Support for Family Caregivers in the Context of Dementia: Promising Programs & Implications for State Medicaid Policy

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  - **National Institute on Aging (R01 AG044504)**
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- **Slides with national figures about dementia and caregiving:**
  - **Alzheimer's Association, *2017 Alzheimer's Disease Facts and Figures*. 2017, Chicago, Illinois.**

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Presentation Outline

- What is dementia?
- Trends in dementia prevalence
- Impact of dementia on families
- Evidence-Based programs for family caregivers of persons with dementia: moving from research to practice
- Care of Persons with Dementia in their Environments (COPE) program translation in Connecticut (COPE CT study)
  - What is it and why is Medicaid interested and involved?
  - Who is eligible and what does study sample look like?
  - Lessons learned to date from COPE CT study
- Implications for other state Medicaid programs and other stakeholders

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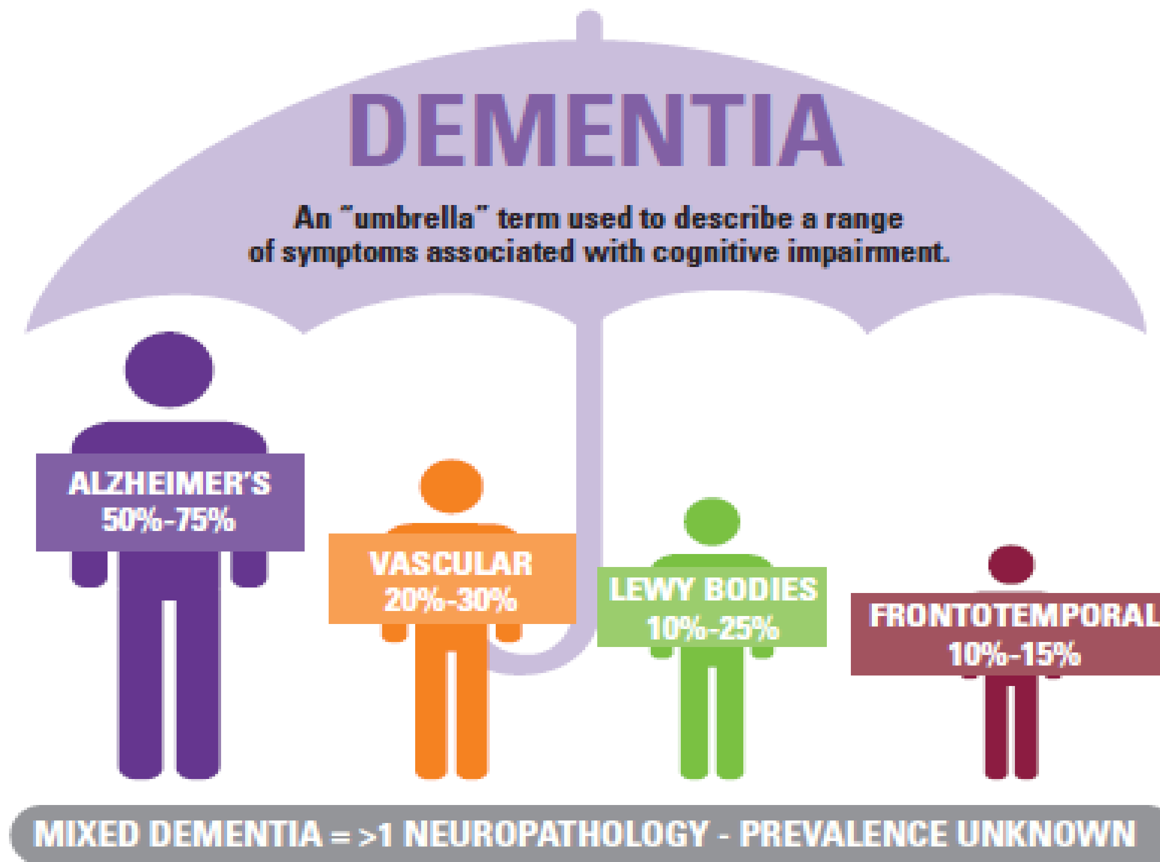

From: Alzheimer's Association. In brief: for healthcare professionals. Issue 7: Differentiating dementias

FIGURE 4

Projected Number of People Age 65 and Older (Total and by Age Group) in the U.S. Population with Alzheimer's Dementia, 2010 to 2050

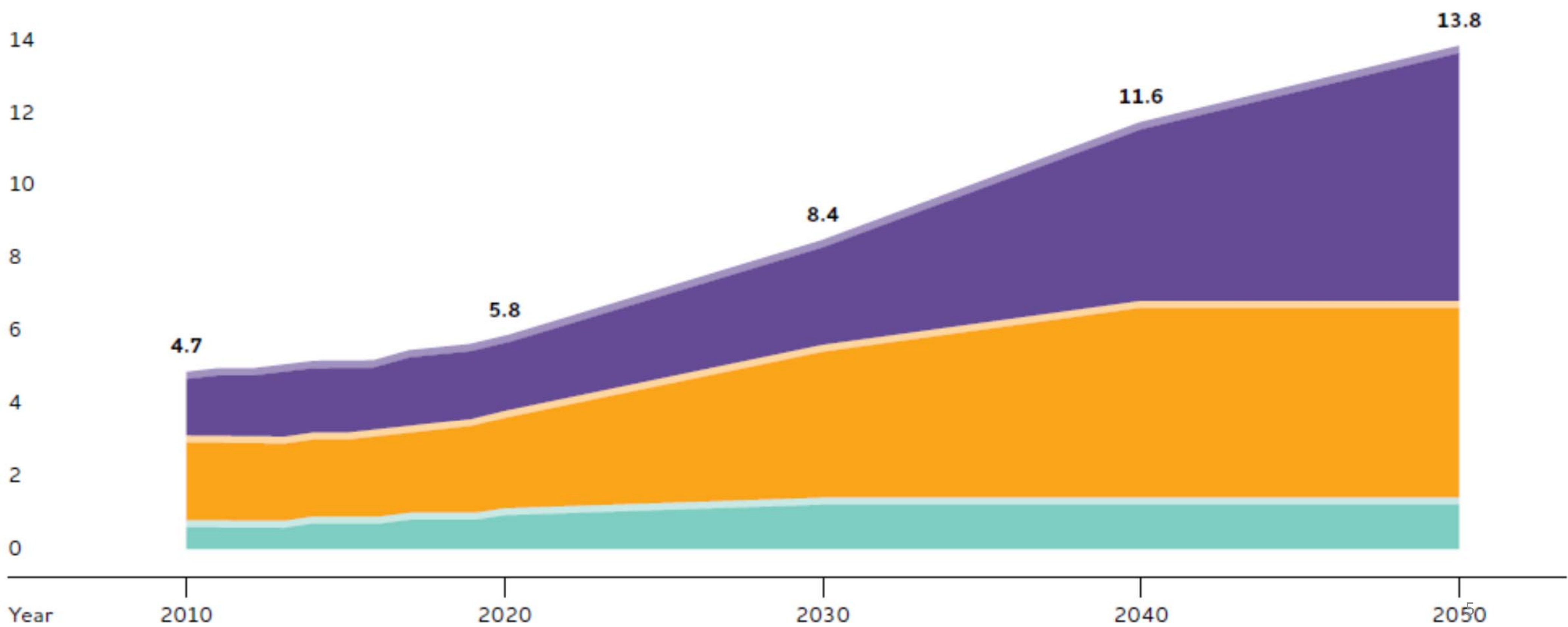

TABLE 4

Projections of Total Numbers of Americans Age 65 and Older with Alzheimer's Dementia by State

State	Projected Number with Alzheimer's (in thousands)		Percentage Change
	2017	2025	2017-2025
Alabama	90	110	22.2
Alaska	7.1	11	54.9
Arizona	130	200	53.8
Arkansas	55	67	21.8
California	630	840	33.3
Colorado	69	92	33.3
Connecticut	75	91	21.3
Delaware	18	23	27.8
District of Columbia	9	9	0.0
Florida	520	720	38.5
Georgia	140	190	35.7
Hawaii	27	35	29.6
Idaho	24	33	37.5
Illinois	220	260	18.2
Indiana	110	130	18.2
Iowa	64	73	14.1
Kansas	52	62	19.2
Kentucky	70	86	22.9
Louisiana	85	110	29.4
Maine	27	35	29.6
Maryland	100	130	30.0
Massachusetts	120	150	25.0
Michigan	180	220	22.2
Minnesota	92	120	30.4
Mississippi	53	65	22.6
Missouri	110	130	18.2
Montana	20	27	35.0
Nebraska	33	40	21.2
Nevada	43	64	48.8
New Hampshire	24	32	33.3
New Jersey	170	210	23.5
New Mexico	38	53	39.5
New York	390	460	17.9
North Carolina	160	210	31.3
North Dakota	14	16	14.3
Ohio	210	250	19.0
Oklahoma	63	76	20.6
Oregon	63	84	33.3
Pennsylvania	270	320	18.5
Rhode Island	23	27	17.4
South Carolina	86	120	39.5
South Dakota	17	20	17.6
Tennessee	110	140	27.3
Texas	360	490	36.1
Utah	30	42	40.0
Vermont	12	17	41.7
Virginia	140	190	35.7
Washington	110	140	27.3
West Virginia	37	44	18.9
Wisconsin	110	130	18.2
Wyoming	9.4	13	38.3

