; Kendall, 1999). Schulz and colleagues broaden the relevance of clinical significance beyond just the traditional psychotherapeutic view of change in symptomatology and categorize clinical significance of caregiver intervention outcomes into four domains believed to be important to the individual or society: *symptomatology, quality of life, social significance*, and *social validity*. Table 1.1 lists these domains and provides their definitions and relevant examples. In sum, recent caregiving intervention studies demonstrate increasing promise in affecting symptomatology, including the treatment of depression, as well as social significance, particularly with regard to delayed institutionalization of the care recipient. In addition, caregivers in most studies rate the interventions as beneficial or valuable, which adds clinical significance support in terms of social validity. However, researchers, policy makers, service providers, and caregivers themselves may hold different views on the relative importance of these domains. The need to examine intervention outcomes in these domains is obviously formidable, given that most outcome measures have been normed on predominantly Caucasian female samples. We recommend further evaluation and potential adaptation to accurately capture the experiences of other caregiving groups. Cultural proscriptions may also encourage different groups of caregivers to hold divergent views on the relative importance of these domains. Still, a recognition of the clinical significance of outcomes and an attempt to measure at least some aspect of each domain will not only help advance caregiver intervention

**TABLE 1.1  Domains of Clinical Significance**

| Domain of Significance | Definition | Examples |
|---|---|---|
| Symptom-atology | Extent to which an individual returns to normal functioning or moves from one diagnostic category to a less severe one. | Measures of depression, anxiety, anger, psychological morbidity, physical health symptoms, clinical health assessments (e.g., blood pressure, exercise stress tests). |
| Quality of Life | Extent to which interventions broadly improve the quality of life of an individual as measured by multidimensional instruments or indicators. | Life satisfaction, morale or marital satisfaction, caregiver burden, social support. |
| Social Significance | Extent to which outcomes are important to society. | Amount of service utilization, patient functional status, time to care recipient placement or time spent on caregiving tasks. |
| Social Validity | Extent to which treatment goals, procedures and outcomes are acceptable to caregivers, care recipients, caregiving families. | Caregiver or expert ratings of the interventions and their impact on their lives and those they care about (their care recipients, their families). Caregiver recommendation of intervention program to others. |

research, but can also help us bridge the translation gap between clinical research, practice, and policy by exploring outcomes in at least some domains relevant to each group of stakeholders.

## PROMISING INTERVENTIONS AT THE MILLENNIUM

Over the years, several types of caregiver interventions and support services have proven useful to caregivers of persons with dementia. However, the magnitude of their utility depends not only on the outcomes measured and their related domains of clinical significance, but also on the care recipient's level of impairment and the caregiver's background characteristics, including their psychosocial strengths and vulnerabilities. Still, numerous literature reviews have been unable

to identify *the* antidote to alleviate caregiver stress and its sequelae (e.g., Bourgeois et al., 1996; Dunkin & Anderson-Hanley, 1998; Kennet et al., 2000; Knight, Lutzky, & Macofsky-Urban, 1993; Pusey & Richards, 2001; Schulz et al., in press). Clearly, no single, easily implemented and consistently effective method exists for achieving the same clinically significant outcomes across caregivers. This is especially true when considering racial and ethnic diversity as it is overly simplistic to assume that interventions successful with caregivers from one background will automatically achieve the same results with another significantly different group of caregivers. Yet these reviews do support the claim that comprehensive, intensive, and individually tailored interventions appear more likely to be effective than interventions without similar characteristics. These characteristics may support in part the successful outcomes associated with multicomponent approaches (e.g., Mittelman, Ferris, Shulman, Steinberg, & Levin, 1996; Ostwald, Hepburn, Caron, Burns, & Mantell, 1999), which through their assortment of intervention techniques may create caregiving interventions that address a wider variety of concerns for more diverse groups of caregivers.

