
Caregiver Depression: *A Growing Mental Health Concern*

POLICY BRIEF

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ABOUT FCA

Founded in 1977, Family Caregiver Alliance serves as a public voice for caregivers, illuminating the daily challenges they face, offering them the assistance they so desperately need and deserve, and championing their cause through education, services, research and advocacy.

Long recognized as a pioneer among caregiver organizations, FCA operates programs at local, state and national levels. FCA is the lead agency and model for California's statewide system of Caregiver Resource Centers. In 2001, FCA established the National Center on Caregiving to advance the development of high-quality, cost-effective policies and programs for caregivers in every state in the country.

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“Too often, attention to mental health services for older people and their caregivers is negligible or absent, despite the fact that mental health problems and caregiver distress are among the leading reasons for institutionalization” (U.S. Department of Health and Human Services, 1999).

INTRODUCTION

Caring for older relatives with a chronic or disabling condition is one of the most prominent issues challenging American families. Currently, an estimated one in four U.S. households provides some assistance to a loved one aged 50+ (National Alliance for Caregiving & AARP, 1997). Informal—and largely unpaid—help is so common, in fact, that families provide nearly two-thirds (64%) of all home and community-based care in the United States (Liu, Manton, & Aragon, 2000).

While most older people prefer to remain at home and in the community, caregiving can exact a heavy toll on those who provide care. A large body of research has documented the physical, financial and emotional toll of caregiving. While stress, burden and anxiety are common hallmarks of the caregiving experience, high rates of depressive symptoms among family and informal caregivers have been noted extensively in the research literature and warrant special attention.

Depression and other mental illnesses are surprisingly prevalent in the U.S. Only recently have mental health issues and their enormous costs to society gained the attention of policymakers, de-

spite the fact that mental illness accounts for the number one cause of disability in the U.S. (President’s New Freedom Commission on Mental Health, 2002). In 1999, the U.S. Surgeon General produced a landmark report entitled *Mental Health: A Report of the Surgeon General*, which brought to light the growth of mental health problems in the U.S. as well as the many barriers to effective treatment and care for those who suffer from these illnesses, including depression. In response, the President’s New Freedom Commission on Mental Health was launched in 2002 to attempt to address the shortfalls in our mental health care system and thereby tackle this costly problem.

This policy brief addresses the economic and health consequences of depression among family caregivers of older adults and younger persons with disabilities in the U.S. It discusses promising practices for recognition and treatment of caregiver depression as well as recommendations for improving the mental health and well-being of family caregivers, thereby safeguarding their continued ability to provide long-term care for loved ones.

EFFECTS OF CAREGIVER DEPRESSION: WHY SHOULD WE CARE?

Psychological health is the area of the family caregiver’s daily life that is most affected by providing care. Studies consistently report higher levels of depressive symptoms and mental health problems among caregivers than among their noncaregiving peers (Schulz, O’Brien, Bookwala, & Fleissner, 1995). As compared to the general

population, primary caregivers are more frequently depressed and anxious, are more likely to use psychotropic medications, and exhibit more symptoms of psychological distress (Schulz et al., 1995; Toseland & Smith, 2001; Zarit & Zarit, 1998). Depression appears to be the most common disorder with 30% to 59% of caregivers

reporting depressive disorders or symptoms

(Cohen et al., 1990; Family Caregiver Alliance, 2001; Mittelman et al., 2002). With an estimated 22 million family and informal caregivers aiding older persons in the U.S. (U.S. Department of Health and Human Services & U.S. Department of Labor, 2003), as many as six to 11 million in-

formal, unpaid caregivers may be battling symptoms of depression or related disorders that have costly consequences.

High rates of depressive symptoms among caregivers put many individuals at serious risk of poor physical health outcomes as well. Depression is a significant risk factor for common chronic conditions, such as coronary heart disease, cancer and diabetes (Cannuscio, Jones, Kawachi, Colditz, & Berkman, 2002; National Institute of Mental Health, 2001). Often, people with undiagnosed depression undergo treatments for physical symptoms, such as headaches and back problems, with little or no relief. In one prominent study of the health effects of caregiving, researchers found that older caregiving spouses who reported strain due to caregiving experienced a 63% higher mortality rate than older spouses who were not involved in caregiving (Schulz & Beach, 1999).

