

Family Caregivers: Recent Findings from West Health

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Outline:



- National survey findings on family caregivers' healthcare needs and perceptions of the healthcare system.



- Formative research on knowledge gaps and needs of caregivers of individuals with dementia.



- Training healthcare providers for best practices in dementia care and caregiver support.

West Health



Applied medical
research



Policy, research
and education



Outcomes-based
philanthropy

West Health Institute



Advancing Senior-Appropriate
Acute Care Models

We're researching how senior-focused care in an acute setting, such as a hospital emergency department, can help seniors age successfully.



Advancing Senior-Appropriate
Chronic Care Models

We are exploring how to improve and delivery care to seniors with serious illness in their home – where they prefer it most.



Advancing Senior-Appropriate
Long-Term Services and Supports

We collaborate to advance community-based programs and nutritional services that support independence for seniors.

Collaborators:

- National Opinion Research Center (NORC)
 - University of Chicago
 - Louise Hawley, PhD
- Center to Advance Palliative Care (CAPC)
 - Diane Meier, MD, FACP, FAAHPM
 - Robin Fail, MPP
 - Brynn Bowman, MPA
 - Expert Faculty Consultants



Caregiver Definition

“Caregiver” refers to any relative, partner, friend, or neighbor who has a significant personal relationship with, and provides a broad range of assistance for, an older person or an adult with a chronic or disabling condition.

Source: Family Caregiver Alliance

Background

- Approximately 17.7 million people in the United States are serving as caregivers for an older adult with majority of these caregivers providing care to an adult with significant health and/or functioning needs.¹
- Caregivers are more likely to experience physical, emotional, and economic harm.²⁻⁴
- Ignoring the physical and emotional aspects of caregiving will not only impact the caregiver's health but can also have detrimental effects on the care recipient.⁵⁻⁶
- In contrast, caregivers whose burden and wellbeing were addressed through innovative medical and social support models have shown reduced health care expenditures and delayed nursing home placement of care recipients.⁷⁻¹⁰

Part 1

Survey of Caregivers & Non-Caregivers : West Health Institute (WHI) and National Opinion Research Center (NORC) Collaboration

Introduction

- Caregiving is a demanding role that can negatively impact the caregiver's health and well-being.
- Caregivers' ability to maintain their own health can significantly impact the ability of the care recipient to remain in their community.
- Understanding how the health system can better serve caregivers is critical to maintaining the health of both caregiver and care recipient.
- Research of caregivers' interactions with the health system has typically focused on the care recipient's health care access.
- In this study, we compared caregivers and non-caregivers perceptions and access to healthcare services.

NORC Survey Methods



Adults (30 to 89 years old) from the National Opinion Research Center AmeriSpeak® panel were asked to complete survey.



Surveys conducted Sept.-Oct. 2016 by phone and web (about 26 min).



Participants were asked views on aging, healthcare & community resource priorities, and views on how well healthcare and services in the community are meeting needs of seniors.



We stratified participants on whether they were currently or had provided ongoing living assistance directly to an older family member or close friend (caregiver).



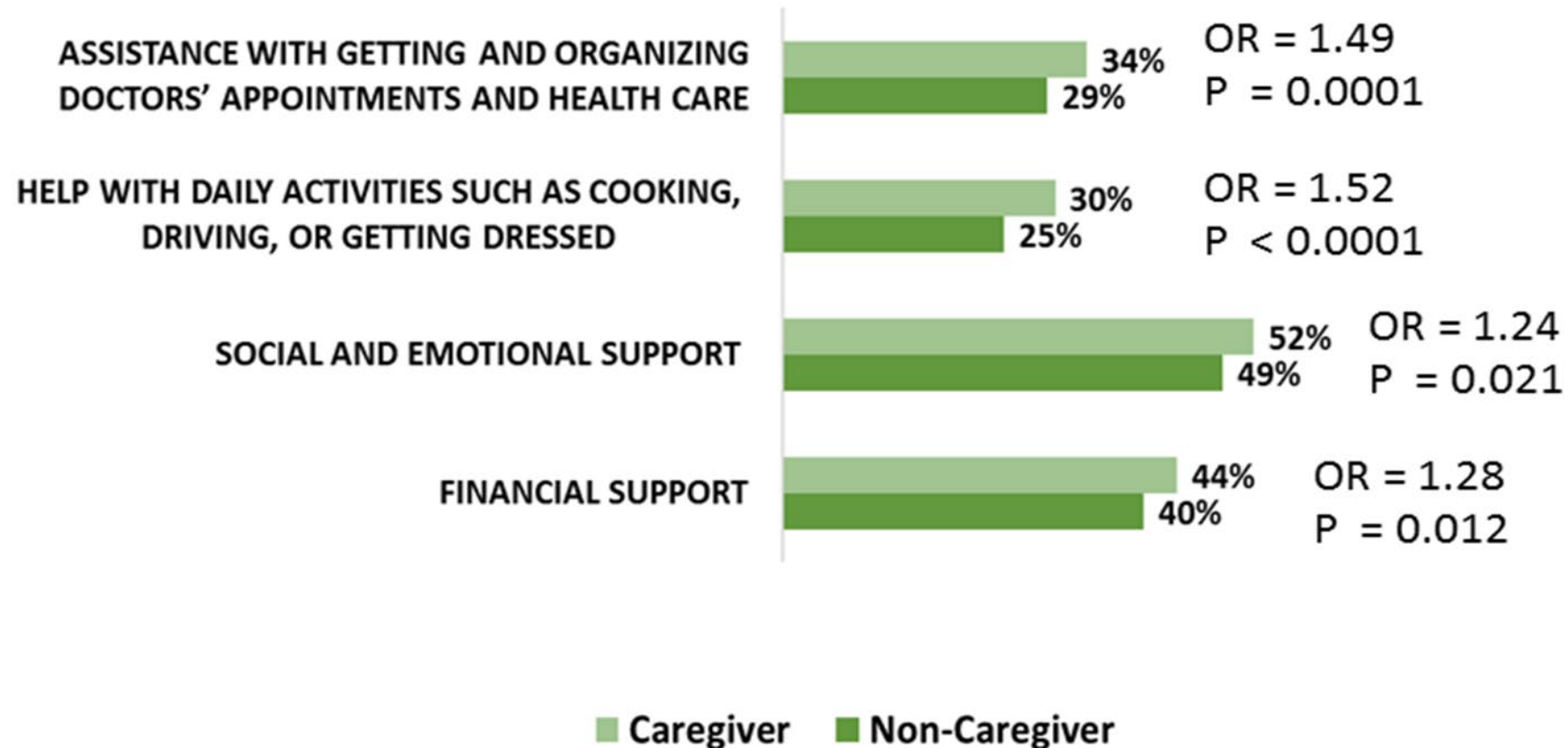
Weighted logistic regression (or linear regression) was used to assess differences between caregivers and non-caregivers controlling for age, gender, race/ethnicity, income, education, home ownership, and metro region.