## Knowledge and Skill Training

In general, caregivers are likely to benefit from enhanced knowledge about disease, the caregiving role, and resources available to assist them in that role. But many caregivers may have additional education and training needs, especially in terms of specific skills necessary to effectively handle care-recipient behavior problems (e.g., Burgio et al., 2002; Teri, Logsdon, Uomoto, & McCurry, 1997) or manage their own thoughts, feelings, and behavior in response to caregiving (e.g., Gallagher-Thompson, Lovett, et al., 2000; Oswalt et al., 1999). Emerging work indicates that such skill programs can be culturally tailored to meet the needs of different racial or ethnic groups, suggesting that further development of skill-training interventions that attend to the special needs of minority caregivers is also necessary (e.g., Burgio et al., 2002; Gallagher-Thompson, Árean, Rivera, & Thompson, 2001; Gallagher-Thompson, Coon, et al., 2002).

## Technological and Environmental Approaches

Similarly, the role of technology in assisting family caregivers of the new century has gained considerable attention—from telephone-based technologies to Web-based education and support—with some intervention studies that examine the successful combination of skill-focused technological interventions, including telephone-based linkages, video training, and computer screen phones as modalities to deliver therapeutic content for stress management (e.g., Czaja & Rubert,

in press; Mahoney, Tarlow, & Sandaire, 1998; Steffen, 2000). As described in chapter 5, preliminary results of family caregiving intervention that combines technological support for linking family caregivers to other family members and to community resources demonstrated positive mental health outcomes, especially for Cuban American caregivers (Czaja & Rubert, in press). As technological advances, including telemedicine, more frequently permeate caregivers' lives, these combined approaches will require shifts in the caregiving models used by researchers and in the skill sets considered necessary for professionals who serve caregiving families. There is also growing evidence of the benefits achieved by simultaneously treating the caregiver and the care recipient (e.g., providing medications or memory retraining in the early stages of impairment), as well as by modifying the social and physical environment so it is supportive of caregiver and patient activities (Gitlin, Corcoran, Winter, Boyce, & Hauck, 2001; Schulz et al., in press). Furthermore, the field could benefit from investigations of interventions that are focused "upstream" in the caregiving process, intervening with patients and caregivers from a prevention perspective before caregivers are already saddled with depression, overwhelmed with patient behavioral disturbances, or embroiled in caregiving crises.

Although the complexity and rigor of interventions studies continue to improve, sample sizes are often too small to detect effects and several methodological concerns remain, including a lack of randomized controlled trials and very little treatment implementation data being collected or reported (Bourgeois et al., 1996; Burgio et al., 2001; Schulz et al., in press). In addition, multicomponent interventions have yet to provide information about the relative effectiveness of their components (Bourgeois et al., 1996; Zarit et al., 1998), fueling questions about the mechanisms that drive their successful outcomes and making it difficult to determine how to maximize the benefits for different groups of caregivers (e.g., different cultural groups, caregivers of individuals with different impairments, employed caregivers, etc.) while minimizing costs to both caregivers and service agencies. Thus, a thorough investigation of the central mechanisms of various multicomponent interventions could help in the development of stepped care approaches that are individualized to meet the needs of diverse groups of caregivers.

## BUILDING SUSTAINABLE PARTNERSHIPS

The formation and maintenance of strong organizational and community partnerships is essential to our goal of identifying and accessing family caregivers and effectively addressing their needs and concerns through proven intervention programs. Partners themselves can be defined as organizations or organizational departments that come together in a social change effort and thereby serve as

conduits to target audiences (Nichols et al., 2000; Nichols et al., 2002), whether the partnership occurs across or within research, university, health care, or community-based systems.

