



Advancing Caregiving as a Public Health Issue: The Need for Surveillance & Intervention

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Why is Caregiving a Public Health Concern?

- The circumstances of caregiving create risk factors that may compromise health:
 - Duration of care
 - Intensity of care
- Caregivers may not obtain routine medical care
- Caregivers neglect own health—not enough sleep or exercise; eating on the run Caregivers may not get well when sick
- Onset of stress, depression and isolation
- Potential for injury
- Rapidly aging population



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Why are state-level data important?

- Prevalence of caregiving varies state-to-state
- Priority needs of caregivers may vary from state-to-state
- Different interventions may be needed to target different priority needs
- Argues for state level data for planning, policy, and programs



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Who's interested in caregiving?

- HP 2010, Chapter 6
- Federal agencies: HHS, DOL, DOE
- State units on aging/disability/mental health
- Developmental disabilities councils
- Area agencies on aging
- Health care delivery organizations
- Business
- Insurance carriers
- Disability organizations
- Disease-specific organizations: Cancer, Alzheimer's disease
- Adult children, spouses, & parents
- Professional & family caregivers
- Aging/injury populations



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CDC's Approach

- *Surveillance*: Magnitude of problems at state level
- *Science*: Body of knowledge to understand dimensions of a problem
- *Policy*: Suggest strategies to address problem
- *Intervention*: Activities to promote health
- *Dissemination*: Knowledge & interventions



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Role of Disability and Health Team in Caregiving

- Improve health of caregiver—allows caregivers to remain active caregivers
- 20% of caregivers report disabilities
- Improve health of people with disabilities—perhaps reduce caregiver burden
- Logic: Better health of caregivers leads to better health and QOL of people with disabilities



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D&H Team Orientation

- Collaboration with CDC partners
- Collaboration with external partners
- Utilize a lifespan approach to caregiving
- Attend to caregiving dyad or triad in their environmental contexts
- Collect state-level data inform practice, education and training, and policy



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BRFSS Caregiving Core Questions 2000 only

1. There are situations where people provide regular care or assistance to a family member or friend who is elderly or has a long-term illness or disability. During the past month, did you provide any such care or assistance to a family member or friend who is 60 years of age or older?
2. Who would you call to arrange short or long term care in the home for an elderly relative or friend who is no longer able to care for themselves?



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BRFSS Caregiving Core Questions 2001 only

1. Are you limited in any way in any activities because of physical, mental, emotional problems?
2. Do you now have any health problem that requires you to use special equipment, such as a cane, wheelchair, a special bed, or a special telephone?



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History

- 2002: Funded Karen Kuhlthau (Mass General/Harvard) Family Caregiving for Children with Disabilities (PEP)
- 2003: Funded Elena Andresen (UFL) Development of BRFSS Caregiver Module (PEP) (w/ CDC Healthy Aging Program support)



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New BRFSS Caregiver Module Development

- Assembled stakeholders to establish critical elements of caregiver surveillance
- Their advice:
 - Information about care recipients
 - Functional & diagnosis aspects
 - Caregiver health
- Result: 10-question caregiver module



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New BRFSS Caregiver Module Development

- 10 questions:
Gender, relationship, condition, ICF impairment (learning, moving around), duration, hours per week, difficulties (finances, time, work), injury, living arrangement
- Plus 3 questions on cognitive functioning
- 26 optional modules in 2005



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Caregiver Module Pilot

- May-August 2005: North Carolina BRFSS piloted the Caregiver Module
 - 895 of 5,681 screened reported they were caregivers (15.3% weighted)
- 20 minute follow-back questionnaire conducted among 401 caregivers



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Caregiver Followback Study

- 100 questions/20 minutes
- Environmental factors
- Access to health care
- Physical, emotional & financial stress
(friends, vacations, costs, supports, exercise)
- Injury (type, seek care, miss work, affect caregiving role)
- Coping/Supports



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Caregiver Characteristics*

	Caregivers (n=895)	Non-caregivers (n=4,964)
Age (mean)	46.4	45.6
Female	59.5%	51.1%
<u>Race - ethnicity</u>		
White	71.5%	69.6%
African Am.**	21.2%	15.8%
Hispanic**	2.3%	10.3%

* Weighted data **p < 0.05



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Caregiver Characteristics*

Hours /week caregiving (mean)	20.1
≤ 8 hours	52.1%
9-19 hours	18.1%
20-39 hours	16.1%
≥ 40 hours	13.6%
<u>Distance from care recipient</u>	
In same house	24.9%
Under 20 minutes away	47.3%

* Weighted data **p < 0.05



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Care Recipient Characteristics*

Age (mean)	65.6
0-5	1.6%
6-17	5.5%
18-29	3.1%
30-49	10.5%
50-64	15.1%
65-74	19.2%
75-84	25.5%
85+	19.6%
Female	67.2%

* Weighted data



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Care Recipient Characteristics*

<u>Relationship</u>	
Spouse/partner	10.8%
Other family member	72.0%
Non-family	16.0%
Paid caregiver	1.2%
<u>Leading health problems</u>	
Heart Disease	12.8%
Cancer	11.7%
Stroke	9.1%
Diabetes	9.0%

* Weighted data



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Care Recipient Characteristics*

<u>Primary functional problems</u> §	
Moving around	41.7%
Self care (eating, dressing, bathing)	41.0%
Learning, remembering, confusion	17.0%
Feeling anxious or depressed	16.4%
Communicating with others	8.7%
Seeing or hearing	7.0%
Getting along with others	6.1%

Cognitive impairment	40.9%
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* Weighted data § up to 2 responses



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History (continued)

- 2006: CDC Director's Discretionary Award
 - Funded three additional states to implement BRFSS module and UFL to conduct analysis
 - Funded Mathematica to develop searchable data base & literature review on caregiver health
 - Began groundwork for cognitive testing of BRFSS module
 - Expert panel support
- 2007: Neugaard, B., Andresen, E. M., Talley, R. C., & Crews, J. E. (2007). **The characteristics and health of caregivers and care recipients--North Carolina, 2005.** *MMWR*, 56, 529-532.
- 2007: Convened Expert Panel on Caregiving
- 2007-2008: Funded Cognitive Testing of Module



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Publications

- Talley, R. C., & Crews, J. E. (2007). **Framing the public health of caregiving.** *American Journal of Public Health*, 97(2), 224-228.
- Talley, R. C., & Crews, J. E. (2007). **Talley and Crews respond.** *American Journal of Public Health*, 97(11), 1931-1932.
- McGuire, L. C., Anderson, L. A., Talley, R. C., & Crews, J. E. (2007). **Supportive care needs of Americans: A major issue for women as both recipients and providers.** *Journal of Women's Health*, 16, 784-798.
- **Caregiving Book Series - Springer**



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Next Steps

- Seek approval of caregiver module for 2009 implementation
- Create state incentives for implementing module: AoA, D&H, state units on aging, developmental disabilities councils, others
- Analyze data to determine intervention development needs
- Publish national report on caregiving
- Pursue Surgeon General's call to action
- Pursue Institute of Medicine report on caregiving
- Create *Healthy Caregivers 2020* Initiative
- Strengthen science to develop & evaluate interventions



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Contact Information

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