Created from data provided to the Alzheimer's Association by Weuve et al.[A8, 189]

TABLE 10

Average Annual Per-Person Payments for Health Care and Long-Term Care Services, Medicare Beneficiaries Age 65 and Older, with and without Alzheimer's or Other Dementias, in 2016 Dollars

Payment Source	Beneficiaries with Alzheimer's or Other Dementias	Beneficiaries without Alzheimer's or Other Dementias
Medicare	$23,497	$7,223
Medicaid	8,182	349
Uncompensated	364	365
Health maintenance organization	1,205	1,475
Private insurance	2,152	1,358
Other payer	895	231
Out of pocket	10,315	2,232
Total*	**$46,786**	**$13,351**

*Payments from sources do not equal total payments exactly due to the effect of population weighting. Payments for all beneficiaries with Alzheimer's and other dementias include payments for community-dwelling and facility-dwelling beneficiaries.

Created from unpublished data from the Medicare Current Beneficiary Survey for 2011.[380]

TABLE 11

Average Annual Per-Person Payments for Health Care and Long-Term Care Services Provided to Medicare Beneficiaries Age 65 and Older, with and without Alzheimer's or Other Dementias, in 2016 Dollars

Service	Beneficiaries with Alzheimer's or Other Dementias	Beneficiaries without Alzheimer's or Other Dementias
Inpatient hospital	$10,415	$3,364
Medical provider*	6,031	3,757
Skilled nursing facility	6,547	448
Nursing home	14,999	726
Hospice	1,966	149
Home health care	2,461	357
Prescription medications†	3,318	2,846

*"Medical provider" includes physician, other medical provider and laboratory services, and medical equipment and supplies.

†Information on payments for prescription medications is only available for people who were living in the community, that is, not in a nursing home or assisted living facility.

Created from unpublished data from the Medicare Current Beneficiary Survey for 2011.[380]

Impact of Dementia on Families

- Great uncertainty about the disease process and how to prepare for the future.
- As dementia symptoms progress, families assume greater decision-making and hands-on care responsibilities.
- Family caregivers shown to be at increased risk for physical and emotional health problems compared to non-caregivers[1]
- Caring under stress shown to be an independent risk factor for mortality among spouse caregivers[2]

[1]Ory, et al, *Gerontologist 1999;39*:177-185

[2]Schulz & Beach, *JAMA 1999;282*:2215-2219

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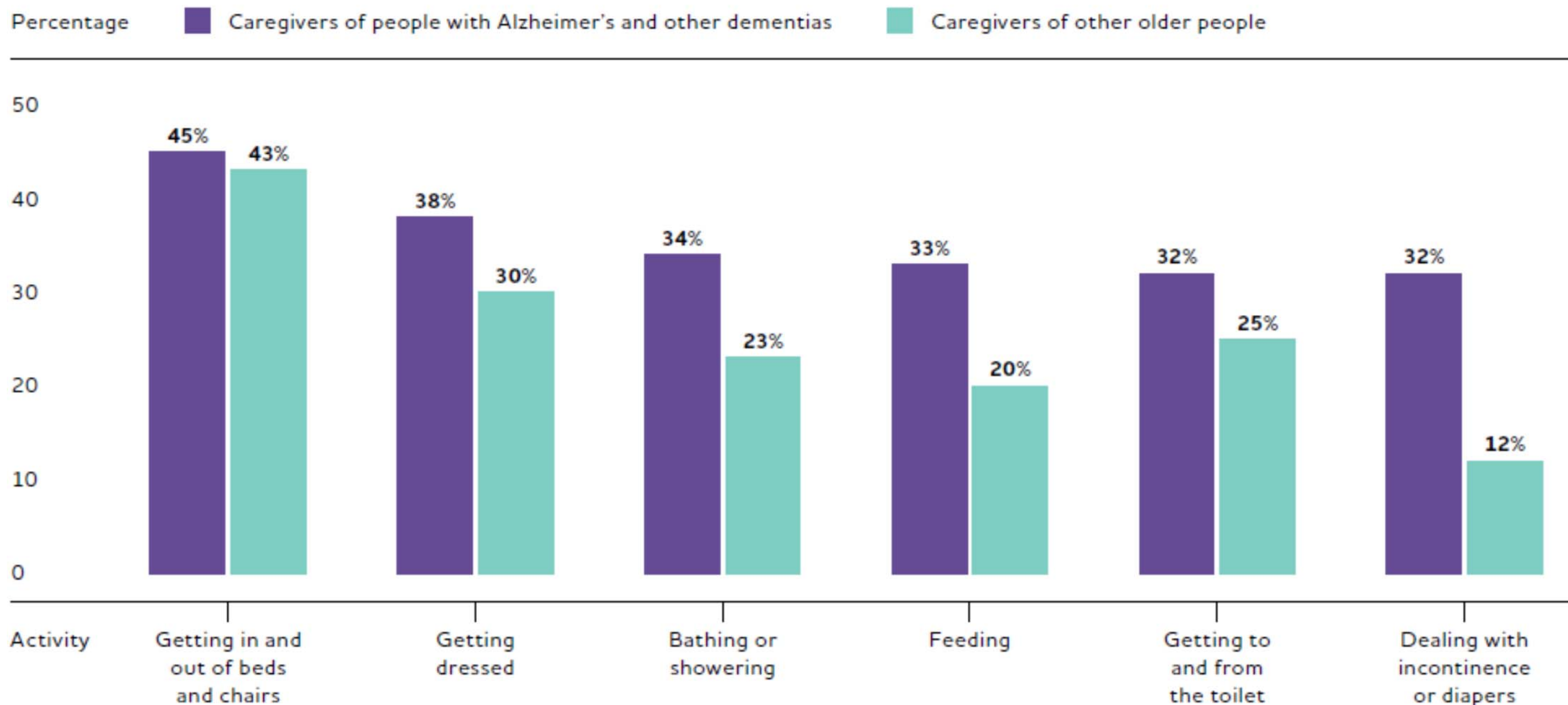


FIGURE 7
Proportion of Caregivers of People with Alzheimer's or Other Dementias Versus Caregivers of Other Older People Who Provide Help with Specific Activities of Daily Living, United States, 2015
Percentage
Caregivers of people with Alzheimer's and other dementias
Caregivers of other older people
50
40
30
20
10
0
45%
43%
38%
30%
34%
23%
33%
20%
32%
25%
32%
12%
Activity
Getting in and out of beds and chairs
Getting dressed
Bathing or showering
Feeding
Getting to and from the toilet
Dealing with incontinence or diapers
Created from data from National Alliance for Caregiving and AARP.[243]

