Care of the Aging Patient: From Evidence to Action

Caregiver Burden
A Clinical Review

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IMPORTANCE Caregiver burden may result from providing care for patients with chronic illness. It can occur in any of the 43.5 million individuals providing support to midlife and older adults. Caregiver burden is frequently overlooked by clinicians.

OBJECTIVES To outline the epidemiology of caregiver burden; to provide strategies to diagnose, assess, and intervene for caregiver burden in clinical practice; and to evaluate evidence on interventions intended to avert or mitigate caregiver burden and related caregiver distress.

EVIDENCE Cohort studies examining the relation between demographic and social risk factors and adverse outcomes of caregiver burden were reviewed. Review of recent meta-analyses to summarize the effectiveness of caregiver burden interventions were identified by searching Ovid MEDLINE, AgeLine, and the Cochrane Library.

RESULTS Risk factors for caregiver burden include female sex, low educational attainment, residence with the care recipient, higher number of hours spent caregiving, depression, social isolation, financial stress, and lack of choice in being a caregiver. Practical assessment strategies for caregiver burden exist to evaluate caregivers, their care recipients, and the care recipient's overall caregiving needs. A variety of psychosocial and pharmacological interventions have shown mild to modest efficacy in mitigating caregiver burden and associated manifestations of caregiver distress in high-quality meta-analyses. Psychosocial interventions include support groups or psychoeducational interventions for caregivers of dementia patients (effect size, 0.09-0.23). Pharmacologic interventions include use of anticholinergics or antipsychotic medications for dementia or dementia-related behaviors in the care recipient (effect size, 0.18-0.27). Many studies showed improvements in caregiver burden–associated symptoms (eg, mood, coping, self-efficacy) even when caregiver burden itself was minimally improved.

CONCLUSIONS AND RELEVANCE Physicians have a responsibility to recognize caregiver burden. Caregiver assessment and intervention should be tailored to the individual circumstances and contexts in which caregiver burden occurs.

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The Patient's Story

Mrs D, at 84 years of age, was the primary caregiver for her functionally impaired 86-year-old husband and shot herself 3 times in a suicide attempt. Mrs D's family did not perceive the severity of the caregiver burden as a family picnic was planned for the day of her attempted suicide. Mrs D did not leave a note and later stated she fully intended to kill herself. While recovering in the hospital, she expressed relief at not having caregiving responsibilities. Two months later, her husband died, which Mrs D described as a release for her.

Mrs D did not have a primary care physician or attend any medical appointments for her own health needs, but she often accompanied Mr D to his appointments. Her 2 adult daughters lived nearby with their families. Reflecting on her caregiving experience, Mrs D stated, *"it didn't seem like there was anything that anybody could do for him,... I was doing all the house and yard work and taking care of him. ...This was very hard for me, physically."*

Mrs D's daughter: *We tried to help where we could, but she was reluctant to accept it....*

Mr D would not accept nonfamily home health care.

Perspectives

Mrs D: *I could not stand another 24 hours. ...I asked my husband more than once, wouldn't he like some of those people to come in and help him? At least bathe and things like that. ... He said no.*

Mrs D's daughter: ... *[S]he thought she was responsible to... do just about all of the caretaking. ...[T]hey did the parent thing of don't worry the kids about how bad off maybe Dad is, or how she was feeling...*

Dr K (inpatient geriatrician): *[The suicide attempt] was originally precipitated by years of caregiver burden. ... Mrs D stated that she was planning this for 2 years. Every day ... when she thought about committing suicide, ... that made her feel better that she had an option.*

Ms M (social worker): *Sometimes [adult children] who still see their parents as being all-functioning and can do everything, may miss subtle cues or don't listen between the lines. ...*

Dr N (inpatient psychiatrist): *She didn't look that depressed and she said she wasn't feeling that depressed. ... It struck me that the most useful thing would be ... changing her situation and changing the drivers for that sense of feeling helpless and feeling trapped.*

Caregiver Burden

A Primer for Clinicians

Mrs D's story illustrates the overlapping domains of physical, mental, and psychosocial health affecting caregivers of older patients. These domains are manifested by late-life depression, geriatric suicide, social isolation, and caregiver burden. Caregiver burden can be the most compelling problem affecting caregivers of chronically ill elderly patients. Overwhelming caregiver burden drove Mrs D to attempt suicide. Although Mrs D's case demonstrates the outcome of extreme caregiver burden, the clinical goal is to prevent or detect caregiver burden early in its course, provide skillful caregiver assessment, and offer appropriate intervention(s) to prevent or treat caregiver burden. This review emphasizes the clinician's responsibility to recognize caregiver burden when treating patients or caregivers, provides tools for assessing caregiver burden, and reviews meta-analyses of interventions that prevent or mitigate caregiver burden.

