Supporting Caregivers Through Education and Training

Ronald W. Toseland

Professor and Director, Institute of Gerontology
School of Social Welfare
University at Albany, State University of New York

and

Tamara Smith

Research Associate, Institute of Gerontology,
University at Albany, State University of New York

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EXECUTIVE SUMMARY

Family caregivers play a vital role in maintaining the health and independence of frail elders. One in four households in the United States provide care for a frail older person, and the economic value of this care has been estimated from 45 to 200 billion dollars. Although caregiving is rewarding, it can also have a detrimental impact on the health and wellbeing of the caregiver. Caregiving has its greatest impact on the emotional health of caregivers, and caregivers of persons with dementia and stroke are at the highest risk for depression and anxiety disorders.

When designing programs to educate, support, and train caregivers, it is important to consider the goals of the programs and whether particular subgroups of caregivers should be targeted. Casting a broad net enables practitioners to reach out to the largest possible group of caregivers, but it is not conducive for providing the kind of specialized information, knowledge and support that caregivers often seek. Some targeting variables to consider when designing programs include: (1) whether the focus should be on prevention or remediation, (2) the nature and extent of the care recipient's disability, (3) the relationship of the caregiver to the care recipient, (4) gender, (5) race, ethnicity and socio-economic status, and (6) special populations, such as grandparent caregivers.

There are many ways to educate and train family caregivers including: (1) single session community workshops and educational forums, (2) lecture series followed by discussion, (3) support groups, (4) psycho-educational and skills building groups, (5) individual counseling and training, (6) family counseling, (7) care coordination and management, and (8) technology-based interventions. The empirical literature does not provide definitive guidance about what method is most efficacious but suggests that multi-component programs may be more effective than single component programs. There is also some evidence that individual training programs may be more effective than group programs in helping caregivers with emotional problems, but that group training may be more effective in building social support and overcoming isolation. With respect to group programs, there is some evidence that structured psycho-educational programs containing a combination of education, problem solving and coping skills training and support may be more effective than single component support group programs. However, more research is needed to confirm these findings. The paper concludes with a discussion of selected planning and implementation issues including: (1) recruitment strategies, (2) reaching out to minority caregivers, (3) monitoring program implementation, and (4) evaluating the impact of caregiver education and training programs. An appendix to the monograph includes three sections: (1) resources for caregivers, (2) resources for professionals working with caregivers, and (3) disease specific resources for both caregivers and professionals.

Family caregivers play a vital role in maintaining the health and independence of frail older persons. Although there are some discrepancies in estimates of family caregiving depending on how caregivers and caregiving is defined, the national economic value of informal family caregiving has been estimated from 45 billion to 94 billion (Administration on Aging) to almost 200 billion dollars per year (Arno, Levine, & Memmott, 1999). To put these figures in perspective, 200 billion dollars represents about 18% of total national health care spending per year (Arno, Levine, & Memmott, 1999). The 1994 National Long-Term Care Survey indicated that there were approximately 5.5 million disabled older adults in the United States, and that over 70% of these individuals received informal care from spouses, adult children or other caregivers (Spillman & Pezzin, 2000). The survey also indicated that there were approximately 2.6 million primary caregivers in the United States, and that about 7 percent of all persons aged 15 or older in the United States had potential caregiving responsibilities (Spillman & Pezzin, 2000). Other surveys, however, have indicated even higher levels of caregiving responsibilities. For example, a national survey conducted by the National Alliance For Caregiving and the American Association of Retired Persons (AARP) indicated that one in four households in the United States have spent some time in the previous twelve month period providing care for a frail older person (National Alliance For Caregiving and AARP, 1997). There have also been estimates that caregivers spend an average of about eight years in the caregiving role (MetLife, 1997; MetLife, 1999).

Despite variations in estimates of the extent of family caregiving, widely accepted demographic data indicate that the percentage of the population that are elderly, particularly the very old, will increase dramatically in the next several decades. Even with improved health and reduced disability (Manton, Corder, & Stallard, 1997; Spillman & Pezzin, 2000), these demographic trends suggests that family caregivers will play an increasingly important role in helping to maintain frail older persons in community settings in future years (Pandya & Coleman 2000; Toseland, Smith, & McCallion, 2001).

THE IMPACT OF FAMILY CAREGIVING

Articles about the impact of caregiving often focus exclusively on its negative aspects. Practitioners should recognize, however, that even though caregiving is often demanding and stressful, it is frequently perceived as a rewarding experience. Rewards of caregiving include: (1) feeling useful, needed, and engaged in a meaningful role that really makes a difference in the life of the care recipient, (2) feeling a sense of accomplishment and competence because one is better able than anyone else to manage complex caregiving tasks and to provide high quality care in difficult caregiving situations, (3) having the opportunity to express feelings of empathy, intimacy and love to the care recipient, (4) experiencing satisfaction that one has fulfilled one's responsibility and paid the care recipient back for all that he or she has done for the caregiver in the past, (5) feeling appreciated by family members and friends for all that one has done for the care recipient, and (6) self-respect and altruistic feelings that one has done all that one can for the care recipient, without being asked (Bass, 1990; Gatz, et. al., 1990; Pearlin, et. al., 1996). The entire family can also experience the rewards of feeling secure in a strong kinship system, learning more about aging and late life development, attaining a better understanding of each other's needs, and gaining greater tolerance for other people's problems (Beach, 1997; Bass, 1990).

Although caregivers may not experience all of these rewards, or they may complain that they do not get the credit they deserve from the care recipient or from family members and friends, it is important for practitioners to encourage caregivers, and to acknowledge, recognize, and articulate the important role that they play in the lives of their frail loved ones. Finding meaning and reward in the caregiving situation has been shown to be associated with reduced perceptions of burden and stress and with better health outcomes (Kramer, 1997, Noonan & Tennstedt, 1997). Therefore, recognizing the important role that caregivers play can help them to cope more effectively with the demands of caregiving.