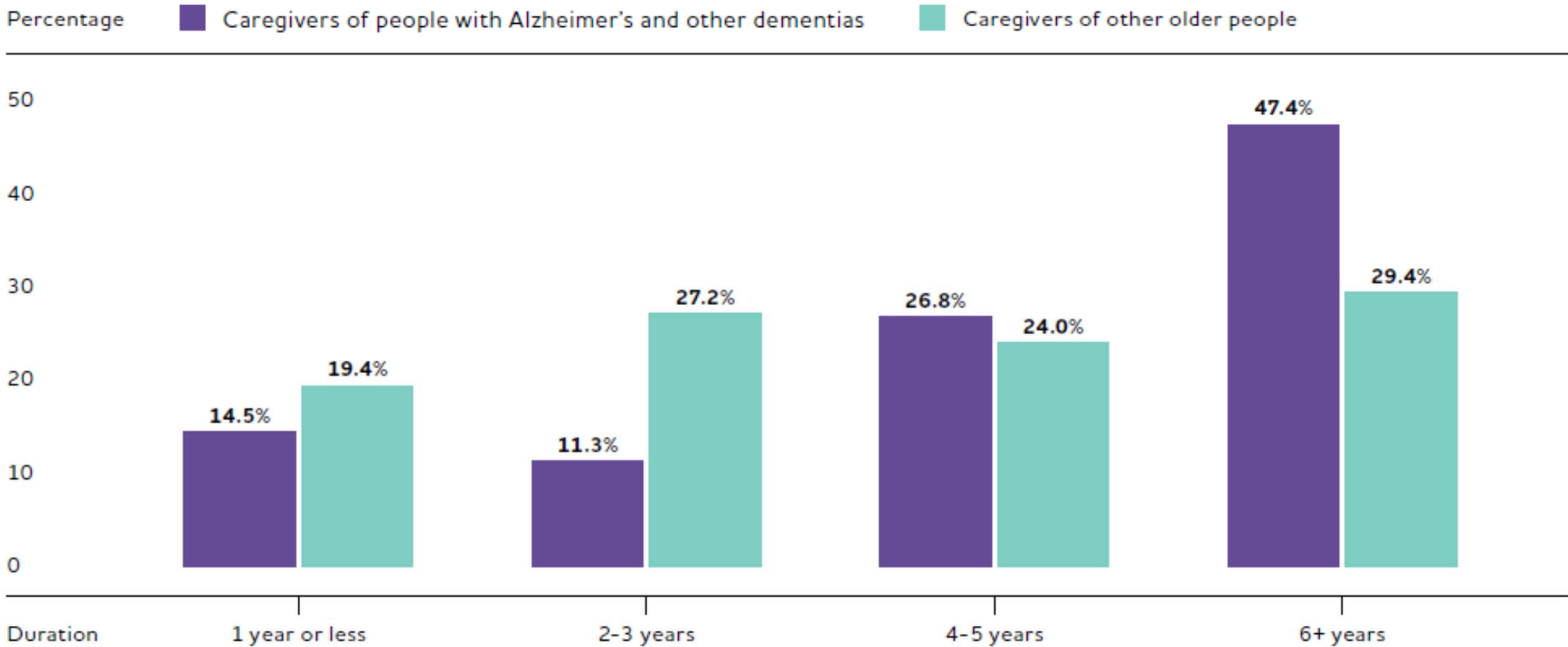
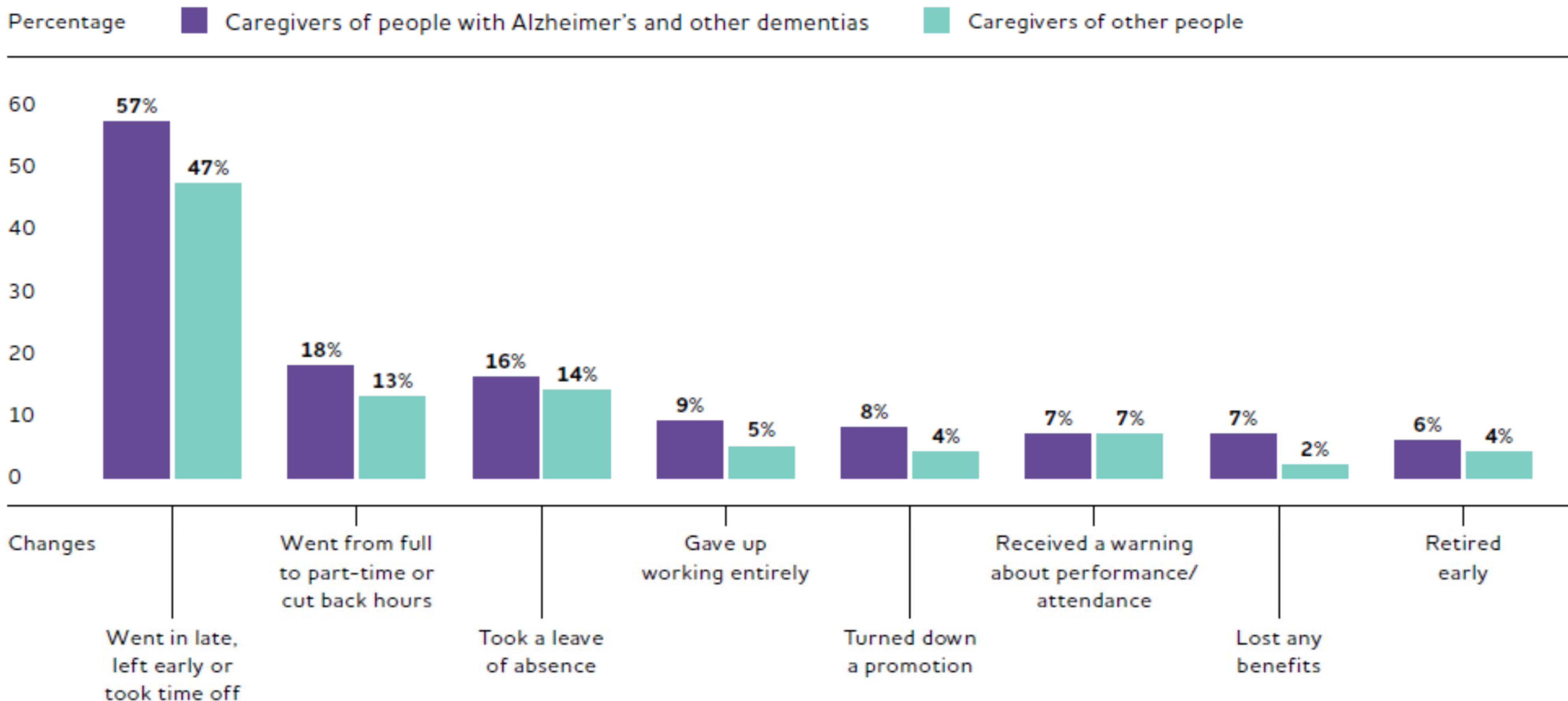


FIGURE 8
Proportion of Alzheimer's and Dementia Caregivers Versus Caregivers of Other Older People in Residential Care Settings by Duration of Caregiving, United States, 2011
Percentage
Caregivers of people with Alzheimer's and other dementias
Caregivers of other older people
50
40
30
20
10
0
47.4%
29.4%
27.2%
26.8%
24.0%
19.4%
14.5%
11.3%
Duration
1 year or less
2-3 years
4-5 years
6+ years
Created from data from the National Health and Aging Trends Study.238

FIGURE 10

Work-Related Changes Among Caregivers of People with Alzheimer's and Other Dementias Who Had Been Employed at Any Time Since They Began Caregiving



Created from data from the National Alliance for Caregiving and AARP.[243]

Evidence-Based Programs for Family and other Informal Caregivers for Persons with Dementia

- Behavioral and skill-building approaches to help families learn how to manage dementia and maintain their own health and well-being.
- “Evidence-based” approaches: tested in RCTs.
- More than 200 tested, but few widely available.
- Commonly studied health outcomes:
  - Family caregiver mental health problem prevention or improvement (burden, depressive symptoms)
  - Family caregiver improved self-efficacy
  - Reduced or lower rate of nursing home admission, ED use, and hospitalization of persons with dementia.

Types of Evidence-Based Programs for Caregivers

- ***Psycho-educational:*** **usually provided by nurses, occupational therapists, or social workers; individualized skill-building protocols in homes or outpatient settings.**
- ***Supportive:*** **group programs for family caregivers or patients; build peer support and teach symptom management strategies.**
- ***Multicomponent:*** **psycho-educational plus physical activity and comorbid disease detection.**

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Alzheimer's Disease Supportive Services Program (ADSSP)

- From 2008-2010, the Administration on Aging (AoA) funded 16 State Units on Aging to translate evidence-based caregiver programs.
- A 2017 report by RTI International evaluating this ADSSP initiative found:
  - Nine different evidence-based programs were translated; all 3 types included.
  - Most community partners were Area Agencies on Aging and Alzheimer's Association chapters.
  - Caregivers in most sites experienced improved health-related outcomes.
  - Delayed nursing home admission and other cost-related outcomes were NOT routinely studied; little evidence of such impacts from this initiative.
  - Sites often modified evidence-based programs to fit local resource availability.
  - Initial AoA grant funding allowed some sites to find additional funding, but many have faced difficulty finding ongoing funding streams to sustain these programs.