Definitions

There is no *International Classification of Diseases, Ninth Revision (ICD-9)* or *ICD-10* code for caregiver burden. In a longitudinal study of husbands and wives as caregivers, Zarit and colleagues proposed a useful definition: "The extent to which caregivers perceive that caregiving has had an adverse effect on their emotional, social, financial, physical, and spiritual functioning."[1] This definition emphasizes the multidimensional toll caregiving may exact on care providers and also that caregiving is a highly individualized experience.[2] Some caregiving circumstances likely cause burden and stress for caregivers (eg, the need for heavy assistance with activities of daily living, social isolation, and financial deprivation as a result of illness and caregiving), but different thresholds exist for triggering caregiver burden. Caregiving, although at times stressful, can be emotionally rewarding because it can affirm family ties, honor past service the caregiver received from the person now needing care, and save family resources.[3]

The Epidemiology of Family Caregiving and Caregiver Burden

Unpaid family or informal caregivers provide as much as 90% of the in-home long-term care needed by adults.[4,5] In 2009, an estimated 65.7 million individuals in the United States served as unpaid family caregivers to an adult or child; of these, 43.5 million (66%) provided care for an adult older than 50 years. An aging population, an increased number of individuals living with chronic disease, and the lack of formal support for caregivers have increased caregiver burden prevalence. A survey of caregiver burden demonstrated that 32% of caregivers have high caregiver burden and 19% have medium caregiver burden based on a measurement of time spent providing care and the care recipient's degree of dependency.[5]

As with Mrs D, the majority of caregivers are women who take care of a relative (86%) or friend (14%). Caregivers spend an average of 20.5 hours per week providing care, with 20% spending more than 40 hours per week.[5] Caregiving includes assistance with basic and instrumental activities of daily living and medical support (eg, medication management, scheduling and accompanying care recipients to medical visits, and making treatment/management decisions). Equally important, the caregiver provides emotional support and comfort.

The economic value of this informal caregiving dramatically surpasses spending for formal home health care and nursing home care.[6] A recent cohort study estimated the cost of informal dementia caregiving at $56 290 annually per patient.[7]

Spousal caregivers, as compared with an adult child assisting a parent,[8] face greater challenges because they are more likely to live with the care recipient, have little choice in taking on the caregiving role, are less aware of the toll that caregiving is taking on them, and are more vulnerable because of their older age and associated morbidities.[9]

Most family caregivers are untrained and often feel ill prepared to take on caregiving tasks. This is especially true for caregivers who provide more medically skilled caregiving such as changing catheter bags, providing wound care, or overseeing complex medication management. Caregivers who are the primary interface with the health care system often receive inadequate support from health professionals and frequently feel abandoned and unrecognized by the health care system.[10]

Risk Factors for Caregiver Burden

Risk factors for caregiver burden include female sex, low educational attainment, residing with the care recipient, depression, social isolation, financial stress, higher number of hours spent caregiving, and lack of choice in being a caregiver (**Table 1**). Mrs D's statement, "I could not stand another 24 hours of watching him the way he was," highlights the detrimental effect of 24/7 exposure to the suffering of a loved one with chronic illness. Around-the-clock care obligations, particularly in situations that may be associated with high or increasing care needs (eg, dementia, cancer, decreased functional status, end-of-life care), and care transitions (eg, hospital to home) are all substantial risk factors for caregiver burden[21,22] and should trigger referrals for caregiver assessment.[23]