For example, the National Institute on Aging and the National Institutes for Nursing Research provided sponsorship for a unique, multisite research project entitled Resources for Enhancing Alzheimer's Caregiver Health (REACH). The primary goal of this effort was to test systematically well-specified and theory-based caregiver intervention approaches that were culturally tailored to meet the needs of racial and ethnic majority and minority caregiving populations (Coon et al., 1999). All six REACH sites, based on their local environments and target populations, formed key partnerships with an array of organizations such as local Alzheimer's Association chapters, community centers, churches, Alzheimer's day-care centers, physician offices, and home health agencies and included sites actively partnering with community-based organizations that served the racial and ethnic populations targeted. Similarly, the Chronic Care Network for Alzheimer's disease demonstration project, mentioned previously, is sponsored by the Alzheimer's Association and the National Chronic Care Consortium and spans seven national sites. Each site in the initiative sought to foster and strengthen partnerships among managed care systems, Alzheimer's Association chapters, and other community agencies. From the outset, the CCN/AD partnerships worked together to develop and put into practice user-friendly tools designed to facilitate the identification and care management of patients with dementia and their family caregivers across the disease trajectory (Maslow & Selstad, 2001).

## Partnerships and the Social Marketing of Interventions

Relevant to the discussion of strong partnerships is the social marketing approach to recruitment and retention of caregivers of persons with dementia in clinical research that has recently emerged in the literature (Nichols, Malone, Tarlow, & Loewenstein, 2000; Nichols et al., 2002). Although social marketing is usually used in public health initiatives to change health behavior, this framework warrants serious consideration in the marketing of interventions, programs and services to family caregivers. Social marketing not only incorporates the concepts of *product, price, place,* and *promotion* into the successful design and marketing of intervention programs, but also emphasizes the important role of *partners* in their successful development, delivery, and continuation. This framework stresses the need to clearly identify and address the needs, perceptions, and values of the intervention's target audience (e.g., family caregivers). Therefore, caregiver interventions (our *product*) must also meet the needs, interests, and values of caregivers at a *price* in terms of time, money, and effort acceptable to the specific group of caregivers targeted (e.g., male caregivers or family caregivers in the

Latino community). In addition, serious attention needs to be given to *place*, *promotion*, and *partners*, including the intervention's accessibility for caregivers, the advertising and incentives necessary to interest the caregiving groups targeted, and the invaluable role of partners in accessing and referring caregivers for continued program enrollment and success. When research, practice, and policy partners work in tandem to develop models that describe caregiving dynamics as well as the intervention frameworks investigated and implemented, it translates to effective programs based on these models that are more likely to garner support for continuance. If an organization's administrators, clinicians, and services providers are viewed as vital members of these partnerships from the partnership's inception, they can, in turn, facilitate both the initial integration and the ongoing maintenance of effective caregiver interventions within their organizations and across the partnership. Unfortunately, well-meaning professionals too often have assumed "if we build it, they will come," rather than taking the time to gather input systematically from other partners and their constituents about these marketing components prior to developing caregiving interventions.

Partnerships like REACH and CCN/AD have already integrated several social marketing components into their projects. They naturally call for multiple disciplines working together as teams to design, develop, and improve caregiver interventions across the continuum of care from prediagnosis and early stages of a disease through end-of-life issues and caregiver bereavement. In addition, these partnerships share recruitment and retention activities for caregiver interventions, programs, and services and plan for ongoing caregiver assistance and the sustainability of successful intervention activities after initial research or other sponsored funding ends. Numerous possibilities exist to form partnerships between various caregiving organizations, religious institutions, local employers, senior centers, and other community agencies to help translate effective caregiver education, training, and support programs from research settings into our communities. Moreover, community partners who provide services to underserved and minority caregivers could help play a central role in disseminating information and translating appropriate interventions into these communities (e.g., Gallagher-Thompson, Árean, et al., 2000; Navaie-Waliser et al., 2001). Chapters by Burgio, Burns, Argüelles and their colleagues in this volume provide additional insight into caregiver interventions that were investigated as part of the REACH and CCN/AD projects.

