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Elizabeth Anne Lynch

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Caregiver Burnout

Elizabeth Lynch

Colchester Family Medicine

September, 2019

Project Mentors: Dr. Sean Maloney, Dr. Zail Berry,
Dr. Stephen Berns

Problem Identification

- By 2030, one in five adults will be > 65
- Estimated 39.5 million Americans are providing care for an adult currently
- On average, caregivers provide care for 4 years with commitment ranging from 21.4 hours/ week (average) to higher-hour care closer to 44.6 hrs/week (spouse or partner care)
- Higher hour caregivers have more stress, physical and financial difficulty and are at greater risk for poor healthcare themselves
- Often assist with Instrumental Activities of Daily Living (IADL) and Activities of Daily Living (ADL's)
- Worst health outcomes reported in caregivers caring for patients with:
 - A) mental health issues
 - B) complex health needs
 - C) co-resident status
 - D) performing medical or nursing tasks

Cost

- Increased rate of depression in caregivers, especially if caring for persons with dementia
- Caregivers report decline in quality of life and an increase in health complications
- The higher the caregiver burden the more likely it is the patient will have unmet health needs
- 63% higher mortality rate in older caregivers living with a patient compared to non caregivers
- One study found 74% of caregivers reported chronic pain which is shown to impact caregivers perception of the patients pain: overestimating pain when serving as a proxy and underestimating pain when depressed

Community Perspective

-“The problem is if they (caregiver) are caring for someone they can’t come in to get their own care. It is not a primary care physician problem, it is a system problem. In the Netherlands they can bring them (elderly) to adult day care ... We don’t have that here. It is a very isolating role.”

- “I am always encouraging caregivers to take care of themselves, put on your own oxygen mask first because if something happens to you this person is up a creek.”

- “A lot of times family caregivers are forced into the position based on finances. It comes down to socioeconomics, people just don’t have the money. It is not just easier, if you are on a fixed income, it is more money than you have (to get outside care).”

*Dr. Zail Berry, Associate Director of Hospice and Palliative Care in the UVM Health Network

Room for improvement:

- 1) Awareness- clinicians should be aware of some illnesses causing higher rates of caregiver burden (dementia as one of the biggest).
- 2) Funds for caregivers- too many times disease fundraising goes to finding a cure. Although that is very important, we also need to find ways to care for caregivers who have higher rates of burnout, illnesses, stress. I would ask philanthropy and also insurers to start thinking about creating caregiver programs for counseling, resources and giving them relief.
- 3) Family Leave- employers should model off of Europe and do longer FMLA programs so people can care for a loved one.

Role of Primary Caregivers:

- 1) Screening- screening for burnout on visitors for patients who have diseases that are at higher risk of caregiver distress
- 2) Awareness- they should be aware of resources that are available and advocate for caregivers
- 3) Empathy- they should validate the emotions and stress that the caregivers have. Conversations should be person centered and include responding to emotion.

*Dr. Stephen Berns, Director of Talk Vermont, Hospice and Palliative Care Department, UVM Medical Center

Community Perspective:

*Tracey Shamberger, Director of Community Outreach and Business Development at Age Well Vermont

“ One of the biggest challenges we’ve identified for the ageing population is social isolation. Especially in Franklin and Grand Isle counties. We aren’t reaching enough of the population there.”

“We need more communities serving local people... to be more engaged. We have over 1000 volunteers that do everything from talk about baseball to go to shows with clients so that they are still active and a part of the community. But we always need more.”

“The ageing New American population needs services too and we provide translators for doctors visits, meals cooked by native Nepalese chefs, Bhutanese events etc.”

Intervention and Methodology

1. Raise my own awareness of the issue as well as provider awareness via a presentation on the topic
2. Provide patient information in the form of an Epic SmartPhrase so providers can seamlessly share resources with patients as part of standard patient communication and discharge instructions
3. Empower providers to name the challenges caregivers face so caregivers know:
 - a. They are not wrong for feeling overwhelmed and frustrated
 - b. They are not alone in their struggle
 - c. That their provider is someone they can be honest and open with and who can offer them supports

Results/ Response

1. .caregiverburnout phrase now available in Epic with local resources for caregivers
2. Shared with every provider at Colchester Clinic
 - a. Under My Smart Phrases, click “open” (file folder icon)
 - b. Search Caregiverburnout
 - c. Template should appear
 - d. Add to “my smartphrases”
 - e. Each provider added as editor so can change as needed
 - f. Now can be inserted into patient education notes

User SmartPhrase – CAREGIVERBURNOUT [272022]

Do not include PHI or patient-specific data in SmartPhrases.

Insert SmartText Insert SmartList

Caregiver Burnout: Caring for a family member is a selfless and fulfilling act at times, but it can also be difficult and stressful. Caring for someone with advanced health care needs, dementia, or a difficult diagnosis can take a mental, physical and financial toll on you as the caregiver. It is important to know there are resources available to help you. Caregivers are at increased risk of neglecting their own health. We want you to know we are always here to care for you. These resources are available for you and your loved ones.

University Vermont MEDICAL CENTER
Community Health Team at Colchester Clinic: Our Community Health Team can help provide you or your loved ones with the resources you need to succeed. Whether it is meeting with a Social Worker, Case Manager, Dietician or Diabetes Educator to determine what resources you need to help you and your family thrive. Call 802-847-0000 or 1-800-358-1144.

UVM Medical Center Support Groups: It is important to know you are not alone and there is a community here to support you in your role as caregiver. Weekly and monthly support groups run by UVM can be found at: <https://www.uvmhealth.org/medcenter/Pages/Wellness-Resources/Support-Groups.aspx> or call 802-847-8821.