Demographics of Caregivers in NORC survey

Demographic and Health Measures	Caregiver N = 1379	Non-Caregiver N = 1638	P-value
Age: Mean (SD)	57 years (13.5)	50 years (14.3)	<0.0001
Gender: Female	59.5%	46.1%	<0.0001
Income : Mean (SD)	\$58,601 (\$44,370)	\$65,632 (\$49,531)	<0.0001
Married or living with partner	57.3%	64.1%	0.001
Education			
• Less than Highschool	11.5%	10.3%	0.011
• High school diploma	56.4%	51.1%	
• College diploma or higher	32.1%	38.6%	
Ethnicity			
• Non-Hispanic White	69%	65%	0.03
• Black	12%	11%	
• Hispanic	12%	16%	
• Other	8%	8%	
Home ownership	73.5%	69.4%	0.034
Living in metropolitan area	85%	88.9%	0.009
Number of co-morbidities: Mean (SD)	2 (1.7)	1.4 (1.54)	<0.0001
Reported health condition/ physical disabilities impact daily life/ limit activities	34.9%	24.5%	<0.0001

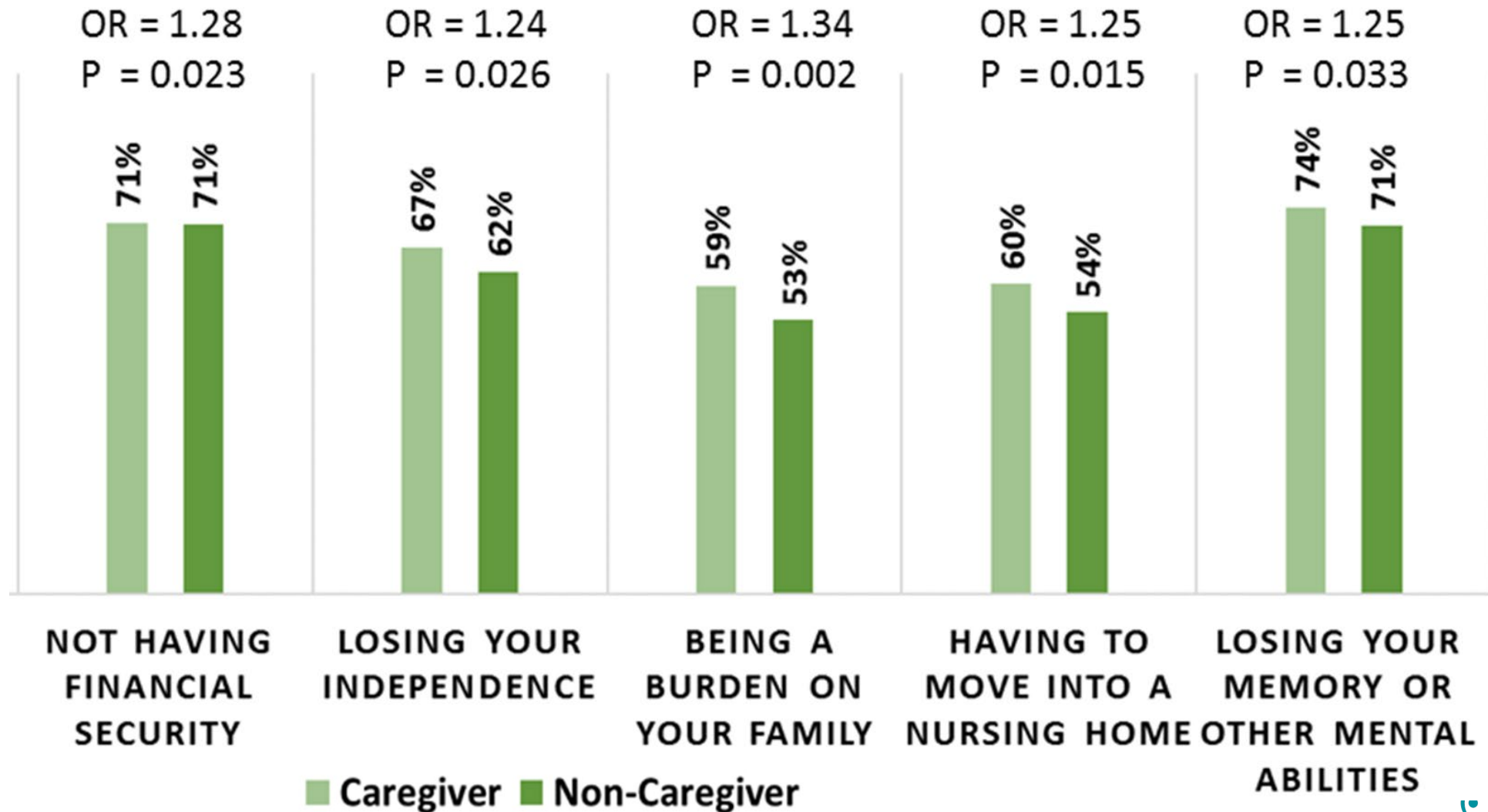
Views on Aging

THINK YOU WILL NEED

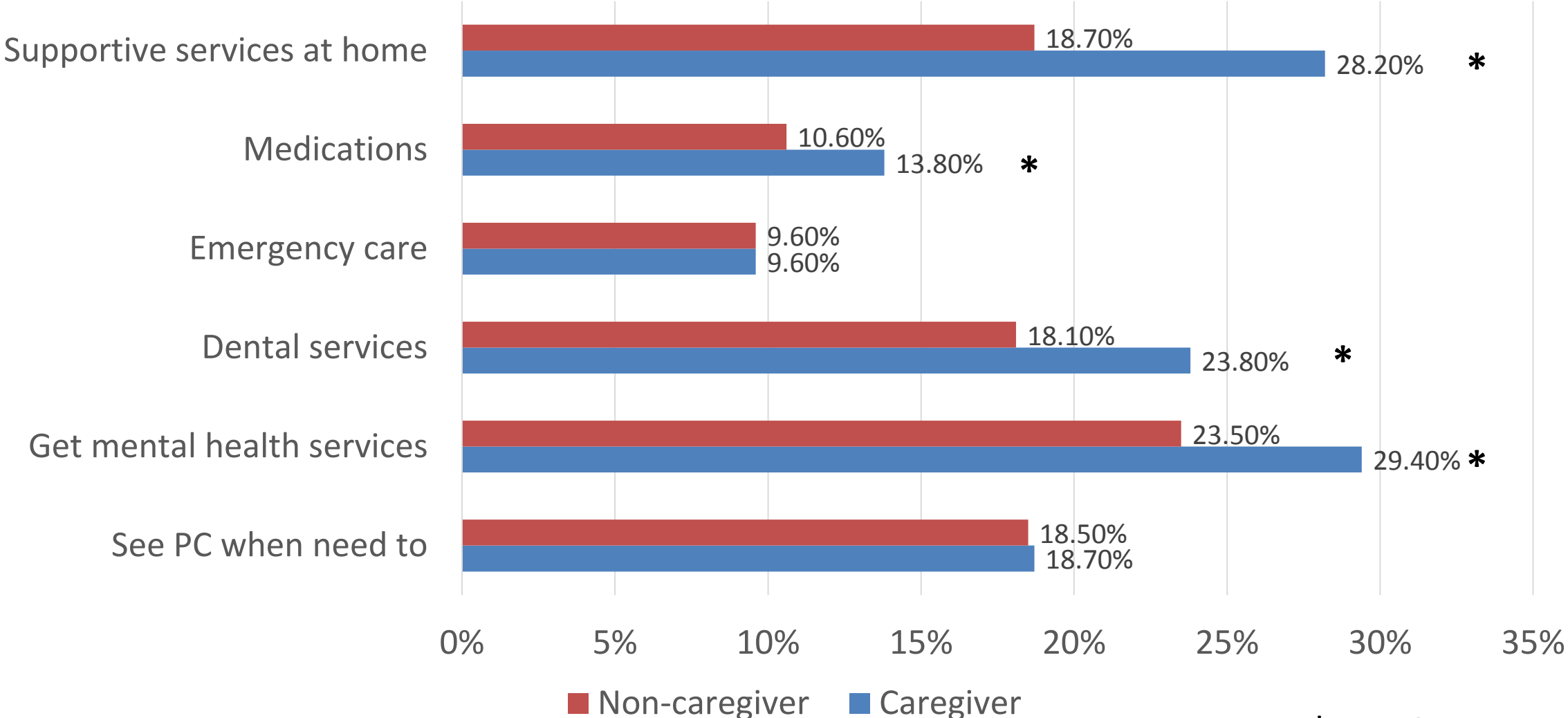


Views on Aging

WORRIED ABOUT THE FOLLOWING HAPPENING WITH AGE



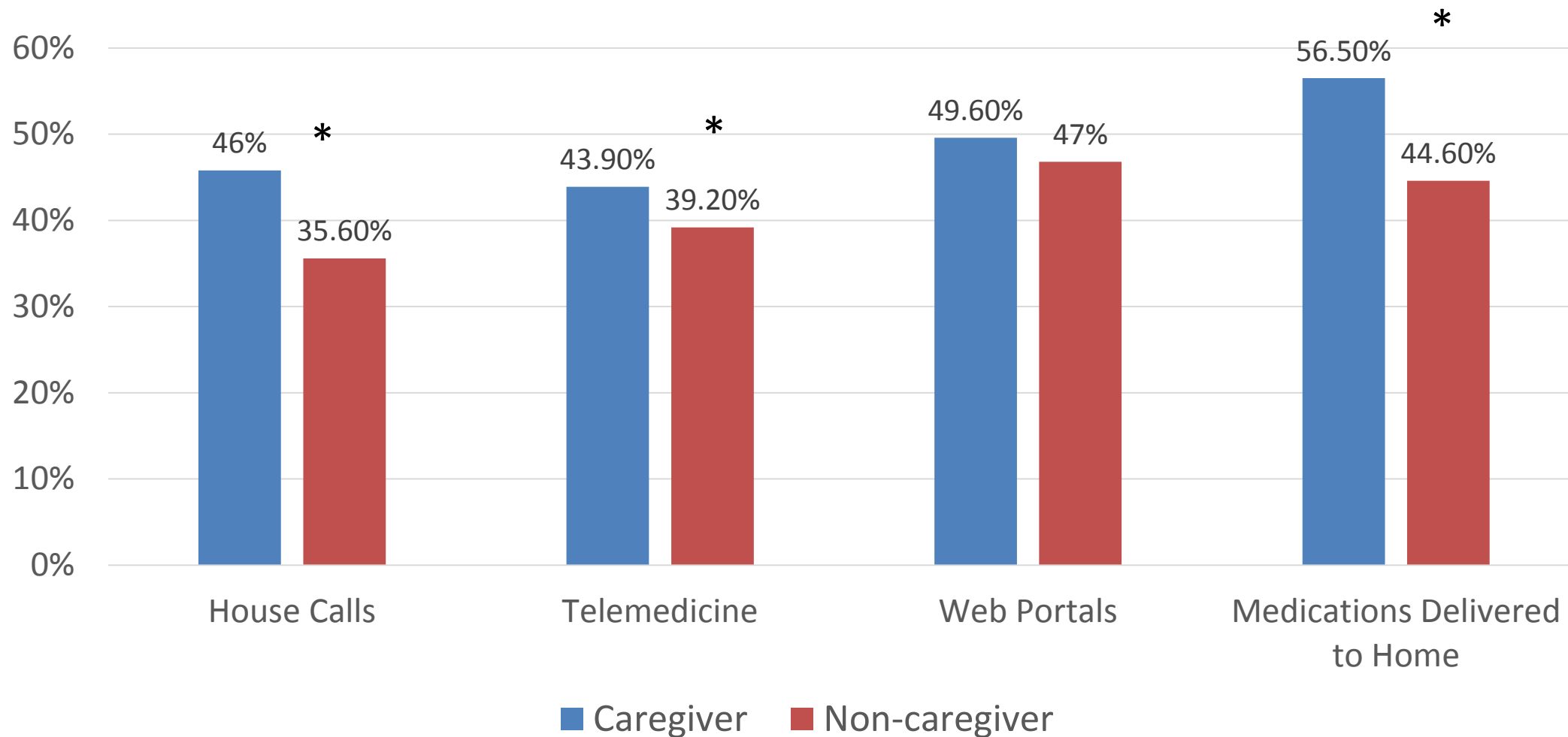
Personal Health Care: Difficult to Get... (% somewhat to very difficult)



* p < .01 

Personal Healthcare Experience

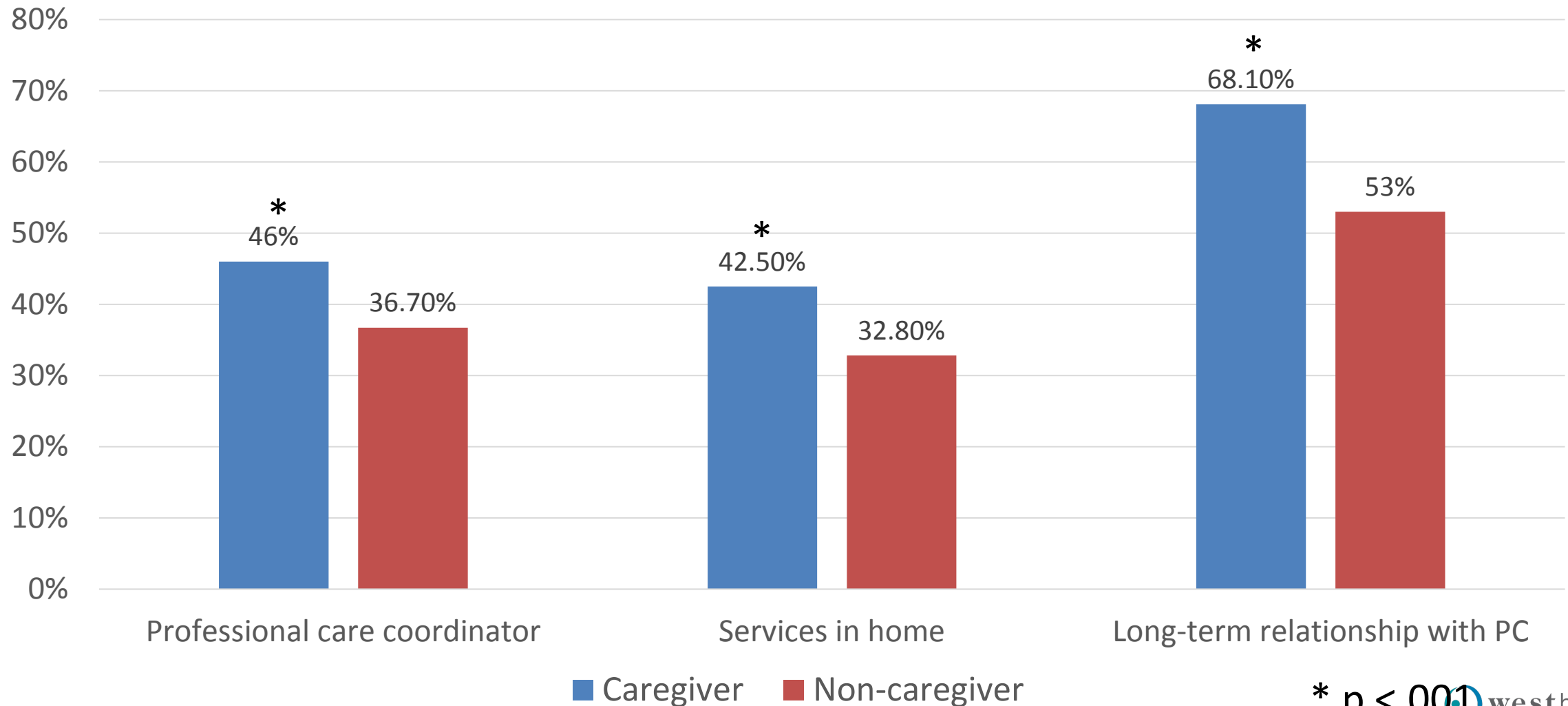
How Helpful Would the Following Services Be To You? (% very to extremely helpful)



* p < .01 

Personal Healthcare Experience

For Your Personal Healthcare, How Important is...? (% very to extremely important)



Correlates of Caregivers Not Having Support Needed to Provide Ongoing Care

	Adj OR	p-value
Age 30 to 64 (ref)		
65 to 89	.67	.039 *
Female (Male ref)	.76	.093
Ethnicity (white ref)		
Black	.53	.035*
Hispanic	1.58	.036*
Other	1.07	.801
Income	1.03	.707
Region (South ref)		
Northeast	.95	.819
Midwest	1.16	.471
West	1.64	.012*
Perceived Health	.92	.439
Health condition or phys disability	.97	.860
# Chronic conditions	1.25	<.001*

Conclusions

- Nearly half of the national sample of US adults 30 to 89 report having ever provided ongoing living assistance to an older family member or close friend.
- Caregivers were more likely to be older, female, less educated, had more chronic conditions and physical disabilities than non-caregivers.
- Caregivers felt they would need more ongoing assistance one day and were more worried about negative outcomes with aging
- Caregivers had more difficulty obtaining some health care and supportive services.
- Caregivers more likely to value care coordination and more likely to want health care services that are easily accessible in the home than non-caregivers.