Despite the rewards of caregiving, the promotion of education, support and training programs is important because substantial evidence has accumulated over the past twenty years indicating that caregiving can have a negative impact on the health and well-being of the caregiver. Physical problems such as exhaustion and fatigue result from providing constant, and seemingly never-ending, attention to the care recipient's needs. These problems may also be exacerbated by the caregiver's own health problems. Physical exhaustion and deteriorating caregiver health often contribute to the development of psychological problems such as depression and anxiety.

Social isolation may occur because the long duration of many chronic illnesses and disabilities can lead to a restriction of caregivers' contacts with friends, neighbors, and other social contacts in the community. The revival or exacerbation of sibling or parental conflicts, and the frustrations and misunderstandings endemic to providing care for someone on a 24 hour on-call basis can also lead to interpersonal conflict with the care recipient and with other family members. Caregivers can become stressed by such tasks as: (1) maintaining family communication and the exchange of information, (2) balancing the needs of the care recipient with the needs of other family members, (3) managing feelings towards family members who do not help, (4) maintaining the family as an effective decision making group over the long term, and (5) asking for help from other family members when necessary.

Caregiving can also place families at financial risk. Medical, pharmaceutical, therapeutic and equipment costs are often not covered by insurance, or only partially covered. An increased use of utilities (e.g., washer and dryer due to incontinence), special diets and clothing etc., can place household budgets in jeopardy. At the same time, caregiving frequently results in reduced employment or unemployment, thus making it especially difficult to meet the increased expenses of caregiving (MetLife, 1999; MetLife, 1997; National Alliance For Caregiving and AARP, 1997; Stone, Cafferata, & Sangl,1987).

Emotional health is the one aspect of the primary caregiver's life that is most affected by caring for a frail elderly family member. Some of the problems that family caregivers find especially difficult to cope with emotionally include: (1) loss of control over one's time, (2) constant demands to do things for care recipients or for the household that care recipients could previously do for themselves, (3) guilt about whether one is doing all that is possible for the care recipient or other family members, (4) guilt about negative feelings that one might have, (5) loss of privacy, (6) grief over the care receiver's decline, and (7) feelings of anger about the care recipient's behavior or physical disabilities, and about unfulfilled relationship expectations during the retirement years. As compared to the general population, primary caregivers are frequently more depressed and anxious, are more likely to use psychotropic medications, and

have more symptoms of psychological distress (see, for reviews, Neundorfer, 1991; Schulz, O'Brien, Bookwala, & Fleissner, 1995; Schulz & Williamson, 1994; Schulz, 2000). Among all of the adverse emotional outcomes that are possible, depression represents the greatest risk. It has been estimated that between 20 to 50 percent of caregivers report depressive disorders or symptoms (Butler, 1992; Schulz, et. al., 1995, Schulz, 2000).

Practitioners should pay particular attention to the emotional health of caregivers of persons with dementia and stroke because they are at the highest risk for depression. These caregivers have to adjust to cognitive and behavioral symptoms as well as the physical impairments of the care recipient which can increase anxiety and depression. At the same time, those in the aging network should also be aware that much of the research on caregiver's emotional health does not adequately account for the great diversity of the resilience and other personal characteristics of caregivers and the nature and severity of the care recipient's disability (Schofield, Murphy, Herrman, Bloch, & Singh, 1997; Schulz & Quittner, 1998). Because the vast majority of researchers have focused on caregivers of persons with Alzheimer's disease and other dementias, less is known about the emotional impact of caregiving for those with other disorders such as heart disease or cancer. Still, given the available evidence, it is important for practitioners to assess all caregivers for symptoms of depression and anxiety.

The risks of family caregiving extend well beyond the primary caregiver to encompass the entire family system. Strawbridge & Wallhagan (1991), for example, reported that as many as 40% of the caregiving families they surveyed had experienced family conflict. Strain on the entire family system may result from such issues as conflict between caregiving obligations and other family tasks, disagreements among family members about the form or amount of caregiving, readjustments in family roles, the emotional impact of caregiving on all involved family members, and feelings of family stigma (Bass, 1990; Gatz, et. al., 1990). Families with the greatest risk for negative outcomes are those having poor communication skills, limited resources, many demands on their time and resources, suppressed or open conflicts, poor parent-child relationships, and high resistance to change (see Toseland, Smith, & McCallion, 1995 for a more complete discussion of the impact of caregiving on the family system). It is important for practitioners, therefore, to assess family functioning, and to encourage family meetings where all those in primary and secondary caregiving roles have a chance to express their feelings about the best care practices for their situation. Family meetings provide an important opportunity to reduce conflict and to develop coordinated care plans among formal and informal caregivers.

CAREGIVER VARIABILITY AND PROGRAM DESIGN

Professionals in the aging network who are planning caregiver education and training programs should carefully consider the characteristics of the caregivers they are intending to serve. A careful assessment of the unique needs, personal characteristics, and resiliency of caregivers who are planning to attend an educational or training program will help the facilitator to ensure that the program is meeting caregivers' needs. It is important, for example, to consider caregivers' needs for support, education, problem solving and coping skills training, and training in personal care skills. When these needs are determined, education and training program components can be tailored more effectively.

It is also essential to define the goals of the educational or training program. When defining the goals of the program it is important to decide whether one wants the program to reach out to all caregivers or to target particular subgroups of caregivers. Casting a broad net is appealing because it allows one to reach out and provide something for the largest possible group of caregivers. In local areas with limited resources, and in sparsely populated areas, this may be the only option. Programs that invite broad participation, however, have to keep education and training activities at a general level. They are less likely than specialized programs to provide education and training tailored to the individual needs of caregivers. Thus, targeting has important implications for program planning.

One of the first factors to consider is whether the program should be focused on prevention or on remediation. Programming for caregivers most frequently focuses on burdened and stressed caregivers who have been in the role for a while, and who are caring for a person who is deteriorating. It is important to also keep in mind all of the healthy older adults who are not currently in caregiving roles but who, nevertheless, could benefit from information to help them plan for caregiving roles that they may encounter in the future. For example, information for this group of seniors might range from the pros and cons of purchasing long-term care insurance to the importance of securing health care proxies and living wills. Also, informing this group about community health and human resources that may be needed in the future, and who to contact for help should it be needed, can be comforting and reassuring.

