CAREGIVER SUPPORT INTERVENTIONS

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INTRODUCTION

Caring for a disabled family member can be challenging, potentially impacting caregivers' health, mental health, work, social relationships, and quality of life. To alleviate caregiver stress, enable caregivers to better cope with the demands of caring for a loved one, and improve caregiver and care recipient outcomes, many interventions have been developed. However, although programs supporting caregivers have proliferated, there exists limited research regarding their effectiveness.

In this section, we examine what is known about caregiver interventions and their outcomes. In particular, we examine existing knowledge regarding the five service areas identified in the National Family Caregiver Support Program (Older Americans Act Amendment of 2000, Title III-E):

1. Information to caregivers about available services;

2. Assistance to caregivers in gaining access to these services;

3. 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 care to enable caregivers to be temporarily relieved from their caregiving responsibilities; and

5. Supplemental services, on a limited basis, to complement the care provided by caregivers.

In general, we find that a variety of caregiver support services are useful in alleviating caregiver strain and helping caregivers to provide care. The magnitude of their utility, however, is impacted by a variety of factors: the outcome chosen for measurement; the caregiver's background characteristics, including their psychosocial strengths and vulnerabilities; and the care recipient's type and level of impairment. Interventions in one service area, though useful, have not been found to be as effective as programs utilizing more than one intervention. The success of these multi-component caregiver interventions may be associated with services that address a wider variety of caregiver concerns for diverse groups of caregivers. The key is to find the best combination of services to meet the diverse nature of caregiver needs and experiences.

EFFECTIVENESS OF CAREGIVER INTERVENTIONS BY NFCSP SUPPORT CATEGORIES

<u>Information</u>

One cannot make meaningful decisions about one's caregiving situation unless adequate and complete information is available. Indeed, some consider information, advice, and referral to be the most needed caregiver services (Friss, 1990), for even when services are available, many caregivers remain unaware of them (Maslow & Selstad, 2001). However, it is important to note that the need for information goes beyond how and where to get help. Information regarding health conditions and their implications, care needs, costs of care, and how to plan for future care needs also is important for caregivers (Feinberg, 1997). As a result, most caregiving interventions strive to increase the caregiver's knowledge of available services, the recipient's disease, and caregiver challenges and solutions (Kennet, Burgio, & Schulz, 2000). However, studies that have been done on the effects of information-only services have not shown evidence of

positive mental or physical health-related outcomes (Kennet et al., 2000). Indeed, intervention studies that use information-only as the "usual care" or control condition, suggest that while increasing caregiver's knowledge is important, it is not a sufficient intervention in and of itself.

Assistance Gaining Access to Services

Information about available services does not necessarily translate into caregiver service utilization. Program and service planners, along with policy-makers, must consider five key elements when analyzing why caregivers may not be using services: availability, accessibility, appropriateness, acceptability, and affordability. First, services needed by family caregivers must be available in their community. Second, these services must be accessible. A caregiver may find difficulty arranging for respite care if the respite worker must commute an hour, or if the nearest adult day care center increases the caregiver's daily commute to work by an additional hour. Support groups or counseling services must be located conveniently enough for the caregiver to arrange for a respite worker and make the appointment within a reasonable amount of time. Service accessibility applies not only to physical location of services, but to the structure of service delivery as well. Working hours must be such that the caregiver can reasonably utilize the formal support network.

Third, offered services must be appropriate to the caregiver's needs. There may be a plethora of counseling and support group services in a particular locale, though caregivers may have a more dire need for education and training relating to their relatives' mental or physical limitations.

Fourth, services must be culturally appropriate and acceptable to the caregiver. Service providers must understand that the cultural position towards familial

responsibility and requesting help from those outside the family can be dramatically different from culture to culture. Cultures hold differing expectations about family responsibilities and appropriate sources of support for caregivers. The value placed on individuality as compared with familial consensus or elder/leader authority varies across cultures (Gallagher-Thompson, Arean, et al., 2000). This can result in differing perceptions regarding the utilization of formal services. Furthermore, services must be linguistically accessible in terms of native language, as well as in terms of level of education within that native language.