## A CALL FOR INTERVENTIONS AT MULTIPLE LEVELS

The needs of care recipients and their caregivers and families vary across the course of dementia, as well as in response to the vicissitudes of life, such that information, interventions, and services that are useful at one point in the care-

giving career may not prove helpful at another. These changes imply that at least periodic if not ongoing assistance is warranted. The future of social and behavioral intervention research with older adults and their families suggests the need for multiple levels of intervention ranging from the *individual* and the *interpersonal* levels to the *organizational, community,* and *policy* levels in order to achieve effective behavior change (Emmons, 2001). Just as there are many pathways to various caregiving outcomes, a diverse collection of proven intervention strategies or techniques at each of these levels will be needed to address the complex needs of caregivers and care recipients in our pluralistic society (Coon & Thompson, 2002). For instance, skill-based interventions that focus on the caregiver (e.g., Gallagher-Thompson, Lovett, et al., 2000) would typify the individual level, whereas skill-based interventions that work with caregiver/care recipient dyads (e.g., Teri et al., 1997) or interventions that include family counseling or integrate family meetings (e.g., Mittelman et al., 1996) would be considered interpersonal in nature.

## Establishing Multilevel Linkages

Such a framework also implies that purposeful linkages must be established between successful intervention components identified at each level in order to help maximize and sustain positive behavior change. Thus, successful caregiver interventions delivered at the individual or interpersonal levels will need to be partnered not only with interventions focused at the organizational level (e.g., interventions directed at or through health care systems, senior centers, or faith-based organizations), but also with interventions disseminated through communities (e.g., within retirement communities, assisted-living centers, or public service areas) and more broadly based policy levels. This approach requires the identification and strengthening of existing partnerships or the creation of new partnerships like those described in the previous section. These partnerships should be designed to help caregivers across the course of dementia by taking into consideration both short- and long-term impacts of caregiving on mental, physical, and social health, such as personal and professional role changes and losses, issues associated with anticipatory grief, transitional stressors related to respite care and institutionalization, and end-of-life issues and caregiver bereavement (e.g., Aneshensel, Pearlin, Mullan, Zarit, & Whitlatch, 1995; Schulz & Beach, 1999). For example, the $125 million in fiscal year 2001 for the National Family Caregiver Support Program allocates $113 million from the federal government to the states to work in partnership with their area agencies on aging and local community-service providers in order to provide five basic services for family caregivers (see Table 1.2). This shift in policy may foster new and ongoing partnerships between providers that have the potential to impact not only the individual and interper-

**TABLE 1.2   National Family Caregiver Support Program's Five Basic Services**

| | Service | Brief Description |
|---|---|---|
| 1. | Information and Referral | Information to caregivers about available services. |
| 2. | Access Assistance | Assistance to caregivers in gaining access to available services. |
| 3. | Caregiver Support and Training | Individual counseling, organization of support groups, and caregiver training to assist caregivers in making decisions and solving problems relating to their caregiving roles. |
| 4. | Respite | Respite care to enable caregivers to be temporarily relieved from their caregiving responsibilities. |
| 5. | Supplemental Services | Supplemental services, on a limited basis, to complement the care provided by caregivers. |

sonal levels, but also the organizational and community levels as well. Table 1.3 provides only a handful of basic examples of possible interventions that could be useful to caregivers at each of the five levels.

Successful development of these partnerships and linkages will also call for a shift from the discrete stances taken by individual providers or organizations to acting as change agents within emerging change agencies or up-and-coming partnerships that are focused on systemic change and connections. Thus, service providers and program directors working with caregivers will need to consider expanding their mission beyond the individual or interpersonal intervention levels and look for new ways to facilitate successful linkages across the range of intervention levels from practice to policy.

Moreover, additional agencies need to develop research initiatives and demonstration grant programs for fostering research and community-based partnerships that will explore linkages between these levels. Agencies can do this by following the lead of community-based organizations like the Alzheimer's Association and government agencies within the Department of Health and Human Services, such as the National Institute on Aging, the National Institute for Nursing Research, and the Administration on Aging. Initial support of this kind not only helps identify efficacious and effective caregiver interventions, but also assists service providers who face the realties of limited resources. Translating research into practice is aided by (a) providing assistance to expand their services to meet the needs of the most prevalent groups of caregivers of patients with dementia within a service area, (b) helping to appropriately tailor and then disseminate existing tools and programs to meet the needs of smaller groups of caregivers, and (c)

