



Special Populations Caregivers

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Disclosures

Relevant financial relationships

- Salaried part time employee of Presbyterian Healthcare Services

Relevant non-financial relationships

- Frequent caregiver contact in professional and private life
- I am a caregiver

Objectives

- Recognize demographics of caregivers
- Describe care recipient needs and caregiving activities
- Explain how caregiving affects caregiver stress, strain, and health
- Develop resources for caregivers



Queen Latifah caregiver
to her mom Rita Owens

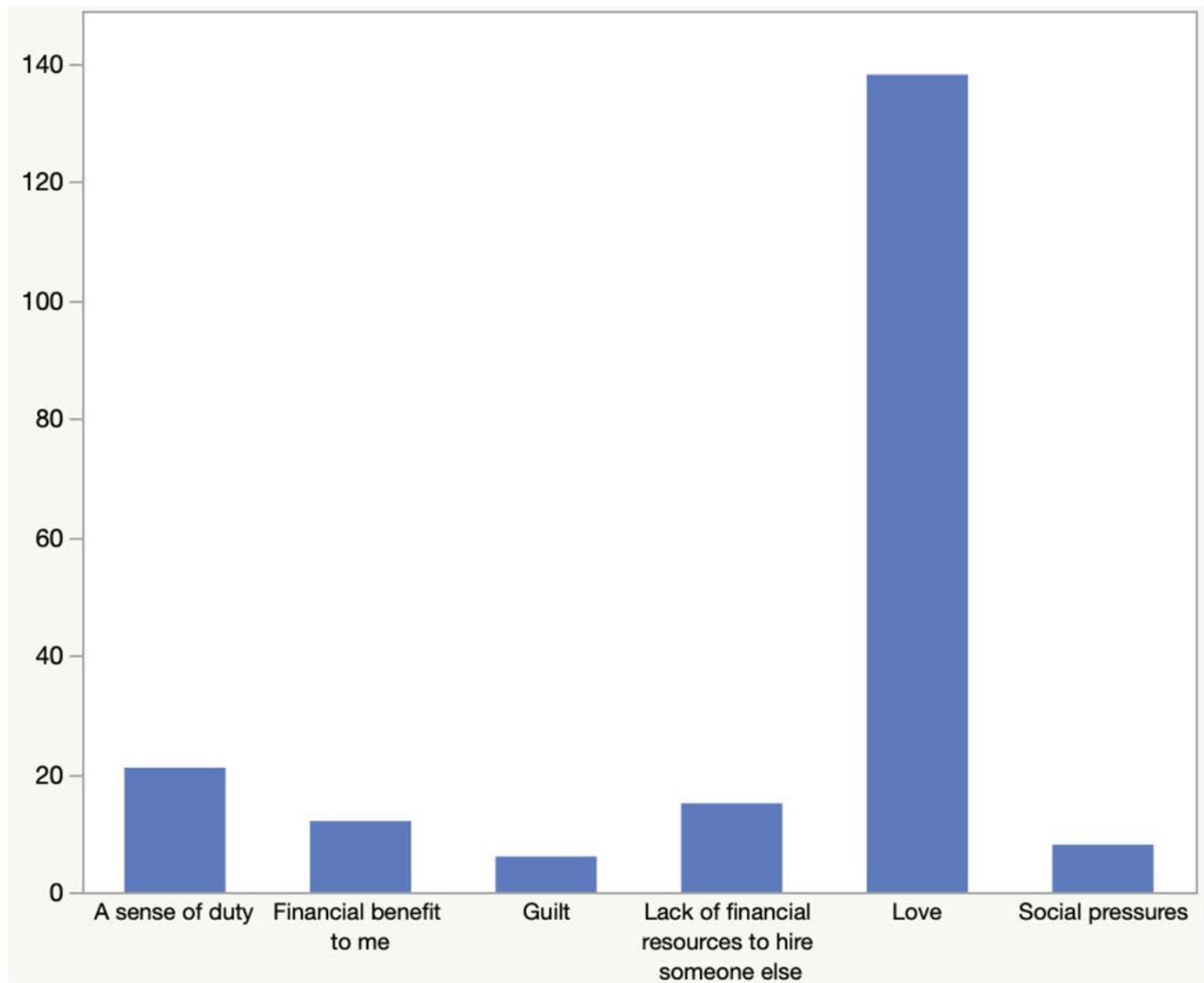
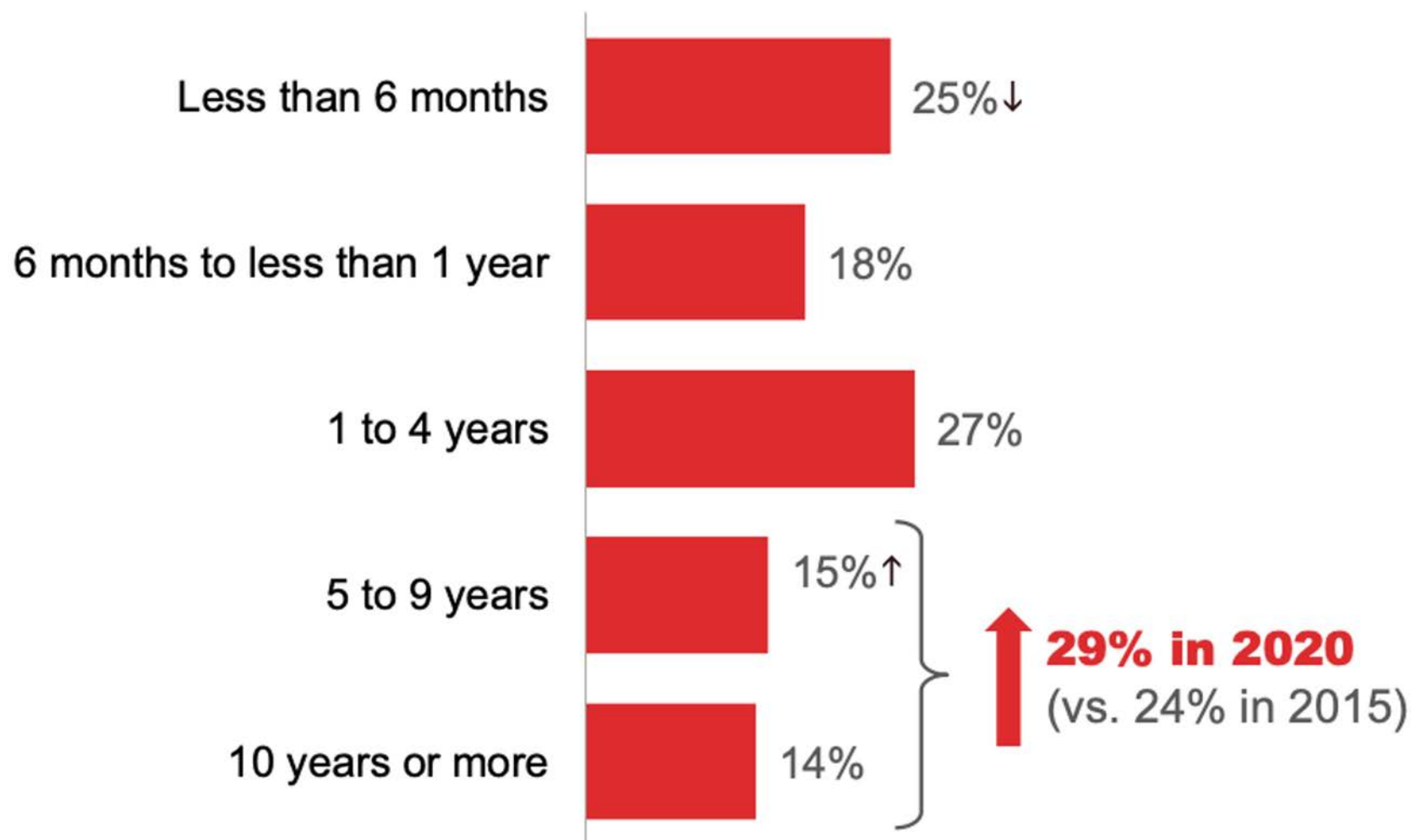
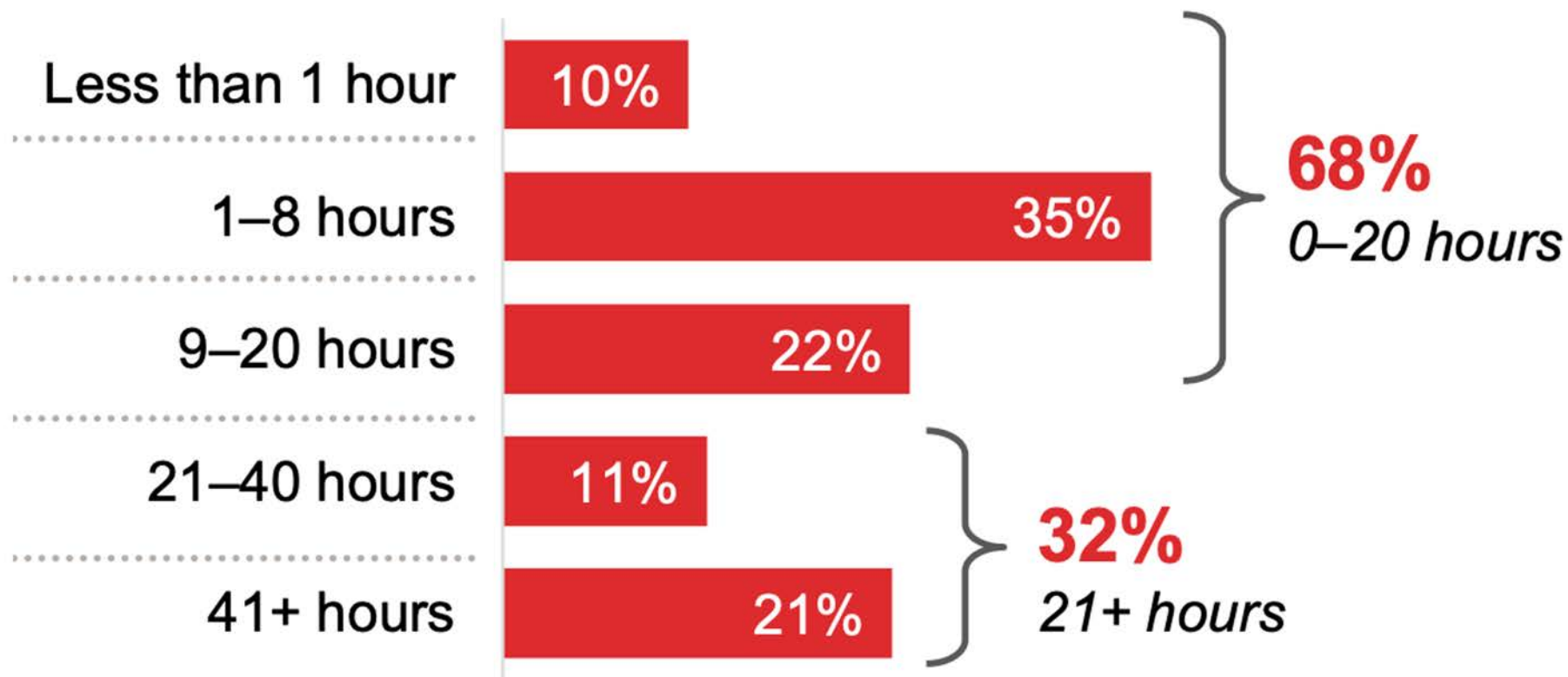