Next steps for Evidence-Based Programs for Caregivers

- **Translate and integrate into existing service and reimbursement systems**
- **Programs most likely to be successfully integrated will fit into service systems and will be Medicaid and/or Medicare reimbursable**
- **For Medicaid, long-term services and supports (LTSS) such as Waiver programs ripe for translation/integration *where large numbers of people with dementia receive in-home care to delay or avoid nursing home admission.***
- **For Medicare fee for service, primary care settings ripe for translation due to growth of Patient-Centered Medical Homes & Accountable Care Organizations.**
- **Medicare Advantage plans growing rapidly; most enrolling dually eligible adults, another potential reimbursement system to facilitate replication.**

Translation of the Care for Persons with Dementia in their Environments (COPE) Intervention for Publicly-Funded Home Care Clients and their Families

Funded by National Institute on Aging (R01 AG044504)
Richard H. Fortinsky, PhD, Principal Investigator
Funding period: 2014-2019

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Why Was Connecticut Medicaid Program Interested?

- **Connecticut is ambitiously pursuing rebalancing initiatives within its Medicaid LTSS system.**
- **Home and community-based LTSS for the older population are integrated within the Connecticut Home Care Program for Elders (CHCPE)**
  - **the CHCPE includes the Medicaid Waiver program for older adults as well as state-revenue funding for individuals eligible, or at risk, for nursing home admission**
  - **25-30% of clients enrolled in the CHCPE have dementia**
- **No CHCPE services engage family caregivers to help them improve their dementia management skills, which might delay/avoid nursing home admission. Medicaid officials understood importance of supporting caregivers.**
- **Medicaid officials agreed that the COPE intervention was highly relevant to the needs and features of the CHCPE population with dementia.**
- **The state's largest care management organization running the CHCPE was enthusiastic about participating, also understood importance of helping train family caregivers.**

COPE Intervention Components

- **Occupational therapist component:**
  - **Up to 10 home visits over 16 weeks**
  - **3 phases: Assessment, Implementation, and Generalization**
  - **Prescriptions (action plans) developed with caregivers to address target problem areas chosen by caregivers**
- **Nurse practitioner component:**
  - **One in-home visit to examine older adult with dementia for dehydration, pain, other symptoms; collect blood and urine samples when possible**
  - **One follow-up phone call with caregiver to report lab test results, arrange to share results with primary care physician.**

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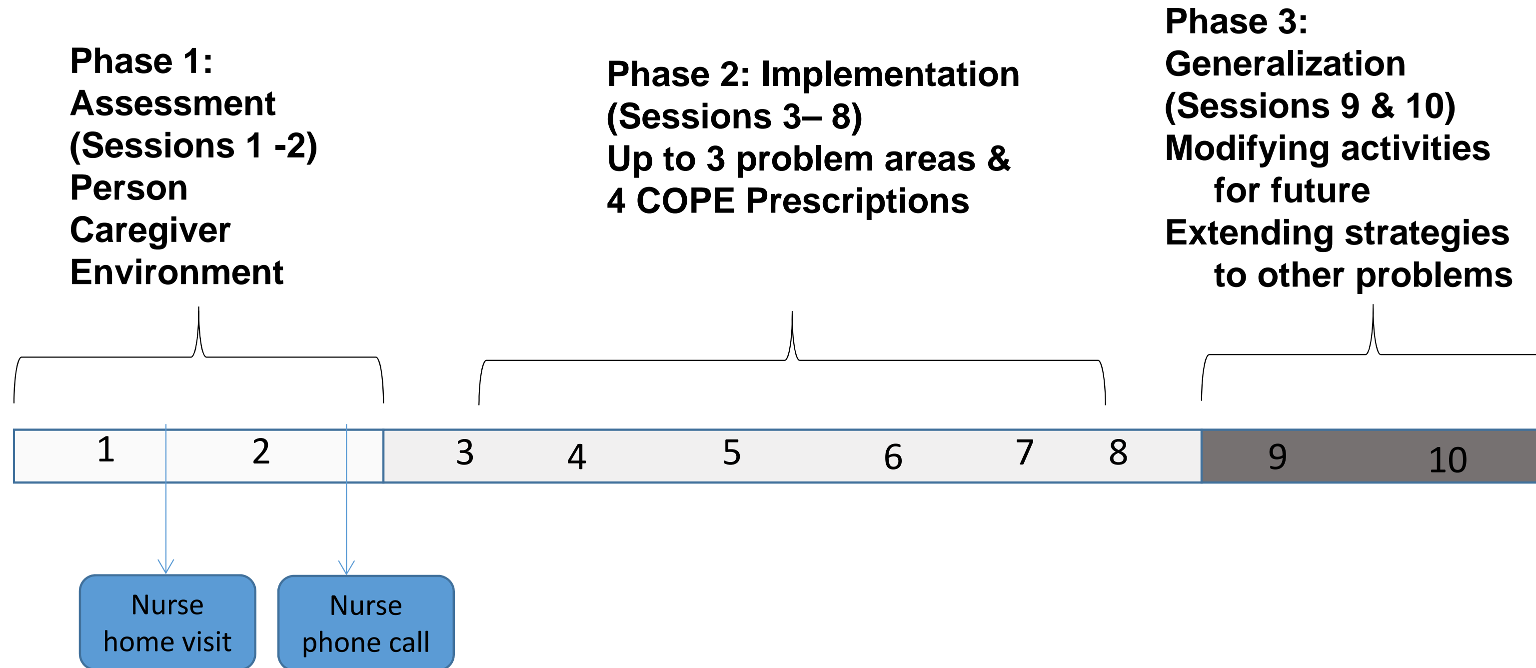
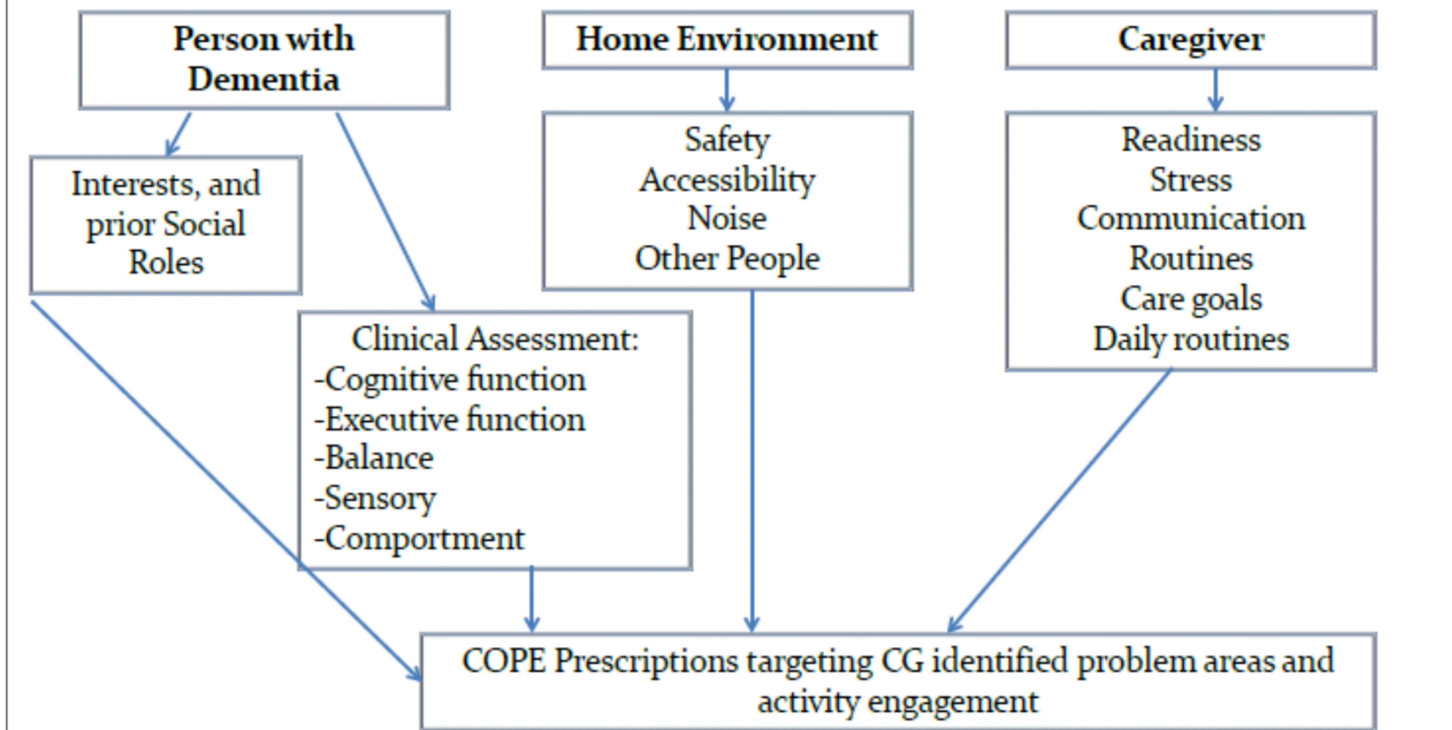
Gitlin LN et al, JAMA, 2010;304:983-991.

