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# Caregiver Burden: Finding Resources, Offering Support

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# CAREGIVER BURDEN

*FINDING RESOURCES, OFFERING SUPPORT*

SARAH JOHNSON, APRIL 2014

MILTON FAMILY PRACTICE; MENTORS: DR. LITTLE, DR. HAGEMAN



# I A. PROBLEM IDENTIFICATION

## *INCREASING NUMBER OF CAREGIVERS*

- Definition: Informal caregivers are unpaid individuals (often a spouse, partner, family member, friend or neighbor) involved in supporting others in activities of daily living.
- Caregiver burden is an emerging public health issue largely attributed to longer life expectancy that not only increases the number of elderly individuals, but also the level of dependency in these individuals. <sup>(1)</sup>
- Despite many formal support services, informal support continues to be the primary source of care for the elderly, dependent and disabled.
- Unpaid family caregivers will likely continue to be the primary source of long-term care in the United States as the aging population will more than double between the years 2000 and 2030 from 35.1 million to 71.5 million. <sup>(2)</sup>
- In 2009, three in ten U.S. households reported at least one person providing unpaid care as a family caregiver. <sup>(3)</sup>
- Caregivers report performing housekeeping and personal tasks, running errands, managing medical needs and more.
- Caregivers spend on average 20.4 hours per week providing care. Those who live with their care recipient spend 39.3 hours per week caring for that person. <sup>(4)</sup>

## I B. PROBLEM IDENTIFICATION

### CAREGIVING IN VERMONT

- In 2004, nine percent of the Vermont population identified themselves as caregivers. These caregivers reported over 60 million hours of care annually, which is valued at over \$640 million dollars. <sup>(5)</sup>
- *“Caregiver burden is something we see quite frequently here in the office and many of us have experienced personally and [while] resources exist many of us aren’t aware of them. I’ve been thankful to have the community health team to help my patients out, having access to a social worker who is tied into community offerings has been invaluable.”*

- Timothy Lishnak, MD, Milton Family Practice

- *“There is a significant financial barrier to formal care services. In Vermont most agencies are fee-for-service and average \$25/hour for activities such as homemaking, companionship, etc, and are not covered by Medicare. Adult day programs can cost on average \$110/day. Most patients rely on family and friends and even neighbors in their care.”*

- Audrey Monroe, Community Health Team

## IIA. PUBLIC HEALTH COSTS

### CAREGIVING EFFECTS ON THE ECONOMY

#### ■ Money Saved:

- Formal caregiving is expensive making it often inaccessible.
- Informal caregiving results in millions of dollars saved in bills from nursing homes, long-term care facilities, hospitals etc.
- In 2011, informal caregiving was valued at an estimated \$375 billion per year. <sup>(3)</sup>

#### ■ Money Lost:

- 70% of working caregivers suffer work-related difficulties due to their caregiving role. Caregivers report having to rearrange work schedule, decrease their hours or take unpaid leave, turn down a promotion, choose early retirement, or give up work entirely. <sup>(6)</sup>
- In 2010, it was reported that 10 million caregivers over 50 who care for their parents lose an estimated \$3 trillion in lost wages, pensions, retirement funds and benefits. <sup>(7)</sup>
- The cost of informal caregiving in terms of lost productivity to U.S. businesses is \$17.1 to \$33 billion annually. This estimation reflects absenteeism, shifts from full-time to part-time work, replacing employees and workday adjustment. <sup>(8)</sup>

## IIB. PUBLIC HEALTH COSTS

### *CAREGIVING EFFECTS ON HEALTH*

- While caregiving can offer personal fulfillment and gratification, many caregivers become ill themselves.
- The following are some of the health consequences of caregiving:
  - Caregivers have higher rates of insomnia and depression.<sup>(3)</sup>
  - Caregivers are less likely to come in for preventative care.<sup>(3)</sup>
  - Caregivers describe their health as fair or poor; 17% describe their health as having worsened since becoming a caregiver.<sup>(3)</sup>
  - Spousal caregivers who report high levels of strain have a 23% higher Framingham Stroke Risk than their non-caregiver counterparts.<sup>(3)</sup>
  - Caregivers have a 23% higher level of stress hormones and a 15% lower level of antibody responses than non-caregivers.<sup>(9)</sup>
  - The often close relationship between the caregiver and care recipient can place a caregiver at higher risk for psychological and physical illness.