Figure 3. Motivations Behind Taking Care of a Patient

Duration of care



Hours of care provided

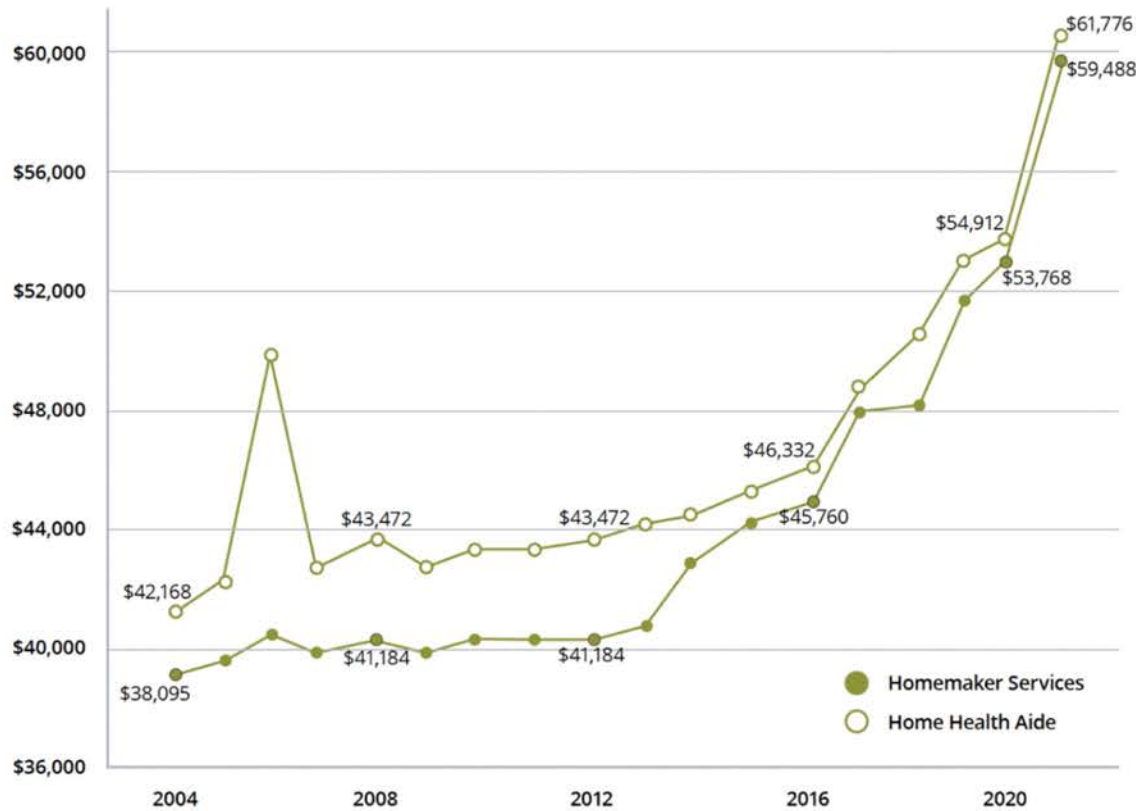




Informal caregiving may be unpaid, however, the value of services provided by caregivers were worth \$470 billion in 2013. At the value of \$470 billion in 2013, this value exceeded paid home care and Medicaid spending, while almost matching the value of Walmart (\$477 billion in 2013).

[National Alliance for Caregiving and AARP. (2015). Caregiving in the U.S.]

In-Home Care Costs⁵

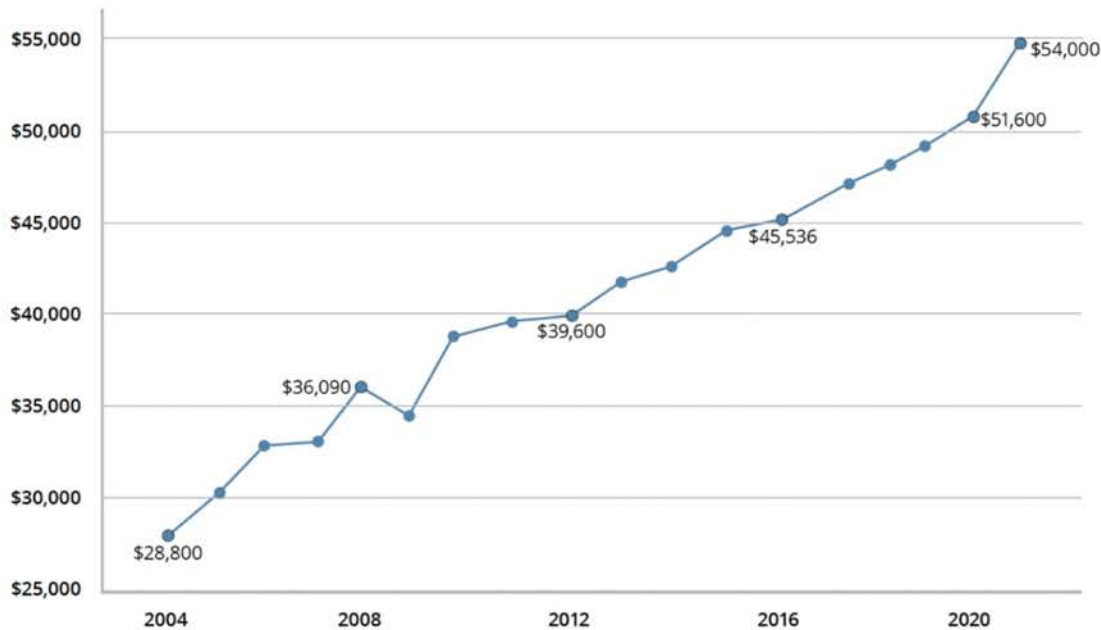


\$27.00

National hourly cost for a Home Health Aide in 2021⁶

The median yearly cost of in-home care in the United States in 2021 was \$61,776 for a Home Health Aide and \$59,488 for Homemaker services. The hourly rate for a Home Health Aide ranged from \$19 in West Virginia to \$36 in Minnesota.

Assisted Living Facility Costs⁸



\$54,000

Annual National Median cost for Assisted Living Facility care services in 2021⁸

The median yearly cost of care in an Assisted Living Facility in the United States in 2021 was \$54,000. The monthly rate for assisted living facility care ranged from \$3,000 in Missouri to \$6,978 in the District of Columbia.

Monthly Median Costs: *New Mexico - State*ⁱ (2021 vs. 2024)

In-Home Care ⁱ	
Homemaker Services ¹	\$2,512
2024* Cost	\$2,745
<hr/>	
Home Health Aide ¹	\$2,537
2024* Cost	\$2,772

Community and Assisted Living ⁱ	
Adult Day Health Care ²	\$1,993
2024* Cost	\$2,178
<hr/>	
Assisted Living Facility ³	\$4,498
2024* Cost	\$4,915

Change weekly In-Home Care hours

The number of hours needed for in-home care can vary based on need.

Enter the number of weekly hours (7-168)

CALCULATE

[Reset hours](#)

For example: 20 hours = 4 hours of care/5 days a week
40 hours = 8 hours of care/5 days a week
168 hours = 24 hours of care/7 days a week

Caregiver Demographics



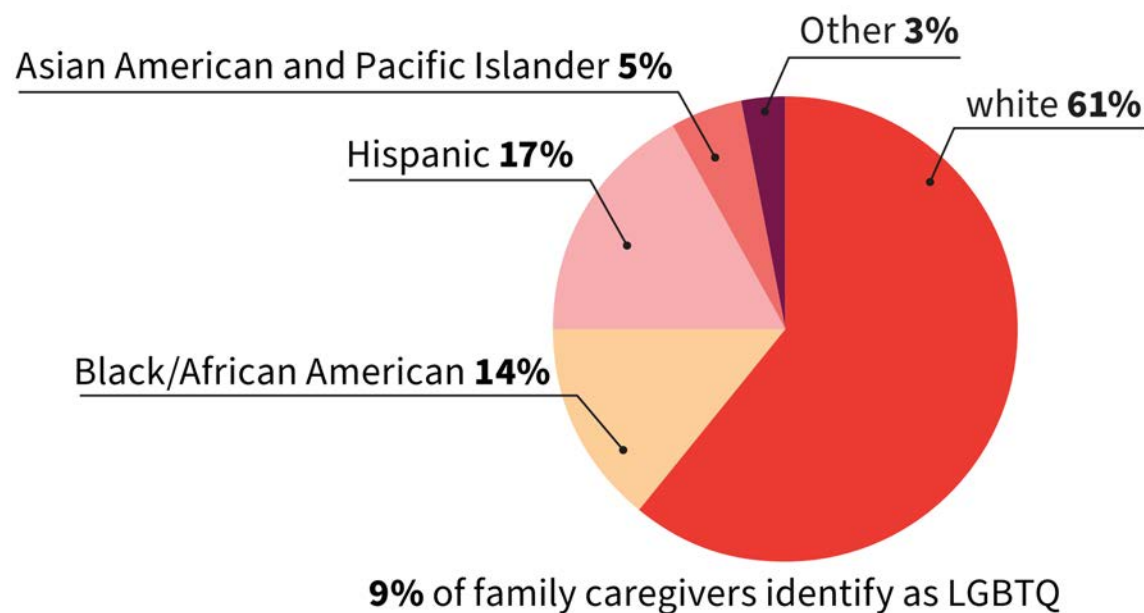
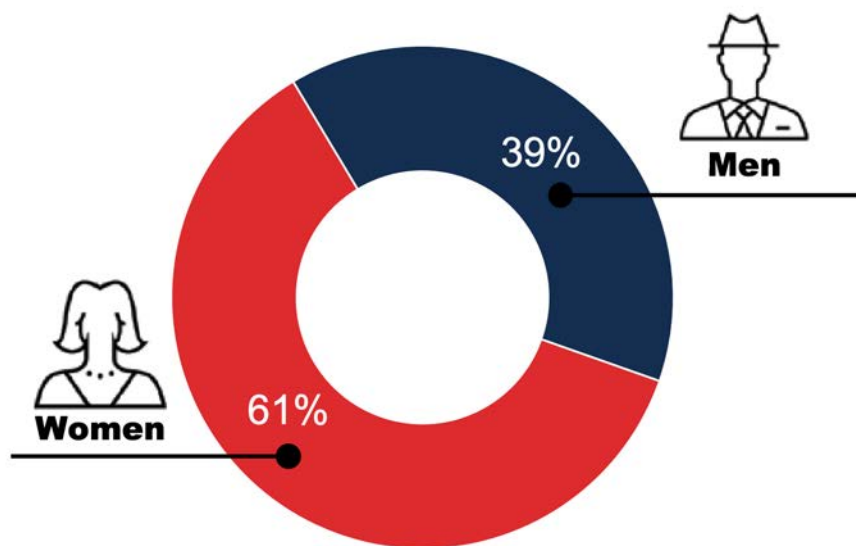
Marcia Gay Harden caregiver to her mom Beverly Bushfield Harden