COPE Intervention Phases



Adapted from Gitlin LN et al, JAMA, 2010;304:983-991

Integration of Assessment Findings



Adapted from: Gitlin LN, et al., Reducing neuropsychiatric symptoms in persons with dementia and associated burden in family caregivers using tailored activities: Design and methods of a randomized clinical trial (in press at Contemp Clin Trials).

COPE CT Study Specific Aims

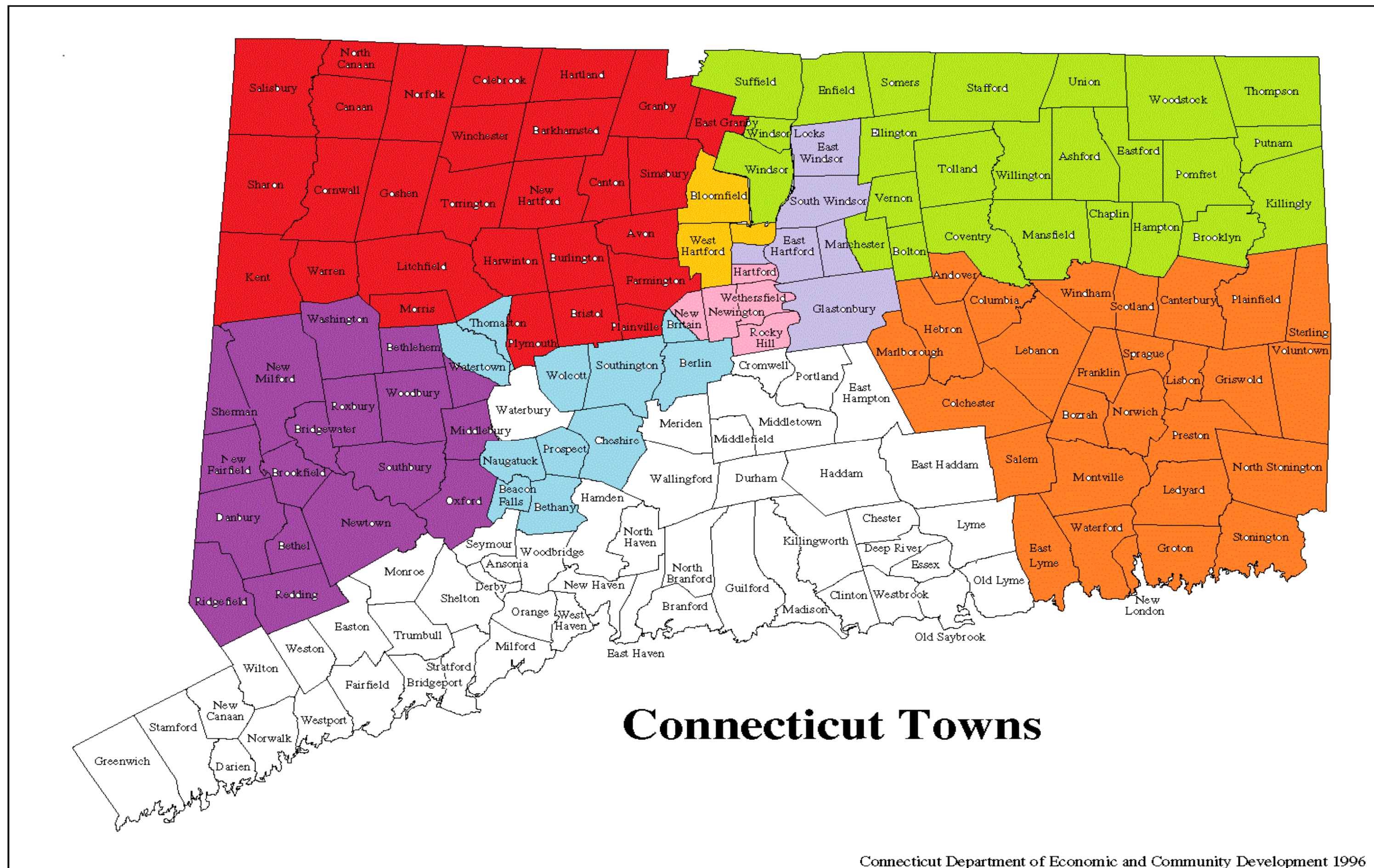
Aim 1: Older adults with dementia: determine COPE effect on functional independence, engagement in activities, quality of life, neuropsychiatric symptoms.

Aim 2: Family caregivers: Determine COPE effect on perceived well-being, confidence using dementia management strategies, ability to keep relative at home.

Aim 3: Determine net financial benefit of COPE, accounting for COPE intervention, nursing home, and other service costs.

Aim 4: Determine feasibility and acceptability of COPE implementation into the CHCPE from multiple stakeholder viewpoints, including home care policy decision makers.

Geographic Area Covered by the COPE CT Study



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Communicating and Sharing COPE Documents with Care Managers

- Care managers for CHCPE clients receive clinical assessments and prescriptions from COPE interventionists.
- Critical translational step in the COPE CT study.
- Focus groups held with care managers and COPE interventionists.
  - To learn how well COPE intervention is being incorporated into care managers' practice; barriers and successes of implementation
  - Many care managers expressed satisfaction with communication with COPE interventionists, but others did not have sufficient communication with the occupational therapist or the nurse practitioner.

COPE Intervention Completion Rates

Based on 94 dyads who have completed the COPE intervention:

- **All but 1 dyad completed home visit and follow-up phone call with nurse practitioner**
- **73 (78%) completed all 10 OT visits**
- **12 (13%) completed 8 or 9 OT visits**

17 dyads currently receiving intervention

10 dyads withdrew or experienced death of one member before completing intervention

Funded by the National Institute on Aging (AG044504)

Selected Baseline Characteristics of COPE CT Study Clients and Caregivers through September 15, 2017 (N=242)

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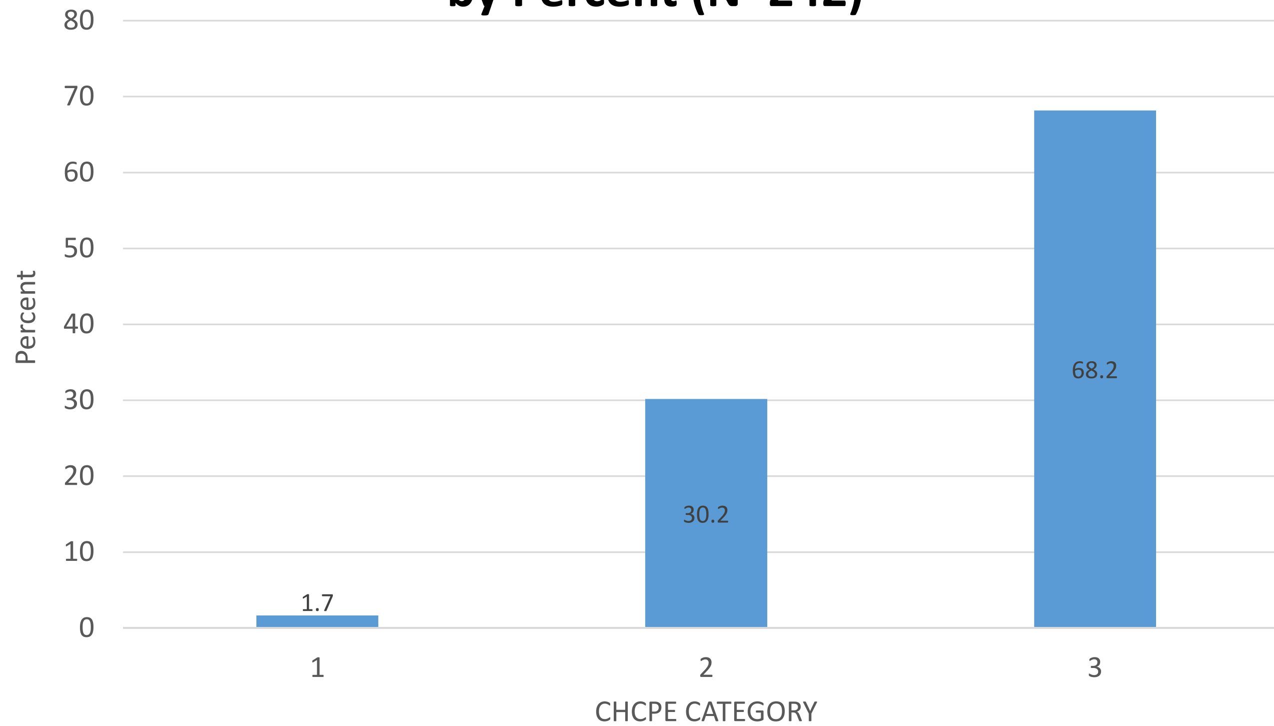
Clients' Eligibility Category in the Connecticut Home Care Program for Elders*, by Percent (N=242)