Table 1. The Epidemiology of Caregiver Burden

Domain/Feature	Risk Factor and/or Outcome Status of Caregiving
Demographic	
Female sex	Risk factor for becoming a caregiver and for caregiver burden (>2-fold rate of high caregiver burden compared with men)[11]
Low education	Associated with the highest levels of caregiver burden in various conditions, including stroke[12]
Cohabitation with care recipient	Associated with caregiver burden
Clinical outcomes of caregiver burden	
Mortality	Caregiver burden identified as an independent predictor of caregiver mortality with a 63% increased risk of death[13]
Weight loss	Caregiver burden associated with caregiver weight loss
Poor self-care	Higher incidence of low self-care behaviors and of ignoring self-health[14]
Sleep deprivation	Especially common in caregivers of dementia patients who have disruption to the sleep-wake cycle and may also be a risk factor for caregiver burden
Psychosocial	
Depression and depressive symptoms	Identified as risk factor for and outcome of caregiver burden[15]
Coping strategies	Using a smaller number of coping strategies (eg, seeking advice, exercising) associated with caregiver burden in caregivers of dementia patients[16]
Perceived patient distress	Greater likelihood of experiencing caregiver burden in caregivers who perceive distress in the care recipient
Social isolation and decreased social activity	Risk factors for caregiver burden and outcomes of caregiver burden[17]
Anxiety	An outcome of caregiving in caregivers to advanced cancer patients[18]
Suicide	An outcome of caregiver burden
Caregiving context	
Caregiving time and effort	Duration in the caregiving role and hours spent caregiving associated with caregiver burden
Financial stress	A risk factor for caregiver burden and an outcome of caregiver burden[19]
Lack of choice	Lack of choice in becoming a caregiver associated with caregiver burden[20]
Inability to continue regular employment	Caregiving may preclude regular employment; when more than 1 potential caregiver exists, the family member who is not regularly employed is more likely to assume the caregiving role

Studies of caregiver burden are limited by an emphasis on homogeneous diagnostic groups (eg, Alzheimer disease, cancer, stroke) that limit generalizability and identification of features that are common across diagnoses. Most studies are cross-sectional, use convenience samples that may not be representative, or have a combination of both of these characteristics. Studies may be confounded (ie, the fact that factors associated with caregiver burden in some studies such as female sex may be associated with becoming a caregiver in the first place) or have identified caregiver burden risk factors that are also outcomes of caregiver burden (eg, depression, poor financial status).

There are advantages to studying homogeneous diagnoses (eg, Alzheimer disease or cancer) since some diseases may result in more caregiver burden than others.[24] Knowing the primary disease of the care recipient can facilitate prediction of caregiving challenges.

Suffering in Silence: The Caregiver as Invisible Patient

Mrs D: *As he got worse, it got very, very bad, ... mentally, for me to cope... But I didn't ever say anything because that's just what I had to do...*

Two aspects of Mrs D's case are illuminating. First, she had regular interactions with the health care system because of her husband's illness, yet from Mrs D's perspective, she did not receive intervention for her stress related to caregiving. Second, her sense of being overwhelmed and trapped by her caregiver burden resolved completely without the need for any psychopharmacologic intervention after she took drastic measures to remove herself from the caregiving role.

Mrs D's case illustrates the need for physicians to interact with families and in particular primary caregivers. Although family caregivers are often critical to maintaining the care recipient's health and enabling the care recipient to remain at home,[25,26] there has been little emphasis on how clinicians should relate to family caregivers. Physicians do not commonly query the caregiver regarding concerns they have about providing care. Caregivers become "the invisible patient" and often have significant health and psychosocial needs that, in turn, affect caregiving.[27,28]

Two decades ago, Fredman and Daly suggested that physicians consider family caregivers as partners with physicians in the care of the patient.[29] In the case of Mrs D, a more proactive and structured assessment might have uncovered her mounting desperation and allowed for earlier integration of home care and/or hospice services, perhaps averting her suicide attempt.

Diagnosis and Assessment of Family Caregiver Burden

Dr K (inpatient geriatrician): *[Mrs D] appreciated hospice but [she questioned] why couldn't this have happened earlier.*

Although assessment of physical, psychological, and social factors is the cornerstone of quality care for older adults, acknowledgment and assessment of the health and well-being of the family care-