Prevalence of Caregiving by Age of Care Recipient, 2020 Compared to 2015

	2020 Prevalence	Estimated Number of U.S. Adults Who Are Caregivers	Estimated Number of U.S. Adults Who Are Caregivers
Overall	21.3%*	53.0 million	43.5 million
Caregivers of recipients ages 0–17	5.7%*	14.1 million	10.2 million
Caregivers of recipients ages 18+	19.2%*	47.9 million	39.8 million
Caregivers of recipients ages 18–49	2.5%	6.1 million	5.6 million
Caregivers of recipients ages 50+	16.8%*	41.8 million	34.2 million

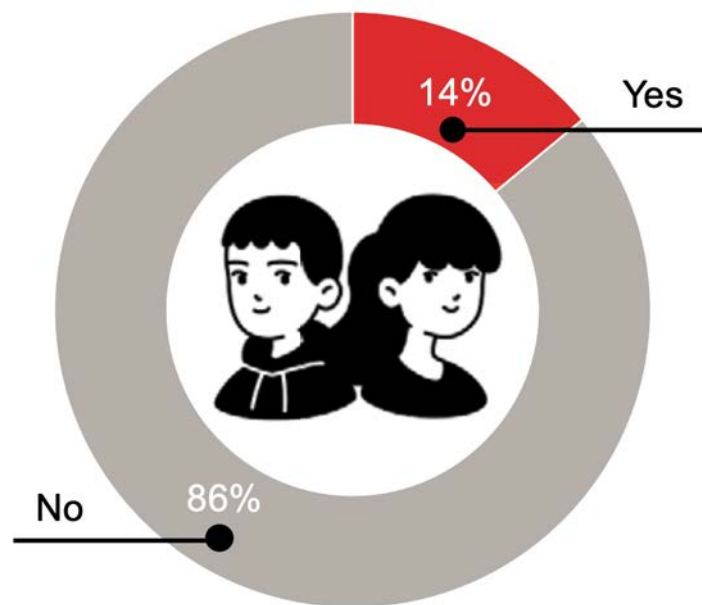
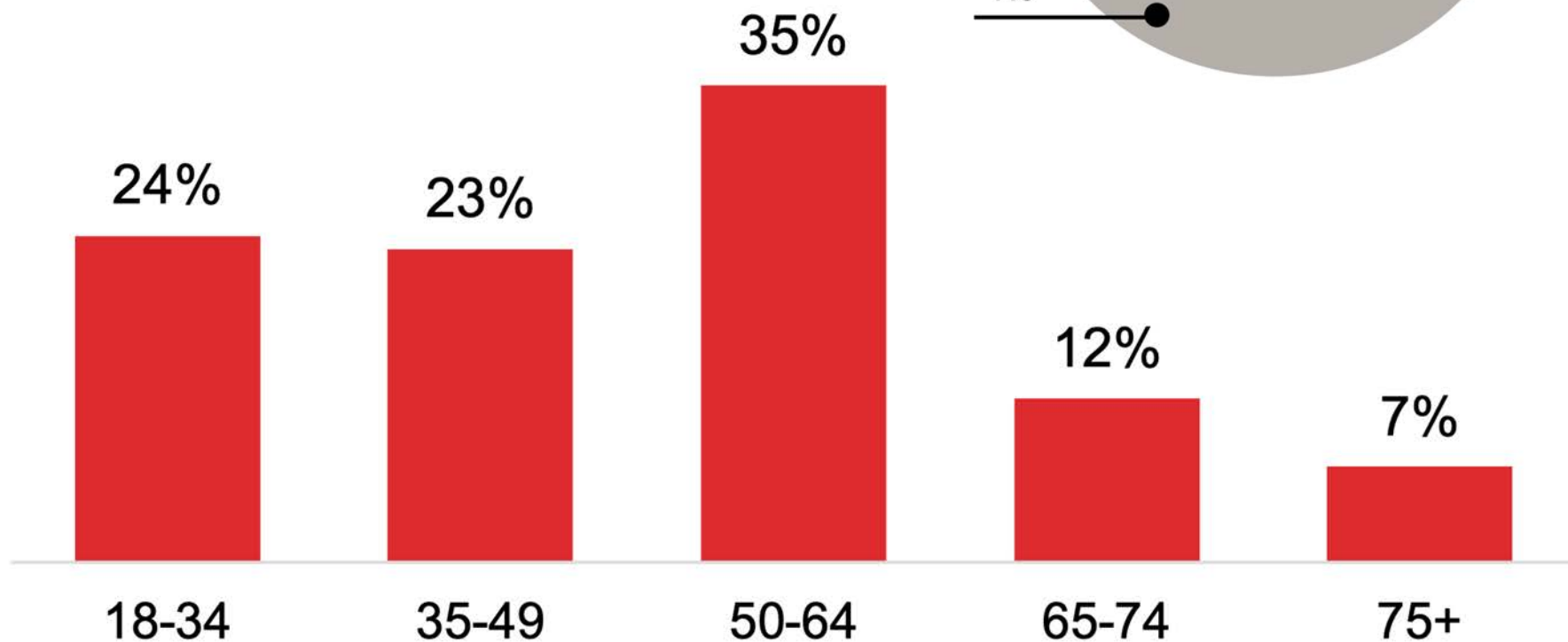
* Significantly higher than in 2015.

Diversity



Caregiver Age

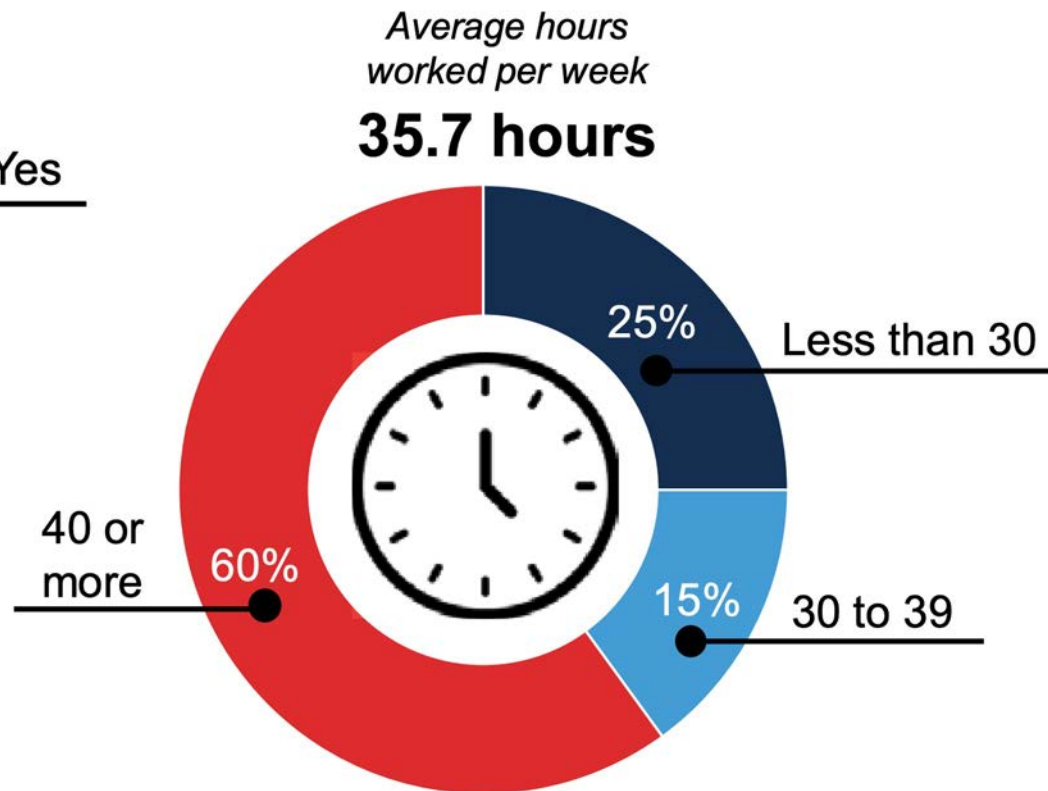
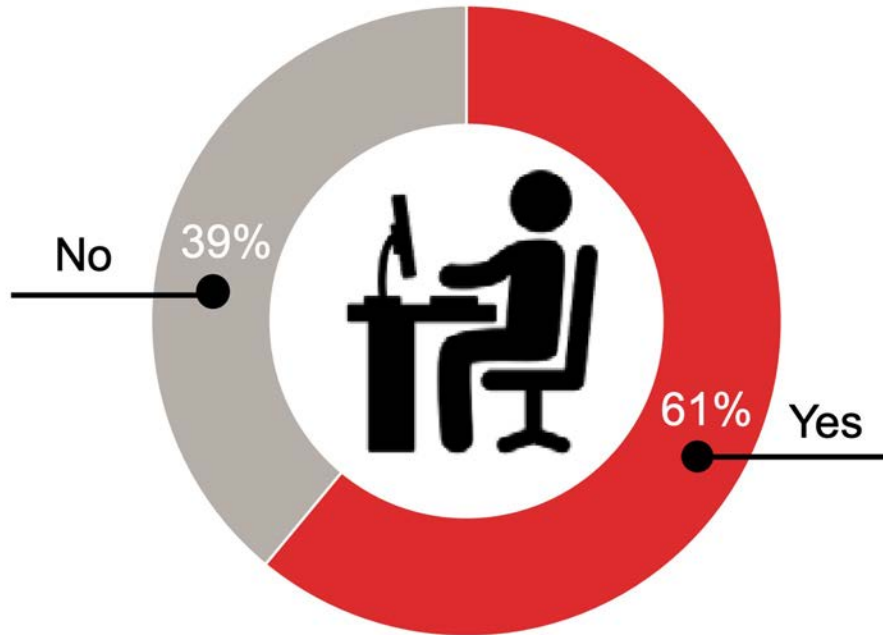
Average Caregiver Age
49.4



