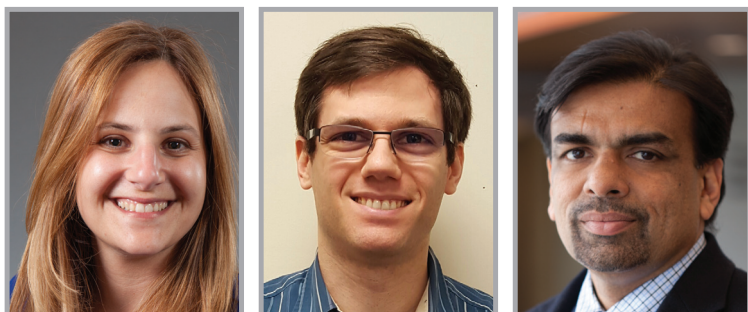


## Dementia and caregiver stress



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According to the Alzheimer’s Association, in 2014, caregivers of people with dementia provided an estimated 17.9 billion hours of informal (unpaid) assistance valued at more than US\$217.7 billion [1]. The US Census Bureau expects the number of people age 65 years and older to double between 2010 and 2050 [2], and this is expected to dramatically increase the need for caregiving in coming decades. More than one in three caregivers of dementia patients are over age 65 years [1]. Caregiver stress is an under-recognized and undertreated health risk that can lead to poor outcomes for both caregivers and patients with dementia, including higher rates of morbidity and mortality. As we plan for the needs of an aging population with high prevalence of dementia, models of care must include caregivers. We describe our center’s approach to this issue in the context of the health risks assumed by caregivers.

### Health effects of caregiver stress

Stress leads to a variety of physiological and psychological responses. Depending

on the nature of the stressor [3], the degree of stress [4] and other factors related to the person experiencing the stress, the stressor and the environment, the effects of stress can vary greatly. Acute stress may promote increased vigilance and other appropriate behavioral changes. With chronic exposure to an unresolved stressor or repeat exposure to stressors of sufficient magnitude, responses and adaptations to stress fail and individuals suffer negative resultant consequences [5]. Compared with caregivers of people with nondementing illnesses, caregivers of people with dementia may be less able to cope with increased stressors as they have twice the rates of substantial financial, emotional and physical difficulties associated with caregiving [6].

Many studies have shown widespread, direct, deleterious health consequences of caregiver stress. For instance, caregivers have compromised immune function compared with noncaregivers [7]. They have elevated markers of cardiovascular disease and impaired kidney function [8,9].

### KEYWORDS

- care coordination • caregiver burden
- dementia care models • stress

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Caregivers have higher rates of emergency room utilization and hospitalization, which are related to the severity of behavioral problems and functional status of their dementia wards [10]. Caregiving is associated with increased risk of mortality. In a prospective population-based cohort study, caregiver ‘strain’ was associated with 63% increased mortality risk, even after controlling for presence of clinical and subclinical cardiovascular disease and sociodemographic factors [11]. Caregivers might even be at higher risk of cognitive impairment or dementia than noncaregivers [12]. Those society depends onto care for people with neurodegenerative illnesses have a much higher risk of getting sick, developing cognitive impairment and dying than do others.

### Dementia care models & caregiver stress

Models of care for older adults with dementia vary widely in scope and resources offered. Those that offer a greater diversity of services with close collaboration among multiple specialties seem to be the most successful. In randomized controlled trials, high-risk older adults cared for by teams of nurses, social workers and physicians had less depression, better functional status and increased socialization compared with patients treated only by a single physician [13,14]. High-risk older adults cared for by teams required less inpatient and outpatient medical care, and cost less to care for in the long term [13,15]. When various psychosocial interventions are offered, they can effectively improve caregiver outcomes [16,17] and patient outcomes, such as decreased rates of institutionalization [18]. A comprehensive review of the literature on multidisciplinary models of care is beyond the scope of this article (though see Galvin *et al.* recent work in this journal [19]). However, most models rely on the primary care physician or one specialist physician and an array of allied health professionals to care for patients. We recently established an outpatient referral center for dementia care that utilizes multiple physician specialists along with other health professionals to meet the challenges faced by those with cognitive impairment and their caregivers.