When caregivers suffer from excessive burden and high rates of depressive symptoms, the potential impact to the family, patient, employer and soci-

ety can be high. Research has shown that depression is a costly disorder if it goes untreated. People with depression have been found to use two to four times more health care than people without mental illness (Goff, 2002). The real costs of depression, however, are the indirect costs associated with disability and lost productivity at work

when depression is not recognized or treated. Given that a full two-thirds of caregivers are in the workforce, juggling caregiving, employment and other family responsibilities (National Alliance for Caregiving & AARP, 1997). The costly impact to employers and business can be staggering. One study found that lost productivity of caregiving employees (due to many factors, including depression) may cost the nation's employers

as much as \$29 billion annually (Metropolitan Life Insurance Company, 1997).

Depression further depletes the caregiver's own resources, increasing care costs for both caregiver and care recipient, including earlier institutionalization. When caregivers feel depressed and overwhelmed by their caregiving tasks, they are more likely to suffer burnout and may make the often agonizing decision to place their loved ones in a nursing home. Research shows that home care is significantly less costly than nursing homes, thus early institutionalization of the ill or frail family member is likely to be more costly than if people can remain at home (U.S. Department of Health and Human Services [HHS], 1999).

The costs of early institutionalization extend beyond the family and fall on the shoulders of taxpayers. While families pay one third of nursing home costs, most of the bill is picked up by publicly funded programs (i.e., Medicare and Medicaid), which pay for 58% of nursing home costs (Kaiser Family Foundation, 2001).

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BARRIERS TO EFFECTIVE RECOGNITION AND TREATMENT OF CAREGIVER DEPRESSION

Barriers to the effective recognition and treatment of depressive symptoms among caregivers have been well documented. These barriers include:

Caregivers do not seek out appropriate mental or physical health care services.

Caregivers often focus on the needs of those they take care of and neglect their own health needs. For example, studies have shown that caregivers with higher depressive symptoms are no more likely than noncaregivers to seek medical help (Commonwealth Fund, 1999; Polen & Green, 2001). Compounding this problem, many caregivers do not have the time to address their own health concerns.

Caregivers may not have access to effective, affordable mental health services.

Mental health services and medications are often too expensive for many people, including caregivers. Many caregivers have limited economic resources and may not have insurance to cover their own medical care: approximately half of all caregivers have a household income of less than \$35,000 (Commonwealth Fund, 1999; Kaiser Family Foundation, 2001). One study found that 25% of women caregivers had difficulty getting medical care compared to 16% of noncaregiving women. Women caregivers were also twice as likely as noncaregiving women to leave prescriptions unfilled because of cost (Commonwealth Fund, 1999).

The current structure of private and publicly-funded insurance programs, including Medicare, also prevents caregivers from accessing necessary mental health services. Medicare, as well as some other private insurance plans, does not cover prescription medications, including antidepressants. This is especially tragic, as antidepressants have been shown to be highly effective in relieving the symptoms of depression (Goff, 2002).

Another barrier to appropriate mental health treatment is the so-called mental health parity issue—many medical plans require a 50% co-payment for mental health services compared to a 20% co-payment for other medical services. This results in higher out-of-pocket costs for those who seek treatment. As a result, many people simply do not receive needed mental health care.

There is a shortage of publicly-funded caregiver support services.

While the number of caregiver support programs that are designed to assist family and friends in meeting their own health and mental health needs has been growing nationwide, there is still a dearth of caregiver support services overall. Effective caregiver support services include specialized information, caregiver training and education, family counseling, caregiver support groups, respite care, and in-home care. The National Family Caregiver Support Program (NFCSP) was enacted as part of the reauthorization of the Older Americans Act in 2000. Although modestly funded, this important program represents the first federal recognition of and commitment to support family and informal caregivers of the elderly. In addition, some states, notably California and Pennsylvania, have devoted some state general funds to programs that explicitly support caregivers. Despite these and other programs, the absence of widespread caregiver support services means that most families are still on their own with limited outside assistance.