Fifth, services must be affordable to caregivers. Caregiver consideration of the affordability of services will not only include financial costs, but also costs in terms of time, effort, potential loss of confidentiality, and potential family conflict. Service utilization and behavior change recommended by service providers, or expected by agencies in order to receive services, have direct and indirect costs. Caregivers must be able to reconcile the perceived costs of service utilization with the perceived benefits. Services with narrow selection criteria or high costs/co-pays significantly undermine the availability and accessibility of formal services for many caregivers. Minimizing such costs increases the likelihood of caregiver service utilization.

It is important to note that simply being provided a brochure or phone number may not be as beneficial as actual linkages to services (Cole, Griffin, & Ruiz, 1986). In a study by Weuve, Boult, and Morishita (2000), caregivers who were provided a detailed care management plan and linked directly to services reported less caregiver burden than a control group, which was only provided written information and service referrals. In fact, though the control group was provided detailed literature, many in the control group could not recall that they received any information or could not find the literature.

Another study by Braun and Rose (1994) evaluated the impact of case-managed in-home care on caregivers, which included the direct linking to, or providing of, services to the experimental group. Caregivers receiving the services reported a decrease in time caregiving, a decrease in burden from caregiving, and a decrease in time-off from work for caregiving duties.

Though there is little research evaluating how effectively caregivers are assisted in utilizing services, there exists a strong implication from these two studies that directly linking clients to services, either through on-going case management or as a "linkage" activity, increases the utilization of services and has a positive impact on caregivers. Additionally, caregiver and family needs typically vary across the course of a disease as well as in response to life changes. Information and services useful at one point may not be helpful at another; further suggesting that periodic or ongoing assistance is often warranted.

Counseling, Support Groups and Training

Counseling

Counseling services offered to caregivers vary greatly. Counseling may include, but is not limited to, traditional psychotherapy, individual problem-solving, couples counseling, group counseling, and family treatment. Counseling, whether conducted in an individual, group, or family format, typically strives to relieve caregiver depression and/or anxiety, resolve pre-existing personal problems which complicate caregiving, mollify conflicts between the caregiver and recipient, and/or improve family functioning.

Many studies have examined the effectiveness of these various types of counseling services. In 1996, Bourgeois, Schulz, and Burgio did a comprehensive review of over 100 Alzheimer's disease caregiver intervention studies and found that individual

counseling interventions have shown positive outcomes for narrowly defined problems. Group counseling, however, failed to yield a similar magnitude of effects. These differences between individual and group counseling were related to variations in individual caregiver goals and needs. Daughters and daughters-in-law of frail elderly parents have been found to make greater gains in psychological functioning and well-being when receiving individual counseling than group counseling; group interventions, however, produced greater improvements in caregivers' social supports (Toseland, Rossiter, Peak, & Smith, 1990). These results suggest that the types of problems and issues specific to an individual caregiver might be the most appropriate intervention determinant (Toseland et al., 1990).

Other studies have looked at family counseling approaches with caregivers. The effectiveness of family counseling is being evaluated currently in Miami with Cuban American and Caucasian caregivers. This program, the Family-Based Structural Multisystem In-Home Intervention, provides family counseling that tries to identify existing problems in communication and to produce changes in interaction patterns that allow the caregiver to harness available family and community resources. The focus of change is not just the individual or the environment, but rather the transaction between the two, which is viewed as embedded within larger social and cultural systems (Coon, Schulz, & Ory, 1999). Preliminary data suggest that this intervention, when combined with technological support that links family caregivers to other family members and community resources, yields positive mental health outcomes, especially for Cuban American caregivers (Czaja & Rubert, in press).

Other researchers have looked at the relative effectiveness of psychotherapy or counseling based on different theoretical orientations, finding that caregivers with

particularly high levels of emotional distress, depression or anxiety can benefit from various approaches. For example, Gallagher-Thompson and Steffen (1994) found that psychodynamic therapy and cognitive behavioral therapy were effective in significantly reducing clinical levels of depression in a sample of 60 family caregivers caring for a person with dementia. This same study also found that psychodynamic counseling proved to be more effective with caregivers who had more recently become caregivers, but cognitive behavioral counseling therapy was more effective with those who had been caregivers for a longer period of time.