There are many variables to consider when thinking about targeting remedial programs for particular subgroups of distressed caregivers. The first consideration is, of course, whether one should target particular subgroups. There are many fine manuals available that address general caregiving issues (see the Resources Section at the end of this monograph). Thus, it is certainly possible to develop and implement caregiver programs with broad appeal. There are, however, at least two advantages to targeting specific caregiver subgroups. First, it allows us to impart specialized information and knowledge that would be of great help to some caregivers, but not to others. Second, it enables us to engage caregivers who might otherwise not be engaged, or who may not be as fully engaged, or helped, in a more general caregiver program.

A second targeting criterion to consider is the nature and extent of a care recipient's disability. Because they are providing care for individuals with cognitive impairments and behavioral symptoms, caregivers of individuals with Alzheimer's disease, for example, often have specialized needs and issues not encountered by other caregivers. There is helpful information, for example, that can be given about how to communicate and interact with persons with moderate and severe dementia (Toseland & McCallion, 1998), and how to help those with troubling behavioral symptoms (see, for example, Mahoney, Volicer, & Hurley, 2000). Similarly, special programs could be developed for caregivers of persons with cancer, cerebral vascular accidents and other chronic health problems. The Resource Section of this monograph contains a reference to a document entitled "Key Websites on Elder Care Resources" (Kelly, 2000) that lists websites focused on different types chronic health problems experienced by the elderly. These websites are a good starting point for those planning programs for caregivers of persons with specific health problems. Program planners should consider developing education and training programs for caregivers of persons with specific disorders, in partnership with local chapters of the national organizations such as the Alzheimer's Association, the American Cancer Society, and similar organizations. Another factor to consider in relation to the level of the care

recipient's disability, is caregiver accessibility. For example, caregivers of those with severe disabilities may respond better to programs delivered in their homes, whereas those caring for persons with milder disabilities may be more able to avail themselves of community based programs, and may welcome the opportunity to socialize and have a respite from caregiving.

The relationship of the caregiver to the care recipient can also have an impact on the content of caregiver education and training programs. Adult children and grandchildren caregivers, for example, often have different needs and issues than spouses. They are more likely, for example, to bring up issues of sibling rivalry and family conflict, work-related conflicts, and the impact of caregiving on their relationship with their husband and children. The caregiving experience is also less normative for adult children than for spouses, so they are more likely to bring up misgivings about being in the caregiving role, and they raise issues about the impact of caregiving on the relationship with their parents that are not pertinent to spouses. Thus, although it is possible to serve spouses, adult children, and caregivers together, consideration should be given to limiting participation to spouses, or to adult children and grandchildren, especially in caregiver programs designed to address psychological and emotional issues.

Gender is another characteristic that should be considered when targeting subgroups of caregivers. In our clinical work with caregiver support groups, for example, we have found that the character of the discussion changes in mixed gender and same gender groups. In general, our observation is that the character of the discussion is richer and franker in same gender groups. At the same time, members of mixed gender groups say that they appreciate learning about the viewpoints of members of the opposite sex.

Race, ethnicity, and socio-economic status are other factors that should be considered when targeting subgroups of caregivers. Practitioners who serve caregiving families should be aware that caregivers' racial and ethnic backgrounds can affect the caregiving situation. Older persons from minority groups are a rapidly growing segment of the population (Angel & Hogan, 1992; Aponte & Crouch, 1995). Whereas minorities constituted 20% of elderly population in 1980, and 26% of elderly population in 1995, they are projected to represent 33% of the population by 2050 (Markides & Miranda, 1997). Also, their needs for service are often greater than the overall population. For example, on most health status indicators, African American and Latino elderly are less healthy than white elderly (Gibson, 1991; Stump, Clark, Johnson, & Wolinsky, 1997). They have less formal education and lower occupational status, are over-represented in the lower socioeconomic strata of society, and have fewer retirement resources (Nickens, 1995; Shay, Miles, & Hayward, 1996). Minority caregivers also tend to have lower incomes, and they are generally less educated and in poorer health than white caregivers (for a review see Pruchno, et. al., 1997). Nevertheless, relatively little attention has been paid to minority caregivers which is reflected in their low utilization of community services and low participation in intervention studies (Cox, 1999; Schulz, O'Brien, Bookwala, & Fleissner, 1995; Toseland & McCallion, 1997; Toseland, Smith, & McCallion, 2001; Toseland & Rossiter, 1989). Therefore, greater attention to the needs of minority family caregivers by those in the aging network is urgently needed.

Relatively little is known about how minority caregivers respond to specific stressors, or about whether intervention programs designed to alleviate caregiving stress are effective with minority populations (Toseland & McCallion, 1997). There is conflicting evidence, for example,

about whether African American and Latino caregivers are more resilient to negative psychological effects of the stress of caregiving than are white caregivers (Connell & Gibson, 1997; Haley, et. al., 1993). One frequently offered explanation for the greater resiliency of Latino and African-American caregivers is that they have more support from extended family members (Johnson, 1995). Another is that Latino and African-American caregivers view caregiving differently than Anglo caregivers i.e., they perceive caregiving as a natural family responsibility, as a source of pride and status, and that help seeking outside of the family is experienced as a failure to meet family obligations (Phillips, deArdon, Komnenich, Killeen & Rusinak, 2000; Schulz, 2000). Some researchers have concluded, however, that African American and Latino caregivers experience at least similar and possibly higher levels of burden and depression than Anglos (see, for example, Aranda & Knight, 1997; John & McMillian, 1998).

It is difficult to separate the effects of ethnicity from socioeconomic, educational, cultural and historical differences (Connell, & Gibson, 1997; Pruchno, Patrick, & Burant, 1997). Those in the aging network should interpret existing research findings cautiously, because comparing racial or ethnic groups is made questionable by the risk of attributing to race or ethnicity what may instead be due to socioeconomic, educational, cultural, or historical differences. In fact, when such confounding factors are taken into account, several authors have concluded that racial differences in the caregiving experience are minimal (see, for review, Connell & Gibson, 1997; Young & Kahana, 1995). Moreover, the possibility that differences exist within and between subgroups of various racial or ethnic populations of family caregivers has been insufficiently examined to date. Gallagher-Thompson and colleagues (Gallagher-Thompson, et. al., 1997), for example, point out that there is a great deal of diversity among Mexican-American, Cuban, and Puerto-Rican caregivers. Stereotyping families by ethnicity may lead practitioners to assume a level of adjustment to caregiving and availability of extended family support that is not true for a particular caregiving family. This may result in a lack of recognition of a caregiver's need for assistance (McCallion, Janicki, & Grant-Griffin, 1997).

