

Improving the Quality of End of Life Care for Older Adults in Health Centers

Session 5: Engaging with family

2018-2019 Learning Collaborative Series

Thursday, January 24, 2019



National Center for Equitable Care for Elders (NCECE)

www.ece.hsdm.harvard.edu

Who We Are- Established in 2017, the National Center for Equitable Care for Elders (NCECE) is a training and technical assistance Center that provides innovative and culturally competent models of care, inter-professional training and educational resources to health care professionals providing care to older adults

Our Mission is to build strong, innovative and competent health care models by partnering with CHCs, PCAs and FQHCs to provide quality, and inclusive care for older adults



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Health Center Resources Clearinghouse

This comprehensive website provides easy access to a broad framework of resources, tools, and information developed by the National Cooperative Agreement (NCA) organizations, and additional partners soon! Check it out at www.healthcenterinfo.org.



Session Leader



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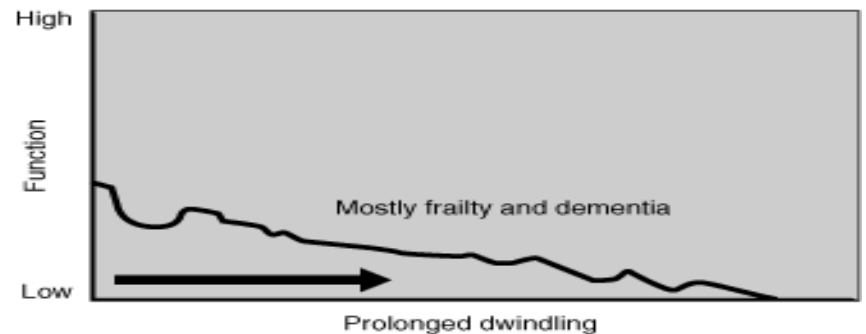
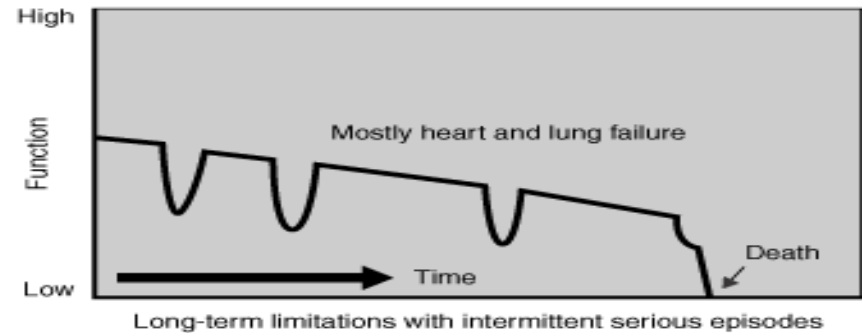
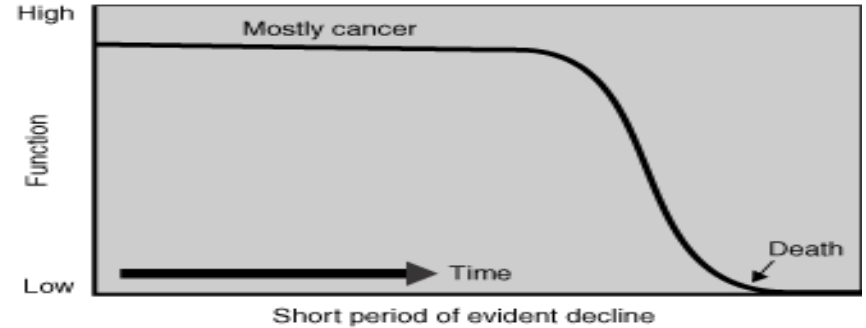
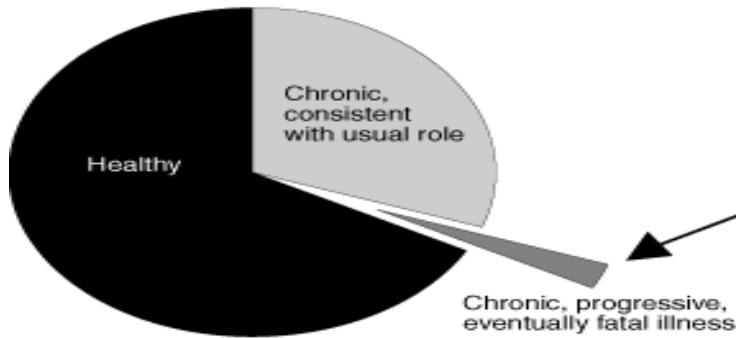
The *Critical Role* of Community Health Centers in Supporting Family Caregivers

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Financial Disclosures

None

Is the Patient with a Serious Illness in their lives the way they want to be? (Ref: RAND Corp)



Caregivers: “The Invisible Workforce”

- 43.5 million Americans are Family Caregivers (2015 NAC/AARP Survey)
- Family caregivers can be a relative, partner, friend, or neighbor
- Women AND Men are family caregivers
- Family caregiving for many is a second full time (unpaid) job

Family Caregiver Role is most often:

undefined

unpaid

In General:

Family Caregivers perform complex medical tasks
for which they receive no formal training

Caregivers often have their own significant unmet health and psychological needs.