### III. COMMUNITY PERSPECTIVE

*“[Taking care of my mother has been a huge struggle. I have to stay with her 24/7. No one else can do it. I sleep on the floor. My chronic back pain is worsening. I can’t work...I’m losing income. My depression medications seem to no longer be enough. I had some relief when she went into the nursing home, but she refuses to stay.]”*

- Patient, Milton Family Practice

*“Caregivers are often older, and often cannot do chores that they used to be able to do, but help with chores inside and out as well as housekeeping, errands, transportation, etc., can be very expensive, and most people cannot afford it. It can be very difficult for caregivers to provide personal care, especially like cleaning up after someone who is incontinent of bladder or bowel, or who simply cannot remember where (or what) the toilet is. Caregivers end up being homebound and socially isolated because they do not feel they can safely leave the care recipient alone. It is physically and emotionally exhausting. I would say that some physician's offices are not as well informed about community options as they should be. Physicians can help by assessing caregivers for stress-related illnesses and directing them to community supports.”*

- Community Program Coordinator at CVAA

*“Caregivers are at risk of many physical and emotional stresses that manifest themselves in all sorts of ways. We are lucky in Vermont to have a pretty coordinated system of care, with many agencies working collaboratively to provide home and community based services. I know it is beyond the scope of many medical offices to provide social work type services, but treating the whole person is what is needed.”*

- HomeShare Vermont Staff Member

## IV. INTERVENTION AND METHODOLOGY

### ■ Providing Resources for the Caregiver

- I created a pamphlet for the waiting room and the Community Health Team room at Milton Family Practice that offers encouraging words, advice for ways to identify and prevent burnout, as well as resources for caregivers such as respite care, transportation, adult day programs, support groups, caregiver classes etc.

### ■ Providing Resources for the Health Care Providers

- I wrote a P.O.E.M (Patient-Oriented Evidence that Matters) regarding caregiver burnout such as the epidemiology, health consequences and the ways to identify and address the issue of burnout and provide support.
- I also created two smartphrases to assist health care providers in addressing caregiver stress/burnout:
  - The first smartphrase (*.caregiver*) includes the Zarit Burden Interview, which is similar to other mental health questionnaires. It is a series of 12 questions scored from 0-4 to help assess the level of burden experienced by the caregiver.
  - The second smartphrase (*.caregiverresources*) is for health care providers to be able to insert into patient instructions at the end of a visit. It includes the resources provided on the pamphlet that will aid the caregiver in making healthy choices for themselves and the person for whom they provide care.



## Information Resources

Champlain Valley Agency on Aging:  
[www.cvaa.org](http://www.cvaa.org);  
Senior helpline 1-800-642-5119

Vermont Department of Disabilities,  
Aging and Independent Living:  
[www.ddas.Vermont.gov](http://www.ddas.Vermont.gov)

HomeShare Vermont:  
[www.homesharevermont.org](http://www.homesharevermont.org)

Family Caregiver Alliance:  
[www.caregiver.org](http://www.caregiver.org)

Caring.com:  
[www.caring.com](http://www.caring.com)

VT Kin as Parents –  
[www.vermontkinasparents.org](http://www.vermontkinasparents.org)

*“I felt that I needed to do this by myself. I didn’t want to burden anyone else. But, then I realized there were people who cared; people there to help and support me and my loved one.”*



## Caring for loved ones



## Caring for yourself



## Who is a caregiver?

A caregiver may be someone who goes to doctor's appointments, picks up prescriptions, prepares food, assists with walking or physical needs, coordinates care and services, listens to, talks with and provides emotional support to another.

While this can be extremely gratifying; it can also be extremely difficult. Often it is easy for a caregiver to put their own feelings, desires, health and needs aside to care for another. This can be detrimental to their health. It can lead to increased stress, diabetes, depression, hypertension, heart disease and more.

It is important that caregivers put time and energy into taking care of themselves. There are many resources to help caregivers do this. Just ask your physician or Community Health Team!

