

Envisioning Better Approaches for Dementia Care

The vast majority of patients with dementia receive their care in primary care settings. Clinicians find it challenging to provide optimal care for these patients and their often-stressed and overburdened caregivers because current reimbursement mechanisms do not support the kinds of practical, time-intensive, team-based processes of care that have been associated with improved outcomes in these settings (1, 2). In this issue, 2 care interventions are described demonstrating that the well-being of patients with dementia and their caregivers can be improved substantially (3, 4). However, clinicians may feel frustrated reading about these interventions because few will be able to implement them for their patients.

Vickrey and colleagues (3) present the results of a novel disease management program for the primary care of dementia. Patients with dementia and their caregivers who were seen in randomly selected primary care clinics were assigned a case manager who worked with and trained the caregiver, assessed and prioritized patient and caregiver needs, and recommended interventions to health care and community service providers. The role of the case manager in integrating care needs within primary care practices and across community service agencies was a novel feature of the program. Quality of care, as measured by adherence to guidelines, was dramatically higher in patients who received the intervention (64% vs. 33%). Patient quality of life improved, and caregivers reported improved social support, mastery of caregiving, and confidence. This intervention bears many similarities to an approach described by Callahan and colleagues (2) that also dramatically improved the processes and outcomes of dementia care.

Also in this issue, Belle and colleagues (4) tested a multicomponent intervention to improve quality of life in a multiethnic group of distressed caregivers. This intervention focused on 5 domains that are important to caregivers: reducing depression, decreasing burden, improving self-care, enhancing social support, and managing problem behaviors. The core intervention was providing the caregivers with access to a trained interventionist who assessed the caregivers' needs and functioned as a coach. Innovative features of the intervention included tailoring its components to the unique needs and concerns of each caregiver and emphasizing self-empowerment. The protocol was intensive, including 9 home visits, lasting 90 minutes each and 3 telephone calls. Caregivers seemed to like the intervention: 60% completed all 12 visits, and more than 90% reported that the intervention made their life easier and improved their ability to provide care. There were meaningful impacts on a global outcome measure that encompassed the 5 intervention domains. Rates of caregiver depression were halved. There was an encouraging trend toward lower rates of nursing home placement, although the sample size was not large enough to be definitive.

More work will need to be done before we can know for certain how well these interventions will work in other settings and how durable their effects will be. For example, the REACH trial intervention seemed to perform slightly differently in various ethnic groups. Also, longer and larger trials are needed to determine whether these interventions delay nursing home placement. Despite these uncertainties, we shouldn't let the perfect be the enemy of the good. If these interventions were drugs, it is hard to believe that they would not be on the fast track to approval. The magnitude of benefit and quality of evidence supporting these interventions considerably exceed those of currently approved pharmacologic therapies for dementia (5, 6).

Both studies illustrate several principles that should guide how care is delivered to patients with dementia. First, caregivers need to be a dominant focus of any effective dementia management strategy. Most patients with dementia who could live in nursing homes stay at home because of the efforts of caregivers. The resultant savings to stressed Medicaid budgets are massive (7). However, being a caregiver for a loved one can present enormous physical, psychological, and emotional difficulties (8, 9). Caregivers often feel that they are invisible to the health system (10). The REACH study offered a level of caregiver support that few clinicians will be equipped to offer to their patients. But the intensity of support is appropriate to the difficulty and importance of the caregiver role.

A second principle is that much of the care that patients with dementia and their caregivers need cannot be delivered in the office setting. The usual fee-for-service approach works poorly for dementia care. As shown by Vickrey and colleagues (3), these patients need medical care that is coordinated among multiple team members and integrated with social and community-based resources. The practice workload of managing such an interdisciplinary team (even if such a team were available) and assisting the caregiver has little relationship to the office visit.

Recently, Larson (11) recommended an approach to primary care in which the internist leads a multidisciplinary team. In this model, the internist is paid for managing the care of patients rather than on a per office visit basis. Such a model would be far superior to the fee per office visit-based approach, which invariably leads to fragmented care that cannot possibly address the needs of the patient and caregiver. A major focus of geriatrics fellowship training is teaching clinicians to provide this type of care and to manage interdisciplinary teams. However, in typical practice settings, current methods of reimbursement make it difficult for geriatricians to deliver the model of care they were trained to provide. Those who try are often undermined by managers whose singular focus on office visit productivity causes them to question why clinicians fo-

cused on care of the frail elderly should be less productive in terms of care visit volume than other providers.

Although dramatic changes in delivery of primary care are a long way off, there are changes that could be implemented now that will improve the well-being of patients with dementia and their caregivers. First, Medicare and other providers should be required to reimburse an extensive array of caregiver support services. Caregivers routinely risk their financial, emotional, and physical well-being to provide care to their relatives or members of their community with dementia. It is time for the public to recognize their part of this social contract (12). The type of services provided by the REACH intervention should be generally available if insurers are willing to pay for them. Second, it is time for Medicare to pay for team-based case management services for elderly persons with dementia, because this approach clearly improves the quality of care. In addition, promotion of adequately reimbursed, integrated programs based on the successes of models, such as Veterans Affairs Medical Center and PACE (Program of All-Inclusive Care for the Elderly), could serve to catalyze implementation of more evidence-based approaches to the care of elderly patients with dementia and those with other frailty syndromes (13). The need for these changes is compelling, but they need advocates and champions. Patients with dementia will probably not be forming a lobby anytime soon, and their caregivers are too busy. It is time for the medical profession to advocate on their behalf.

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