Part 2

Formative Research on Challenges, Knowledge Gaps, and Needs of Caregivers of Individuals with Dementia

Background: Caregivers Caring for Persons with Dementia

- More than 15 million caregivers provide unpaid care to persons with Alzheimer's disease or related dementia (ADRD)¹¹
- Dementia caregivers provide care for longer periods than other caregivers, with 57% providing care for 4 or more years.^{11,12}
- People with ADRD have higher emergency department (ED) utilization than those without ADRD and the average cost of care for someone with ADRD over 5 years is 80% higher than of someone with heart disease or cancer.
- It is estimated that only half of the people living with ADRD have been diagnosed, and fewer still have the diagnosis document in their medical record.⁷

Rationale

- Family caregivers are often expected to provide complex medical care for their care recipients.
- Interviews with caregivers of patients with dementia revealed they did not receive help with dementia-related problems from their care recipient's health care professional.(Jennings et al., 2015)
- We aimed to understand the training available to caregivers for people with dementia and what gaps need to be filled.

Formative Market Research Work



- Focus Groups



- National Survey



- Environmental Scan of Open Access Resources



Focus Groups

- Four in-person sessions
 - Caregivers of individuals with cognitive impairment
 - September 28-29, 2016
 - 36 participants
- One online bulletin board focus group
 - Caregivers of individuals with cognitive impairment
 - Moderated online from November 14-17, 2016
 - 20 participants

Market Research: Focus Group Results

Caregivers' Biggest Challenge



Market Research: Focus Group Results

Liked



Did Not Like



Wanted images that depicted “support” and “happy but not too happy”

Market Research: Focus Group Results



Caregivers were often not aware of resources available to them.



Caregivers sometimes use internet resources but prefer to get information from a health care or medical resource.

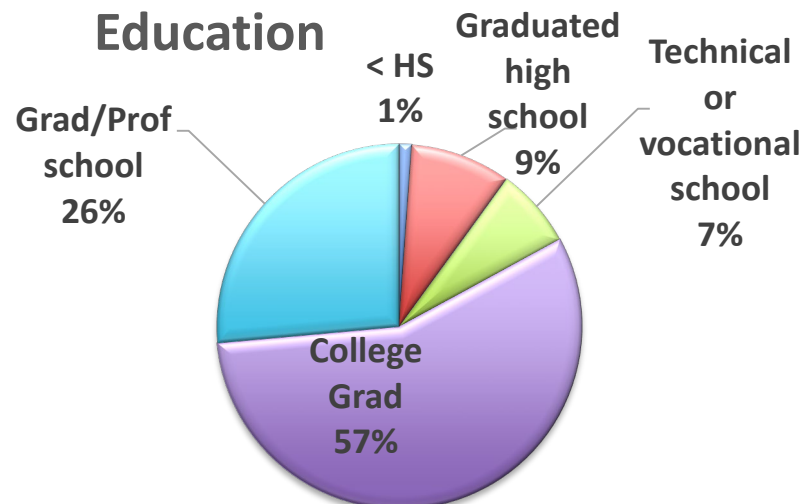
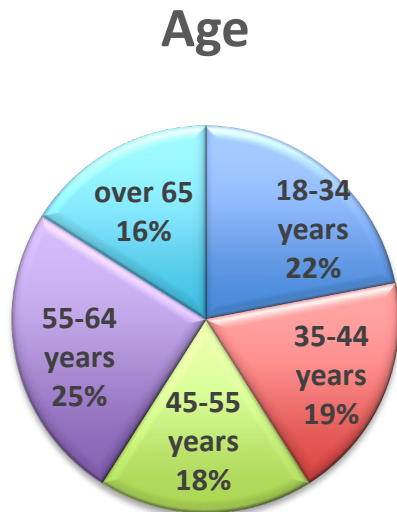
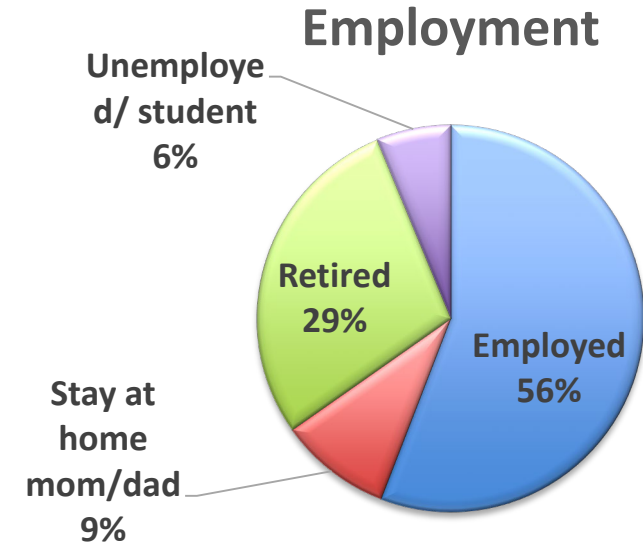
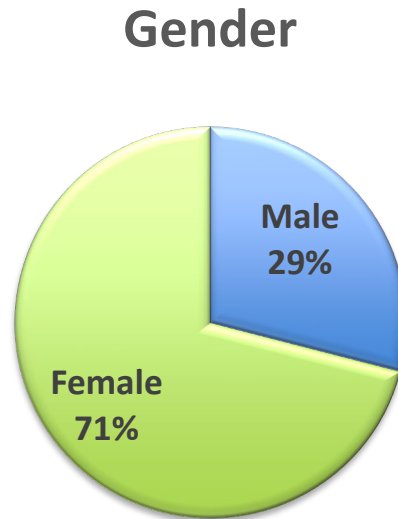
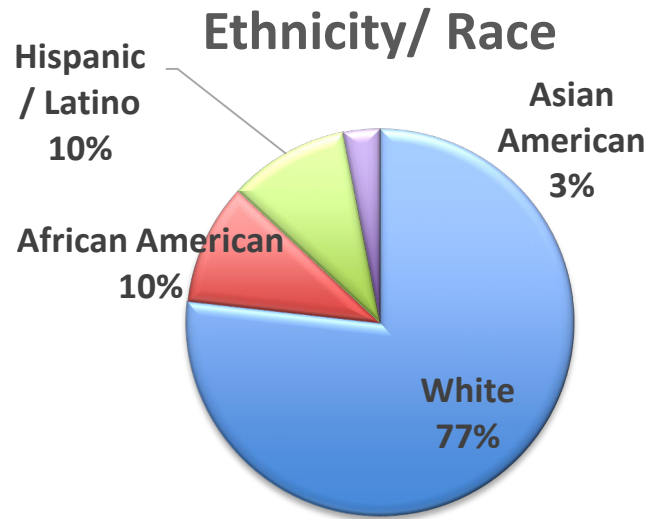


Their care recipient's physician considered the **most reliable sources for information.**

National Survey

- 500 Caregivers of individuals with Alzheimer's disease or dementia
- Jan-Feb 2017
- Recruited from an opt-in online panel of participants
- Inclusion Criteria:
 - Provide care currently or past year
 - Over 18
 - Not employed in health care
 - Not a paid caregiver
 - Perform at least one ADL or IADL activities

Market Research: National Survey Demographics



Market Research: National Survey

Relationship to Caregiver

Parent or In-Law	67%
Spouse	12%
Grandparent	10%
Friend	7%
Aunt/Uncle	4%
Brother or sister	3%
Another family member	1%
Child	1%