AGE WELL
Age Well Vermont: Age Well Vermont offers services to caregivers and patients navigating ageing and new health conditions. From events and classes to Meals on Wheels, Age Well can help support your needs so there is less pressure on you to provide everything needed for your patient. Age Well also helps with tough transitions to different care situations, for example, coming home from the hospital or going into a senior living facility. <https://www.agewellvt.org/> or call 802-865-0360. For immediate help call the Helpline: 1-800-642-5119.

BURLINGTON INCLUSION CENTER SENIOR CENTER
Champlain Senior Center: Offers classes, drop in activities and community events for seniors M-F. Located in downtown Burlington, the center also offers daily lunch for senior citizens. Call 802-316-1510 for more information.

Colchester
Bayside Activity Center: Located right on Mallets Bay, the activity center offers classes for seniors who want to stay fit, learn to cook, prepare for retirement or learn how to play an instrument. Call 802-264-5500 or check out the [Active Generation](#) programs available in the Activity Guide.

The Center on Aging
Memory Café's: Vermont hosts a number of memory café's for people living with dementia and their caregivers as a place for support and interaction. Find the closest memory café for you and your loved one at <http://www.med.uvm.edu/centeronaging/events/cafes>

the Y
The YMCA of Greater Burlington offers Low Impact and Senior Programs including Senior Swim, Senior Exercise, and Active Older Adults, Yoga, Tai Chi, and Pickleball specifically for the ageing community members to help people stay active and involved. Call (802) 862-9622 for more information



A graphic titled "10 TIPS FOR FAMILY CAREGIVERS" featuring a diverse group of people of various ages and ethnicities. The text "10 TIPS" is in a blue box, and "FOR FAMILY CAREGIVERS" is in white text on a blue background.

Effectiveness/ Limitations

Limitations:

- Colchester specific, not generalizable
- Requires awareness and vigilance to screen and intervene
- Physicians already responsible for many other screenings in addition to managing patients concerns on each visit
- Resources for caregivers are limited and adequate support isn't built into our healthcare system yet

Effectiveness:

- Will be difficult to assess because requires data collection on whether caregivers follow up on resources provided. We know caregivers often can't come to appointments or follow up due to constraints on their time
- Requires caregivers to reach out for help rather than resources contacting caregivers, which puts the burden on already overwhelmed caregivers
- Not a system based change, only a small intervention that acts more as a temporary solution to a much larger structural issue

Recommendations

**Increase screening for caregiver burnout

*Use Caregiver Self-Assessment Questionnaire

** Advocate for caregiver support during community planning meetings, through roles in UVM Medical Center administration and through conversations with other family members so they are aware of the challenges caregivers face

Screening interventions: A) During Rooming Process: have you recently become a caregiver for anyone in your family?

B) Physician screening: have there been any updates in your family health history? Are you a primary caregiver for anyone in your family currently?

C) Give questionnaire to every patient over 40 coming in for annual visit along with SODH screening forms

Caregiver Self-Assessment Questionnaire

How are YOU?

Caregivers are often so concerned with caring for the relative's needs that they lose sight of their own well-being. Please take just a moment to answer the following questions. Once you have answered the questions, turn the page to do a self-evaluation.

During the past week or so, I have ...

- | | | | |
|--|--|---|--|
| 1. Had trouble keeping my mind on what I was doing.... | <input type="checkbox"/> Yes <input type="checkbox"/> No | 13. Had back pain..... | <input type="checkbox"/> Yes <input type="checkbox"/> No |
| 2. Felt that I couldn't leave my relative alone..... | <input type="checkbox"/> Yes <input type="checkbox"/> No | 14. Felt ill (headaches, stomach problems or common cold)..... | <input type="checkbox"/> Yes <input type="checkbox"/> No |
| 3. Had difficulty making decisions..... | <input type="checkbox"/> Yes <input type="checkbox"/> No | 15. Been satisfied with the support my family has given me..... | <input type="checkbox"/> Yes <input type="checkbox"/> No |
| 4. Felt completely overwhelmed..... | <input type="checkbox"/> Yes <input type="checkbox"/> No | 16. Found my relative's living situation to be inconvenient or a barrier to care..... | <input type="checkbox"/> Yes <input type="checkbox"/> No |
| 5. Felt useful and needed | <input type="checkbox"/> Yes <input type="checkbox"/> No | 17. On a scale of 1 to 10, with 1 being "not stressful" to 10 being "extremely stressful," please rate your current level of stress. _____ | |
| 6. Felt lonely..... | <input type="checkbox"/> Yes <input type="checkbox"/> No | 18. On a scale of 1 to 10, with 1 being "very healthy" to 10 being "very ill," please rate your current health compared to what it was this time last year. _____ | |
| 7. Been upset that my relative has changed so much from his/her former self..... | <input type="checkbox"/> Yes <input type="checkbox"/> No | | |
| 8. Felt a loss of privacy and/or personal time..... | <input type="checkbox"/> Yes <input type="checkbox"/> No | | |
| 9. Been edgy or irritable..... | <input type="checkbox"/> Yes <input type="checkbox"/> No | | |
| 10. Had sleep disturbed because of caring for my relative..... | <input type="checkbox"/> Yes <input type="checkbox"/> No | | |
| 11. Had a crying spell(s)..... | <input type="checkbox"/> Yes <input type="checkbox"/> No | | |
| 12. Felt strained between work and family responsibilities... | <input type="checkbox"/> Yes <input type="checkbox"/> No | | |

Comments:

(Please feel free to comment or provide feedback.)

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