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# Caring for Caregivers: Addressing Caregiver Burden in Newtown, Connecticut

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# Caring for Caregivers

Newtown Primary Care, Connecticut

Zac Wunrow

Family Medicine, September 2017

Dr. Cate Shanahan and Lauren Mihaylo, RN

# Problem Identification

- ▶ In 2015, 34.2 million Americans provided unpaid care to an adult age 50 or older
  - ▶ In the coming years, the demand for family caregivers is only expected to increase, due to an aging population, increased number of individuals living with debilitating disease, shorter hospital stays, changes in insurance reimbursement, and proliferation of in-home care technology and services
- ▶ One-third of caregivers rate their burden of care as “high”
  - ▶ These caregivers are more likely to live with the care recipient, be in poorer health, have financial stress, and perceive they had no choice in accepting the role
- ▶ The combination of prolonged stress and the physical demands of caregiving increases the risk for physical health problems
  - ▶ Schulz et al. (1999): “being a caregiver is an independent risk factor for mortality.” 63% increased four-year mortality for caregivers over non-caregivers
  - ▶ Half of all caregivers have at least one chronic condition
  - ▶ Higher rates of insomnia and depression

# Public Health Cost

- ▶ A majority of caregivers describe having less time for family and friends, having increased emotional stress, and neglecting self-care, including exercise, dietary habits, and adequate sleep
  - ▶ 72% of caregivers report “not going to the doctor as often as I should” since they began providing care
  - ▶ Half of the caregivers that report a decline in their own health state that their ability to provide care has been consequently compromised
- ▶ Wolff et al. (2016): caregivers have a 5x risk of experiencing participation restrictions in valued activities; 3x risk of experiencing decreased work productivity

# Community Perspective

- ▶ “[During the interview with patient and caregiver, PCPs should] acknowledge that **one person cannot do it all**. Caregivers need permission not to feel guilty getting help. Our system and our culture do not support a grown child caring for their elderly parent at home or without support. Part of the problem with our system is **there is no one person to go to for information on how to navigate the system**. There are so many layers and each agency has their protocol.”
- ▶ “Visiting nurse and other Medicare-covered services are very good, but they don’t begin to scrape the tip of the iceberg when it comes to care at home for an elderly person. Visiting nurse is a few hours a week and for a limited time. Caregivers often believe this is enough. It is not. We encourage patients and families to start the process of researching care options and having a conversation about what that would look like for their family. Tour a facility and get on their waitlist. Being on the waitlist for a long-term care facility doesn’t mean the person has to be admitted. It just means they have the option. Then, when a crisis occurs, i.e. mom falls and fractures a hip, and they are in the hospital needing to choose a skilled nursing facility, they already have their choices narrowed down. I also encourage family members, as hard as it is, to **have those conversations with mom or dad when they are still cognitively intact and able to weigh in on what will happen to them**. It will give the patient self-determination, and help the family make decisions when the time comes. **Don’t ever promise you won’t put mom or dad in a nursing home. That’s unrealistic**. Promise them they will receive good nursing and that you will manage their care and needs the way they would like. We realize these are difficult topics to broach, but we encourage people to make pre-paid funeral arrangements, discuss code status and complete advance directives like living will, POA and health care agent. All this helps take the burden off the caregiver when it is time to make decisions.”
- ▶ Pamela Shepperd Katra, LCSW, Director of Social Services at Filosa Nursing and Rehabilitation Center, Danbury, CT

# Community Perspective

- ▶ “Part of every assessment [performed by Connecticut Community Care] evaluates, as appropriate, caregiver stress. We ask the client and the supporter a designated set of questions which include their concerns about each other. We always assess the caregivers for sleep disturbances, exhaustion, feeling sad or lonely, anger, frustration, happiness and always, **do their caregiving responsibilities interfere with their own well-being.**”
- ▶ “Generally caregivers are not reluctant to accept home care services, they are simply not aware of them. **This is a role for the PCP who needs to be able to provide options for home care** including an independent (conflict-free) assessment to assure that appropriate levels of care will be provided and that the client is taking advantage of all programs they may be eligible for.”
- ▶ “[I was recently told] Danbury is the 21st most diverse city in the United States; therefore, dignity and respect from a cultural perspective is critical to the success of any intervention. Take the time, as a physician, to understand and immerse yourself in the community, outside of the office walls! **Pay close attention to the social determinants of health.** If a newly diagnosed diabetic does not have access to healthy food, they are never going to have an A1C less than 7. **Things like transportation, safety, healthy eating, support systems, health literacy and access to care are as important as the medical diagnosis and the treatment plan.**”
- ▶ Gayle Kataja, MS, RNC, CMC, Director of Quality Improvement at Connecticut Community Care, Bristol, CT