Youth caregivers

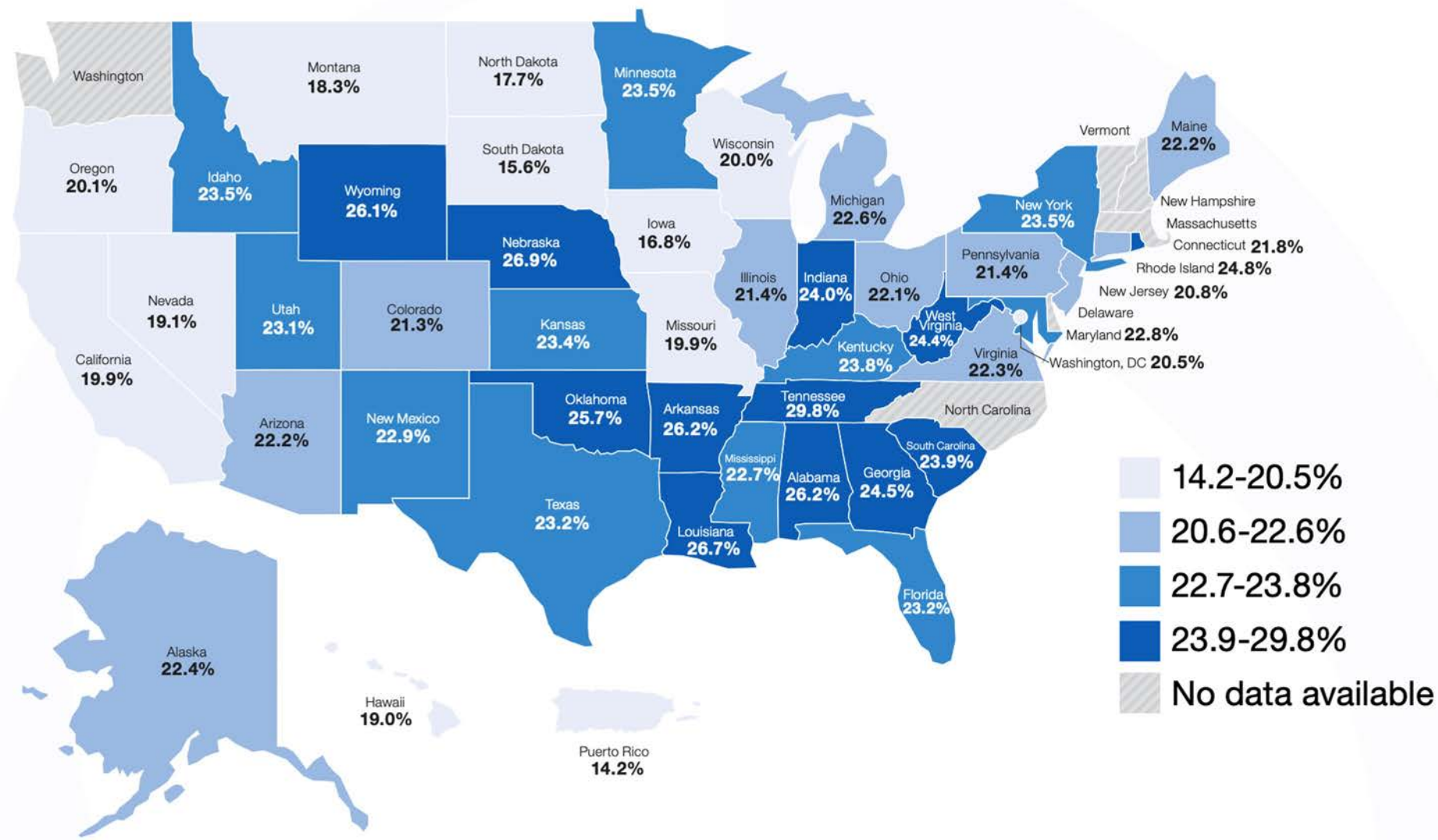


Employment



Characteristics of Caregivers and the Caregiving Situation

Figure 1: Adults aged 45 years or older who reported being a caregiver to a friend or family member