They can be held to moral and legal responsibility that jeopardizes their own health and wellbeing.

Family Caregiver Burden Increases as Patient Function Decreases

Serious Illness Diagnosis

Complex Disease Directed Therapy such as chemo/radiation

Progressive Functional Decline/Loss of Reserve

Mounting Caregiver Responsibilities

Insurance Loss/JOB LOSS/mounting debt

Food, Housing, Energy Insecurity

Family Decompensation

Crisis Hospitalizations

Social Isolation

Caregiver Burden



Who Makes the 911 Call?

Community Health Centers: Anchor in a Sea of Uncertainty and Confusion

More likely to understand and recognize:

- *local cultural and social norms
- *neighborhood safety issues, transportation and food and housing insecurities
- *social networks, local resources
- *gaps in social services

Recognizing and Screening for Family Caregiver Burden

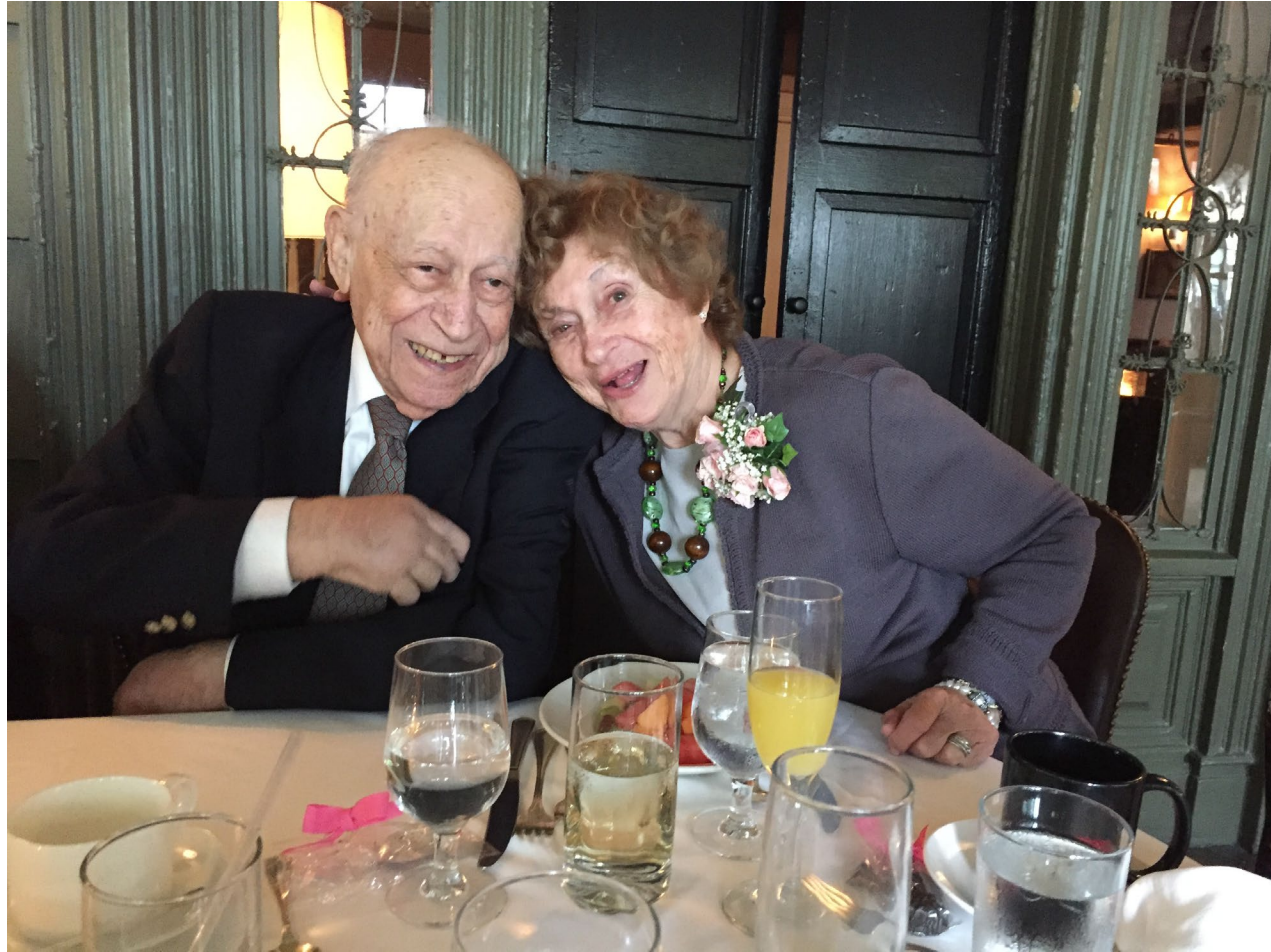
- **Where is your patient in illness trajectory?**
- **Has the patient had major changes in function over the past year?**

