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Supporting Caregivers Of Patients with Dementia

John Fernan, Third-year medical student

UVM Family Medicine – South Burlington, June 2022

Problem Identification

- There are an estimated 6.5 million Americans 65 and older living with dementia. In Vermont there will be an estimated 17 thousand adults with dementia by 2025. This is a 30% increase compared to 2020.
- 80% of help provided to adults comes from family, friends, or other unpaid caregivers, and nearly half of this care is provided to someone with Alzheimer's or another dementia.
- Caring for an elderly individual can take a physical and mental toll. The demands of being a caregiver can limit one's ability to take of oneself. Family caregivers of persons with dementia are at higher risk of depression, anxiety, and poorer quality of life.

Public Health Cost

- In 2021, an estimated 11 million family members provided 16 billion hours worth of care to people with Alzheimer's and other dementia. The value of this unpaid caregiving is about \$271 billion dollars.
- Beyond the financial cost, the strain of caregiving also increases risk for emotional stress and negatively impacts physical and mental health.
- One prospective study found that elderly spousal caregivers have a relative risk of mortality of 1.63 over 4 years, compared to non-caregivers.
- Caregivers that experience high levels of strain often report low confidence in their ability to manage caregiving and access help.

Community Perspective

- “Awareness of local resources, picking up a phone and calling someone. They just need help ... understanding what to expect, what to look for. Knowledge is big. When they might be able to manage stuff on their or when they might need to get their spouse to the hospital or call the doctor. For everyone talking about advanced care planning. Getting them the right support to make some planning before things deteriorate further.”
-David Reisman, Family Medicine Physician
- “I usually accompany my wife [with mild cognitive impairment] to her appointments and have been doing that now for some time, and to the extent there are personalized recommendations, such as several patients have had really good luck with this organization, having that kind of advice would be helpful. Being told to expect significant mental decline is hard to come to terms with, and [as an older spousal caregiver] it is extra challenging to be low on energy and feeling that I have to pick up more daily tasks of living than I’m used to.”
-Christopher McCandless, family caregiver

Intervention

- This project hypothesizes that caregiver strain can be reduced by promoting greater self-efficacy and awareness of local support resources.
- A template in the EMR was created that would give family medicine providers a list of information they can provide to caregivers.
- This template included an explanation of useful strategies such as respite care and support groups, a summary of some of the available local resources, and a list of general tips for reducing caregiver stress.

Smartphrase Template

Caring for someone with dementia can be challenging work that can be hard on you despite the fulfillment it may bring. To be a good caregiver, it is important you take care of yourself. There are a number of strategies and resources available. Respite care and support groups are two resources that many people find helpful.

Respite Care: One way to maintain your own health is to give yourself short breaks from caregiving responsibilities by letting someone else take care of them for a block of time. Respite care can involve friends, family, paid caregivers, or adult day programs. It can be helpful to identify certain caregiving tasks you want help with, or times that you want to prioritize for yourself. More information about finding paid caregivers or enrolling in structured day programs can be found through accessing resources listed below.

Support Groups: Support groups can allow you to share your experiences with others in a similar situation. You can learn about the challenges others have faced and solutions they have found, and also learn about new resources. More information about local support groups can be found through the resources listed below.

There are many local organizations that are dedicated to supporting those with dementia as well as their caregivers:

Alzheimer's Association: The Alzheimer's Association has a wide variety of information, tips, and resources. They can help you understand how the role of a caregiver changes as the disease progresses and the different stages and behaviors you may face with Alzheimer's. They can also connect you with educational programs to build your caregiving skills. The Vermont chapter offers information about local events and services.

<https://www.alz.org/vermont> or call the 24/7 helpline at 800-272-3900.

Age Well: Age Well is a state-designated agency that coordinates a system of services for supporting the aging population. They provide information about caregiver classes and meal delivery for elders through Meals on Wheels. They also provide help with applying for dementia respite grants to unpaid caregivers that can be used to help pay for care in or out of the home. Age Well also can help with getting legal assistance and financial planning and planning for transitions to different care situations such as a senior living facility.

<https://www.agewellvt.org/> or call 802-865-0360. For immediate help call the helpline at 1-800-642-5119.

Age Well also has compiled a list of caregiver resources including support groups, in-home and out-of-home respite care, long term care, veterans directed programs, senior housing, and legal and financial planning.

<https://www.agewellvt.org/documents/age-well/78-caregiver-resources-1> for the list of resources.

Age Well's general tips for caregivers:

1. Plan ahead
2. Take one day at a time
3. Accept help
4. Get enough rest and nutrition
5. Be good to yourself
6. Learn about available resources
7. Develop contingency plans
8. Make YOUR health a priority
9. Make time for leisure, rest, and relaxation
10. Share your feelings with others

Implementation and Results

- In Burlington there are many resources for support including a local chapter of the Alzheimer's organization and Age Well, the state-designated agency for supporting the elderly in Northwest Vermont. Improving awareness of these resources among the primary care office as well as caregivers is important to increasing their access.
- This template is a simple and convenient way for providers to distribute this information to caregivers at the end of a visit. It was shared with primary care providers at the UVM Family Medicine office in South Burlington.

Evaluation and Limitations

- Limitations include that the template was primarily aimed towards caregivers who can manage the needs of the person with dementia through in-home care. The tips for respite care and some of the resources provided are not as relevant if the person with dementia is living in a long-term senior living home.
- Resources listed were only ones that caregivers could access independently. Some services, such as social workers, were not included because they require referrals.
- There was not enough time to evaluate the response of caregivers to the information provided. Additionally, family medicine providers could be surveyed to gauge their pre-existing familiarity with the types of support and resources listed in the smartphrase.

Recommendations for Future Projects

- Create a survey aimed towards caregivers to track utilization of resources that were provided in template.
- Track use of template in EMR and impact on caregiver strain at subsequent visits with screening tools such as the Modified Caregiver Strain Index (MCSI).

Resources

- 1. 2022 Alzheimer's disease facts and figures. *Alzheimers Dement*. 2022;18(4):700-789. doi:10.1002/alz.12638
- 2. Black BS, Johnston D, Rabins PV, Morrison A, Lyketsos C, Samus QM. Unmet needs of community-residing persons with dementia and their informal caregivers: findings from the maximizing independence at home study. *J Am Geriatr Soc*. 2013;61(12):2087-2095. doi:10.1111/jgs.12549
- 3. Schulz R, Beach SR. Caregiving as a risk factor for mortality: the Caregiver Health Effects Study. *JAMA*. 1999;282(23):2215-2219. doi:10.1001/jama.282.23.2215
- 4. Jennings LA, Reuben DB, Evertson LC, Serrano KS, Ercoli L, Grill J, Chodosh J, Tan Z, Wenger NS. Unmet needs of caregivers of individuals referred to a dementia care program. *J Am Geriatr Soc*. 2015 Feb;63(2):282–9. doi: 10.1111/jgs.13251.