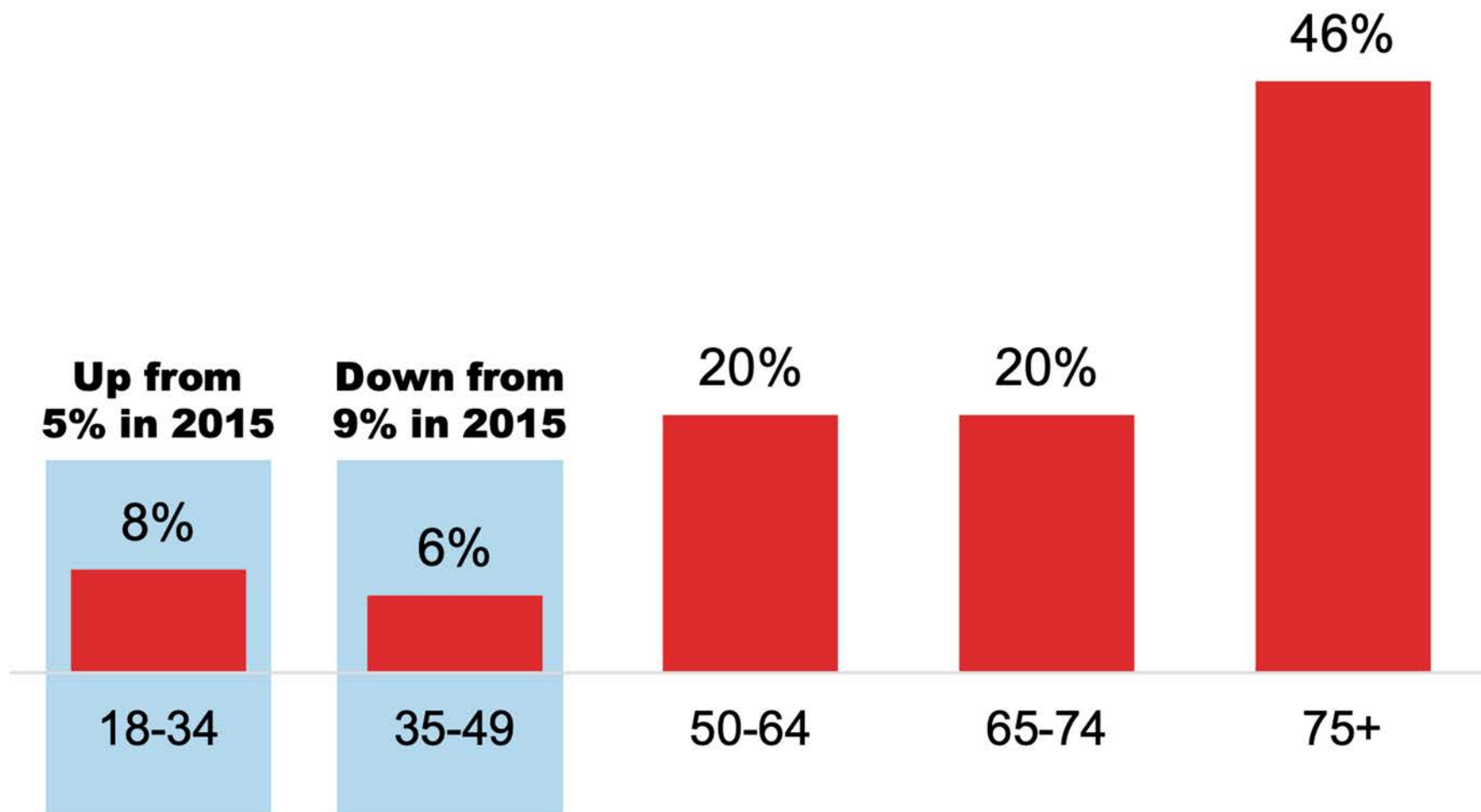
Care recipient needs

Michael J. Fox and his family

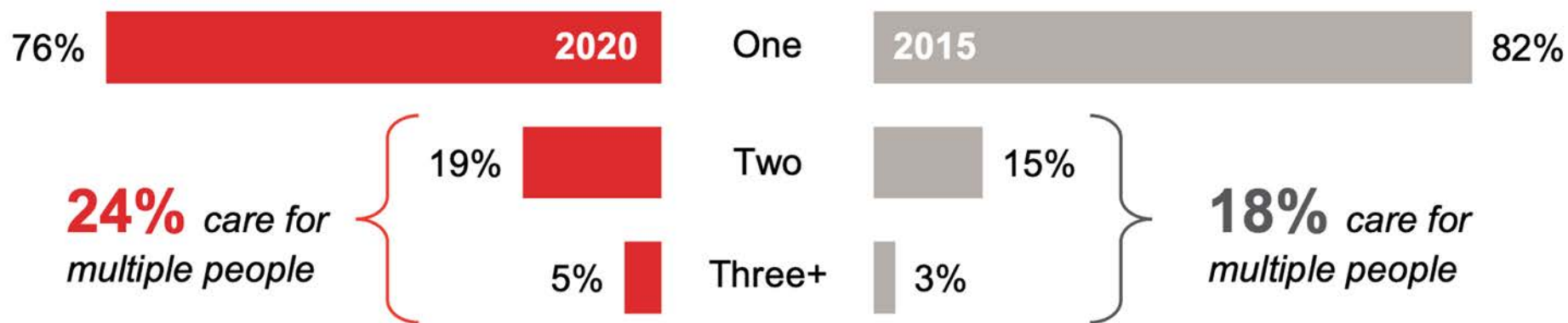


Care recipient age

Average Care Recipient Age
68.9

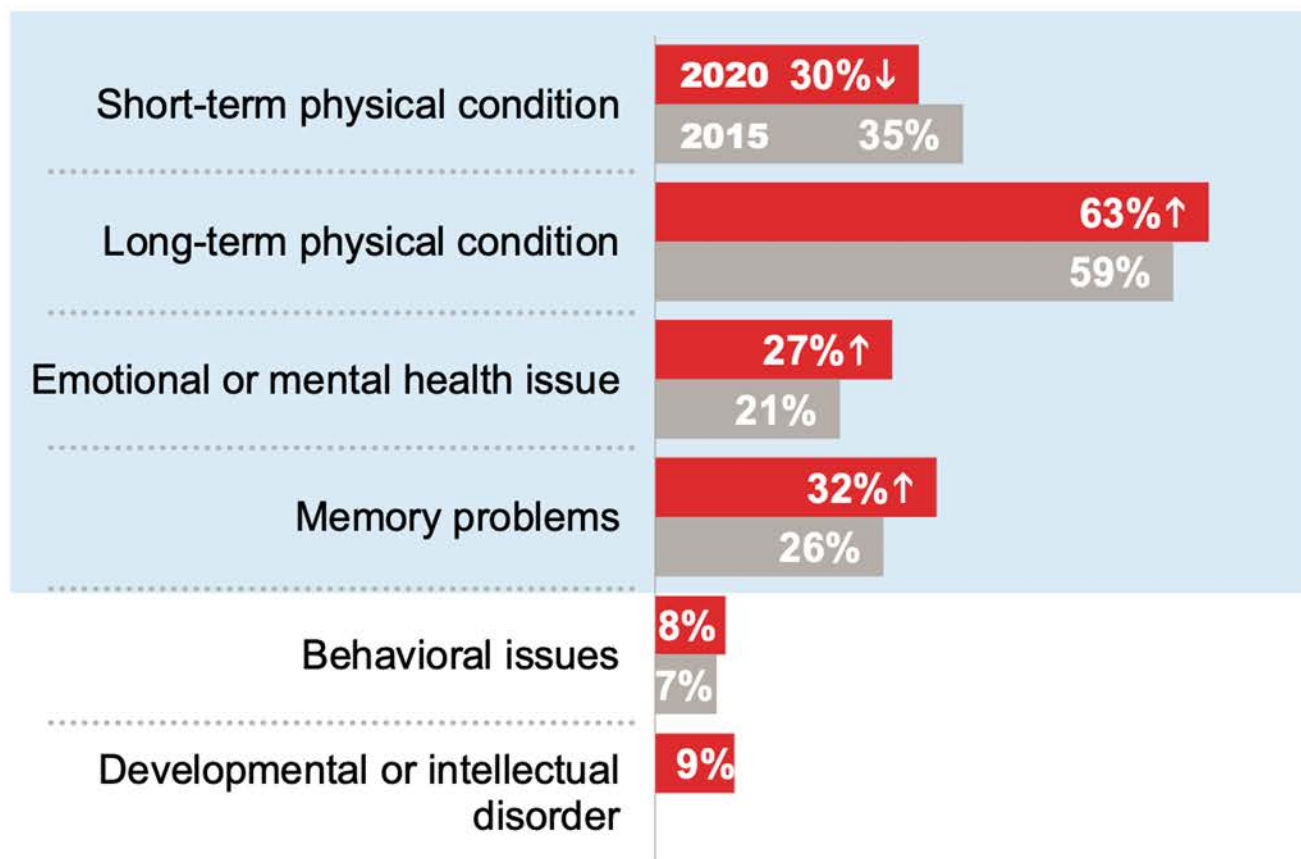


Number of care recipients

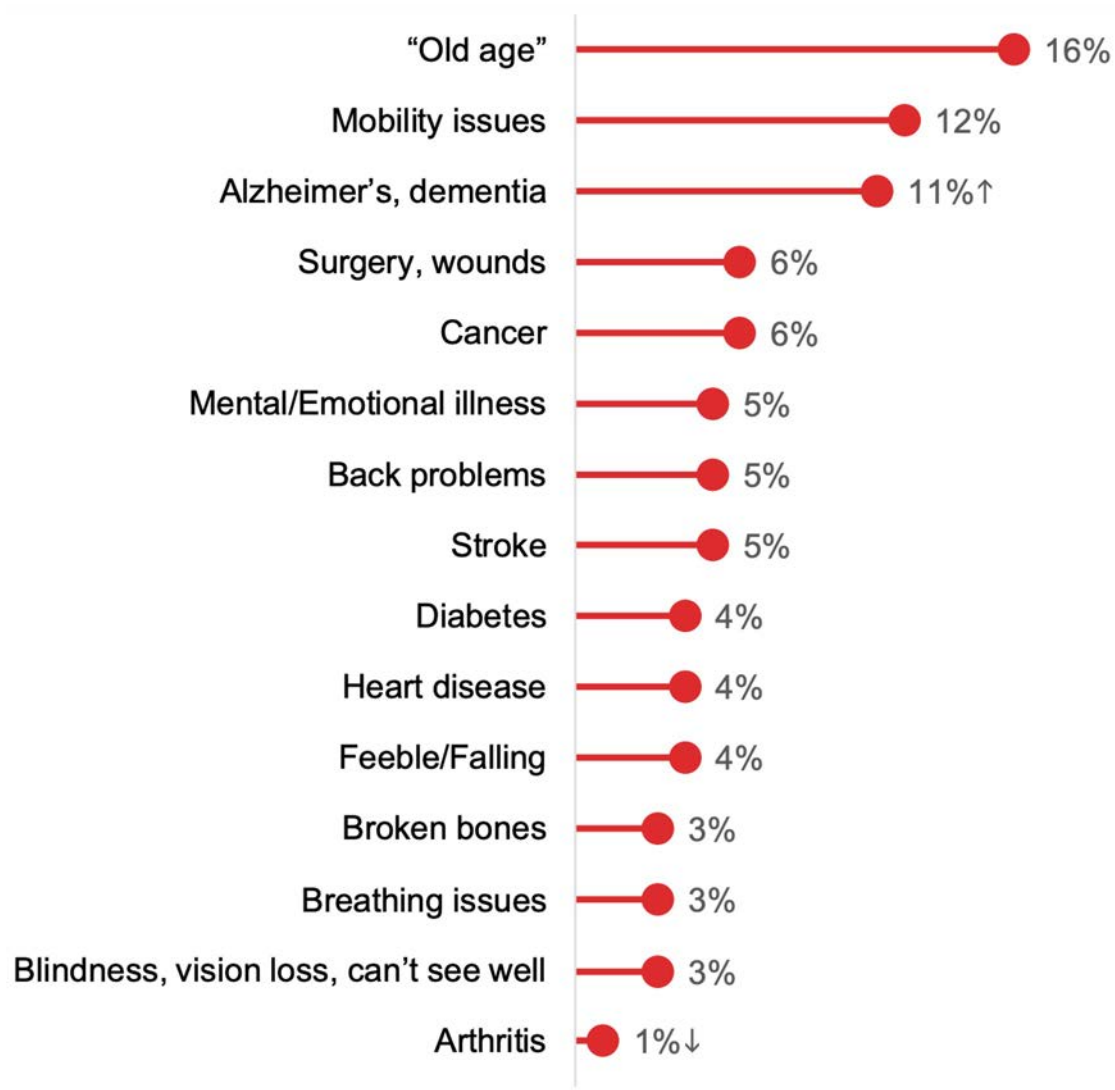


Types of Care Recipient Conditions

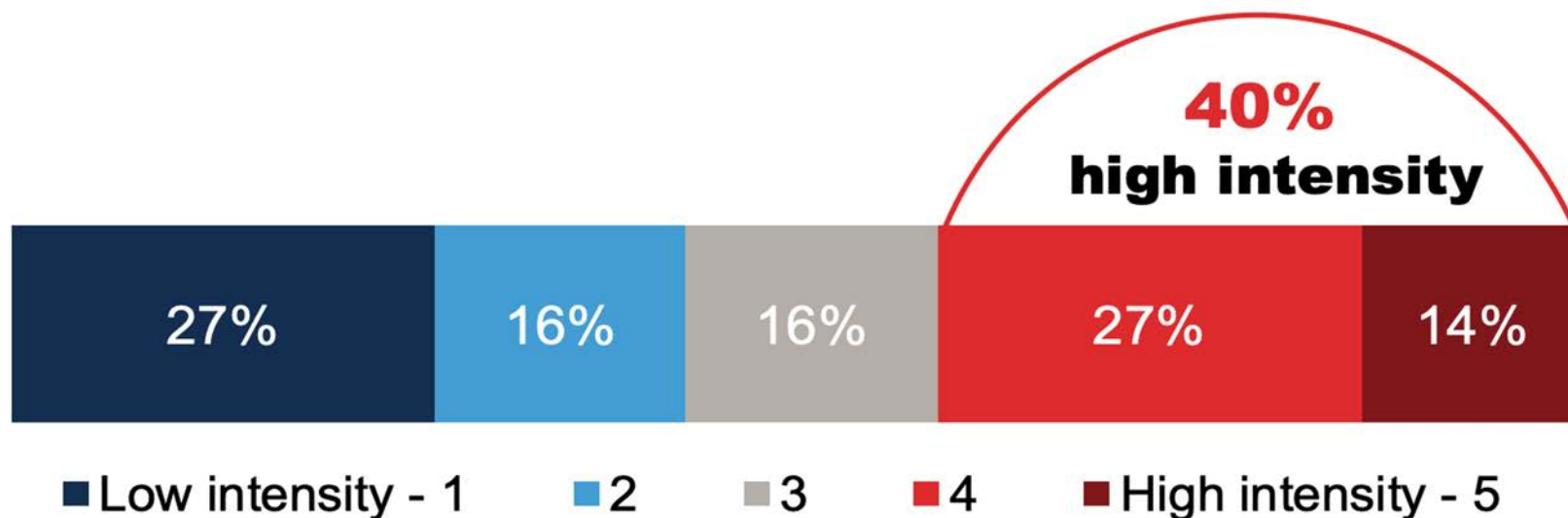
Number of reported conditions is up