Investigations of the lower usage of caregiver intervention programs by members of cultural minorities have found a greater reliance on filial piety, availability of extended family supports, distrust of formal structures, and cultural beliefs that one should take care of "one's own" (for a review see McCallion, Janicki, & Grant-Griffin, 1997). Thus, it will take special efforts by those in the aging network to reach out to African-American, Latino, Asian, and other ethnic/racial minorities. A first step is to recognize and respond to society's structural barriers to service use that may result in minority caregivers receiving fewer services than white caregivers. These barriers include the experience of discrimination, legal status concerns, and alienation from services that have been developed for, rather than by, the families to be served (Johnson, 1995; Lockery, 1991). There are also economic, religious, transportation, financial, and insurance barriers. Other common barriers to service use among minority caregivers include feeling: (1) unwelcome by other participants, (2) like an outsider in the service locations chosen for an education or training program, and (3) that the intervention programs were not designed to meet their needs or the context of their caregiving situation (Henderson, Gutierrez-Mayka, Garcia, & Boyd, 1993, McCallion, et. al., 1997). The aging network can respond by developing and implementing culturally sensitive interventions, involving locally based multi-cultural service agencies in outreach and service delivery, employing bilingual and ethnically/racially matched providers, and ensuring that the location of the intervention, the timing of sessions, and

the range of issues to be addressed are appealing to the particular ethnic group who are being served (Gallagher-Thompson, et. al., 1997; Henderson, et. al., 1993; Henderson & Gutierrez-Mayka, 1992; McCallion, et. al., 1997; McCallion & Grant-Griffin, in press; Toseland & Rivas, 1998).

It is also important to consider whether one wants to reach out to special caregiving populations, such as older adults taking care of adult children with mental health or developmental disabilities, and grandparent caregivers. Older adults caring for adult children with mental health or developmental disabilities struggle with issues such as permanency planning, which often are not important issues for other caregivers. Similarly, grandparent caregivers struggle with issues such as formal custodial arrangements that are not relevant to other caregivers. For additional information about intervention strategies for grandparent caregivers see Landry-Meyer (1999). For more information about caregivers of the mentally ill see Biegel, Robinson, & Kennedy (2000), and Biegel & Schulz (1999).

EDUCATION AND TRAINING MODELS

There are many ways to educate and train family caregivers. The most common methods include: (1) community workshops and educational forums, (2) lecture series followed by discussion, (3) support groups, (4) psychoeducational and skills building groups, (5) individual counseling and training, (6) family counseling, (7) care coordination and management, and (8) technology-based interventions.

Community Workshops and Forums

Workshops and forums are often single session educational events lasting anywhere from one hour to a full day. They may be held in conjunction with other events such as a senior health fair, a senior expo, or similar event. Sometimes they are sponsored by health and human service organizations working collaboratively and may include corporate sponsorship. Workshops and forums typically last one half day or a full day. They may feature a keynote speaker or a series of speakers, followed by breakout sessions that are more interactive. The focus of workshops and forums is frequently on educating caregivers about community resources and services, caregiving skills, and dealing with psychological and social issues.

Lecture Series Followed by Discussion

Another common type of caregiver education and training program, rarely written about in the literature, is the lecture series and group discussion. Frequently, leading clinicians are asked to speak on topics of interest to caregivers. For example, a neurologist may be asked to speak about the latest findings in the treatment of Alzheimer's disease, a pharmacist might be asked to speak about medication management, a nurse may be asked to speak about home health management skills and assistive devices, or a social worker may be asked to speak about resources for long-distance caregiving. Each lecture may be followed by a question and answer period, by small group discussions with trained facilitators, or by a large group discussion.

Psycho-Educational, Skills Building, and Support Groups

Most of the published literature on caregiver education and training focus on the impact of small group programs. These programs range from long-term unstructured support groups in which the agenda is set by members, to short-term structured groups with specific agendas planned by the leader. Longer-term unstructured groups aim to educate members by mutual sharing of information and by encouraging reciprocal help and self-help among members. In contrast, short-term structured groups aim to help members by educating them about caregiving resources and skills and by teaching specific problem solving and coping skills. Many community groups blend both approaches. The resource section of this monograph lists several manuals that can serve as models for professionals who wish to lead psychoeducational, skills building, and support groups for caregivers (see, for example, Toseland, McCallion, & Ramos, 2001; Rosalynn Carter Institute for Human Development, 1998).

Individual Counseling and Training

Individual counseling can be done within a health or human service organization, or in caregivers' or care recipients' homes. Caregiver education and training is often presented by home health care staff as a routine part of the service, but individual counseling also takes place in hospital and institutional settings, and in community centers, senior centers, senior housing, and family service agencies. Individual counseling can focus on a wide range of topics. Among the most frequent are: (1) caregivers or care recipients emotional reactions to chronic illness, (2) family conflict resolution, (3) personal care skills, (4) problem solving skills for difficult caregiving situation, (5) behavior management skills for care recipients with cognitive and emotional impairments, (6) information about caregiving resources and services, and (7) care coordination and care management skills. In addition to being a provider of individual counseling services, the aging network has an important role to play by encouraging the development of such services, by educating providers about resources and services, and by putting on professional education workshops to better prepare professionals and paraprofessionals for direct one-on-one practice.

Family Counseling

Given the fact that caregiving is often a family affair, it is surprising how little has been written about family counseling interventions for caregivers of the frail elderly. Family counseling interventions are not limited to family service agencies. Practitioners in many different types of health and human services counsel family members about how to sustain their loved ones in both community and institutional settings, and how to interact with formal care providers. For example, family counseling is a part of good quality day care, home care, respite care, hospice care and nursing home service programming.