Among The 72% Currently Taking Care of Loved One

EARLY STAGE Occasional memory slips or forgetfulness	21%
MIDDLE STAGE Forgets recent events or people's names, gets lost at home, needs help getting dressed or showering, becomes anxious or upset easily	61%
LATE STAGE Does not recognize friends or family much of the time, has trouble walking, needs help with most activities, may quickly become angry	16%
Not Sure	2%

Market Research: National Survey



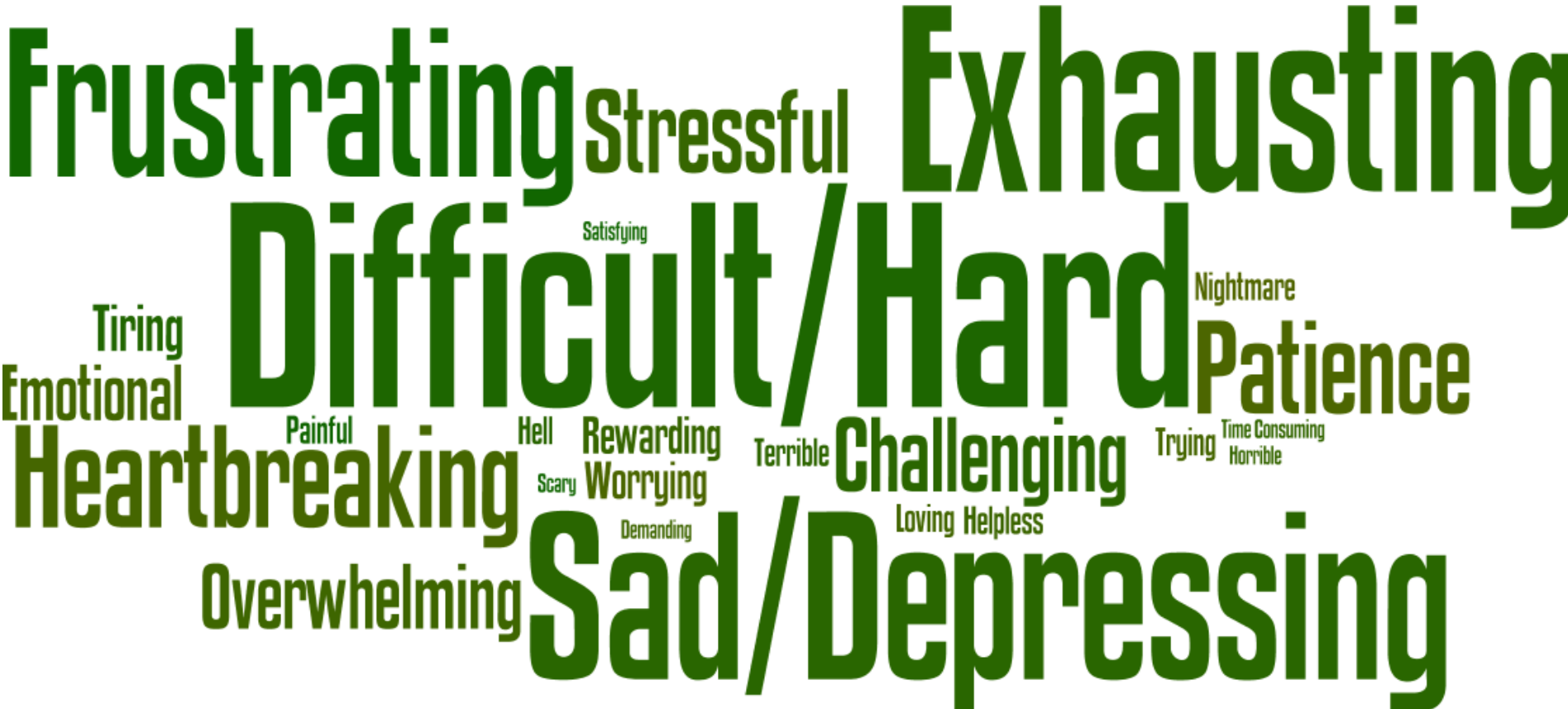
**Loved One
Receives(d)
Palliative
Care**

36%



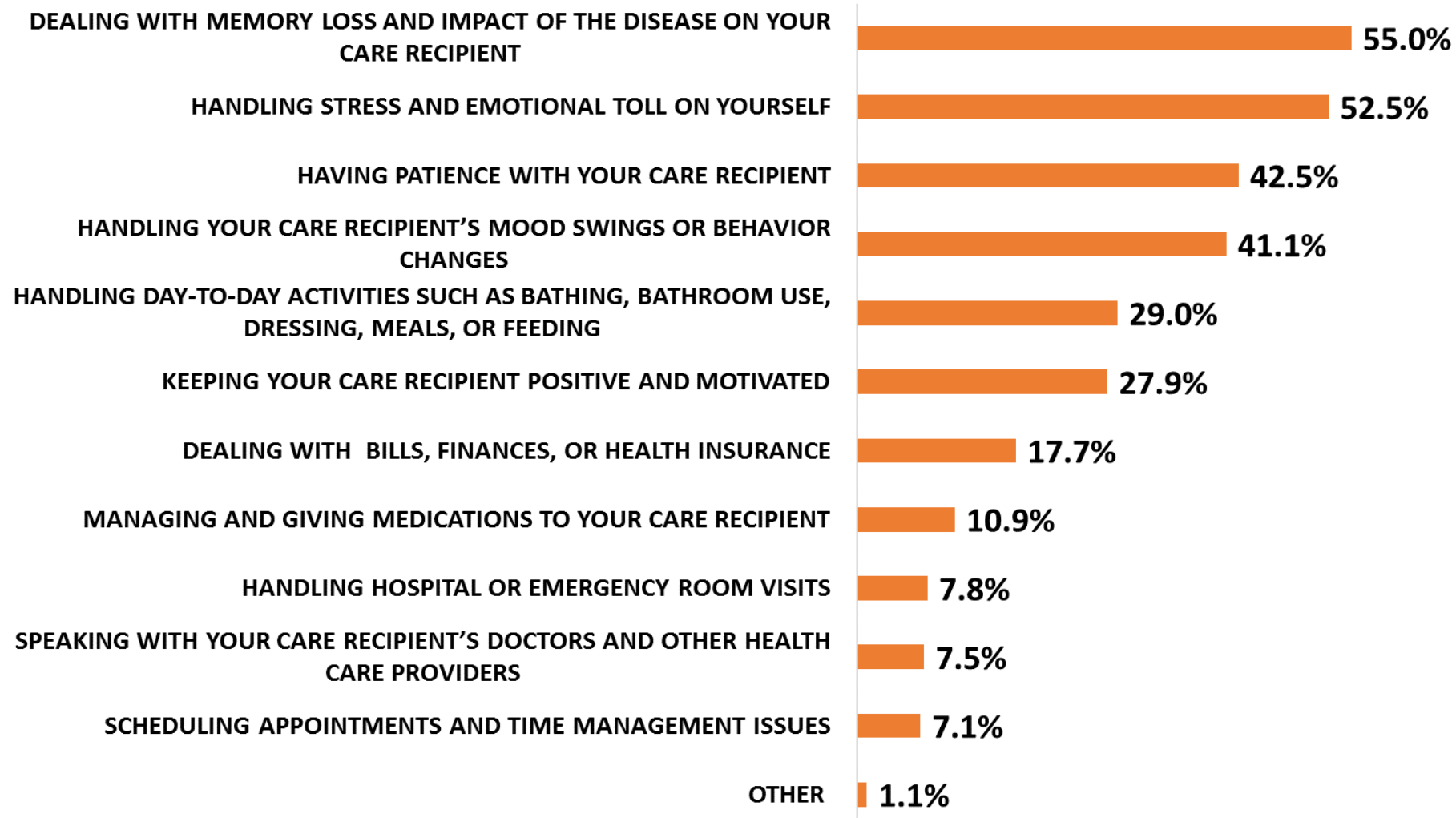
Hospitalized	20%
Emergency Room	17%
Both	41%