Table 2. Topics and Selected Questions for Caregiver Assessment

Category	Question
Context of care	
Caregiver relationship to care recipient	What is the caregiver's relationship to the patient? How long has the caregiver been in this role?
Family caregiver profile	What is educational background of the caregiver? Is the caregiver employed?
Additional caregivers	Are other family members or friends involved in providing care? Are paid caregivers (eg, home health aides) involved?
Living arrangements	Does the caregiver live in the same household as the care recipient?
Physical environment	Does the care recipient's home have grab bars and other adaptive devices and necessary equipment to assist with care? Is the care recipient homebound?
Caregiver's perception of care recipient's overall health	
Cognitive status	Is the patient cognitively impaired? How does this affect care provision?
Health, functional status, prognosis, and goals of care	What medical problems does the care recipient have? What is the caregiver's perception of the care recipient's medical problems and prognosis, and goals of care? What are the goals of care according to the care recipient?
Caregiving needs	Is the care recipient totally dependent 24/7 or is only partial assistance required? Is there evidence that the caregiver is providing adequate care?
Assessment of caregiver values	
Willingness to provide and agree to care	Is the caregiver willing to undertake the caregiver role? Is the care recipient willing to accept care provision?
Cultural norms	What types of care arrangements are considered culturally acceptable for this family?
Assessment of caregiver health	
Self-rated health	How does the caregiver assess his or her own health?
Health profile	Does the caregiver have any functional limitations that affect the ability to act as caregiver?
Mental health	Does the caregiver feel she or he is under a lot of stress? Is there evidence of anxiety, depression, suicidal ideation?
Quality of life	How does the caregiver rate his or her quality of life?
Impact of caregiving	Is the caregiver socially isolated? Does the caregiver feel his or her health has suffered because of caregiving?
Assessment of caregiver knowledge and skills	
Caregiving confidence	How knowledgeable does the caregiver feel about the care recipient's condition?
Caregiver competence	Does the caregiver have appropriate knowledge of medical tasks required to provide care (wound care, transferring patient, health literacy for administrating complex medication regimen, etc)?
Assessment of caregiver resources	
Social support	Do friends and family assist the care recipient so that the caregiver has time off?
Coping strategies	What does the caregiver do to relieve stress and tension?
Financial resources	Does the caregiver feel financial strain associated with the caregiving? Does the caregiver have access to all financial benefits and entitlements for which the care recipient is eligible?
Community resources and services	Is the caregiver aware of available community resources and services (caregiver support programs, religious organizations, volunteer agencies, respite services)?

Adapted from the Family Caregiver Alliance,[32] Zarit et al,[33] and Parks and Novielli.[34]

giver is not routine.[30] Physicians should play a greater role in assessment of family caregivers, often in collaboration with social work colleagues. This requires identification of factors that may be causing distress (ie, physical demands, the psychological effect of providing care, conflicts between the care recipient and others in the family, financial stresses, and behavioral issues of the care recipient that make caregiving stressful)[31] (**Table 2**).

The National Consensus Development Conference for Caregiver Assessment recommended the following approach: (1) identify the primary and additional caregivers; (2) incorporate the needs and preferences of both the care recipient and the caregiver in all care planning; (3) improve caregivers' understanding of their role and teach them the skills necessary to carry out the tasks of caregiving; and (4) recognize the need for longitudinal, periodic assessment of care outcomes for the care recipient and family caregiver.[32,35]

In addition to the aforementioned approach, physicians should also explore the caregiver's sense of well-being, confidence in abilities to provide care, and need for additional support. The Family Caregiver Alliance has developed a helpful toolkit for comprehensive caregiver assessment.[32,36]

Table 2 provides suggested topics and questions to help physicians assess caregivers. These findings, along with those obtained from more comprehensive caregiver assessment,[32,36] will help the physician and interdisciplinary team to create a coherent, comprehensive, individualized care plan that plays a central role in sup-

Box. **Discussion Catalysts for Engaging Family Caregivers**

Caregiver Health

To provide the very best patient care, I find I need to also pay attention to my patients' caregivers. Can you tell me a bit about how you are feeling/doing?

We know that caregivers often neglect their own health. When was the last time you saw your physician?

Do you have your own physician? Is she or he aware of your caregiving situation? What has she or he advised about it?

Quality of Life

I know that many family caregivers find the role to be very stressful. How are you coping with these responsibilities?

How would you describe your quality of life these days?

How often do you get out?

What do you do for fun?

Support

Many caregivers don't want to burden others—especially their children. Are there times when you really need help but don't ask for fear of being a burden?

Who gives you support? How helpful is this support?