Care Coordination and Management

An important role of professional care coordinators and care managers is to educate caregivers about how to perform informal caregiving roles more effectively, and how to interface with formal caregivers. Care coordinators and managers spend a considerable amount of time educating, supporting and teaching family caregivers specific caregiving skills as well as

specialized skills to manage particular mental and physical disabilities. Those in the aging network can be helpful by organizing special training programs for care coordinators and care managers that they might not otherwise receive. For example, programs on elder abuse, suicide, dementia detection and treatment of late life depression, etc. can help care coordinators and care managers to identify and address key issues they may otherwise overlook.

Technology-Based Interventions

In recent years there has been an increase in innovative, technologically assisted methods to educate and train caregivers. These include (1) telephone-mediated groups, (2) computer-mediated groups and (3) video-conferencing. In some situations, it is not possible or convenient for caregivers to meet face-to-face. For example, in rural communities, health and social service agencies often serve large geographic areas. Even in urban and suburban communities, some health and social service agencies, such as regional hospitals, serve the needs of special populations dispersed over a large area. In other situations, caregivers simply do not feel able to leave the care recipient alone long enough to attend.

Technological advances have made it possible to have telephone conversations among a number of individuals, and it is possible to use these teleconferencing capabilities to educate and support caregivers of the frail elderly (Kelleher & Cross, 1990; Toseland, 1995). Galinsky, Rounds, Montague, & Butowsky (1993) and Bertcher (1990) have prepared manuals on how to set up and operate telephone groups, and a more complete discussion of the benefits and drawbacks of using telephone-mediated groups to educate and train caregivers can be found in Toseland & Rivas (2001).

Computer-assisted education and training has also seen a sharp rise in popularity in recent years. Chat-rooms, bulletin boards, e-mail, and listservs are just some of the methods that can be used to educate and train caregivers (Santhiveeran, 1998). Recently, computer-assisted technology has even been used as a resource to occupy care recipients with dementia when caregivers need time a respite from caregiving (Schulz, 2000). Caregivers can also use search engines to locate websites with helpful information.

Video-conferencing can also be used to educate caregivers. Many colleges and universities, as well as some public libraries, hospitals and other health and human service organizations now have the capability of two interactive videoconferencing capabilities. Experts can present lectures or workshops, and can answer questions and engage in dialogue with informal and professional caregivers who are located in remote sites throughout a region or an entire state.

EMPIRICAL SUPPORT FOR CAREGIVER EDUCATION AND TRAINING PROGRAMS

Over the past two decades there have been hundreds of studies of the effectiveness of programs to educate and train caregivers of the frail elderly in this country and in other nations. Beginning in 1989, researchers have reviewed this literature with the aim of drawing conclusions about the effectiveness of caregiver education, support, and training programs (see, for example, Bourgeois, Schulz, & Burgio, 1996; Knight, Lutzky, & Macofsky-Urban, 1993; Kennet, Burgio, & Schulz, 2000; McCallion Diehl & Toseland, 1994; McCallion & Toseland, 1995; Toseland & Rossiter, 1989; Toseland, Smith, & McCallion, 1995; Toseland, Smith & McCallion, 2001; Zarit

& Teri, 1992; Zarit, Gaugler, & Jarrott, 1999). Several conclusions can be drawn from these reviews. Almost all of the studies have focused on short-term individual and group intervention programs. Minimal data are currently available about the impact of workshops and community forums, although these are common caregiver education and training venues in community settings. Also, little research has been conducted about the effectiveness of family intervention programs, or telephone and computer-mediated programs. Few of the studies reviewed included substantial numbers of minority caregivers.

Almost all of the reviews conclude that caregiver education and training programs have small or moderate effects on (1) increasing knowledge about services and resources for caregiving, (2) improving psychological and social well-being of caregivers, and (3) increasing problem solving abilities and reducing pressing problems related to caregiving. Relatively few of the studies have examined changes in the physical well being of caregivers. Recently, however, a few studies have demonstrated that caregiver programs can have a positive impact on delaying institutionalization of the care recipient, or on reducing the care recipient's use of outpatient and inpatient health care services (see, for example, Brodaty & Peters, 1991; Brodaty, McGilchrist, Harris, & Peters, 1993; Peak, Toseland, & Banks, 1995; Mittelman, et. al., 1996). These latter studies are important because they can build a case for the cost-effectiveness of interventions to support caregivers of the frail elderly.

Reviews of the literature are less clear about the differential effectiveness of particular types of educational and training programs for caregivers. For example, although Knight and colleagues concluded that individual training programs were more effective than group programs, their meta-analytic study compared separate studies of individual and group intervention programs with different populations and in different settings (Knight, Lutzky, & Macofsky-Urban, 1993). However, when Toseland and colleagues compared individual and group intervention programs on the same population and in the same setting they concluded that individual intervention programs were better at addressing psychological problems, but group programs were better at building social support and imparting information about community resources and services (Toseland, Rossiter, Peak, & Smith, 1990). Both individual and group interventions were effective in reducing caregiver stress.

There is some evidence that multi-component interventions are more effective than single component programs (Biegel & Schulz, 1999). For example, a program for caregivers of dementia patients developed by Mittelman and colleagues (Mittelman, et. al., 1993; 1995; 1996) used a combination of individual, group and family intervention strategies. This program, which also provided "the continuous availability of counselors to caregivers and families to help them deal with crises and with the changing nature and severity of patient's symptoms," was effective in both increasing the psychosocial well being of caregivers as well as delaying the institutionalization of care recipients (Mittelman, et. al., 1996, p. 1726).

In a comprehensive review, however, Bourgeois and colleagues conclude that "more" may not always be "better" (Bourgeois, Schulz, & Burgio, 1996). Setting clear goals that are understood and agreed to by all participants, agreeing on the tasks needed to reach goals, creating demands for work that lead to systematic and sustained goal achievement efforts, and developing cohesion and interpersonal bonds in group interventions and positive therapeutic alliances in individual interventions, may be equally important factors (Toseland, 1995). Some

researchers and clinicians have also argued that structured psycho-educational and skills building approaches with clear agendas and goals, which are tailored to individual member needs, are more likely to be effective than less structured interventions that focus on support alone. (Biegel & Schulz, 1999; Bourgeois, et. al., 1996; Toseland & Rivas, 2001; Schulz, 2000). Manuals and books that provide clear guidance for how to organize and implement these more structured caregiver educational and training programs are available (see, for example, Toseland, 1995; Toseland & McCallion, 1998; Toseland, McCallion, & Ramos, 2001).