Market Research: National Survey Results



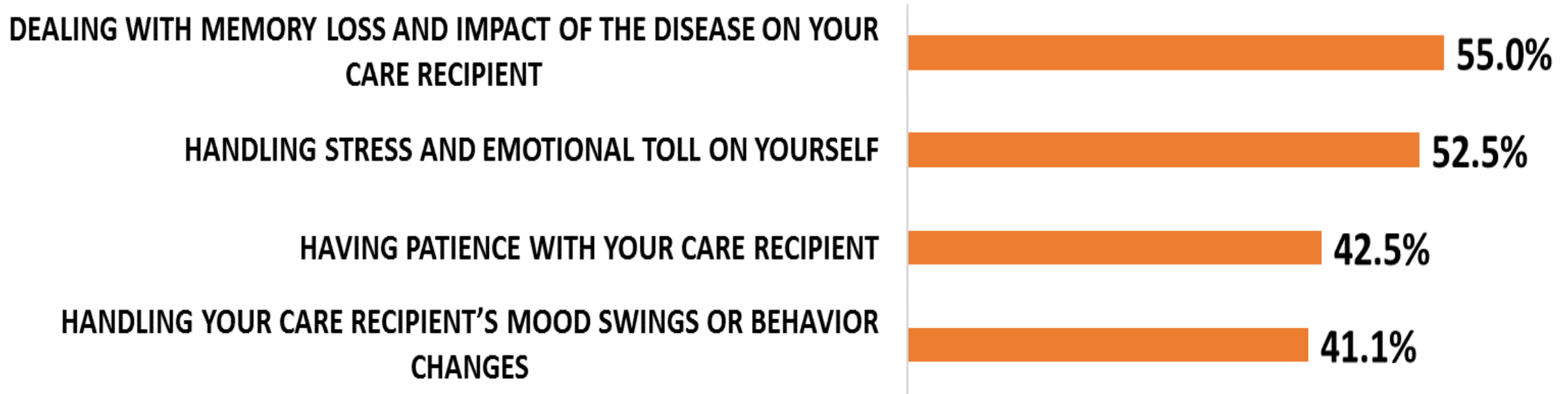
Market Research: National Survey Results

CAREGIVER'S CHALLENGES WHEN CARING FOR PERSON WITH ADRD (1ST, 2ND, 3RD CHOICE COMBINED)



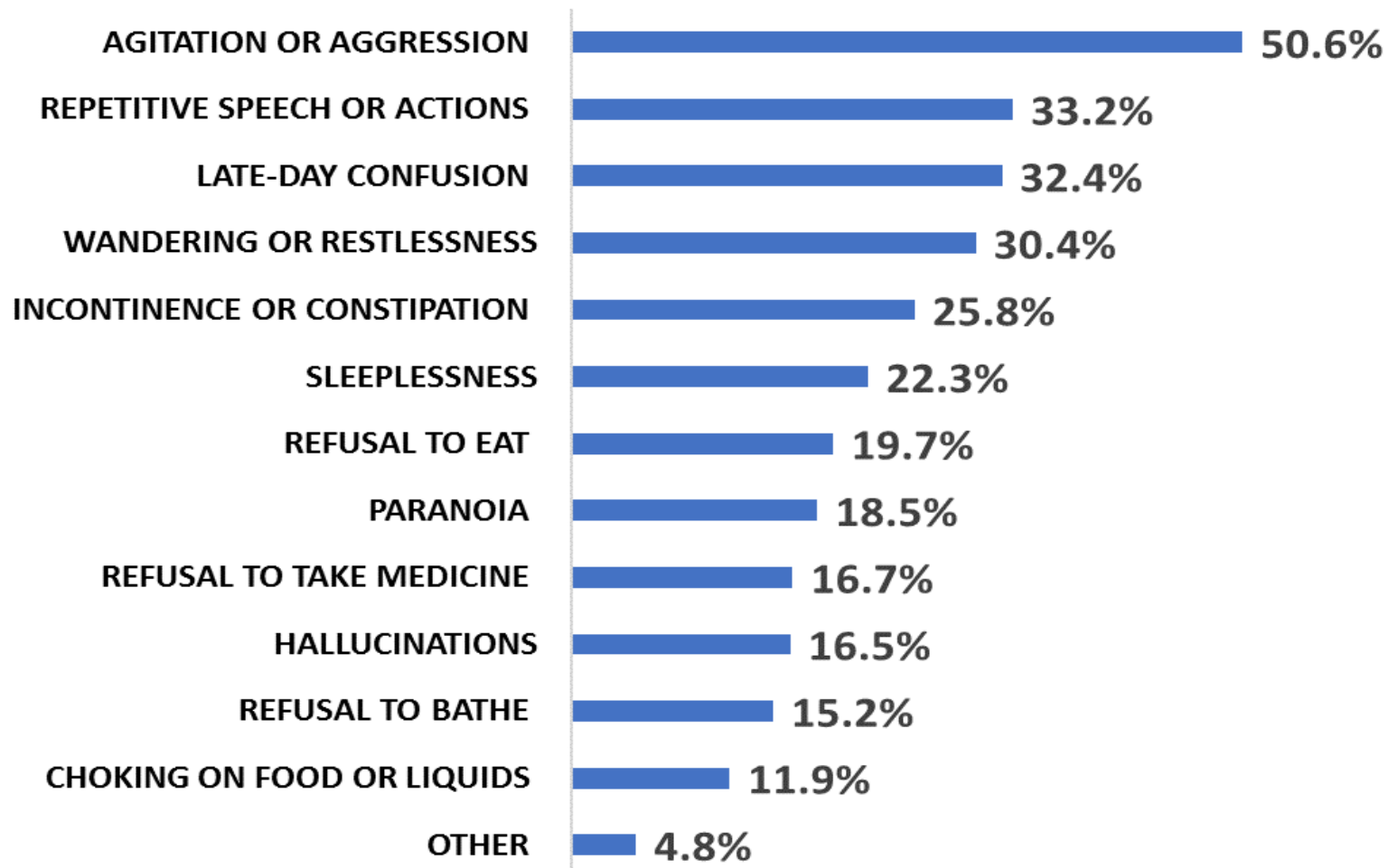
Market Research: National Survey Results

CAREGIVER'S CHALLENGES WHEN CARING FOR PERSON WITH ADRD (1ST, 2ND, 3RD CHOICE COMBINED)



Market Research: National Survey Results

CHALLENGING BEHAVIORS WHEN CARING FOR LOVED WITH DEMENTIA AND ALZHEIMER'S DISEASE (1ST, 2ND, 3RD CHOICE COMBINED)



National Survey: Interest in 16 Topics

Topic	Extremely Likely/ Very Likely
Knowing what to expect at every stage of the illness	84.9%
How to manage behavior changes in your loved one such as screaming, aggression, agitation, paranoia, hallucinations, restlessness, wandering, late-day confusion	82.9%
How to know when you need to seek medical help and when it may not be necessary	73.0%
How to assess risk versus benefit of treatments	71.6%
Managing your loved one's physical pain	70.0%
Dealing with other medical conditions and possible complications	69.9%
How to talk with doctors and the essential questions you should ask your loved one's doctor	68.8%
How to respond and what to do when your family member or friend refuses to eat or refuses to take their medicine	68.4%
How to manage patient's difficulty walking or tendency to fall	68.1%
Assistance in decision-making and coordinating care with family members and others	63.3%
Deciding if or when nursing home placement may be necessary	62.4%
How to manage incontinence or constipation	61.1%
How to handle emergencies and hospital or emergency room visits	58.2%
How to respond when your family member or friend refuses to bathe	56.7%
How to manage your loved one's medications	50.2%
What you need to know to make a decision about tube feeding or artificial nutrition	45.3%

Market Research: National Survey Results

Rate likelihood of using each of the following:

	Extremely Likely	Extremely/Very Likely
Fact Sheets	42%	76%
Checklists	40%	72%
Tutorials/videos	39%	72%
Brain games for your loved one	37%	64%
Caregiver discussion forum	33%	62%
Live online chat with a nurse or social worker	33%	62%
Calendars for keeping track of doctor appointments, medication schedules, and new symptoms	31%	55%
Quarterly caregiver newsletter	29%	64%
Caregiver and patient stories or testimonials	27%	58%
Webinars	20%	51%
Podcasts	19%	45%

Market Research: National Survey Results

Have you used any online tools or specific websites to help you better care for your loved one with Alzheimer's or Dementia or provide you with information or help?