Support Groups

Support groups are among the most popular and most prevalent interventions available to caregivers. In general, support groups are designed to provide informal peer support, information about diseases and disability, and referrals for caregiver support services. Support groups often are affiliated with a social service or non-profit agency targeted to help older adults and their families, and frequently are led by peers or paraprofessionals. Many support groups include periodic speakers as part of a forum that addresses issues and concerns relevant to caregivers, although the actual structure and content can vary substantially.

Studies have shown that participants in support groups typically evaluate these programs as quite useful and helpful (Gonyea, 1989; Toseland, Rossiter & Labrecque, 1989). In addition, there is some evidence that they provide knowledge and enhance informal support networks (Bourgeois, Schulz, and Burgio, 1996). However, there is much less evidence of their effectiveness in improving caregiver mental and physical health or ability to manage their caregiving situation (Dura, Stukenberg, & Kiecolt-

Glaser, 1991; Monahan, Greene, & Coleman, 1992; Russo, Vitaliano, Brewer, Katon, & Becker, 1995; Toseland et al., 1989).

Education and Training Programs

Education and training programs strive to help caregivers by educating them about resources and by teaching specific problem solving and coping techniques (Toseland & Smith, 2001). Studies assessing the effectiveness of skills training have produced equivocal and, at times, contradictory results. However, teaching specific caregiver skills that are clearly operationalized, practiced, and used to resolve real-life problems have been found to produce significant changes in outcome measures directly related to those skills (Bourgeois, et al., 1996).

Problem-solving and behavior management interventions have been found to demonstrate the greatest effectiveness (Pusey & Richards, 2001). For example, Teri, Logsdon, and Uomoto (1997) found that a nine-week behavior treatment program teaching caregivers skills to manage care recipient depression effectively (increasing pleasant events and problem-solving strategies) decreased depressive symptoms in caregivers. Gallagher-Thompson, Lovett, et al. (2000) found that psycho-educational interventions teaching either mood management skills or problem-solving skills were effective in reducing depression, reducing burden, and increasing coping.

Researchers have begun investigating culturally-targeted education and training interventions. Recent work by Gallagher-Thompson and colleagues (2001), Gallagher-Thompson, Coon, et al. (under review), and Gallagher-Thompson, Solano, et al. (under review) suggest that culturally-tailored skills programs can be more effective with Latinas and Caucasian women than a traditional support group in reducing caregiver depression, increasing positive coping, and fostering aspects of social support. The

REACH Skill Training intervention in Alabama found that behavior management skills training with care-recipients and problem-solving training with caregivers (Coon et al., 1999) resulted in a lower frequency of care recipient behavioral problems, reduced caregiver appraisals of bother, and increased caregiver leisure activities. However, there was some evidence that interventions had differential impacts by race. African-American caregivers showed the greatest reductions in stressfulness appraisal following behavioral skills training, while white caregivers showed greater improvement after receiving only educational support. Results suggest that further work attending to the special needs of minority caregivers is important (Burgio, Stevens, Guy, Roth, & Haley, under review).

Multi-Component Counseling Programs

Programs which offer a combination of counseling, support, and education services have been found to be especially effective. Mittelman, Ferris, Shulman, Steinberg, & Levin (1996) looked at the long-term effectiveness of a comprehensive support and counseling program for spouses and family members of patients with Alzheimer disease in postponing or preventing nursing home placement. The researchers found that a program of counseling and support not only can help prevent increased caregiver depression but it can also substantially increase by up to 326 days the time spouses are able to care for Alzheimer's patients at home, particularly during the early and middle stages of dementia when nursing home placement is generally least appropriate. The latter finding was particularly true for caregiving husbands.

Health Education (HEP) Group Intervention Programs combine multiple aspects of support, counseling, and training services, including emotion-focused and problem-focused coping strategies, education, and support. Members of Kaiser Permanente-Northeast, a regional HMO, were recruited to participate in a study comparing outcomes

of HEP and the staff model of "usual care" offered to caregivers in health maintenance organizations. Participants in this study have been found to have lower rates of depression, greater social integration, increased effectiveness in solving pressing problems, increased knowledge of community services and how to access them, improved feelings of competence, and enhanced responses to the caregiving situation. However, the intervention was not associated with changes in caregiver burden, role strain, or the physical and emotional demands of caregiving (Toseland et al., 2001). A recent multi-component psychoeducational intervention that included education, skills training, and family support significantly reduced caregivers' negative reactions to disruptive behaviors and caregiver burden over time (Ostwald, Hepburn, Caron, Burns, & Mantell, 1999).