PLANNING AND IMPLEMENTATION ISSUES

Among the many issues to consider when planning and implementing caregiver education and training programs, some of the most important are: (1) recruitment strategies, (2) reaching out to minority caregivers, (3) monitoring program implementation, and (4) evaluating program impact.

Recruitment Strategies

Program planners and practitioners frequently ask about effective strategies to involve caregivers in education and training programs. A variety of strategies can be used including (a) contacting caregivers directly, (b) mailing and posting announcements, (c) preparing television and radio announcements and appearing on television and radio programs, and (d) issuing press releases and making appointments with feature writers of local newspapers.

Some evidence suggests that direct contact with potential clients is the most effective recruitment method (Toseland & Rivas, 2001). When potential group members can be identified from agency records or from caseloads of colleagues, providers may wish to set up initial appointments by letter or by telephone. Providers can then interview prospective members in the office or at home. However, person-to-person contact, particularly in-home contact, can be quite expensive in terms of the worker's time and therefore may not be feasible.

Brief, written announcements can also be useful for recruiting caregivers but they must be sent to the correct audience. To be effective, mailed and posted announcements must be seen by caregivers or potential referral sources. Therefore, careful targeting of the audience is essential. Too often, workers rely on existing mailing lists developed for other purposes or post announcements where they will go unnoticed by the target group. Computerized record systems are becoming more widely available and can be useful in identifying and targeting individuals who may need a particular service. If providers have a list of potential members, announcements can be mailed directly to them. Providers may also mail announcements to workers in other social service agencies who are likely to have contact with potential group members. Experience suggests that a follow-up phone call to those who have received announcements will increase the probability that referrals will be made. Announcements can also be posted on community bulletin boards, in senior housing, public gathering places, and in local businesses. In rural locations, announcements can be posted at firehouses, church halls, schools, general stores, and post offices. Providers can also ask that announcements be read at meetings of community service groups, church groups, business associations, and fraternal organizations.

The Internet has also increased accessibility to caregivers. Group announcements can be posted on local area networks, community computer bulletin boards, or be sent to targeted users

of particular computing services. It is also possible for organizations within the aging network to enhance their web sites by creating web pages that contain more detailed service information. Information about the group could also be made available through public speaking and through local television or radio stations. Many civic and religious organizations welcome guest speakers. A presentation on the need for the group, its purpose, and how it would operate can be an effective recruitment tool. Commercial television and radio stations broadcast public service announcements deemed to be in the public interest, and the proposed group program might be eligible for inclusion in such broadcasts. Commercial television and radio stations also frequently produce their own local public interest programs, such as talk shows, public discussions, special news reports, and community news announcements. Although public access cable television channels generally have smaller audiences, they can be used to describe a group service and to invite members to join.

Press releases and newsletter articles are another way to recruit members. Most newspapers publish a calendar of events for a specified week or month; brief announcements can be placed in the calendar. An article in the features section of a newspaper also can reach many caregivers that might be interested in attending a particular program. Newspapers frequently publish stories about new group services or particular social problems. The worker should consider whether the group is newsworthy and, if so, contact a local editor and request an interview with a reporter. My experience suggests that feature newspaper stories are excellent for recruiting caregivers.

Reaching Out to Minority Caregivers

A number of steps can be taken to increase the participation of minority caregivers in education and training programs. An important first step is to recognize the need that minority caregivers have for assistance. Because minority caregivers often keep needs and problems within their extended family systems or their cultural community, minority caregivers can be overlooked or ignored by the aging network. Because trust and familiarity are key issues in organizing caregiver programs in minority communities, a second step is to hire providers with ethnic/racial and linguistic backgrounds similar to the caregivers being served. If this is not possible, workers from other cultures should get to know the community where minority caregivers reside, its leaders and key informants, and its caregiving members. A third step is to work with health, human service, civic, and religious organizations that are known and trusted by caregivers. For example, when recruiting African Americans, holding a caregiver forum or workshop after church in the meeting hall of a Baptist church with the strong support of the minister is likely to be a much more effective strategy than holding the same meeting in a family service agency or senior center in a location where African-American caregivers might not feel as welcome. Similarly, when reaching out to Latinos and Latinas, program planners should consider partnering with organizations such as Centro Civico. A fourth step is to make sure that the program is presented in a culturally sensitive fashion, paying close attention to the norms of caregiving among particular ethnic groups, and the appropriateness of the information and the handouts that are distributed. For more information about culturally sensitive group programming for minority caregivers in general, see chapter 4 in Toseland & Rivas (2001). For some very helpful information about how to reach out to Hispanic caregivers in particular, see Gallagher-Thompson, et. al., (1997).

Monitoring Program Implementation

It has been pointed out that although much attention has been focused on planning caregiver education and training programs, little attention has been paid to ensuring that they are implemented correctly (Bourgeois, et. al., 1996). When planning programs, it is important to build in training and supervision for those implementing the program. It is also important to monitor program implementation. Experience in implementing structured psycho-educational programs for caregivers over the years suggests that even seasoned clinicians can benefit from close supervision. We have found audiotaping or videotaping group sessions can be effective in helping trainers to improve their program implementation skills.

Evaluating Program Impact

Program evaluation should be a routine part of any caregiver education and training program. At a minimum, caregivers should be asked about their evaluation of the instructor and the usefulness of the program, what features were least and most helpful, and what uncovered issues should be included in future programs. More extensive evaluations can include assessments of the impact of a particular program on members' knowledge and skills, their ability to problem solve or to cope with pressing problems, or their well being. The choice of outcome measures should be guided by the goals of the program.

CONCLUSION

The aging network has an extremely important role to play in supporting family caregivers in their efforts to provide the highest possible quality of care to their loved ones. The United States Congress has recognized the importance of this role by making funding available to State Units on Aging and local Area Agencies on Aging to help educate and train caregivers for their important role. We in the aging network have the responsibility to use these funds to support family caregivers' efforts to maintain the independence and dignity of frail older adults throughout the United States.