***Category 3: Medicaid waiver funding; Categories 1 and 2: State revenue funding**

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Clients' Cognitive Impairment Level (Dementia vs Mild Cognitive Impairment), Based on SLUMS Score and Educational Attainment

Educational Attainment	Dementia	MCI	Total
High School and above	158	13	**171**
Less than High School	70	1	**71**
Total	**228**	**14**	**242**

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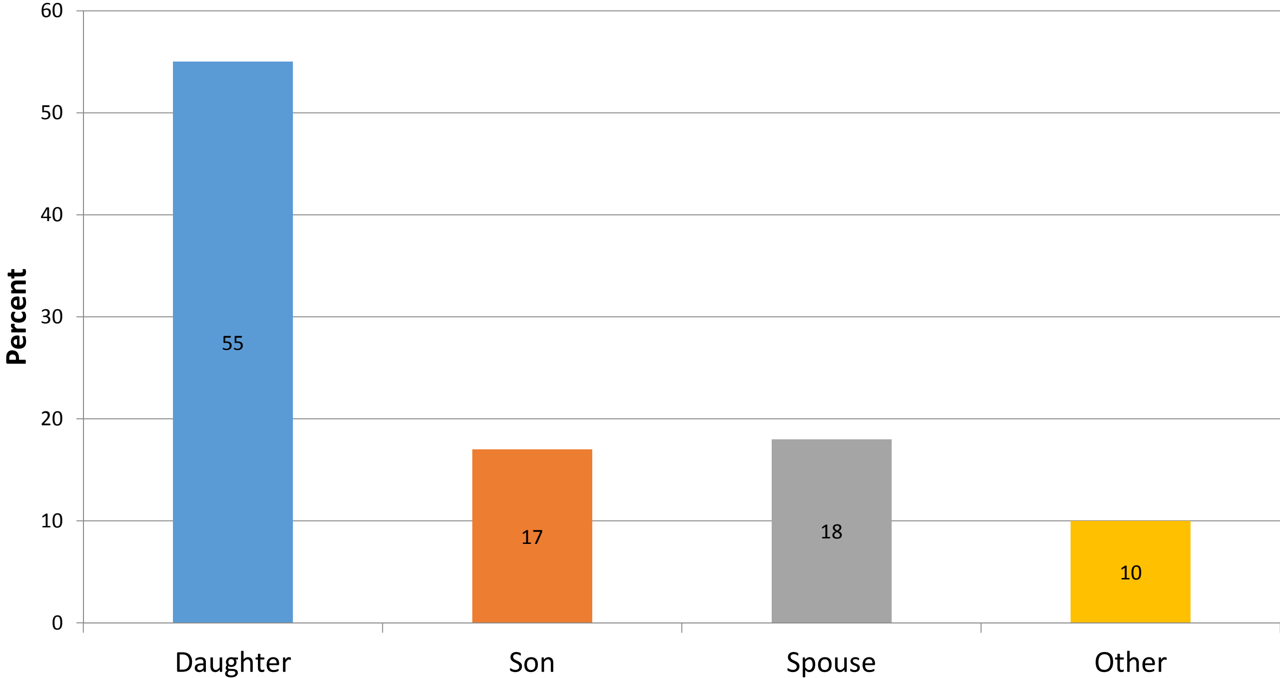

Other includes: Sibling (5), Grandchild (4), Niece/Nephew (4), Significant Other (5), Friend (3), Other (4)

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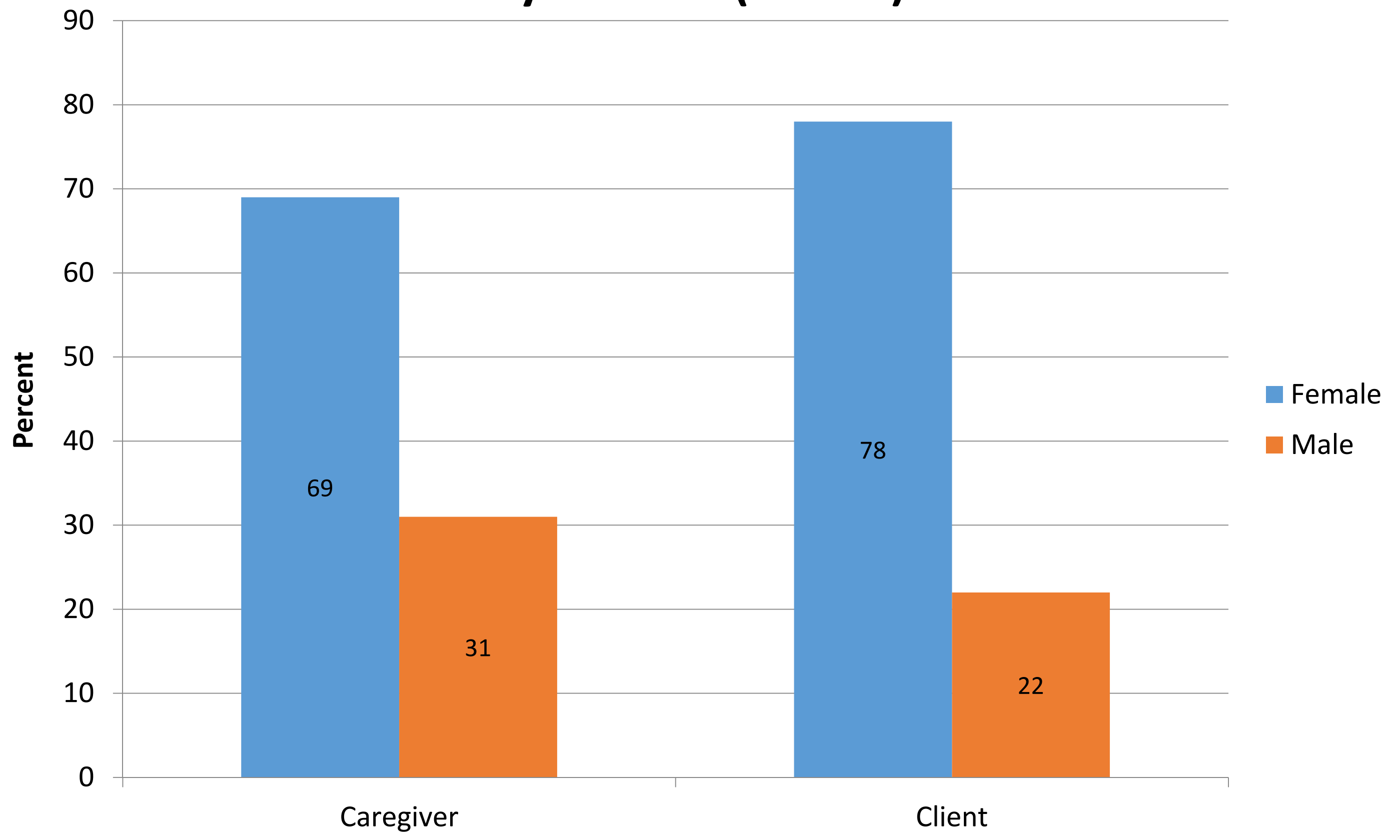
Gender Distribution of Clients and Caregivers, by Percent (N=242)