Primary care physicians do not address family caregiver needs and issues.

Primary care physicians who treat older adults living in the community are in the best position to identify caregivers at risk and to refer them to needed services (HHS, 1999). Yet, this family-centered approach is not common practice, because the physician typically focuses on the patient only. To address this challenge, new treat-

ment models are being developed and promoted. These include the simultaneous evaluation and treatment of the family caregiver and care recipient by their primary care physician (Hooker et al., 2002).

Primary care physicians regularly under-diagnose and under-treat depression.

Numerous studies have shown that general practitioners miss 30% to 50% of depression diagnoses in the primary care setting. Further, even when depression is accurately diagnosed, it is often undertreated (Goff, 2002). Despite these facts, collaborative and systematic depression management interventions in the primary care setting have been shown to be medically effective, fairly easy to implement and cost-effective (Katon et al., 1995; Katzelnick, et al., 2000). Comprehensive depression management interventions, which link psychiatric and primary care practitioners, result in better outcomes for patients. In addition, these models have received favorable responses from primary care physicians and have been shown to reduce overall medical costs by depressed patients who are often high-utilizers of medical care.

PROMISING PRACTICES TO ALLEVIATE DEPRESSIVE SYMPTOMS AMONG CAREGIVERS

The high rate of depressive symptoms among caregivers is a serious problem. The good news, however, is that research shows that existing programs and interventions can effectively alleviate depressive symptoms among informal caregivers who provide family care. Some of the most promising practices include:

Multi-component caregiver support interventions

Flexible and comprehensive caregiver support programs have proven to be the most successful in alleviating caregiver strain and addressing depressive symptoms and distress (Mittelman et al., 1995; Zarit & Zarit, 1998). One innovative caregiver intervention to address depression uses

individual and family counseling sessions, the availability of counselors to assist with crises and provide ongoing support at any time, and participation in a support group. Results indicate that caregivers who received the treatment compared to those in the control group had lower depression scores and were able to delay institutionalization of their loved ones with Alzheimer's disease by one year (Mittelman et al., 1995).

Respite to reduce caregiver burden

Respite programs, which give family members a break from their caregiving responsibilities, can include in-home, community-based or institution-based services. Respite breaks can be provided for a few hours or for multiple days. Because respite programs have proven very popular and helpful to caregivers, these programs have increasingly become an integral part of comprehensive caregiver programs aimed at alleviating caregiver depression and burden (HHS, 1999; Schulz et al., 1995). One major study assessing the effectiveness of respite to reduce psychological distress found that dementia caregivers who used adult day care services (one form of community-based respite), decreased their own care-related stress and depressive symptoms compared to dementia caregivers who did not use adult day care services (Zarit et al., 1998). Though the enactment of the NFCSP has increased somewhat the availability of respite programs throughout the country, the existing need for respite care to sustain caregivers greatly exceeds the availability of services.

Financial support to alleviate the economic stress of caregiving

Family caregivers provide an estimated \$257 billion dollars worth of unpaid, informal care in the U.S., more than the annual spending on home health care (\$32 billion) and nursing home care (\$92 billion) combined (Arno, 2002). Yet, the families providing this care rarely receive payment for their services and are often in more difficult financial circumstances as a result of their caregiving (Commonwealth Fund, 1999).

The Cash and Counseling Program, which allows payments to family caregivers, is one national model that may prove promising in addressing financial stress among low-income caregivers. This model project, funded by the U.S. Department of Health and Human Services and the Robert Wood Johnson Foundation, is a national demonstration project designed to increase consumers' control over their personal care and assistance in the home without increasing costs. The Cash and Counseling Program enables eligible Medicaid care recipients in three states (Arkansas, Florida, & New Jersey) to use monthly cash allowances to hire their own direct care workers, including family members and friends. Expanding this innovative program to allow more family caregivers to be paid through state and federally funded caregiver support programs could greatly alleviate the economic and emotional/mental health needs of low-income family caregivers.