## Tips for Caregivers:

- ❖ Plan Ahead
- ❖ Take one day at a time
- ❖ Accept help
- ❖ Get enough rest and nutrition
- ❖ Be good to yourself
- ❖ Learn about available resources
- ❖ Develop back-up plans
- ❖ Make time for leisure, rest, and relaxation
- ❖ Share your feelings with others
- ❖ Make your own health a priority

## Watch for Signs of Burnout:

- ❖ Losing interest in activities you enjoyed
- ❖ Trouble sleeping
- ❖ Feeling isolated
- ❖ Feeling guilty about spending time on yourself
- ❖ Getting sick more often
- ❖ Showing impatience or irritability

## Caregiver Support

### In-home/Respite Care

- Champlain Valley Agency on Aging (1-800-642-5119) can help set you up with:
  - Caregiver classes and support groups
  - Case Management
  - Weekly senior companionship
  - Housekeeping needs
  - Meals on Wheels
- Residential Care Homes and Nursing homes also offer space on a weekly basis for respite care
- Homeshare Vermont [www.homesharevermont.org](http://www.homesharevermont.org); 802-863-5625

### Transportation

- Addison County – 802-388-1946
- Chittenden County – 802-878-1527
- Franklin County – 802-527-1527
- Grand Isle County – 802-371-6425

### Caregiver Registry

- Vermont Direct Care Registry  
[www.rewardingwork.org/vt](http://www.rewardingwork.org/vt); 1-866-212-9675

### Adult Day Programs

- CarePartners Adult Day Center; St. Albans  
[www.carepartnersvt.org](http://www.carepartnersvt.org); 802-527-0548
- Project Independence; Middlebury, VT  
[www.elderlyservices.org](http://www.elderlyservices.org); 802-388-3983
- Visiting Nurse Association; Colchester, Williston, South Burlington, VT [www.vnacares.org](http://www.vnacares.org); 802-658-1900

### Support Programs

- The Community Health Team
- Lotsa Helping Hands [www.lotsahelpinghands.com](http://www.lotsahelpinghands.com)  
A free caregiving coordination web service where caregivers can create a private calendar accessed by friends and family members willing to help out.
- National Family Caregiver Support Program  
Designed to provide unpaid caregivers with the assistance they need.

## V. RESULTS

- Created and distributed 25 pamphlets to both the patient waiting room and the Community Health Team room. I also emailed a copy of this pamphlet to the Community Health Team.
- The P.O.E.M and two smartphrases were emailed to the staff, clinicians, nurses and other health care providers at Milton Family Practice. Handouts were also placed in the break room.
- Access via PRISM was shared for both of the smartphrases.
- Feedback from health care providers at Milton:
  - “Thank you. It is great to have these resources for patients.”
  - “We see this problem of caregiver burnout so often in practice. I am excited to have the ability to offer some tangible resources for these patients.”

# VI. EVALUATION OF EFFECTIVENESS AND LIMITATIONS

## ■ Effectiveness

- Health care providers at Milton are really excited to be able to have these resources at their fingertips.
- I think that as the pamphlets are around longer they will continue to have more exposure with patients who are caregivers. I believe that they will provide some of the support they are looking for, and hopefully begin a more meaningful discussion with their provider.

## ■ Limitations

- Unfortunately, I felt that due to time constraints I was not able to personally see the smartphrases I made put into use or any response from patients on the pamphlets.
- Resources are constantly changing, which means the smartphrase `.caregiverresources` and the pamphlet will also need to change. I am hopeful that the Community Health Team will continue to be dedicated to addressing caregiver burden and providing resources even when the resources I provided become outdated.
- Many tools such as smartphrases can be lost/forgotten about in PRISM.

## VII. RECOMMENDATIONS FOR THE FUTURE

- I think it would be extremely useful to spread this to more health care providers in the area. Many providers know these resources are out there, but the pamphlet and smartphrases can give them any easy and concise way to offer them to their patients. I think the P.O.E.M validates physicians desire to treat caregiving as another aspect of their patient's health/problem list.
- I think that it would also be helpful to have the Zarit Burden Interview incorporated into PRISM similar to how other mental health questionnaires are inputted. This would allow for continuity in how questionnaires like this are found and implemented during the patient encounter.
- Another – probably lofty – step in this project could be advocating to congressman for better options for caregiving for the elderly. Unfortunately, Medicare does not cover the services offered by most agencies. We need to find better options for our elders.

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