Respite

Respite care programs are designed to offer temporary or periodic relief from the time demands of caregiving by providing care for care recipients who are unable to remain alone due to mental or physical impairment. Respite is a secondary benefit received by the caregiver of a service provided to the care recipient. This relief affords the caregiver the opportunity to attend to other tasks, such as shopping, running errands, visiting the doctor, relaxing, or socializing.

Respite services are categorized into three main forms: in-home care, adult day care, and overnight respite. In-home respite consists of someone providing care at periodic intervals in the care recipient's home for a specified amount of time while the primary caregiver is away or occupied by other activities. Forms of in-home respite may include assistance with household chores, physical care, or care recipient companionship and supervision (Kropf, 2000; Zarit, Gaugler, & Jarrot, 1999). Adult day care consists of

care during daytime hours for individuals with dementia or other disabilities in a supervised, structured, congregate environment; care may be medical, social, and/or behavioral (Gelfand, 1999; Kropf, 2000; Zarit et al., 1999). Finally, overnight respite consists of 24-hour care in a nursing home, hospital, or other extended care facility. Stays range from one night to two or more weeks, depending on the needs of the caregiving family. The type of care that is most useful to the caregiver will depend on the caregiver's and care receiver's needs (Administration on Aging, 2001; Bourgeois et al., 1996; Kropf, 2000; Toner, 1993; Toseland & Smith, 2001; Zarit et al., 1999).

Respite services, mainly in the form of in-home and adult day care, have been shown to contribute to decreases in caregivers' perceived stress, burden, anxiety, and somatic complaints, and an increase in caregiver morale, although respite use does not necessarily relieve caregiver depression (Biegel & Schultz, 1998; Bourgeois et al., 1996; Lyons & Zarit, 1999; Zarit, Stephens, Townsend, & Green, 1998; Zarit et al., 1999) Caregivers using respite care also tend to report reduced social and emotional isolation, and increased self-esteem, assertiveness, and control over their lives (Bourgeois et al., 1996). Caregivers typically report being "satisfied" to "highly satisfied" with the benefits of respite care to themselves and to the care recipient (Bourgeois et al., 1996; Feinberg & Whitlatch, 1997; Toseland et al., 2001; Zarit et al., 1999).

Early use of respite care is especially important if caregivers are to receive the greatest positive impact. Early intervention has been shown to relieve more caregiver stress and other negative outcomes than respite services offered after the caregiver has been providing care for many years (Lyons & Zarit, 1999). Moreover, research indicates that regular, on-going use of respite services, in contrast to intermittent, inconsistent use, can result in lower levels of caregiving-related stress, reduced feelings of overload and

burden, and better psychological well-being (Bourgeois et al., 1996, Toseland et al., 2001; Zarit et al., 1998).

A 1997 study conducted by Feinberg and Whitlatch compared the use of two different auspices under which in-home respite care could be provided: agency-based respite services and "direct pay" respite services using vouchers. Interestingly, the study found the direct pay voucher system to be more cost-effective than the agency-based model. Users in both groups spent approximately $282 per month on respite care, yet direct pay users received 36.6 hours of respite care while agency based users received 28.1 hours of respite per month. The principal reason for this difference is that direct pay users hired family and friends as respite aides at lower rates (an average of $7.70 per hour) than agency respite workers were paid (an average of $10.10 per hour), and thus were able to receive more hours of respite care per dollar spent than agency-based users.

Few studies investigate the impact of respite care on care receivers. However, there is some evidence that dementia patients receiving respite care show improvement in reported problem behaviors (Burdz, Eaton, and Bond, 1988, in Bourgeois et al., 1996), although this may not be associated with changes in caregiver burden. Adult day care programs are especially likely to have salutary effects for participants, which may increase with continued use (Gilleard, Belford, Gilleard, Whittick, & Gledhill, 1984, in Bourgeois et al., 1996). Generally, care recipients appear to experience decreased confusion, improved mood and life satisfaction, and improved well-being as a result of adult day care attendance (Zarit et al., 1999).