Care Recipient Main Problem or Illness

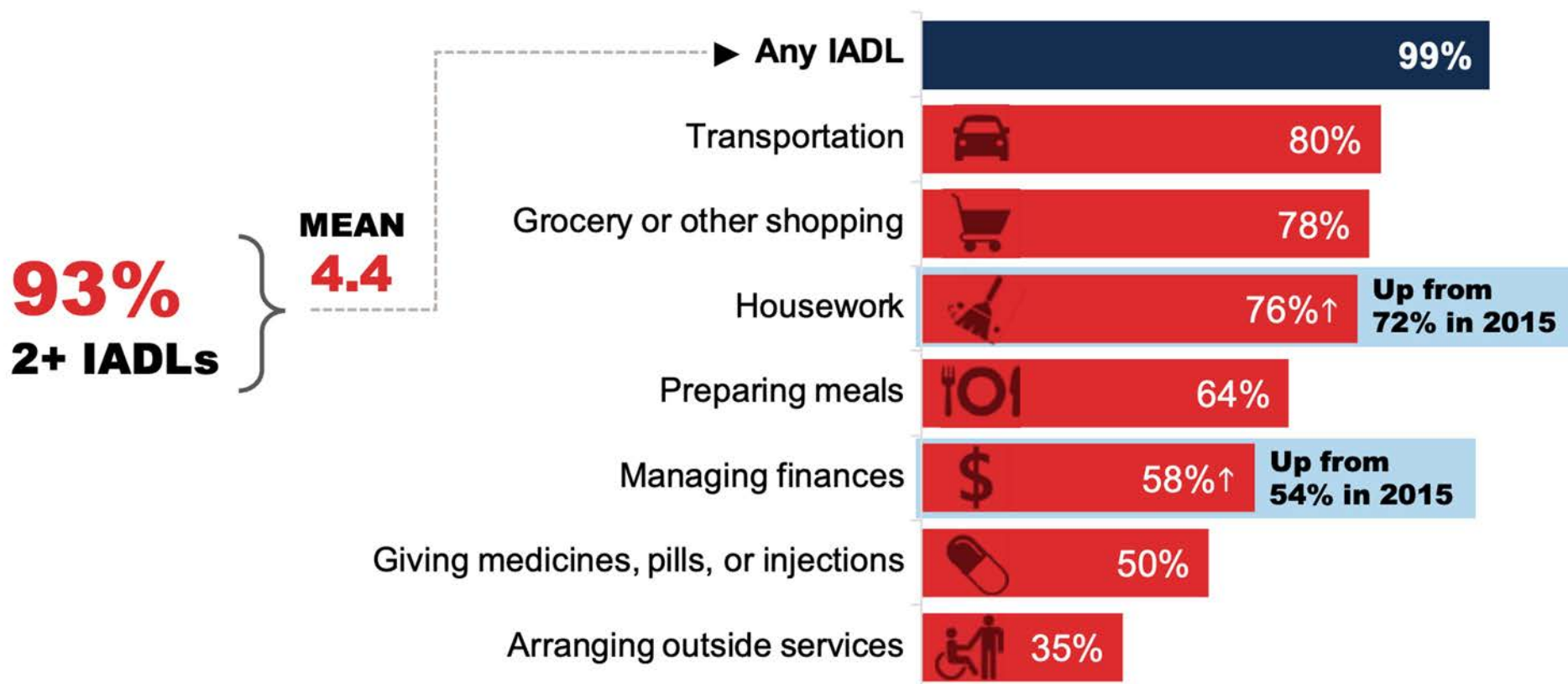


Level of Care Index

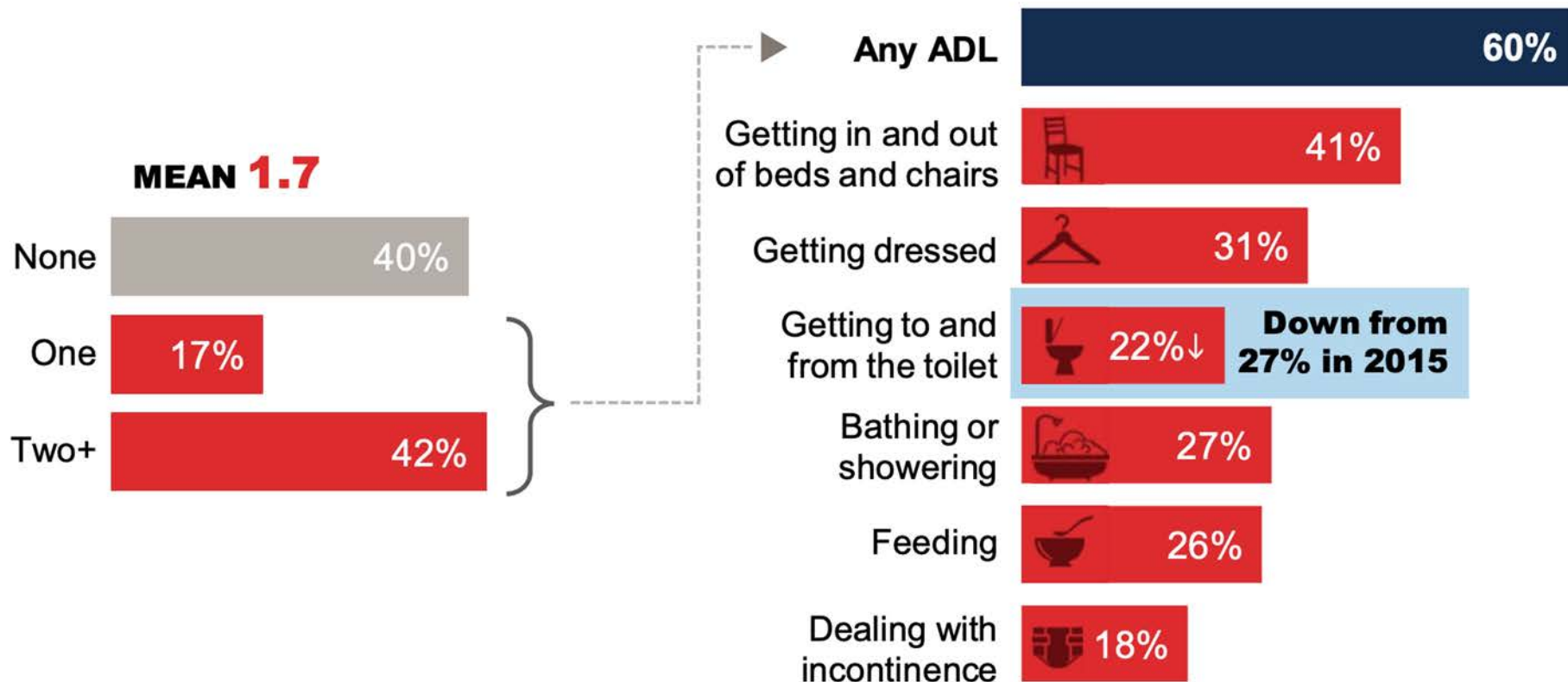


	Low Intensity (n = 595)	Medium Intensity (n = 231)	High Intensity (n = 559)
Hours of care per week	5.4	9.7	48.9
Number of ADLs out of six total	0.2	2.2	3.0
Number of IADLs out of seven total	3.5*	4.3	5.5*

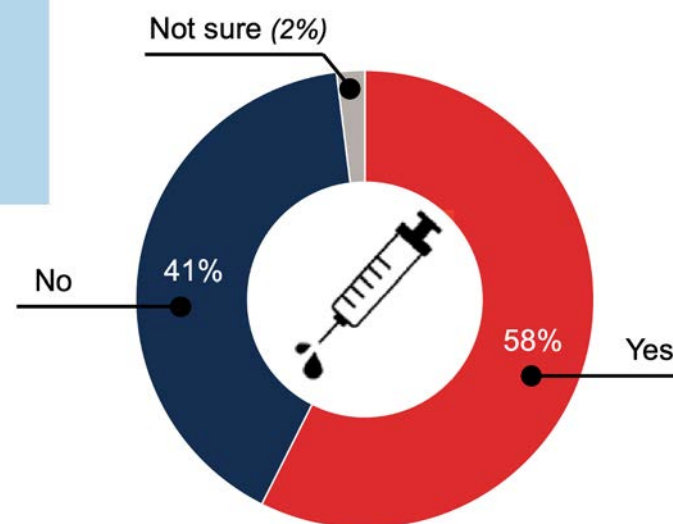
Help with Instrumental Activities of Daily Living