Montefiore is an urban hospital system that serves the Bronx and surrounding counties in New York State. Outpatient dementia care is provided in two main settings, Montefiore-Einstein Center for the Aging Brain (CAB) and Montefiore Memory Disorders Center (MDC). Our social work and care-coordination

model was piloted at MDC, and the full model has been implemented in the newly opened CAB. The CAB follows a consultative model where patients referred to the center receive a comprehensive, three-step evaluation from a geriatrician, a neuropsychologist and a cognitive- or geriatric-trained neurologist. As needed, a geriatric psychiatrist and a physiatrist are also available at the same center. Each specialist identifies opportunities for intervention and helps educate patients and their caregivers about etiologies of cognitive decline, possible treatments and mitigating factors and prognosis. Each physician can also refer and confer with the center’s licensed clinical social worker as needs and challenges are identified, including various sources of caregiver stress. Additionally, all patients complete a questionnaire prior to their first visit, which includes assessments of caregiver stress, activities of daily living, medical issues, medications, functional status and goals of care [20]. Caregivers who screen positive for significant stress or depressive symptoms are automatically scheduled to meet with the social worker.

At MDC, a Leslie R Samuels and Fan Fox grant supports the role of our social worker/care coordinator. Since the pilot program’s inception 18 months ago, the social worker has evaluated 307 caregivers and conducted over 1300 interviews. One of the most common interventions offered is problem-solving treatment (PST) sessions. PST is a widely accepted form of short-term therapy that focuses on stress reduction and adaptive techniques for managing patients with neurodegenerative disease. Poor insight and perseverative behavior are often part of dementia and other memory problems. Shifting attention to avoid a direct conflict within a caregiver–patient dyad is a typical area of focus. Over 573 PST sessions have been provided to our caregivers. The PST plans have been well received. Aside from counseling for both patients and caregivers, our bilingual and bicultural social worker identifies literacy and language barriers to navigating the healthcare system in our large Hispanic population. She works to increase the available concrete services and helps patients and their families connect with community resources and support networks. She facilitates goals of care and end-of-life discussions and can provide crisis intervention as needed, including referrals for home visits. Additionally, the social worker provides case management by facilitating communication with the primary care provider and other

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specialty providers. We do not have sufficient longitudinal outcomes data on our caregiver interventions as our center was only established a year ago; however, we hope to provide follow-up reports on the effects of our interventions in the future.

As a center, we have expanded our outreach program to reduce service fragmentation. We have developed strong relationships with community-based organizations to help with referrals to and from our center. While Montefiore offers a large, integrated system of healthcare, we operate in an underserved area where resources are limited. Developing relationships with our community partners and facilitating communication with them allows us to function as a referral center, as opposed to assuming primary care responsibilities for our patients. By embracing the concept of a ‘center without walls’, we can serve as a resource to primary care physicians and neurologists in the community, and maximize the care we can provide. Although each patient and their caregivers require a great deal of time, including a significant amount of direct care by subspecialty trained physicians, we believe our effects are magnified through our partners to ultimately provide better and more efficient care for both patients and their caregivers. In the future, we hope to conduct fiscal analyses of our resource-intensive model, in addition to evaluating outcomes of patients and caregivers.

### Challenges

Developing a new dementia care model that incorporates caregivers and caregiver stress poses significant challenges. Staffing is limited compared with the population at risk in our evergrowing catchment area. We are developing educational programs for primary care physicians, case workers, nurses and other providers to help them identify cognitive impairment in older adults, improve symptom management and increase awareness of caregiver stress. We

have started to hold conferences with other clinical partners in the area, including occupational therapists, speech pathologists and other community physicians. Finally, as we incur high short-term costs in anticipation of long-term benefits, improving buy-in from payers will be crucial. Our hospital system is moving away from a fee-for-service paradigm, and we hope to fund an ever expanding center through the cost-savings integrated care can provide to the system.

### Conclusion

Caregiver stress is pervasive in our society, and it is expected to increase substantially in the years to come. We depend on caregivers to help with the increasing burden of neurodegenerative disease associated with an aging population, yet we know that their health is at risk. Other models to deal with caregiver issues have been described and we hope to report comparative analyses with our model in the future. Only with new, comprehensive approaches that improve identification and support of caregivers in need can we hope to decrease the burden on caregivers and optimize patient outcomes. At Montefiore, we have built a coordinated, multidisciplinary team that will hopefully achieve this.

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