**TABLE 1.3    Multiple Levels of Caregiver Interventions**

| Level | Examples |
|---|---|
| Individual | • Caregiver education regarding dementia and its progression.<br>• Individual counseling or support groups for caregivers.<br>• Caregiver relaxation training to manage caregiver stress.<br>• Caregiver skill training to manage their own depression or anger.<br>• Caregiver respite. |
| Interpersonal | • Caregiver skill training to help manage care recipient behavior problems.<br>• Caregiver and care recipient early stage dementia groups for spouses. |
| Organizational | • Faith based organizations pooling resources for congregation education on dementia and caregiving, and the development of friendly visitor and respite programs for caregivers.<br>• Partnerships between community-based organizations and primary care setting to create pathways of care for caregivers and care recipients. |
| Community | • Media and community/service campaigns to increase dementia and caregiving awareness.<br>• Continuous care retirement community education, training and support interventions for the entire community to teach both caregivers and their neighbors and friends about dementia and dementia caregiving. |
| Policy | • National Family Caregiver Support Program funding allocated to states for their area agencies on aging.<br>• American Medical Association addition of Caregiver Health Assessment and related caregiving material on its web site.<br>• Government and private foundation support for caregiver intervention research and demonstration projects. |

supporting the design and development of new intervention programs for diverse groups of caregivers. This support can be designed in ways that strengthen partnerships across multiple intervention levels to increase the likelihood of transportability and sustainability beyond the grant period. Another way to further the translation of research into practice and policy across intervention levels is to encourage interdisciplinary partnership training that includes current and future cost considerations and their evaluation from the outset (Mahoney, Burns, & Harrow, 2000).

However, we must exercise caution in attributing costs solely to the partnership. Interventions must be affordable to caregivers, too; that is, caregivers must be able to reconcile the perceived costs of service utilization with their perceived

benefits. Caregivers consideration of the affordability of services includes not only financial costs, but also costs in terms of time, effort, potential family conflict, potential loss of confidentiality, and the like. Stepped care models or approaches that incorporate components from multiple levels of intervention as needed by groups of caregivers or individual caregivers may help minimize these costs, which should increase the likelihood of caregiver service utilization.

Undoubtedly, key challenges remain in the development and dissemination of effective family caregiver interventions. Given the complexity of caregiving issues and the scope and diversity of caregiving, our solutions must now be comprehensive in level and scope and yet flexible enough to be effectively tailored to meet the needs of families within their particular sociocultural contexts (Coon & Thompson, 2002). A multilevel framework should also encourage family caregiver education and intervention to encompass multiple settings and life domains, take advantage of various delivery points for intervention messages, and deliver interventions through multiple modes and communication channels. This approach should encourage us to pinpoint effective ways to embed interventions within ongoing community programs and services as another way to keep costs down and increase transportability. Messages and interventions at multiple levels could go a long way in helping "normalize" the experience of family caregiving in our society. This normalization might in turn foster the readiness of caregivers to accept change (e.g., Keller & White, 1997; Prochaska, Norcross, & DiClemente, 1994)—a readiness that is needed for constructive engagement in service utilization and the adoption of effective intervention strategies.

## CAREGIVING INTERVENTIONS
## FOR A PLURALISTIC SOCIETY

The pluralistic nature of our society is reflected in the variety of beliefs that distinct groups of family caregivers hold about the etiology of dementia, the responsibilities of family caregiving, and the role of formal and informal social support in dementia care. And even though more published literature is emerging that expands our understanding of the needs and experiences of diverse types of family caregivers (e.g., Hinton, Fox, & Leukoff, 1999; Janevic & Connell, 2001; NAC/AARP, 1997; Yeo & Gallagher-Thompson, 1996), the vast majority of today's research on caregiver interventions focuses on the intervention experiences of Caucasian female caregivers. However, family caregivers enter intervention programs with individual histories shaped by multiple layers of social influence, including years of family expectations and peer pressure, social class standing, racial and ethnic identifications, and other cultural influences. These factors help form a complex set of beliefs, values, and expectations regarding dementia and family caregiving that influence the proper courses of action to