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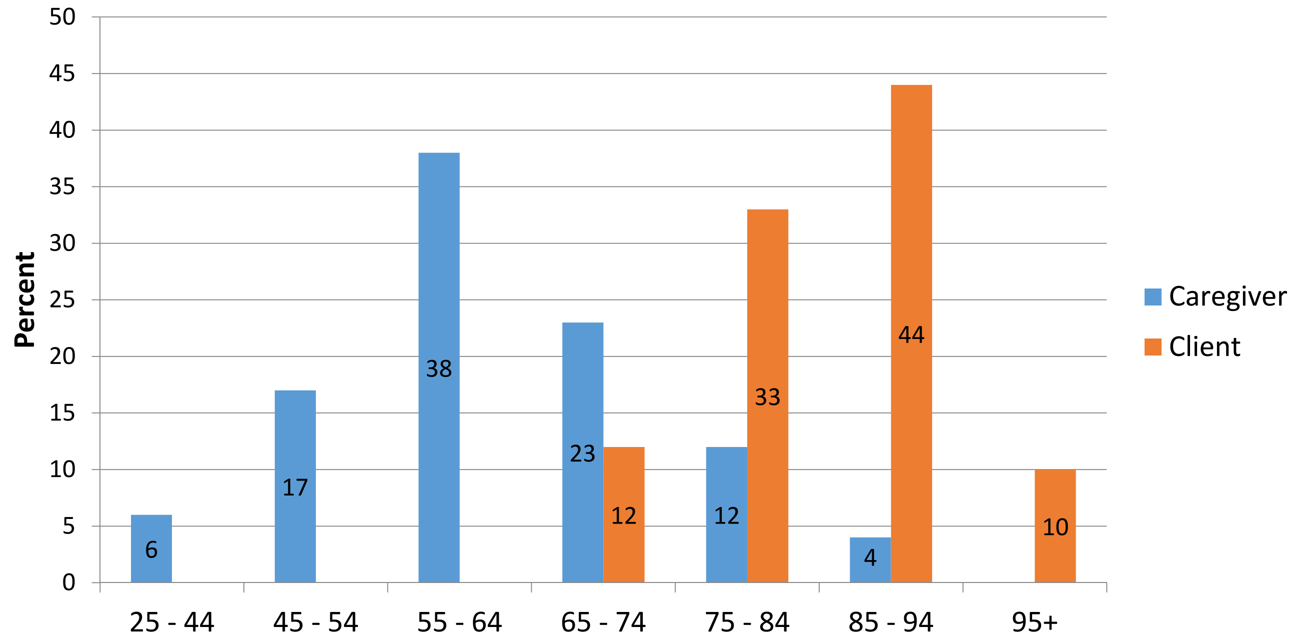

Caregiver Age
mean (SD): 62.1 (11.7) years

Client Age
mean (SD): 84.8 (8.0) years

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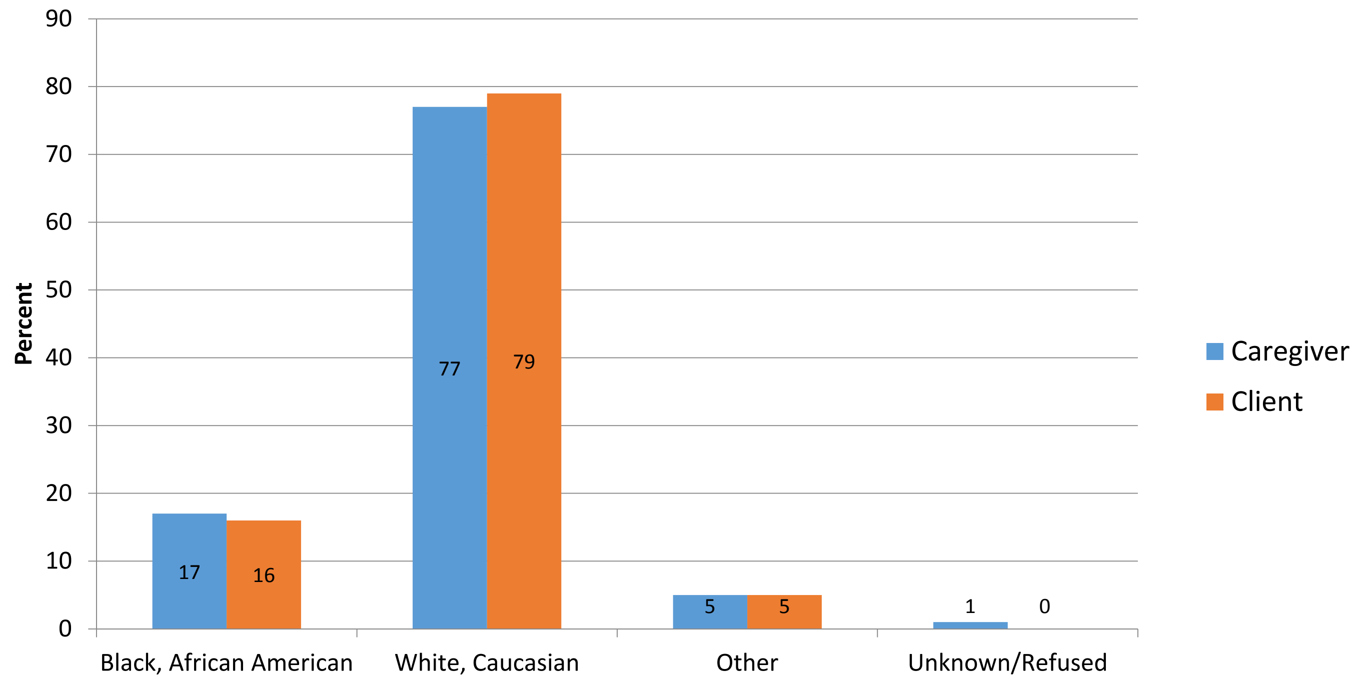

*7 Caregivers and 5 Care Recipients indicated Hispanic Ethnicity

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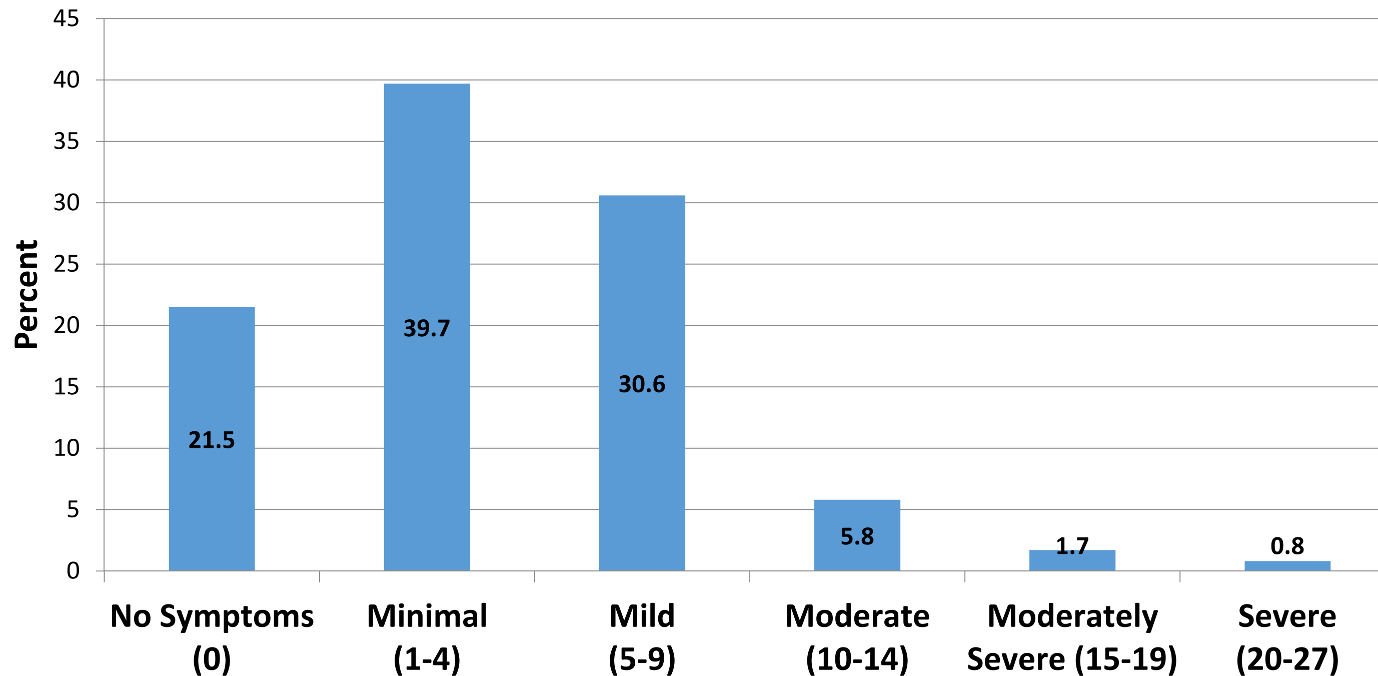
Caregivers' Self-Reported Depressive Symptom Severity, Based on PHQ-9 Total Scores, by Percent (N=242)