AUTHOR DESCRIPTION

Dr. Ronald W. Toseland is Director and Professor, Institute of Gerontology, School of Social Welfare, University at Albany, State University of New York, and a licensed clinical social worker practicing part-time at the Consultation Center. He serves on a number of editorial boards including *Gerontological Social Work, Social Work With Groups*, and *Small Group Research*. He has published 6 books and over 75 articles and book chapters, many of which have focused on clinical practice with the frail elderly and their family caregivers. His most recent books are Toseland, R. (1995) *Group Work With the Elderly and Family Caregivers*. NY: Springer Publishing Company; Toseland, R. and McCallion, P. (1998). *Maintaining Communication With Persons With Dementia*: *The MCPD Program*. N.Y.: Springer Publishing Co.; and Toseland, R. and Rivas, R. (2001). *An Introduction to Group Work Practice* (4th.ed.). Needham Heights, Mass.: Allyn and Bacon.

Tamara Smith is a Ph.D. Candidate in the sociology department at the University at Albany, State University of New York. As a Research Associate for the Institute of Gerontology for the past year, she has acted as the Project Director for two federally funded grants pertaining to caregiving issues. Additionally, she has taught a variety of Gerontology and Family courses for the University at Albany.

ACKNOWLEDGEMENTS

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RESOURCES FOR CAREGIVERS

Internet Resources

www.aagpgpa.org

American Association of Geriatric Psychiatry site with information for both caregivers and care recipients; includes depression and dementia fact sheets, resources for caregivers, and the latest caregiver research.

www.caregiver.org

Web page for the Family Caregiver Alliance Resource Center. This site provides information on variety of caregiving resources; 40+ Fact Sheets (some in Spanish and Chinese); online support groups and care planning consultation; policy alerts.

www.caregiverzone.com

Caregiverzone lists over 750,000 resources nationwide (facilities, day programs, care managers, etc.); has basic information on eldercare and operates an online store for long term care supplies.

www.caregiving.org

National Alliance for Caregiving site which provides tips for caregivers, links to other caregiving resources, and the AXA Family Foundation Family Care Resource Connection, a comprehensive database of books, websites, and other family caregiving resources.

www.careguide.com

Children of Aging Parents, a nonprofit organization website that provides information and support to caregivers of older people. Site includes information and online caregiver support groups for issues such as finding the right care, paying for care, legal issues, specific elder care situations, and general caregiving tips and support.

www.familycareamerica.com

Familycare America, a private company, features a website with a comprehensive library of caregiving information, instant access to localized caregiving resources and services, and community features like the Care Chain Project, an effort to encourage caregivers to share their stories with others.

www.nfcacares.org

The National Family Caregiver Association (NFCA) provides an internet site where caregivers can sign up for information about participating in caregiver research, caregiver welcome kits, and a quarterly caregiver newsletter.

www.oregoncares.org

Website provided by the Oregon Department of Human Services. Offers easy-to-understand communication tips for interactions between caregivers and physicians, caregivers and care receivers, and caregivers and family members.

www.wellspouse.org

This website is provided through the Wellspouse nonprofit organization. It provides spouses of the frail elderly with a virtual support community, including message boards and live Internet chats with other spouse caregivers. Links to disease-specific Internet sites are also highlighted.

Online Print Materials

Talking with Your Doctor: A Guide for Older People (no date). National Institute on Aging. Available at www.nih.gov/nia/health/pubs/talking/. One of the few extensive, consumer-oriented publications on patient-doctor communication. The book begins with a discussion of how to choose a doctor and ensuing chapters discuss topics such as how to prepare for an appointment, how to broach sensitive subjects, and how to involve family and friends.

Your Guide to Choosing Quality Health Care (1988). Agency for Healthcare Research and Quality. U.S. Department of Health and Human Services. Available at www.ahcpr.gov/consumer/qualguid.pdf. This 52-page handbook offers advice and resources on choosing health plans, care facilities, doctors, and treatment regimens, along with information on how to improve communications with medical professionals.

Kinship Foster Care, Grandparent Caregivers: A National Guide (2001). Legal Services for Prisoners with Children and the Brookdale Center of Aging. This is available at www.prisonactivist.org/lspc/ngcm/foster.html/. The article highlights the legal definition of kinship foster care, providing a guideline for grandparents navigating the legal foster care system.

Readings

Brandt, A. (1997). Caregiver's Reprieve: A Guide to Emotional Survival When You're Caring for Someone You Love. Atascadero, CA: Impact Publishers, Inc.

Caregiver guidance combined with four personal vignettes.

Caroll, D.L. (1990). *When Your Loved One Has Alzheimer's: A Caregiver's Guide* (revised). New York, NY: Harper and Row.

A caregiver's guide based on methods developed by the Brookdale Center on Aging.

Carter, R.(1994). Helping Yourself Help Others: A Book for Caregivers. New York, NY: Times Books.

This book provides a relatively extensive description of the communication problems caregivers can have with professionals and then provides advice on how those problems can be overcome.

Gray-Davidson, F. (1996). The Alzheimer's Sourcebook for Caregivers: A Practical Guide for Getting Through the Day. (revised) Boston: Lowell House.

This book discusses the emotional hardships of caregiving for an Alzheimer's patient: family crisis, acceptance, letting go, and moving on are all highlighted.

Mace, N. & Rabins, P. (2001*). The 36-Hour Day*. (revised) New York: Warner Books.

This is a family guide to caring for persons with Alzheimer's Disease and related dementia disorders. Explanation of what dementia is and what symptoms accompany it.

Morris, V. and Butler, R. *How to Care for Aging Parents*. 1996. New York, NY: Workman Publishing.

This caregiver guide specializes in the situations that adult children will confront when caring for parents: how to avoid "parenting" your parent, easing caregiver guilt, how to deal with nursing home issues and "saying good-bye".

Pennsylvania Department of Aging. (no date) A Guide for Family Caregivers of Older Pennsylvanians.

This comprehensive guide, developed to assist family caregivers, details the issues pertaining to caregiving, as well as many resources available to help caregivers cope with their loved one's illness.