The benefits of overnight respite use for the caregiver and the care receiver are less clear. Although overnight respite can reduce caregivers' physical and mental strain (Burdz et al., 1988; Scharlach & Frenzel, 1986;), this relief may only be temporary (Zarit

et al., 1999). In fact, elders placed in overnight respite frequently are institutionalized at higher rates than are other elder care recipients, with increases of 12% (Foundation for Long-Term Care, 1983) to 29% (Larkin & Hopcroft, 1993). One possibility for this increased rate of institutionalization may be that overnight respite acts as a bridge to placement for caregivers, helping accustom them to relinquishing care of their care recipient (Zarit et al., 1999).

<u>Supplementary Services</u>

Supplementary services encompass other services which complement the care provided by caregivers. The area of supplementary services is loosely defined, as each state is afforded the opportunity to develop creative supports for its caregivers. For example, by using Medicaid waivers, states have the flexibility to offer home and vehicle modification programs, as well as assistive devices. The California Department of Aging includes home modification, home security and safety assistance, assistive devices, personal care, chores/homemaker services, home delivered meals, legal assistance, visiting caregiver, and assistance with placement in an appropriate living arrangement as examples of supplementary services. The assumption is that by providing these benefits, informal caregiving is strengthened by making it less taxing for caregivers to assist the care recipient (Smith, Doty, & O'Keefe, 2000).

A review of research supports the use of supplementary services. For example, supplemental services such as the installation of emergency alarms, provision of meals, and minor home modifications, when coupled with case management, can result in positive outcomes overall for caregivers (Braun & Rose, 1994).

Multi-Component Programs

Most programs offer more than one service to better meet the needs of individual caregivers, as they face different challenges during various stages of their caring careers. These multi-component programs may include two or more of the five service areas outlined in Title III-E of the Older Americans Act. For example, the Brooklyn Hospital Center's program, Supporting Family Caregivers of Neurologically Impaired Patients, offers individual counseling, home visits, information, as well as support groups. The state of Pennsylvania also offers various caregiver services, including information and referral, family consultation, care management, legal consultation, respite care, home modifications, emergency response, support groups, caregiver education and training, counseling, and financial assistance (Feinberg & Pilisuk, 1999).

Research has shown that multi-component interventions, especially those that contain a skill training component, generate larger effects than narrowly-focused interventions (Kennet et al., 2000). Multi-component programs have been found to have positive effects on caregivers in areas such as subjective burden, caregiver depression, service utilization, stress levels, and perceived quality of life (Kosloski and Montgomery, 1993; Mittleman et al., 1996; Mohide et al., 1990; Montgomery & Borgatta, 1989; Ostwald et al., 1999; Seltzer, Ivry, & Litchfield, 1987; Zarit et. al, 1998). However, studies done on multi-component programs offer little insight into the relative effectiveness of specific program components (Bourgeois et al., 1996; Zarit et al., 1998), making it difficult to determine which specific interventions are most helpful and how to create cost-effective treatments that maximize potential benefits to caregivers.

SUMMARY AND CONCLUSIONS

Caregivers typically grapple with more than one caregiving concern. A review of current literature demonstrates that programs flexible enough to meet the unique needs of different caregivers can be most successful. Programs which incorporate multiple aspects of the service areas discussed are better positioned to affect positive outcomes for caregivers. Despite what is known about interventions in these five caregiver service areas, future program design and implementation would benefit from further investigation. The following section outlines some of the implications and limitations of current research, and suggests new directions for caregiver services.

Implications

Interventions should be geared to the specific needs of particular caregiver populations. The needs of caregivers of demented individuals differ substantially from the needs of other caregivers, for example. A study by Ory, Hoffman, Yee, Tennstedt, and Schulz (1999) found that the two groups differ not only with regard to stressors and perceived stress, but also with regard to the type and amount of long-term care and caregiver support services needed.

Culture and ethnicity also need to be considered in designing services for caregivers. Although a number of recent studies have included greater sensitivity to racial, ethnic, and other cultural features, most intervention research has been done exclusively on Caucasians (Burgio et al., under review; Czaja & Rubert, in press; Gallagher-Thompson, Arean, et al., 2000; Gallagher-Thompson, Coon, et al., under review; Gallagher-Thompson et al., 2001; Hersen & Van Hasset, 1998; Janevic & Connell, 2001). More intervention studies culturally tailored to specific groups are

needed to enhance our knowledge of how to develop more culturally competent caregiver programs and to better address individual differences and needs.

