



## **Caring for the Care Collaborator: *Building and Sustaining the Competent Team***

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NACNHSC

# Description and Learning Objectives

Understand the Problems

Implement Approaches – things that work

Building a Better System

*Via Personal Reflections and Your Questions*

# Context

## The Aging Demographics

More older Americans and Fewer (relatively) Younger

## Association of Age with Functional Dependency and Dementia

Care needs

## Multi-Morbidity

## Limited Social Supports Systems in America

## Wide Variations

Disease states, cultural, resources

# Our job is tough, but not the toughest

No single health care or social service discipline is charged with providing assistance with self-care and household tasks, providing emotional support, and performing health and medical tasks around the clock, 7 days per week; advocating for an older adult's needs, values, and preferences in multiple health care and LTSS settings; and functioning in a legal capacity as a surrogate decision maker. Health and social service professionals and direct care workers “hand off” responsibility to others, whereas many family caregivers do not have the option of handing off their responsibilities.

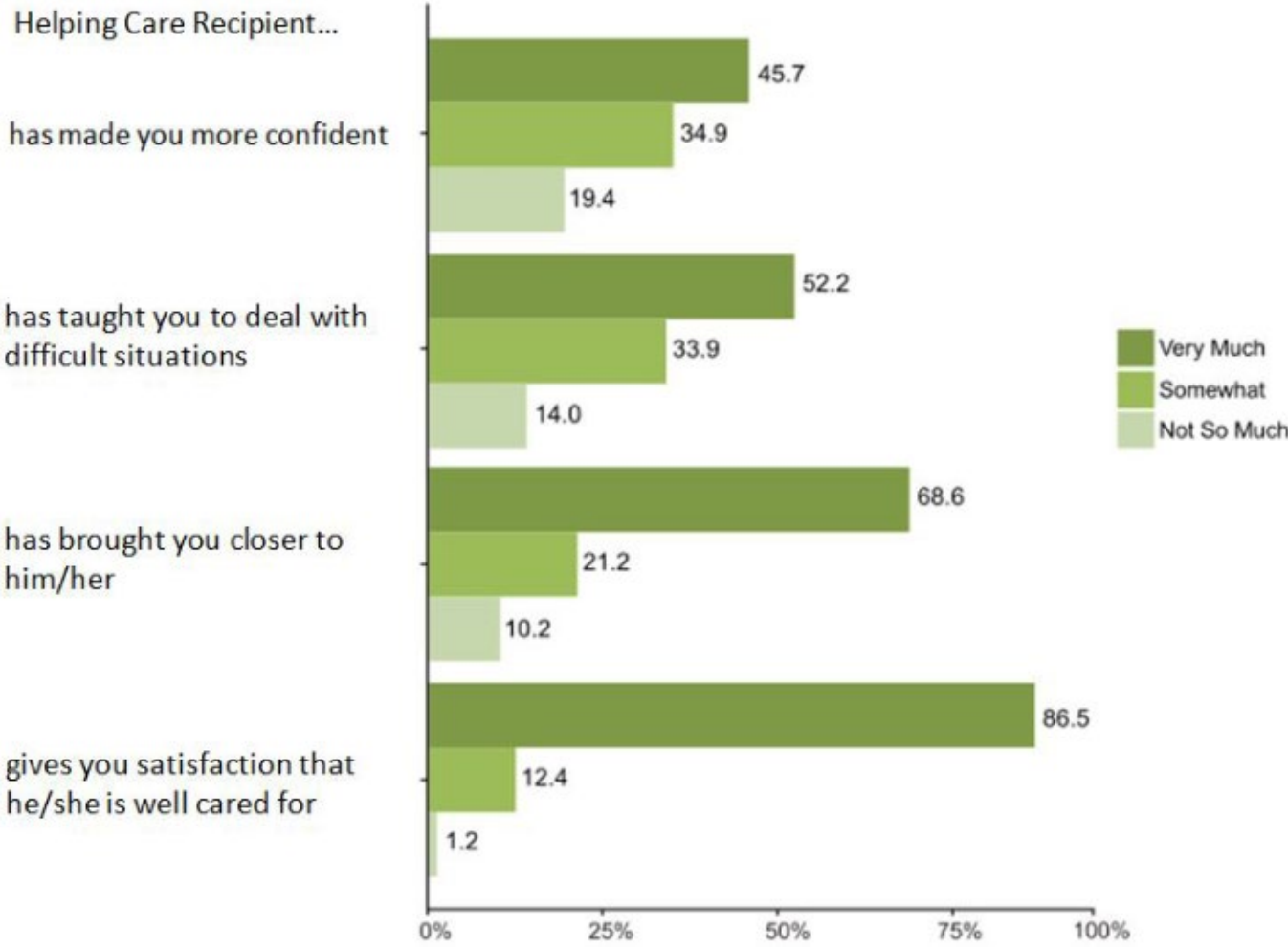
National Academies of Sciences, Engineering, and Medicine.  
2016. Families caring for an aging America. Washington, DC: The National Academies Press. doi:10.17226/23606.