Rau, M.T. (1993). Coping with Communication Challenges in Alzheimer's Disease. San Diego, CA: Singular Publishing.

Communication difficulties are one of the paramount issues when caring for someone with Alzheimer's Disease. This book describes common communication problems, and offers concrete solutions to these problems.

Rosalynn Carter Institute for Human Development. (1998). Atlanta, GA: The University of Georgia Press.

This manual highlights: what it means to be a caregiver, taking care of yourself, building cooperative relationships, preventing and solving problems, and accessing and developing resources.

Schmall, V., Cleland, M., & Sturdevant, M. (2000). *The Caregiver Helpbook: Powerful Tools for Caregiving*. Portland, Oregon: Legacy Health System.

This healthbook provides caregivers with the necessary tools to reduce personal stress, communicate effectively, practice self-care, and problem solve effectively.

RESOURCES FOR PROFESSIONALS WORKING WITH CAREGIVERS

Internet Resources

www.caregiver.org

Web page for the Family Caregiver Alliance Resource Center. This site provides information on variety of caregiving resources; 40+ Fact Sheets (some in Spanish and Chinese); online support groups and care planning consultation; policy alerts.

www.nfcacares.org

The National Family Caregivers Association (NFCA) provides information for professionals, including NFCA special reports, a Caregiver Outreach Kit (a starter kit of NFCA materials to help you help family caregivers), National Resource Referrals, and information about NFCA materials and publications.

Print Materials

Caring for You, Caring for Me- Leader's Manual (1998). Rosalynn Carter Institute for Human Development. Manual based on research related to the characteristics and needs of caregivers; includes activities and exercises used in program, and information about various aspects of caregiving. This program is "generic"- it includes information for all caregivers, regardless of specific health situations.

Caring to Help Others: A Training Manual for Preparing Volunteers to Assist Caregivers of Older Adults (2001). Eisai, Inc. This manual offers limited, but clear advice on effective communication with primary caregivers and patients and effective navigation of doctors' offices.

Kinship Foster Care, Grandparent Caregivers: A National Guide (2001). Legal Services for Prisoners with Children and the Brookdale Center of Aging. This is available at www.prisonactivist.org/lspc/ngcm/foster.html/. The article highlights the legal definition of kinship foster care, providing a guideline for grandparents navigating the legal foster care system.

Leading Caregiver Support Groups: A Model Psychoeducational Program (unpublished manuscript). Toseland, R.W., McCallion, P. and Ramos, B.

Manual for facilitating a psychoeducational program for caregivers of the frail elderly. Provides detailed program of eight weekly, and ten monthly follow-up meetings with attention given to emotion-based coping, problem solving, and support. Includes information on facilitating a culturally competent group.

Living with Grief: A Practical Guide for Faith Communities (1999). Hospice Foundation of America.

Offers practical general advice on how faith communities can help individuals cope with illness and death by remaining in close communication and offering support through meals, respite care, running errands, etc.

Maintaining Communication with Persons with Dementia: An Educational Program for Nursing Home Staff and Family Members- Leader's Manual (1998). Toseland, R.W. and McCallion, P. New York, NY: Springer Publishing Company.

A group leader's resource with instructions for leading an educational program. Includes leader guidelines for facilitating group interaction and group activities. This manual provides a reference and additional reading list. Leader's Video is also available.

Maintaining Communication with Persons with Dementia: An Educational Program for Nursing Home Staff and Family Members- Workbook (1998). Toseland, R.W. and McCallion, P. New York, NY: Springer Publishing Company.

Activity workbook for educational program participants. Communications, personal memory albums, and activities for interacting with Alzheimer's Disease patients are highlighted.

The Caregiver Resource Directory (2000). Fraidin, L., Glajchen, M., & Portenoy, R.K. New York: Beth Israel Medical Center.

Much more than a "resource directory," this guide for family caregivers provides clear, concise advice on topics ranging from how to communicate with medical staff to self-care for caregivers. The guide also provides blank forms to be used for such things as assessing personal resources, emergency information, medication schedules, and other features such as a "fatigue journal" to help the caregiver track a patient's energy levels and a page of heavy paper with slits arranged to hold the business cards of physicians and other professionals. Much of this material is also available at www.stoppain.org.

Readings

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DISEASE-SPECIFIC RESOURCES

http://www.apdaparkinson.com

Official website of the American Parkinson Disease Association. Provides information about the disease, referral and information resources, information booklets, and a state-by-state support group finder.

http://www.alsa.org/

The ALS (Lou Gerhig's Disease) Association provides a web page with links to information and referrals, local and national ALS events, and information about this disorder.

http://www.alz.org/

This is the official Alzheimer's Association and Related Disorders web page, dedicated to providing a resource for both family caregivers and professionals caring for individuals with Alzheimer's disease and related disorders. A caregiver's guide, programs and resources, links to local chapters, and information in Spanish are highlighted on this site.

http://www.americanheart.org/

The American Heart Association's web page is a resource for both heart disease and stroke suffers. This site includes information about heart attack and stroke, as well as recent publications, research, and statistics.

http://www.arthritis.org/

This website for the Arthritis Foundation provides information about arthritis as well as local chapter Arthritis Foundation branches.

http://www.cancer.org/

The American Cancer Society provides a site with a wealth of information about cancer, including prevention, detection and symptoms. The site also provides information on types of treatment, brochures available, and other resources.

http://www.diabetes.org/

Official site of the American Diabetes Association. Information about Diabetes available in English and Spanish. Provides tips for patients and caregivers, as well as a section dedicated to professionals working with Diabetes patients.

http://www.hdsa.org/

National website for the Huntington's Disease Society of America. Find local chapters, information about Huntington's Disease, service providers and support groups on this site.

http://www.nmss.org/

Web page for the National Multiple Sclerosis Society. Provides local chapter information, professional education programs, and research highlights.

http://www.nof.org/

The National Osteoporosis Foundation provides a service locator, information for professionals, and support group resources for those with Osteoporosis.

http://www.stroke.org/

The National Stroke Administration website includes survivor and caregiver resources, information about strokes, and a stroke network for professionals.