HEALTH AFFAIRS BLOG

END OF LIFE & SERIOUS ILLNESS

RELATED TOPICS:

CAREGIVERS | DEMENTIA | HEALTH CARE PROVIDERS | SYSTEMS OF CARE | PATIENT CARE | DISEASES
| COSTS AND SPENDING | QUALITY OF CARE | COST REDUCTION | BEST PRACTICES

A Study Of Family Caregiver Burden And The Imperative Of Practice Change To Address Family Caregivers' Unmet Needs

Jill Slaboda, Robin Fail, Gregory Norman, Diane E. Meier

JANUARY 11, 2018

10.1377/hblog20180105.914873



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– CaringKind (NYC)

– Caregiver Action Network



– UCLA Health



– Alzheimer's Medical Advisor (UNC)

– Next Steps in Care

– UCSF Memory & Aging Center



Gap Analysis: Free Access Online Videos

www.AARP.org/home-family/caregiving/

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AARP Real Possibilities Join Renew Help Member Benefits

Basics

Basics · Care at Home · Medical · Financial & Legal · Caregiver Life Balance · Community · Local Resources & Solutions · Stories

CAREGIVER LIFE BALANCE
Anger May Fade to Sadness and Regrets After Caregiving Ends 8 Comments
Try a little tenderness and taking a long view of the relationship

FINANCIAL AND LEGAL
Tax Tips for Caregivers 0 Comments
What the IRS allows

CAREGIVER LIFE BALANCE
When Being a Family Caregiver Is No Longer an Option 0 Comments
Ideas for how to handle the transition

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Warren Adler's Story: Caregiving for a Wife With Dementia 3 Comments
How the novelist is keeping a lifetime of shared memories alive

AARP developed "Prepare to Care: A Resource Guide for Families" to make the job more manageable. Here's how to obtain a free copy.

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Learn more about CareJourney with this short interactive video and demonstration.

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[National] [View larger map]




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Dementia, Caregiving, and Controlling Frustration

The Stresses of Caregiving

Caring for an individual with Alzheimer's disease or a related dementia can be challenging and, at times, overwhelming. Frustration is a normal and valid emotional response to many of the difficulties of being a caregiver. While some irritation may be part of everyday life as a caregiver, feeling extreme frustration can have serious consequences for you or the person you care for. Frustration and stress may negatively impact your physical health or cause you to be physically or verbally aggressive towards your loved one. If your caregiving situation is causing you extreme frustration or anger, you may want to explore some new techniques for coping.

When you are frustrated, it is important to distinguish between *what is and what is not within your power to change*. Frustration often arises out of trying to change an uncontrollable circumstance. As a caregiver of someone with dementia, you face many uncontrollable situations. Normal daily activities—dressing, bathing, and eating—may become sources of deep frustration for you. Behaviors often associated with dementia, like wandering or asking questions repeatedly, can be frustrating for caregivers but are uncontrollable behaviors for people with dementia. Unfortunately, you cannot simply change the behavior of a person suffering from dementia.

When dealing with an uncontrollable circumstance, you do control one thing: *how you respond to that circumstance*.

In order to respond without extreme frustration, you will need to:

- Learn to recognize the warnings signs of frustration.
- Intervene to calm yourself down physically.
- Modify your thoughts in a way that reduces your stress.
- Learn to communicate assertively.
- Learn to ask for help.

Get Involved

- ▶ Subscribe to FCA newsletters
- ▶ Join an online support group
- ▶ Share your caregiver story

Education and Events Calendar

« April 2019 »

S	M	T	W	T	F	S
	1	2	3	4	5	6
7	8	9	10	11	12	13
14	15	16	17	18	19	20
21	22	23	24	25	26	27
28	29	30				

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CAREGIVER STORIES

The Caregiver's Mantra: Doing the Best We Can

I'm going to bury my face in a pillow and scream if one more person tells me to be sure to take care of myself. Go for a walk, take a vacation, they advise. I know they are trying to help, but really? Telling me one more thing to do? Oh well, they are just doing the best they can.

Conclusions from Formative Research & Next Steps

- Caregivers are frustrated, challenged, overwhelmed, depressed.
- Caregivers do not know what to expect as their care recipient's dementia progresses.
- They are lacking information that would help them manage the behavioral symptoms associated with dementia.
- Only 45% use online tools and websites.
- High quality resources and training videos are available for caregivers.
- Caregivers indicate that their health care provider is their most trusted source of information.

Part 3

Address the Needs of Dementia Patients and their Caregivers: Training Modules for Health Care Providers

Rationale

- CAPC and WHI worked with national leaders in dementia care to develop training for all providers who encounter people with cognitive impairment and their caregivers.
- The healthcare system has neither the fiscal resources, infrastructure, nor workforce to support dementia patients without the work of the nation's family caregivers.
- Understanding the challenges and needs of dementia caregivers can help to alleviate burden and sustain this informal, but critical, workforce.

Convening and Organizing Phase

- **Advisory Committee:**

- **Tena Alonzo, MA:** Director, Education & Research, Beatitudes Campus
- **Mary Mittleman, DrPH:** Research Professor, Departments of Psychiatry and Rehabilitation Medicine, NYU Langone Health
- **Kathy Kelly, MPA:** Executive Director, Family Caregiver Alliance
- **Ann Wyatt, MSW:** Manager of Palliative & Residential Care, CaringKind
- **Carol Levine, MA:** Director, Families and Health Care Project, United Hospital Fund

- **Lead Course Author:**

- **Eric Widera, MD:** Director, Hospice & Palliative Care Service; Program Director (San Francisco VA Medical Center), Geriatric Medicine Fellowship Program (University of California San Francisco)

Convening and Organizing Phase

- **Course Development Committee:**
 - **Andy Esch, MD:** Consultant, CAPC
 - **Cindy Barton, RN, MSN, GNP:** Nurse Practitioner, Neurology, UCSF Memory and Aging Center
 - **Stefanie Bonigut, MSW, ASW:** Family Care Specialist, Alzheimer's Association of Northern California and Northern Nevada
 - **Jim Palmer, MSW, LCSW:** Clinical Social Worker, Mount Sinai Medical Center
 - **Marta Kazandjian, MA, CCC-SLP, BCS-S:** Clinical Director, Speech Pathology & Swallowing, New York Presbyterian/Queens
 - **Gina Decker:** Caregiver
 - **Phil Higgins, PhD, MSSW, LICSW:** Clinical Social Worker/Therapist

Best Practices in Dementia Care and Caregiver Support

1. Discussing Your Patient's Dementia Diagnosis
2. Communicating About What to Expect as Dementia Progresses
3. Understanding and Responding to Behavioral and Psychological Symptoms of Dementia Courses
4. Planning for the Future with People Living with Dementia and Their Caregivers
5. Supporting the Caregivers of People Living with Dementia ([open access](#))
6. Mood and Sleep Disturbances in People Living with Dementia
7. Critical Decisions in Advanced Dementia

Sample From Discussing Your Patient's Dementia Diagnosis

Rosa says to you:

"So, what did they find out with all of those tests of my memory?"

Your Reply:

.

Expert Reply:

"I wonder if you can tell me what worries you most about these memory problems?"