Primary care interventions that address caregiver needs

Primary care physicians can play a critical role in addressing caregiver depression. Resources for Enhancing Alzheimer's Caregivers Health (REACH), is an initiative begun in 1995 by the National Institute of Health. Its primary purpose is to develop and test new ways to help families manage the daily activities and the stresses of caring for people with Alzheimer's disease or a related disorder. The initiative is designed to reduce depression and burden among family caregivers by addressing problem behaviors in the care recipient. REACH combines treatment of dementia problem behaviors through medications and behavior modification techniques and

caregiver education and counseling programs (Burns et al., 2003).

POLICY RECOMMENDATIONS

Decision-makers in both the public and private sectors are beginning to grapple with a growing issue facing the U.S.: how to support and sustain those who are the backbone of our long-term care system—family and informal caregivers of the elderly and adults with disabilities (Feinberg, Newman, & Van Steenberg, 2002). Caregiver depression and other mental health issues represent serious public health concerns. The following policy recommendations are offered to stimulate debate and action about ways to better support family and informal caregiving.

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depression and other mental health issues represent serious public health concerns. The following policy recommendations are offered to stimulate debate and action about ways to better support family and informal caregiving.

- ◆ Produce a first Surgeon General's Report on Caregiving. Building on the 1999 landmark report, *Mental Health: A Report of the Surgeon General*, the federal government should commission a Surgeon General's Report on Caregiving to mobilize public attention regarding the growing mental health needs of caregiving families.
- ◆ Include family caregivers of the elderly as consumer representatives on all federal commissions related to mental health and long-term care. President Bush's New Freedom Commission on Mental Health should add representatives from the family caregiving community to ensure that the mental health needs of family caregivers are addressed.
- ◆ Increase funding for existing caregiver support programs so that family caregivers are considered true partners in long-term care.

The funding level of the NFCSP and state-funded caregiver support programs should be increased so that family caregivers have more access to valuable support services (e.g., family counseling, support groups, training and education, respite care) that will help prevent burnout and mental health distress.

- ◆ **Encourage programs to offer cash benefits to family caregivers to alleviate the economic strain of caregiving.** Publicly funded caregiver support programs should include cash benefits (such as the Cash and Counseling model) for low-income families struggling to care for loved ones at home rather than placing care recipients in expensive institutional settings.
- ◆ **Support parity in mental health and physical health.** Public and private health insurance programs should expand mental health coverage and ensure parity, so that psychotherapy services are available and affordable to caregivers suffering from depression and other mental health distress. In addition, Medicare benefits must include prescription drug coverage—a benefit that would assist eligible family caregivers with anti-depressant medication coverage, if needed.
- ◆ **Encourage specialized training of health care providers to recognize and treat depression in family caregivers.** Physicians and other health care providers need to be educated about the physical and emotional impact of caregiving and encouraged to treat family members in conjunction with their patients. Health care practitioners conducting medical assessments of patients, especially those with dementia, should also

screen the patient's caregiver for health and depression risks as well. Physicians should offer evidence-based treatments (e.g., psychotherapy, anti-depressants) to caregivers if needed.

CONCLUSION

Family and informal caregivers provide the majority of long-term care in the U.S. Given the dramatic aging of the U.S. population, family caregiving will become an even more important issue in the coming decades. This policy brief addresses the reasons that improved recognition and treatment of depression among family caregivers is a growing mental health concern and why caregiver depression should be considered a public health priority. It also underscores the serious and costly consequences of depression among family caregivers, and the effects on the care recipient, employers and society.

A substantial body of research suggests that comprehensive caregiver support services improve the physical and emotional health of caregivers and reduce government expenditures on nursing home care. Further, increasing financial assistance and assuring appropriate mental health and medical care for family caregivers are important steps towards addressing caregivers' psychological health.

It is imperative that we adopt policies and put systems in place that will assist and support family caregivers who are at such high risk of depression and poor physical health. Without these necessary support services, providing care to a loved one at home or in the community will become an even greater challenge for our families—the most important and valuable component of our nation's long-term care system.

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