# Intervention and Methodology

- ▶ This project hypothesizes that the prevalence and severity of caregiver burden might be partially decreased via two interventions:
  - ▶ 1) Caregivers are provided with more education about resources and local services available to them
  - ▶ 2) Providers are made aware of the scope of caregiver burden, and actively aid caregivers towards achieving adequate support
- ▶ In order to address #1, a pamphlet for caregivers was generated that lists support groups, mental health services, adult day care centers, home care assistance, financial assistance, advanced care planning, and more
- ▶ For #2, a presentation was developed that summarizes studies elucidating the poor health outcomes associated with caregiver burden, and that offers recommendations on how PCPs can address these issues

# Results

- ▶ Pamphlet for caregivers: the compilation of resources is meant to act as a convenient stepping stone for the caregiver in determining what may be needed to appropriately take care of the patient-caregiver dyad. The pamphlet is to be distributed in all public waiting areas at Newtown Primary Care.
- ▶ Presentation: a ten-slide powerpoint was presented to healthcare providers at Newtown Primary Care including Dr. Cate Shanahan.



## Caring for Caregivers

Taking care of a loved one and helping to relieve their suffering can yield **immense personal fulfillment.**

Yet studies have shown that caregiving can also be associated with a **myriad of physical and psychological stresses.**

Do you have the **support** that you need?

### How Can PCPs Help Relieve Caregiver Burden?

- When a patient resists the idea of accepting home health care services, a physician's strong recommendation may be more likely to be considered and ultimately adopted
- Discuss advance care planning and determine if referrals are necessary
  - End of life discussions, particularly those that occur before the last month of life, are associated with improvements in quality of life, receipt of desired care, reduced physical suffering, improved family coping, and increased use of hospice
- Physicians have a responsibility to raise these issues with patients as the disease begins to worsen
- Possible suggestions and referrals: home care, rehabilitative services (speech, PT/OT), mental health services, spiritual services, caregiver support groups, nutritional services, community volunteer services, medical devices (including automatic medication dispensers, mobility monitors, scooters and lifting systems), food delivery, and palliative care
- In a study of individuals utilizing palliative care, access to professional support was demonstrated to improve quality of life for patients and caregivers, lower the burden of home care for the caregiver, improve symptom management, and decrease unnecessary hospital/ER utilization



# Evaluation of Effectiveness and Limitations

- ▶ Although I was inspired to pursue this project based on an interaction with a caregiver who felt overwhelmed by the prospect of maintaining her husband's peritoneal dialysis, I think it would have been valuable to this project to have been able to converse with more caregivers about their stressors.
- ▶ During this project, I discussed caregiver burden with multiple primary care physicians, social workers, and a care coordinator. It would have been useful to elicit perspectives from other disciplines involved in end-of-life care (including hospice and palliative care).
- ▶ With the assistance of a care coordinator, I was able to develop a lengthy list of caregiver resources for inclusion in the pamphlet. However, many important resources were likely overlooked. If caregivers had been interviewed for this project, they might have been able to contribute resources to this list as well.

# Recommendations for Future Projects

- ▶ Considering that 81% of caregivers feel inadequately trained for the skills that they perform, a future project might feature a training/education workshop for important caregiving skills (e.g. wound care, or proper positioning when lifting)
- ▶ The topic of caregiver burden might also be approached through interviews of Newtown Primary Care patients and their caregivers, in order to gain a better sense of the socioeconomic and cultural stresses unique to the Newtown community
- ▶ A future project might focus on improving advance directive completion rate in the community, which may indirectly decrease caregiver burden

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# Interview Consent Forms

Thank you for agreeing to be interviewed. This project is a requirement for the Family Medicine clerkship. It will be stored on the Dana Library ScholarWorks website. Your name will be attached to your interview and you may be cited directly or indirectly in subsequent unpublished or published work.

✓ The interviewer affirms that he/she has explained the nature and purpose of this project.

✓ The interviewee affirms that he/she has consented to this interview.

Yes

Name:

Zac Wunrow



Name:

Pamela Sheppard Motter, PhD

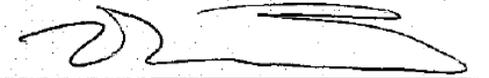
✓ The interviewer affirms that he/she has explained the nature and purpose of this project.

✓ The interviewee affirms that he/she has consented to this interview.

Yes

Name:

Zac Wunrow



Name:

Gayle P. Kataja

