THE BURDEN ON DEMENTIA CAREGIVERS
How Can Communities and Health Care Organizations Help?

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Family members are integral to the care, safety and overall well-being of persons with Alzheimer’s disease and related dementias. Being a caregiver is often associated with significant isolation as well as emotional, psychosocial and financial burden. In recognition of the toughness of this job and the increasing prevalence of dementia, there has been growing momentum among public policy makers and within communities and the health care system to address the challenges caregivers face. This article describes efforts in Minnesota communities to do so. The authors make recommendations for communities and health care systems.

More than 46 million people worldwide are living with dementia, and that number is projected to double every 20 years. Dementia has an impact on not only the individuals who experience it but also the ones, often family members, who care for them.

In the United States, an estimated 15 million people provide full-time care, typically without pay, for a loved one with cognitive impairment. The care that these individuals provide has been shown to improve quality of life and delay time to nursing home placement for persons with dementia. Yet caregivers often struggle with the emotional ramifications of their responsibilities. This is commonly referred to as “caregiver burden.” Given that a person with dementia may live for many years with their disease, those who care for them may experience significant caregiver burden for many years resulting in psychosocial and physical consequences.

Increasingly, it is being recognized that communities and health care systems need to do more to support both persons with dementia as well as their caregivers. Many communities and health care systems are taking steps to better assist people with dementia and those who care for them. This article describes efforts already underway in Minnesota and explores opportunities for future improvement.

Engaged Communities
A dementia diagnosis often leads to isolation for caregivers as well as their patients. Businesses, religious organizations, community organizations and local services are not routinely equipped to acknowledge, accommodate and support persons with dementia and their caregivers. If a community does have a resource, often it is a dementia program such as an adult day program. Although such programs provide needed respite for caregivers, they are typically separated from the mainstream of the community, which can perpetuate the stigmatization and marginalization of those with dementia. And such marginalization exacerbates the isolation of caregivers.

Communities in Minnesota have been looking for new ways to care for those affected by dementia and change attitudes about it. ACT on Alzheimer’s, a statewide, volunteer-driven collaboration, is seeking large-scale societal change and building community capacity to transform Minnesota’s response to Alzheimer’s disease. ACT on Alzheimer’s provides a number of tools (www.actonalz.org/dementia-friendly-toolkit) to help communities identify their priorities and specific actions to take to become “dementia-friendly.” Currently, more than 40 communities in Minnesota are engaged in this work.

Many of the communities have identified dementia education and awareness as their top priorities. Rochester, Minnesota, for example, has taken steps to improve awareness that have included the creation of an educational booklet, “Living in our Dementia Friendly Communities.” The booklet targets a broad audience, including those with age-related memory loss, mild cognitive impairment or dementia, as well as families, friends, youth, neighbors and businesses in the city and surrounding areas. The booklet emphasizes that each person in the community has a role to play in making sure that people living with memory loss, as well as their caregivers, feel understood and respected, and are given opportunities to participate and thrive in the community.

ACT on Alzheimer’s is also helping communities train individuals and people in businesses and community groups to become more dementia-friendly through two programs: Dementia Friends (www.actonalz.org/dementia-friends) and Dementia Friendly @ Work (www.actonalz.
org/dementia-friendly-work). To date, Rochester has trained more than 500 hundred people in the community through these programs. In Dementia Friendly @ Work seminars, businesspeople learn to better recognize and offer assistance to persons with dementia and their caregivers, and to modify their environments to make it easier for persons with dementia to navigate. The training covers issues such as how to respond to looks of distress, how to provide assistance with and allow extra time for decisions or transactions, and how to create clear signage.

Some Minnesota communities are offering caregiver-preparedness courses. In addition, they are creating opportunities for both caregivers and individuals with dementia to recreate together such as by singing in choirs (www.givingvoicechorus.org) and offering “memory cafes,” which are safe places where they can gather and share their experiences (www.memorycafedirectory.com/memory-cafes-in-minnesota/).

Beyond Minnesota are national initiatives, including Dementia Friendly America (www.dfamerica.org), with the same passion to help communities become better able to meet the needs of those with dementia and their caregivers. Currently, Dementia Friendly America is helping to expand work that started in Minnesota to Tempe, Arizona; Santa Clara County, California; Denver, Colorado; Prince George’s County, Maryland; Knoxville, Tennessee; and the state of West Virginia.

Opportunities for Health Care Organizations
Health care organizations are realizing they need to improve in a number of areas if they are to effectively meet the needs of patients with dementia and their caregivers. One area of need is around communication. Caregivers typically have to navigate the health care system on behalf of a loved one with Alzheimer’s disease or a related dementia, which adds to the overall burden of caregiving. Health care teams rely heavily on caregivers and other family members to communicate with the individual about the progression of their disease and to help enact a care plan. Training for health care providers on how to integrate family caregivers into the shared decision-making conversation is needed. Also needed is training for staff members on how they should approach, communicate with and interact with persons with dementia.

There also is a need for more early diagnosis of dementia. One of the goals of National Alzheimer’s Project Act is early and appropriate diagnosis of dementia. Clinically, there may be some reluctance on the part of health care providers to give a patient a diagnosis of dementia because of the difficulty of diagnosing the disease in its early stages and the lack of effective treatment options. A delayed diagnosis, however, may lead to fewer opportunities for persons with dementia and their caregivers to engage in anticipatory planning regarding care preferences. It also may delay their connecting with support groups or community programs.

Another need is around identifying and supporting caregivers. The presence of a caregiver is rarely documented in electronic health records. Even when clinicians recognize a caregiver is strained, there may be no integrated mechanism to formally assess the caregiver’s needs. Health care organizations need to develop ways to routinely identify caregivers and assess their needs and preferences in order to support their well-being, as it has an impact on the well-being of the patient as well.

Finally, caregivers need training when their loved one is being discharged from the hospital. Legislation requiring caregiver training prior to hospital discharge has been passed in at least 32 states, including Minnesota. Health care organizations may in the near future find they are required to better train caregivers during this care transition time.

ACT on Alzheimer’s has a number of tools including video tutorials that health care organizations can use to help their clinicians become more comfortable doing cognitive screening, delivering a diagnosis of Alzheimer’s disease or a related dementia, and managing the patient with dementia (www.actonalz.org/provider-practice-tools).

Conclusion
There is growing recognition of the significant impact of dementia on patients, their families and their caregivers, and there is increasing momentum for whole communities and health care organizations to support people with dementia. There also is growing recognition of the importance of caregivers and the need to provide support and training for them. Many academic and community organizations in Minnesota have been on the forefront of a movement to better respond to the needs of those with dementia and their caregivers; however, others including health care institutions, have fallen short. All organizations need to work toward acknowledging, accommodating and supporting persons with dementia and their caregivers. Health care organizations need to create streamlined systems for identifying and working with caregivers of persons with dementia. They also need to educate staff about how to approach, communicate with and interact with these patients and their caregivers. Doing so will enable their staffs to feel more comfortable diagnosing and talking with patients about the disease, and allow patients and their caregivers to better plan for the future.

Communities and health care organizations can do much to support caregivers and individuals with dementia. And with better alignment of that work, there is the potential of better outcomes for everyone involved.

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REFERENCES


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