Palliative Care Performance Scale: (PPS)

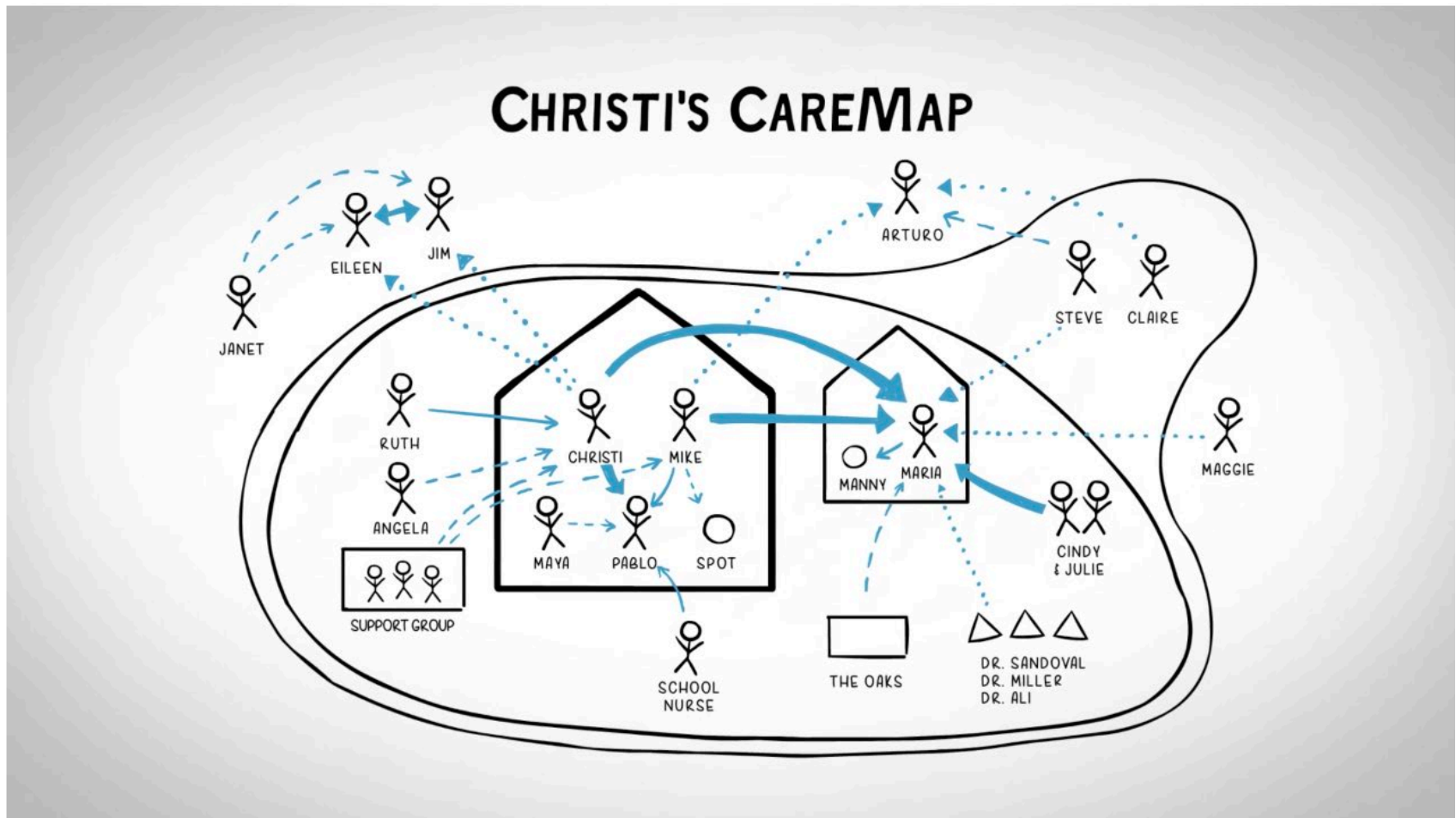
<https://www.vitas.com/partners/hospice-eligibility-reference-guide/palliative-care-plans-for-your-hospice-patients>

Unpacking Family Caregiving Networks:

**Tasks are often divided between
family caregivers**



Atlas of Caregiving



Caregiver Assessment: *Ask Them*

What are you most worried about?