We work with a social worker who is an expert in assisting caregivers. May I refer you to this individual?

Caregiving is a very hard job and the best way to do it well is to take advantage of some of the resources available for help. Are you using any of these? May I help you with a referral?

In Case of Emergency

If anything should happen to you, have you made arrangements for someone to take care of [name patient here]?

porting the care recipient and caregiver. The care plan might include respite for caregivers (provision of short-term relief with an in-home temporary caregiver or inpatient respite, through which the care recipient stays in a facility for several days or weeks), supplemental services, limitations on medical interventions, and many other considerations.

The **Box** provides suggested openings to initiate conversation with a caregiver. It is helpful to educate caregivers about the difficulties inherent in caregiving and they should be counseled regarding their need for help and support.[32] If Mrs D had known that patients often initially resist the idea of accepting home health care services, she may have experienced her husband's refusal as something to be negotiated over time vs the final word. If a care recipient or a caregiver is reluctant to accept support, the reasons should be explored. Potential causes might be financial concerns, fears about allowing strangers into the home, feelings of shame regarding care needs, or anxiety over the loss of independence or privacy. Often when the care recipient's physician strongly recommends support for the family caregiver, it is more likely to be considered and ultimately adopted.

Although a complete assessment may not always be feasible, the situation should be sufficiently assessed to devise a comprehensive care plan. The caregiver should be referred to a social worker or a community agency capable of further assessing and providing supportive services. The physician and the interdisciplinary team do not complete this responsibility by referral alone, but only by ensuring that a competent assessment and plan have been put into place.

Interventions for Caregiver Burden

Recent meta-analyses and systematic reviews of intervention studies intended to reduce caregiver burden and associated distress are shown in **Table 3**[37-44] (see eAppendix 1 and eAppendix 2 in Supplement). Caregiving was assessed for caregivers of individuals with dementia in 7 of the meta-analyses and for cancer patient caregivers in 1 study. These analyses showed that certain psychosocial and pharmacological interventions have mild to modest efficacy in mitigating caregiver burden and other aspects of caregiver distress. These findings are consistent with a very recent systematic review of interventions in dementia-caregiver dyads that did not formally calculate a summary effect size for caregiver burden[45] and also the most comprehensive single study of caregiver burden intervention.[46] Support groups or psychoeducational interventions for caregivers of individuals with dementia were modestly effective and had effect sizes ranging from 0.09 to 0.23. Summary effect size was typically calculated and reported as Cohen's d, which is the difference in the post-treatment measure between the treatment and control group divided by pooled standard deviation, or the closely related Hedge's g, which corrects for biases in smaller sample sizes.[47] For either measure, an effect size of 0.2 is considered weak, 0.5 is considered moderate, and 0.8 is considered strong. Pharmacologic interventions (including anticholinergic or antipsychotic medications, treating the patient's dementia or dementia-related behaviors) reduced caregiver burden (effect size, 0.18-0.27). A meta-analysis of psychoeducational interventions, skills training, and therapeutic counseling for caregivers of cancer patients showed caregiver burden was reduced but that improvements in caregiver burden were lost with time (effect size, 0.22 at 3 months; and 0.08 after 6 months). Many studies showed improvements in symptoms associated with caregiver burden (eg, mood, coping, self-efficacy) even when caregiver burden itself was not substantially improved.[38,39,41] Given these broad effects on many distressing caregiver symptoms, attempts at lower-risk (ie, nonpharmacologic) interventions are probably warranted, even when effect sizes on burden are modest or small.

Practical Interventions to Reduce Caregiver Burden

Encourage the Caregiver to Function as a Member of the Care Team

Caregivers may be reluctant to articulate problems related to caregiving. Therefore, during all clinic visits, physicians providing care for chronically ill patients should proactively explore potential problems a caregiver might be experiencing.[28,48] Older married couples should be evaluated together, exploring their health status and the caregiving demands at home. Treatments should account for the needs of the patient and the caregiver.[13] Optimally, physicians should additionally evaluate the patient and caregiver separately. This facilitates communication of confidential information such as elder mistreatment and caregiver stress.[49,50]

Encourage Caregivers to Improve Self-care and Maintain Their Health

Caregivers often have chronic medical conditions, neglect their own health, and are less likely to engage in preventive health measures.[13,24,28,51] When the physician provides care for both the care