Rationale:

This reply is an assessment of what the patient perceives about her symptoms of dementia. While some people with dementia and their loved ones anticipate their diagnosis, others have not previously considered dementia as a possible cause for their problems. Exploring the patient's perspective also enables you to link explanations to their personal experience, which may facilitate understanding.



Sample From Discussing Your Patient's Dementia Diagnosis

Scenario 1: Good But Not Great

Mike said: "I'm not even sure why I'm seeing you. I guess this means I'm really in bad shape."

Expert reply: "Tell me what you heard from the oncologist."

Did you suggest or consider any of these common good-but-not-great answers?

"It sounds like they didn't explain what is happening."

This reply assumes behavior from prior MD.



CAPC Toolkit: Available at capc.org/dementiatoolkit

The Case for
Improving
Dementia Care

Getting Started

Clinical Tools &
Training for Best
Practices in
Dementia Care

Case Studies

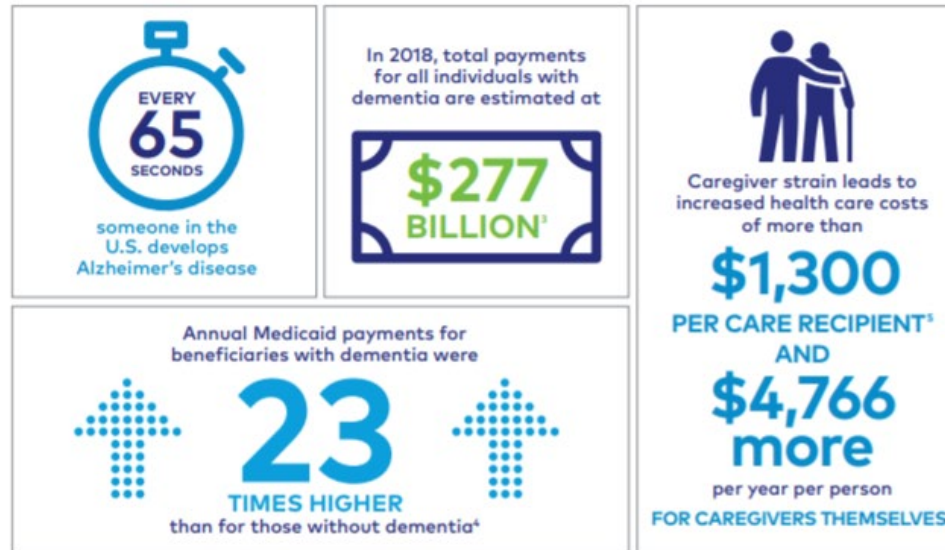
CAPC Toolkit: Making the Case Infographic

The Case for Improving Dementia Care



The Case for Improving Dementia Care

Dementia is among the most feared and costliest diseases in our nation.¹ People with dementia have higher ED utilization, readmissions, and mortality rates than those without dementia.²

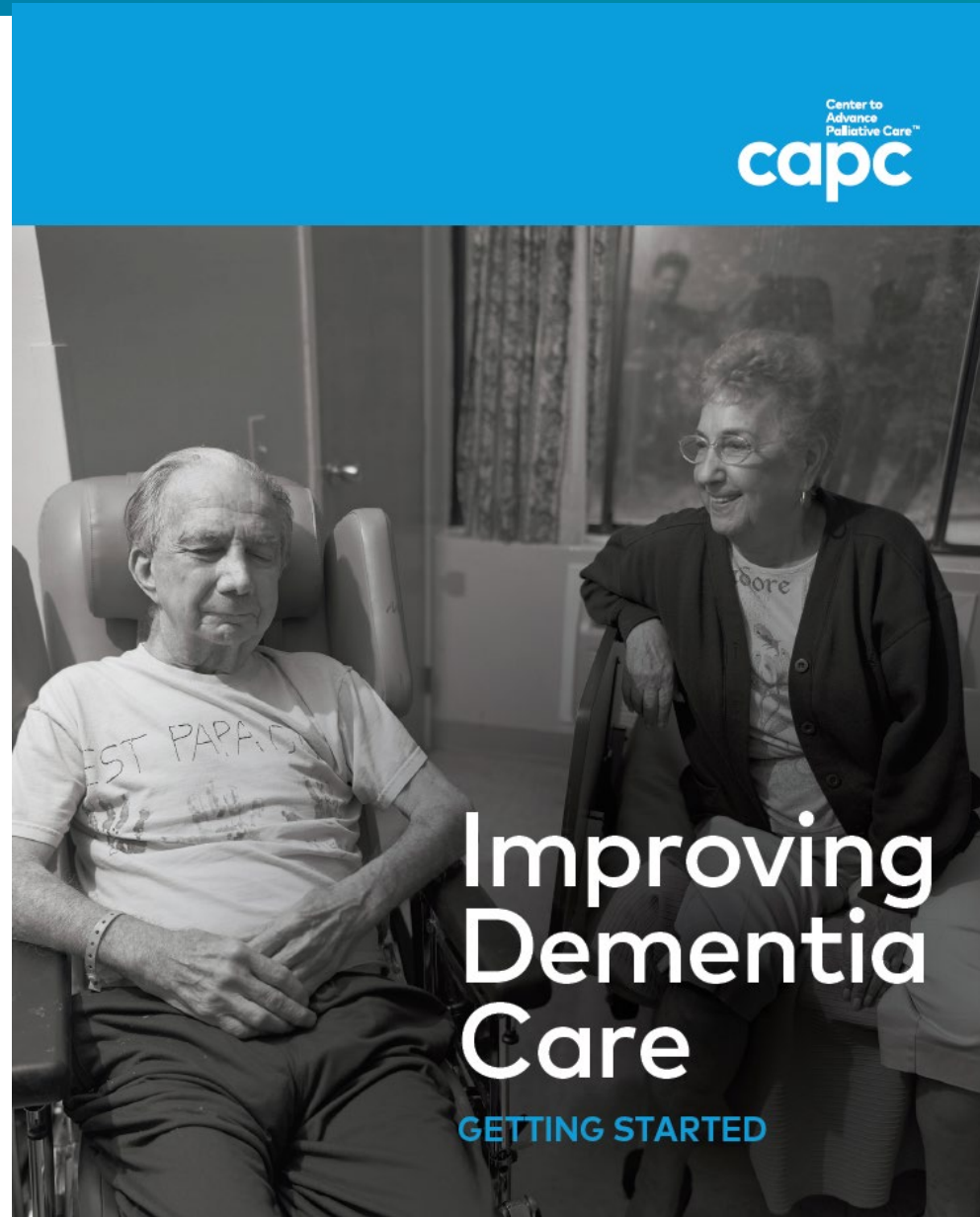


Failure to address the unmet needs of people facing dementia could bankrupt our health system.



CAPC Toolkit: Available at capc.org/dementiatoolkit

Getting
Started



Operational Toolkit Workgroup:

- **David Bass, PhD:** Senior Vice President and Director, Center for Research and Education, Benjamin Rose Institute on Aging
- **Alan Stevens, PhD:** Director, Center for Applied Health Research, Director, Program on Aging and Care, Baylor Scott & White
- **Maribeth Gallagher, DNP, PMHNP-BC, FAAN:** Dementia Program Director, Hospice of the Valley's Palliative Care for Dementia Program
- **Debra Cherry, PhD:** Executive Vice President, Alzheimer's Greater Los Angeles
- **Jennifer Schlesinger, MPH, CHES:** Director, Professional Training & Healthcare Services, Alzheimer's Greater Los Angeles
- **Greg Sachs, MD:** Division Chief, General Internal Medicine and Geriatrics, Indiana University; Center Scientist, Indiana University Center for Aging Research

Overall Conclusions

- Identify caregivers in the clinic setting
- Make caregivers part of the care team & care plan
- Help all health care professionals to talk with patients and caregivers about dementia
- Direct caregivers to resources
- Disseminate effective tools and supports

Thank you for your time!

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