PHQ-9 Mean Total Score (SD): 4.2 (4.2) Median: 3

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Most Common Target Problem Areas Reported by Caregivers, by Percent (N=83 caregivers)

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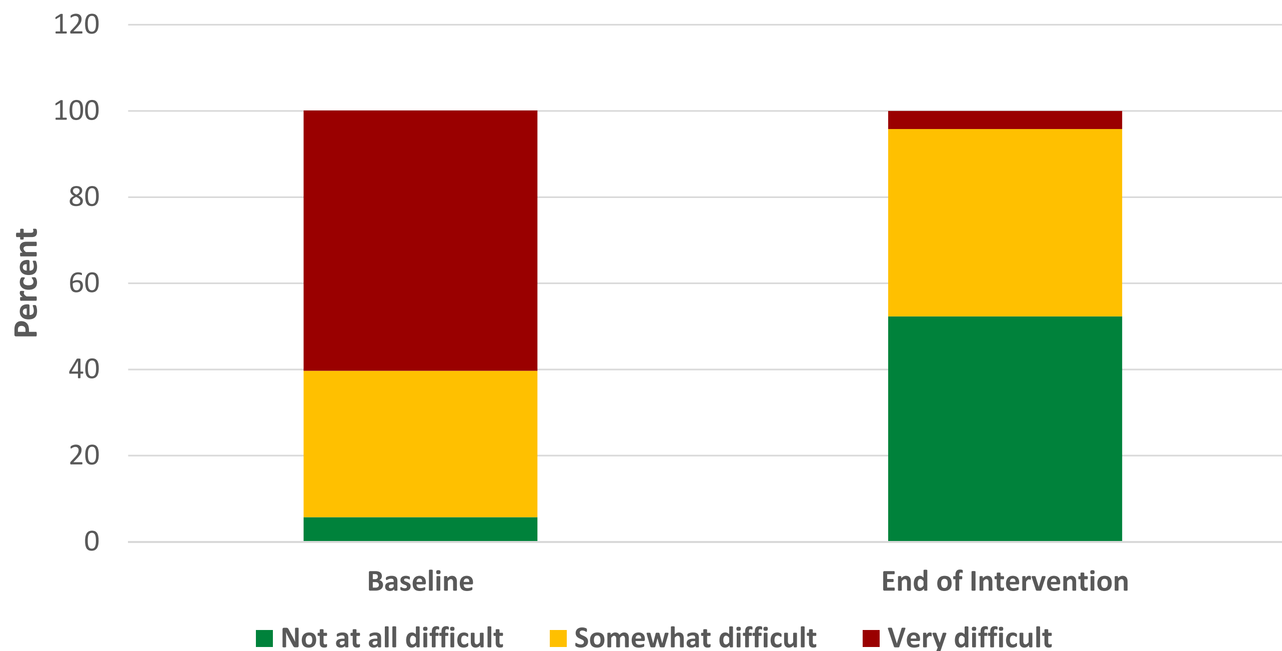
Level of Difficulty Managing Target Problem Areas, Baseline and End of Intervention, by Percent



Number of problems at baseline=212; number of problems at end of intervention=216

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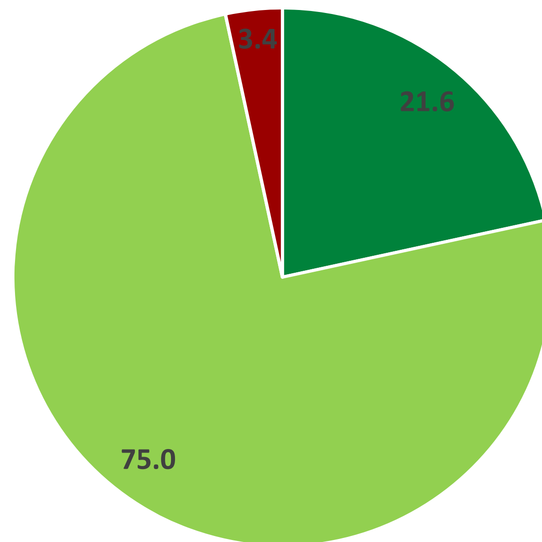
Target Problem Areas, Level of Resolution at End of Intervention, by Percent (N=208 problems)



Eliminated Reduced Got worse

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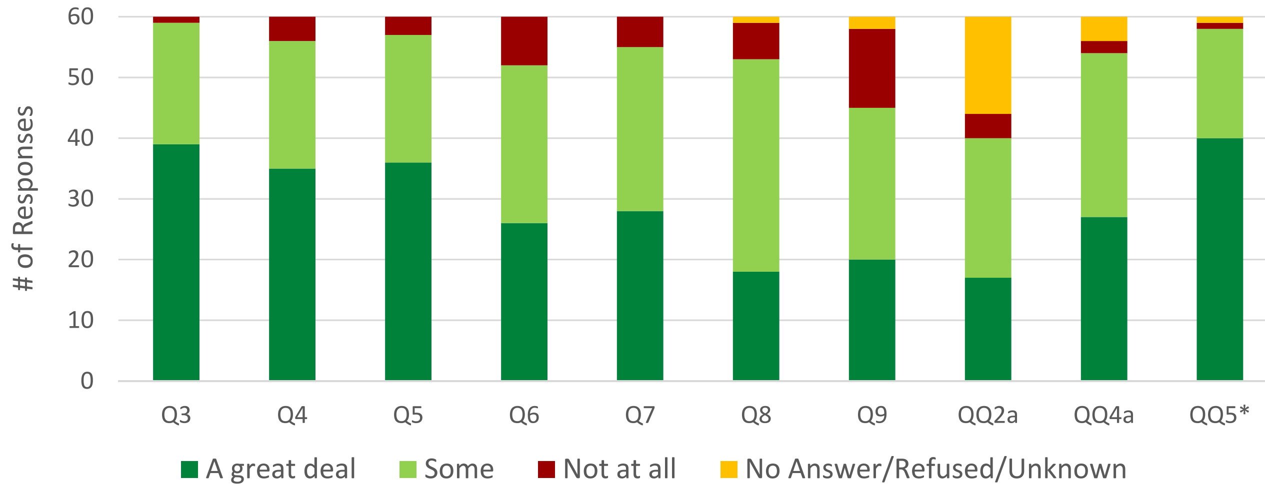

Q3. How much did you benefit from participation in COPE?
Q4. How much did COPE help you understand dementia and its effect?
Q5. How much did COPE help you feel more confident in dealing with CR behaviors?
Q6. How much did COPE make your life easier?
Q7. How much did COPE enhance your ability to care for your CR?
Q8. How much did COPE help improve your CR's life?
Q9. How much did COPE help to keep your CR living at home with you?
QQ2a. How helpful was nurse's information and guidance in managing your CR's health?
QQ4a. How helpful have you found activities from the OT to be in managing the daily care of your CR?
QQ5. How satisfied are you with what you learned from the OT visits?
***[Responses: Very satisfied, Satisfied, Very Dissatisfied, N/A]**

Funded by the National Institute on Aging (AG044504)

Lessons Learned to Date

- Costs of the COPE intervention and willingness of caregivers to pay
  - Preliminary results based on first 85 completers
    - Estimated cost based on visit and travel costs: $1,000-$1,200 ($250-300/month for 4 months). Telephone communication and monitoring costs, and supply charges, excluded
    - 75% of caregivers reported willingness to pay some amount for a COPE-like intervention
- Identifying CHCPE clients most eligible based on dementia documentation has proven to be quite successful
- Care managers have learned to appreciate the value of COPE services
  - COPE prescriptions useful for their ongoing care management
  - by talking with family caregivers of their CHCPE clients—testimonials
- Challenges include:
  - need to systematize communication between COPE interventionists and care managers
  - care manager turnover requires educating replacements about the COPE study
  - Sustaining COPE intervention fidelity once investigators finish the study

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Implications for Other State Medicaid Programs

- COPE might be considered if in-home occupational therapy and nurse practitioner services are reimbursable in state plan Medicaid, and Medicaid waiver programs.
- Care management organizations running Medicaid waiver programs might find COPE suitable and a "missing link" in menu of available waiver program services for persons with dementia.
- If found acceptable in terms of "return on investment", however defined, COPE might be offered as another choice for clients and families affected by dementia, as part of their capitated care plan.
- COPE, or other suitable evidence-based programs, might be offered by state Medicaid programs through collaboration with Medicare Advantage plans that insure dual eligibles with dementia (and possibly their spouses, the caregivers).
- State Medicaid programs might also collaborate with physician practices that have formed Accountable Care Organizations to implement suitable evidence based programs.

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