Help with Activities of Daily Living

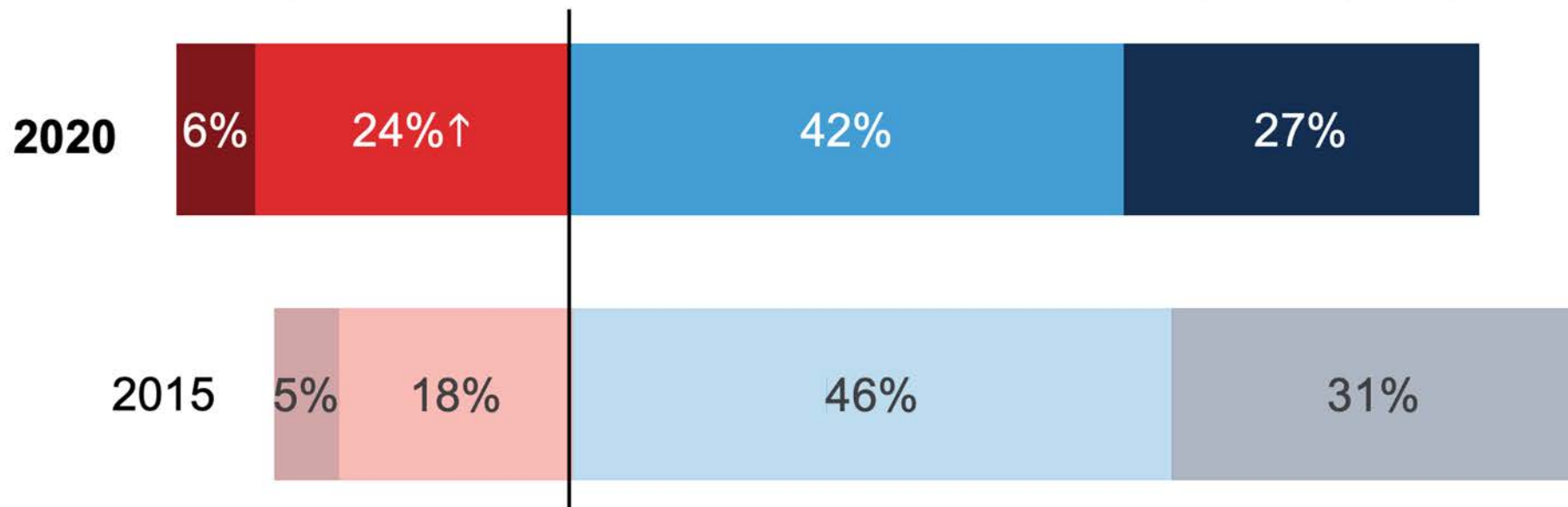


Help with other key activities, medical & nursing tasks

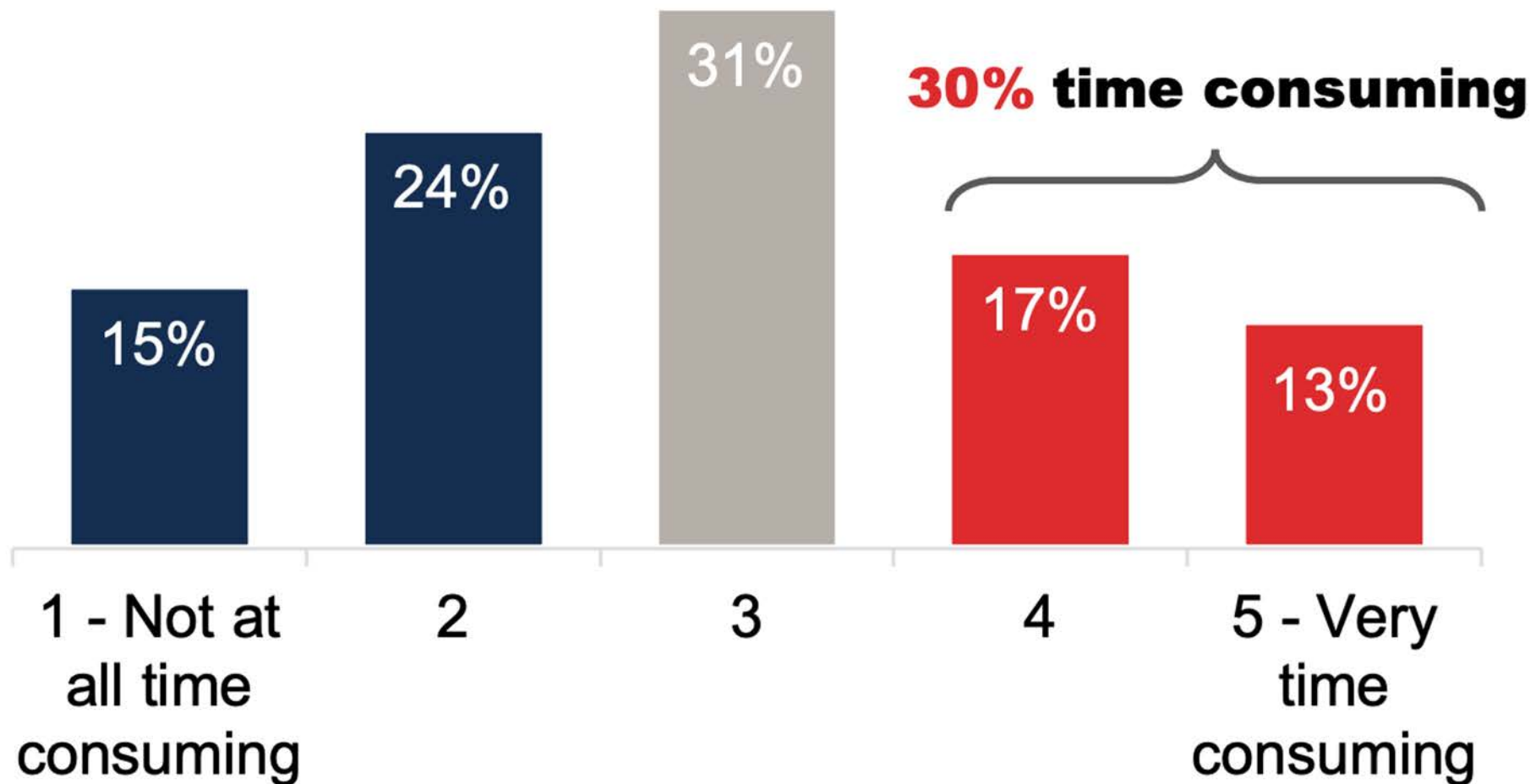


Ease of coordinating care















■ Very difficult ■ Somewhat difficult ■ Somewhat easy ■ Very easy



Time spent managing care recipient finances



"Do you help..."
[IF YES] Does anyone else help with that too?

(n=213 caregivers)	Percent Yes	<u>Others Help Too</u>	(n)
Keep [Name] company	 96%	93%	(205)
[Name] with household chores	 85%	90%	(181)
[Name] with grocery shopping	 65%	87%	(138)
Prepare meals for [Name]	 63%	85%	(135)
[Name] get in and out of beds or chairs	 42%	85%	(89)
[Name] get around the neighborhood/city	 35%	91%	(74)
[Name] take medicine or pills or shots	 30%	83%	(64)
Feed [Name]	 27%	86%	(57)
[Name] get dressed	 19%	78%	(40)
[Name] talk with doctors or nurses	 17%	78%	(37)
[Name] with paperwork or paying bills	 17% †	76%	(25)
Call or arrange for someone else to come in to help [Name]	 15% †	91%	(22)
[Name] use the bathroom or diapers	 8%	88%	(16)
[Name] bathe or shower	 8%	88%	(16)

New Mexico Care Receiver Demographics

Care Receivers	NM	US
▪ % Population 18-64 years w/Disability	14.1	10.7
▪ % Population 65+ w/Disability	36.7	32.6
% 65+ with		
▪ Hearing Difficulty	17.2	13.3
▪ Vision Loss	7.7	6
▪ Ambulatory	22.4	20.5
▪ Self-Care	7.8	7.1
▪ Cognitive	9.5	7.8
▪ Independent Living Difficulty	14.3	13.2