Secondly, appropriate and realistic outcome measures are needed in order to evaluate the effectiveness of caregiver programs (Bourgeois et al., 1996). Too often interventions fail to assess relevant proximal outcomes, making it difficult to understand how and why an intervention did or did not work (Schulz, 2000). More attention needs to be given to using general outcome measures that facilitate comparisons with non-caregiver groups; also needed are outcome measures that are sensitive to change and that have good test-retest reliability, so that effects are not underestimated (Farran, Keane-Hagerty, Salloway, Kupferer, & Wilken, 1991).

A third important limitation of most intervention research is the failure to examine the possible ramifications of caregiver programs for the care recipient and for the caregiver/care-recipient dyad. Unfortunately, most programs and studies are concerned only with caregiver needs and outcomes. Little is known about the ways in which caregiver interventions may impact the care received by care recipients, or the quality of the caregiver-recipient relationship. Yet, there is some beginning evidence to suggest that important synergies may be achieved by simultaneously treating the caregiver and care recipient and/or altering the social and physical environment of the caregiver/care-recipient dyad (Schulz, 2000). For example, services that provide respite to family caregivers may allow them to provide higher-quality care for a longer period of time, and services that benefit patients may ease some of the demands of caregiving for the care provider (Zarit et al., 1999).

Fourth, although the vast majority of research delineates negative effects of caregiving, an emerging literature suggests that caregiver stress and burden may be

counterbalanced, in part, by the positive aspects of caregiving (Kramer, 1993a, 1997;

Lawton, Moss, Kleban, Glicksman, & Rovine, 1991; Lawton, Rajagopal, Brody, &

Kleban, 1992; Miller & Goldman, 1989). This relatively new caregiver literature

provides increasing support for the 'gains' perspective as a potentially meaningful arena

for program development. A number of studies have suggested that the decision to

become or remain a caregiver over an extended period of time may be associated with

positive motivations such as: the opportunity to give back to the care recipient; an

improved relationship with care recipient or other family members; prevention of further

care recipient deterioration or feeling good about the quality of care provided; the

opportunity to serve as a role model; increased self-esteem; feeling appreciated; an

enhanced sense of meaning or purpose; and feelings of pleasure (Farran et al., 1991;

Harris, 1998; Kramer 1993a, 1993b; Lawton, Kleban, Moss, Rovine, & Glicksman, 1989;

NAC/AARP, 1997).   Such positive aspects of caregiving may have beneficial effects for

caregivers and care-receivers alike (Miller & Lawton, 1997). Moreover, interventions

that enhance positive aspects of the caregiving experience may be more acceptable that

those focused on alleviating strain.

A fifth issue which merits additional attention is how technological advances may

improve caregiver outcomes. Home videos, computer programs, telephone services, and

online education and support are just a few of the many ways technology may enhance

services. The few studies to date that have looked at the effectiveness of technological

programs have found generally positive results. For example, a study conducted by

Leirer, Morrow, Tanke and Pareante (1991) found that a computer network enhanced the

instrumental and emotional support provided by nurses to caregivers. A current study is

looking at the effects on caregiver stress of a Telephone-Linked Care (TLC) program,

which provides a 24-hour automated telecommunication system through a computer-controlled human voice system that speaks with caregivers at home (Coon et al., 1999). Programs such as these are on the rise and it is important to understand the value of the various types of technological interventions in order to utilize them appropriately for the development of future interventions.

Lastly, the importance of creating and sustaining partnerships is a central issue in the development of successful caregiver interventions. Improving caregiver well-being requires moving beyond the individual caregiver to the organizational, community, and policy levels. Tomorrow's interventions should be directed at enhancing coordination among employer health care systems, churches, senior centers, and other community based organizations (the organizational level), within the context of retirement communities, cities, counties, and service regions (the community level), as well as the broader-based policy level, in order to more effectively assist our increasingly diverse population of family caregivers (Coon & Thompson, in press).

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