Table 3. Meta-analyses and Systematic Reviews of Caregiver Burden Interventions

Source[a]	Total No. of Studies	Interventions (No. of Studies)	Caregiver Burden Measures (No. of Studies)	Findings, Effect Size (95% CI)	Comments
Meta-analyses					
Pinquart and Sorensen,[37] 2006	127	Psychoeducational, cognitive behavior therapy, counseling/care management, general support, respite, training of care recipient, multicomponent	ZBI (32) Other (53)	Burden reduction (all intervention types): −0.12 (95% CI,−0.17 to −0.007)[b] Binomial effect size display: 53% of intervention recipients experienced above-average improvement in burden compared with 47% of control participants[c]	Significant but small effects on burden Psychoeducational interventions that required active participation of caregivers had the broadest effects Counseling, cognitive behavioral therapy, and respite also had effects on burden
Brodaty et al,[38] 2003	30	Psychosocial interventions	ZBI (8), CAT (1) CHS (1) SCB (1) MBPC (1) RS (1) OBS (1)	Weighted for burden 0.09 (95% CI, −0.09 to 0.26)	Significant benefits in caregiver psychological distress, caregiver knowledge, any main caregiver outcome measure, and patient mood, but not caregiver burden
Chien et al,[39] 2011	30 Total (24 measured caregiver burden)	Caregiver support groups	Not summarized	Weighted for burden −0.23 (95% CI, −0.33 to −0.14)[d]	Support groups lowered burden slightly and had larger effects on caregiver psychological well-being, depression, and social outcomes Support group interventions that were modest in size (6-10 participants), involved education and training, and were longer in duration and follow-up had greater effects on burden
Schoenmakers et al,[40] 2009[e]	8 Total (6 measured caregiver burden, caregiver distress, or both)	For dementia-related behaviors: Anticholinergic drugs (5) Antipsychotic drugs (1)	CAT CSS CBS SCB NPI-D RSSS	Antipsychotics: 0.27 (95% CI, 0.13-0.41) Anticholinergics: 0.23 (95% CI, 0.08-0.33)	Use of medications had a small but significant effect on caregiver burden and was also associated with less time caregivers spent in direct caregiving
Northouse et al,[41] 2010[f]	22 Total (11 assessed caregiver burden)	Psychoeducational (20) Skills training (9) Therapeutic counseling (6)	Not reported	Data reported by assessment interval after the intervention: 0-3 months, 0.22 (95% CI, 0.08-0.35) 3-6 months, 0.10 (95% CI, −0.04 to 0.25) >6 months, 0.08 (95% CI, −0.19 to 0.34)	Interventions had small to medium effects on caregiver burden, caregivers' ability to cope, self-efficacy, and improved quality of life Paradoxically, greater numbers of sessions were associated with less burden reduction
Systematic reviews					
Linger L, et al,[42] 2005[g]	17 Total (10 measured caregiver burden; 4 of these met quality criteria for inclusion in the meta-analysis)	Drug therapy of Alzheimer disease (mostly donezipil), in which caregiver burden was a secondary outcome	NPI-D (5) SCB (2) RSS (4) PD (1)	0.18 (95% CI, 0.04-0.32)	Small decrease in caregiver burden in treatment group Future Alzheimer disease drug trials should include higher-quality caregiver measures and methodology
Thompson et al,[43] 2007[h]	44	Measured caregiver burden: Psychoeducational studies (3) Support interventions (2)	Not specified	Support intervention: −0.40 (95% CI, −5.69 to 4.90) Psychoeducational intervention: −2.15 (95% CI, −5.97-1.66)	Interventions were not effective in reducing caregiver burden Group-based interventions affected psychological morbidity Clinical significance was unclear
Vernooij-Dassen et al,[44] 2011[i]	11	Cognitive reframing (changing caregivers' maladaptive behaviors or beliefs) measured burden (3)	ZBI CSI	Burden: −0.14 (95% CI, −0.32 to 0.03)	Cognitive reframing did not significantly reduce caregiver burden but had beneficial effects on caregiver anxiety, depression, and subjective stress

Abbreviations: CAT, Caregiver Assessment Tool; CBS, Caregiver Burden Screen; CHS, Caregiver Hassles Scale; CSS, Caregiver Stress Scale; MBPC, Memory and Behavioral Problem Checklist; NPI-D, Neuropsychiatric Inventory caregiver distress scale; OBS, Objective Burden Scale; PD, Cognitive Subscale of the Poulshock and Deimling; RDS, Relatives' Distress Scale; RS, Rankin Scale; RSS, Research School of Social Sciences; SCB, Screen for Caregiver Burden; ZBI, Zarit Burden Interview.