**TABLE 3-3** Family Caregiver Reports of Emotional, Physical, and Other Difficulties, by Care Recipient’s Dementia Status and Level of Impairment, by Percentage, 2011

Difficulties	Care Recipient’s Dementia Status and Level of Impairment			
	Dementia Only	No Dementia; Has Two or More Self-Care Needs	Dementia; Has Two or More Self-Care Needs	No Dementia; Has Less Than Two Self-Care Needs
Percentage of caregivers reporting . . .				
Emotional difficulty	48.8	45.5	56.5	38.1
Physical difficulty	20.4	28.5	39.6	16.4
Percentage of caregivers responding “very much” . . .				
Exhausted at night	17.0	19.6	25.3	11.8
More things to do than they can handle	26.7	18.0	23.9	11.7
Don’t have time for themselves	23.3	14.3	24.3	10.0

National Academies of Sciences, Engineering, and Medicine.  
 2016. Families caring for an aging America. Washington, DC: The National Academies Press.  
 doi:10.17226/23606.

**FIGURE 3-4** Percentage of caregivers responding very much, somewhat, not so much to positive aspects of caregiving.



National Academies of Sciences, Engineering, and Medicine. 2016. Families caring for an aging America. Washington, DC: The National Academies Press. doi:10.17226/23606.

# Impacts Are Significant but Modifiable

Emotional Health

Physical Well Being (including mortality)

Financial

Social

*The effects vary greatly, but often the least advantaged are most impacted*

# Important Variables

What is your role?

Is your patient the one who needs care or the caregiver or both

Challenges of not knowing patient

What is the condition?

Short term

Many years

Progressive/Static/Terminal



# Common Complaints of PCPs

Insufficient time

Low reimbursement

Difficulties with Specialists

Poor connections to Social Services

Lack of teams to provide Care

*Remarkable parallels for the caregivers*

# Effective Care Characteristics

Assessment of Risks and Needs

Tailored Interventions

Education and Skills Training (Active Involvement)

Environmental Modifications

Care Management and Coordination

Counseling

Goal to Create Confidence and Efficacy

## BOX 5-1 Domains of Caregiver Assessment

1. **Context:** describes situational information regarding the relationship between the caregiver and the older adult such as the living arrangement, environmental characteristics, duration of caregiving, caregiver's interactions with health care teams and long-term services and supports systems, financial status, and employment status, among other factors.
2. **Caregiver's perception of health and functional status of care recipient:** describes activities of daily living, instrumental activities of daily living, psychosocial needs, cognitive impairment, behavioral problems, and medical tests and procedures. This is sometimes supplemented with the assessment of the care recipient's cognitive status.
3. **Caregiver values and preferences:** measures the caregiver and care recipient's willingness to assume or accept care, perceived obligation to provide care, cultural norms that influence the care preferred or provided, as well as preferences for scheduling and delivering care and services.
4. **Well-being of the caregiver:** encompasses self-rated health, health conditions and symptoms, depression or emotional distress, and life satisfaction or quality of life.
5. **Consequences of caregiving:** describes the perceived challenges and perceived benefits of providing care.
6. **Skills/abilities/knowledge to provide care recipient with needed care:** reflects caregiving confidence and competencies as well as appropriate knowledge of the care recipient's health conditions and medical care tasks.
7. **Potential resources that caregiver could choose to use:** describes services, education, and training provided by formal and informal networks to assist in supporting the care recipient, caregiver, or both.