How are things going?

What works well for you?

What do you need that might make things easier?

Zarit Burden Interview (ZBI)

http://dementiaphways.ie/filecache/edd/c3c/89-zarit_burden_interview.pdf

Caregiver Assessment Changes Over Time

- Identify and Document Family Caregiver
- Recognize the limitations of a single clinic visit in identifying family caregiver needs
- Family caregiver assessments should be ongoing over time and by all members of the interdisciplinary care team

Bernie and Violet

Bernie is the 80 yo. family caregiver of Violet, his wife of 55 years. Violet, age 78, has Alzheimer's dementia. She needs assistance with dressing, bathing, and feeding. Violet is otherwise healthy, ambulatory, and has not been in the hospital. Bernie handles all the family finances, household chores, medical care, and transportation. They have a small fixed income and have no savings. They have lived in the same neighborhood for many years, however, most of their friends have moved away or died. The neighborhood, since the 2008 housing crisis, has many abandoned houses and the closest grocery store is 10 miles away. Their adult daughter lives 2 states away and calls her parents every evening.

Bernie and Violet

- *You are the Primary Care Provider for Violet at their Community Health Center. You have an appointment with Violet scheduled tomorrow. Bernie is always present at the visits.*
- *Today you get a call from Bernie's daughter. She is upset and frustrated with her father. He refuses to accept help and is determined to have Violet live out her life in their own home. Last time she visited she found a cluttered house, little food in the refrigerator and a stack of overdue bills. Her mother smelled of urine. Daughter is seeking your help to convince her father to put her mother in a nursing home.*

Pop Quiz

You should tell the daughter:

1. It is a HIPAA violation to speak with her
2. You will fax her a list of local nursing homes
3. Call adult protective services
4. Thank her for the call and reassure her you will assess her parents for caregiver needs

Bernie and Violet continued...

You ask Bernie how things are going?

He tells you lately things have gotten more difficult. Violet is up several times during the night with requests to use the bathroom, often without any result and he can no longer get a good night sleep. She is occasionally incontinent of urine. She has been less cooperative with bathing and sometimes spits out her food. Last week he had to call 911 to help him get Violet back into bed after she slipped off the toilet.

Explore Caregiver Needs With Bernie AND Violet

What are you most worried about?

What works well for you?

What do you need that might make things easier?

Zarit Burden Interview (ZBI)

http://dementiapathways.ie/filecache/edd/c3c/89-zarit_burden_interview.pdf

Possible Actions with Family Caregivers by Community Health Centers

- Education: related to a serious illness
- Counseling/caregiver support
- Family Meetings
- Identifying and Addressing Resource Gaps
- Palliative Care Consultation
- Hospice Referral (< 6 months of life)

Do Not Wait Until the Patient Dies to Address Bereavement

Anticipatory Grieving

Loss of Role as Family Caregiver

References:

- **National Institute on Aging:**
<https://www.nia.nih.gov/health/doctor-patient-communication/talking-with-your-older-patient>
- **United Hospital Fund** <http://www.uhfnyc.org/>
- **Next Step in Care** <http://www.nextstepincare.org/>
- **For Family Caregivers:**
https://www.nextstepincare.org/Caregiver_Home/HospiceCare Mapping
<https://atlasofcaregiving.com/>
- **National Alliance for Caregiving**
<https://www.caregiving.org/caregiving2015/>
- **Caregiving in the U.S.** https://www.caregiving.org/wp-content/uploads/2015/05/2015_CaregivingintheUS_Executive-Summary-June-4_WEB.pdf.
- Himmelstein DU, Thorne D, Warren E, Woolhandler S . Medical bankruptcy in the United States, 2007: results of a national study. *The American Journal of Medicine*. 2009;122, 741-746.

Resources (con't)

- Caregiver resource centers
- Next Step in Care (www.nextstepincare.org)
- Volunteer groups
- Family Caregiver Alliance
(www.caregiver.org)
- Geriatric assessment centers
- Well Spouse Association
(www.wellspouse.org)
- Eldercare Locator (www.eldercare.gov)

From the Center to Advance Palliative Care (www.capc.org)