[a] Condition studied was dementia unless otherwise indicated.

[b] Effect size was calculated as the difference in posttreatment measure between the treatment and control group divided by pooled standard deviation.

[c] Binominal effect size display was calculated as the percentage of participants in each group with above-average response to intervention.

[d] Effect size was calculated as Hedge's g.

[e] Condition studied was drug treatment of dementia-related behaviors.

[f] Condition studied was cancer.

[g] Study was a systematic Cochrane review with meta-analysis. Condition studied was Alzheimer disease.

[h] Systematic review was of information and support interventions for caregivers of individuals with dementia.

[i] Systematic review was of cognitive reframing for caregivers of individuals with dementia.

recipient and the caregiver, scheduling consecutive visits on the same day enables regular medical follow-up, avoiding extra trips. Suggesting respite care or other support such as food delivery may provide enough relief for the caregiver to engage in health-promoting behaviors such as exercise and other activities that improve quality of life.[10]

Provide Education and Information

Caregivers should be educated about the care recipient's illness and specific care needs.[13,24,28,48,52] Training regarding proper technique for lifting and transferring patients to avoid back strain may be beneficial. Counseling about caregiver stress, its consequences, and ameliorative strategies will help the caregiver to better cope. Caregivers may obtain relief by learning how to ask for help, engaging other family members to help, participating in support groups, and ensuring preservation of their own health. Physical and occupational therapists, nurses, and social workers may provide much of this training. Physicians should pursue advance-care planning that accounts for goals of care and incorporates patient and caregiver preferences into care plans. Long-term care placement should be discussed. Websites outlining resources to assist with counseling are provided online (eBox in Supplement).

Use the Support of Technology

Technology can facilitate independent functioning for care recipients and reduce dependency on caregivers. Emergency response systems allow cognitively intact care recipients to call for help through a monitoring center if the caregiver is not at home. Home intercom systems or a webcam may be used for monitoring. Mobility monitors can track dementia patients who wander. Emerging technologies may offer additional supportive measures (eg, home monitors that alert for unusual activity patterns, medication dispensers with alarms or voice reminders). Lift systems can be used for immobile care recipients. Socialization for homebound or isolated older patients and their caregivers can be improved using technology (eg, live educational programs can be brought to homebound elders using an integrated phone system or Skype and iPhone technologies). Caregiver support groups are available online.

Coordinate/Refer for Assistance With Care

Caregivers may not be aware of assistance available to them or know if they qualify for help. Some assistive services can be obtained by self-referral such as volunteer programs (eg, Alzheimer Association), nonmedical home care services (eg, housekeeping, cooking, and companionship), and home safety modification. Other services require physician referral such as home health care services (eg, visiting nurses and physical therapy), medical adult day programs, and some transportation and meal delivery services. Legal, financial, and individual and family counseling about grief and loss are also helpful.[53] Structured cognitive behavioral interventions such as problem-solving intervention may also be effective.[34,51,54] Helping caregivers cope with and address their care recipient's suffering is a major challenge the physician must address.[21,22] Attention to symptom relief for care recipients with chronic medical conditions may improve their quality of life and help alleviate caregiver distress.[55]

Encourage Caregivers to Access Respite Care

Respite services provide relief by having someone else stay with the care recipient for a brief period of time. Alternatively, the care recipient may spend brief periods in an outside adult day program or PACE (Program of All-inclusive Care for the Elderly) program. Respite care may be paid for by Medicare for hospice patients. Evening daycare programs for dementia patients may provide relief for caregivers.

Conclusions

Family caregivers play an essential role in supporting the well-being and care of older people. Physicians must recognize the importance of family caregiving since the health of their patients depends on the quality of home-based caregiving. Physicians should identify their patients' caregivers, inquire about their caregiving experience, and perform a caregiver assessment. They should engage family caregivers as proactive partners in care, be cognizant of caregiver burden, and intervene in a timely manner to help reduce this burden.

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