SOURCE: Family Caregiver Alliance, 2006.

# Assessments- The Foundation of Care and Relationships

What is the condition?

How is the caregiver involved and what is the history of the relationship?

How are the patient and caregiver doing?

What are the needs of the patient?

How well is the caregiver?

What are the goals and values of both?

What resources are present and being used?

# *There's No Cure for Alzheimer's Disease*

But:

We care for the patient and caregiver

We provide support

We are there for them

We try to treat symptoms

We are best to not let the medical dominate

*Maybe we should look at a nursing home*

Validation of each individual's limitations

There is no perfect place

There will still be caregiver "duties"

ALF dementia care units

Beware of shocking "misunderstandings"  
(compared to our knowledge)

## *It's a Marathon Not a Sprint*

Provide perspective while staying positive

Encourage the caregiver to have personal time and participate in self care because it will make them a better caregiver

Rally the troops and use community resources

Overcome resistance

*Every morning mom refused to go to adult day care and every afternoon she refused to leave adult day care.*

# *What We Know and What They Want*

Provide an overview of disease course  
acknowledging our limitations in prediction

Prepare for the future in a general sense

Contingency plans if caregiver is ill

Counter myths (eg violent behavior)

Based on:

Readiness

Values

Culture



# The 5 M's – Geriatrics Foundations

Meds

Mobility

Mentation

**Matters Most**

Multi-morbidity

*I have had a good life. I just do not want to be a burden to my family.*

# Patient Autonomy- the tale of two daughters

# Special Challenges

The person needing care is not a nice person and never was

Elder abuse/neglect vs protected to death

No identified caregiver

The impaired caregiver

Family Conflict

The young patient and older caregiver

Home bound

# Team Based Interventions

## Healthcare Team

Primary Care

Social Worker

Care Manager

OT (eg home assessment/activities)

Dementia Expert RNP/other specialties

Hospice

Home visit services

Home care

# Team Based Interventions

## Community

Agencies on Aging

Adult Day/Respite Care

Volunteers

Legal/Financial

Protective Services

# What does Medicare Cover?

Annual Wellness Visit

Transitional Care Management

Chronic Care Management

Caregiver Behavior Management Training (96202, 96203) – will consider payment

Other professionals – health and behavioral assessment and intervention, OT/PT, psychiatry services

***Many services are associated with better outcomes but not used.***

# Building and Sustaining the Competent Team

Geriatrics knowledge base/approach added to knowledge most PCPs have. And to other specialties.

Age friendly health system

Learn in Teams, Train in Teams, Work in Teams

Better community based long-term services and supports and better linkages to clinical care

Leveraging technology

# Resources

HealthinAging.org

Trusted Information. Better Care.

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About Us

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Vaccinations For Older Adults

...your close personal relationship with the person you are caring for helps you to understand and interpret their feelings, moods, and needs. You are also the first to become aware of many physical and emotional problems, the first to deal with those problems, and often are the person who carries out plans that you and other team members develop. As a team member, your job is to work cooperatively with other members of the team-both family and professional-in solving caregiving problems. To do this you need to use the four **COPE** problem-solving steps:

**Creativity** by looking for new ways to solve problems,

**Optimism** by having positive expectations for achieving your goals,

**Planning** by thinking about the steps you can take to reach your goals, and

**Expert Information** by asking for guidance from health professionals and people who have dealt with similar problems in the past.

<https://www.healthinaging.org/a-z-topic/caregiver-health>



Thank you!

Questions and Comments??