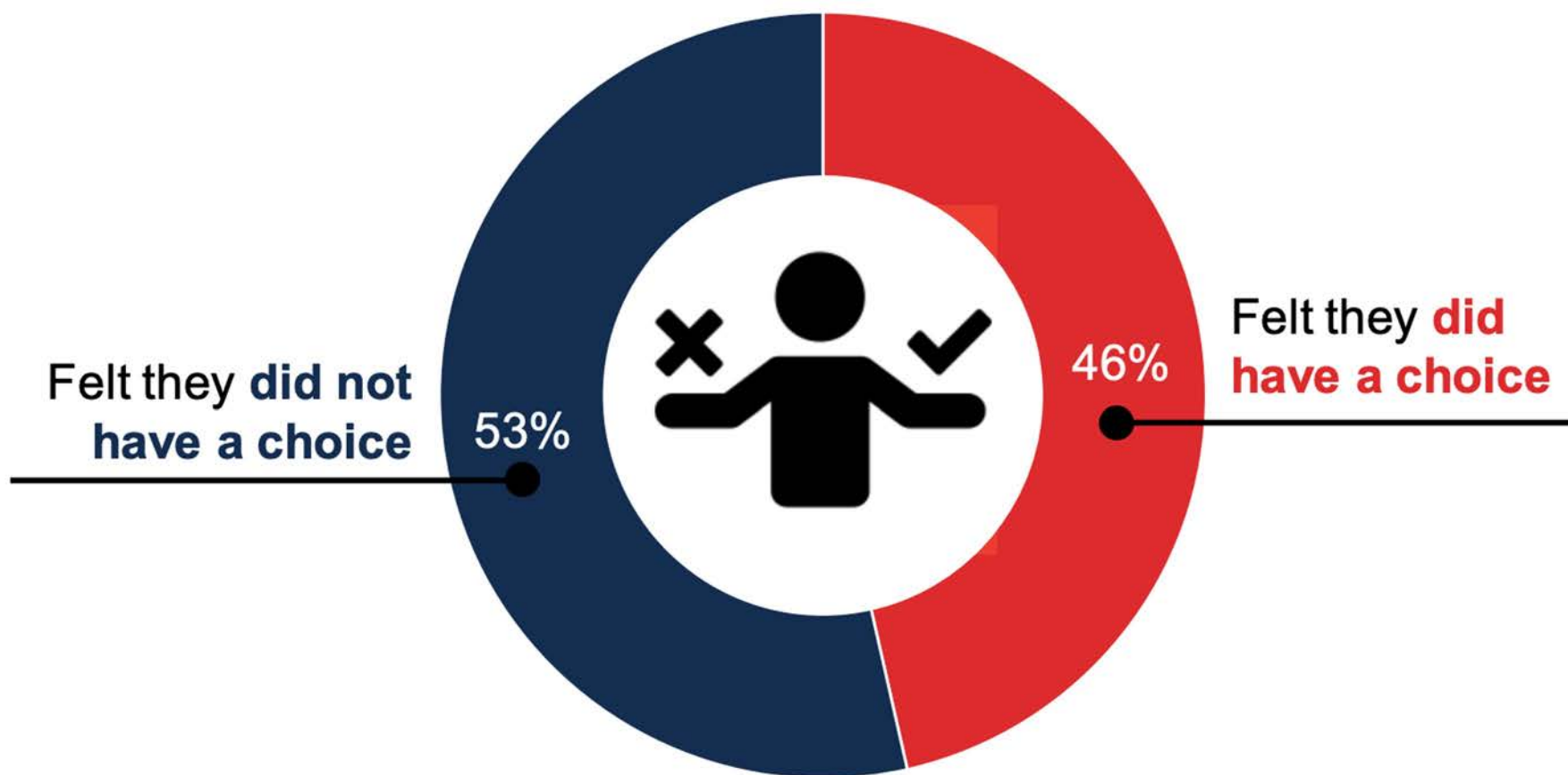
Caregiving Burden



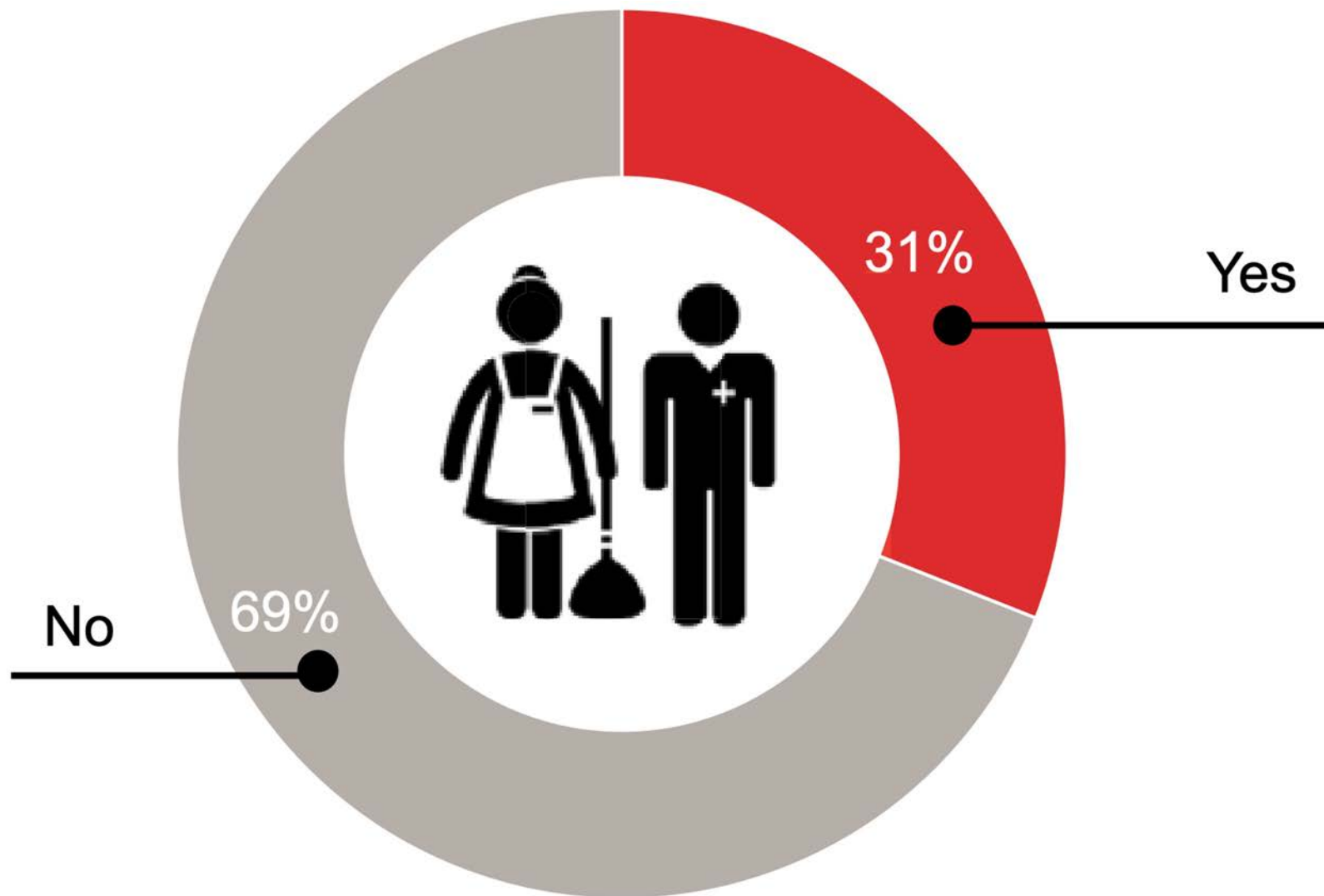
Emma Heming Willis caregiver to husband Bruce Willis

It took me a whole year to openly say
“I am a caregiver.” It wasn’t an easy
step. But I like to think it was one of
the best decisions I took. I am a
lawyer, but I am also a caregiver.

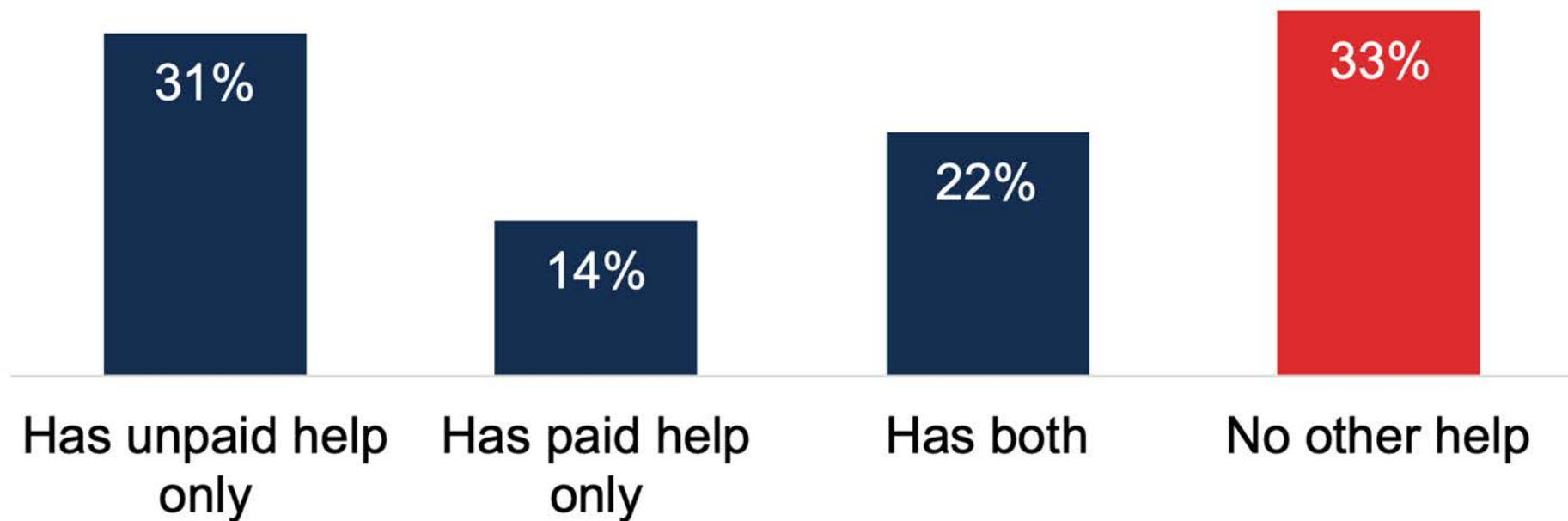
Choice in taking on caregiver role



Use of paid help

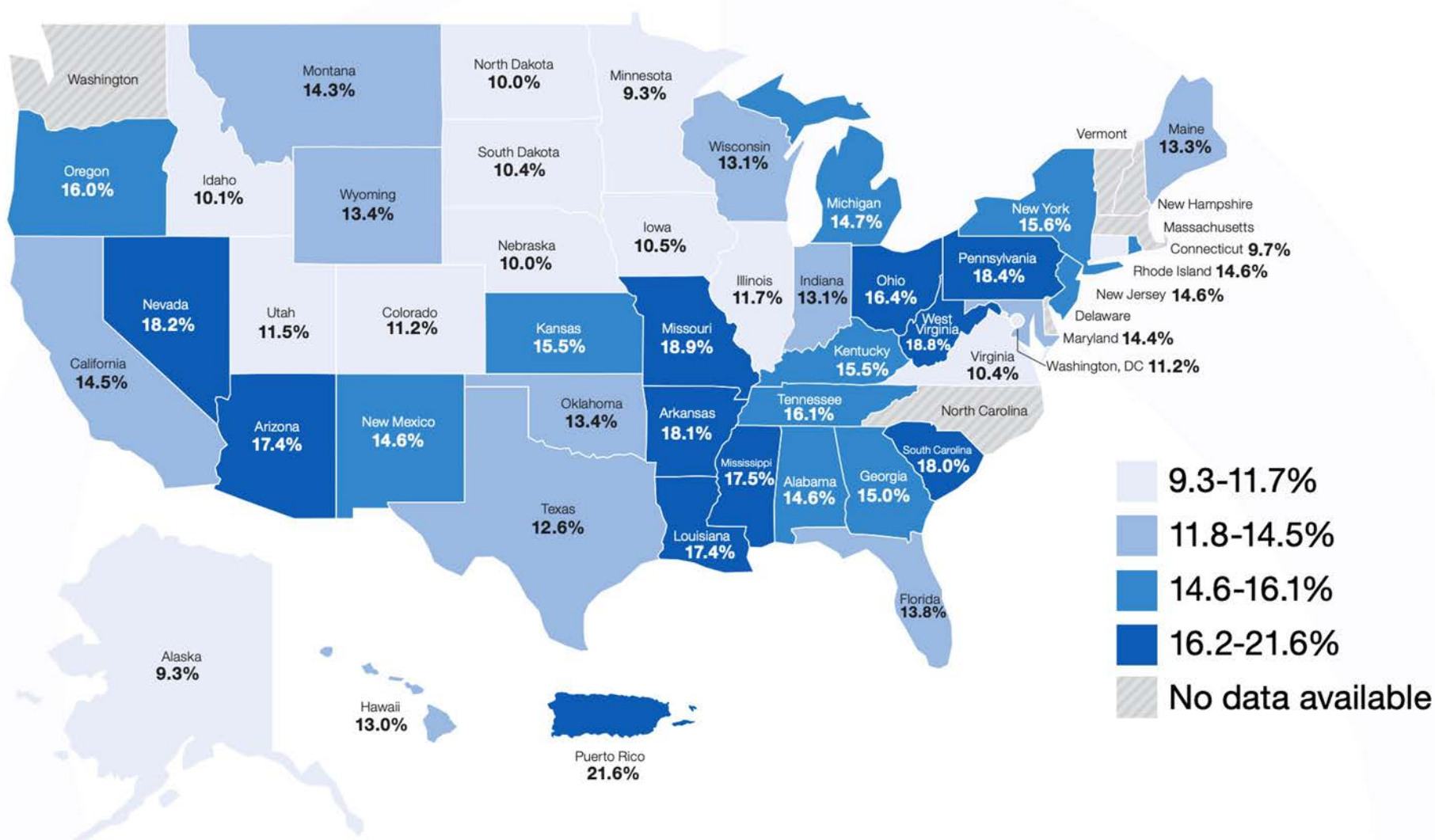


Combination of paid and unpaid help



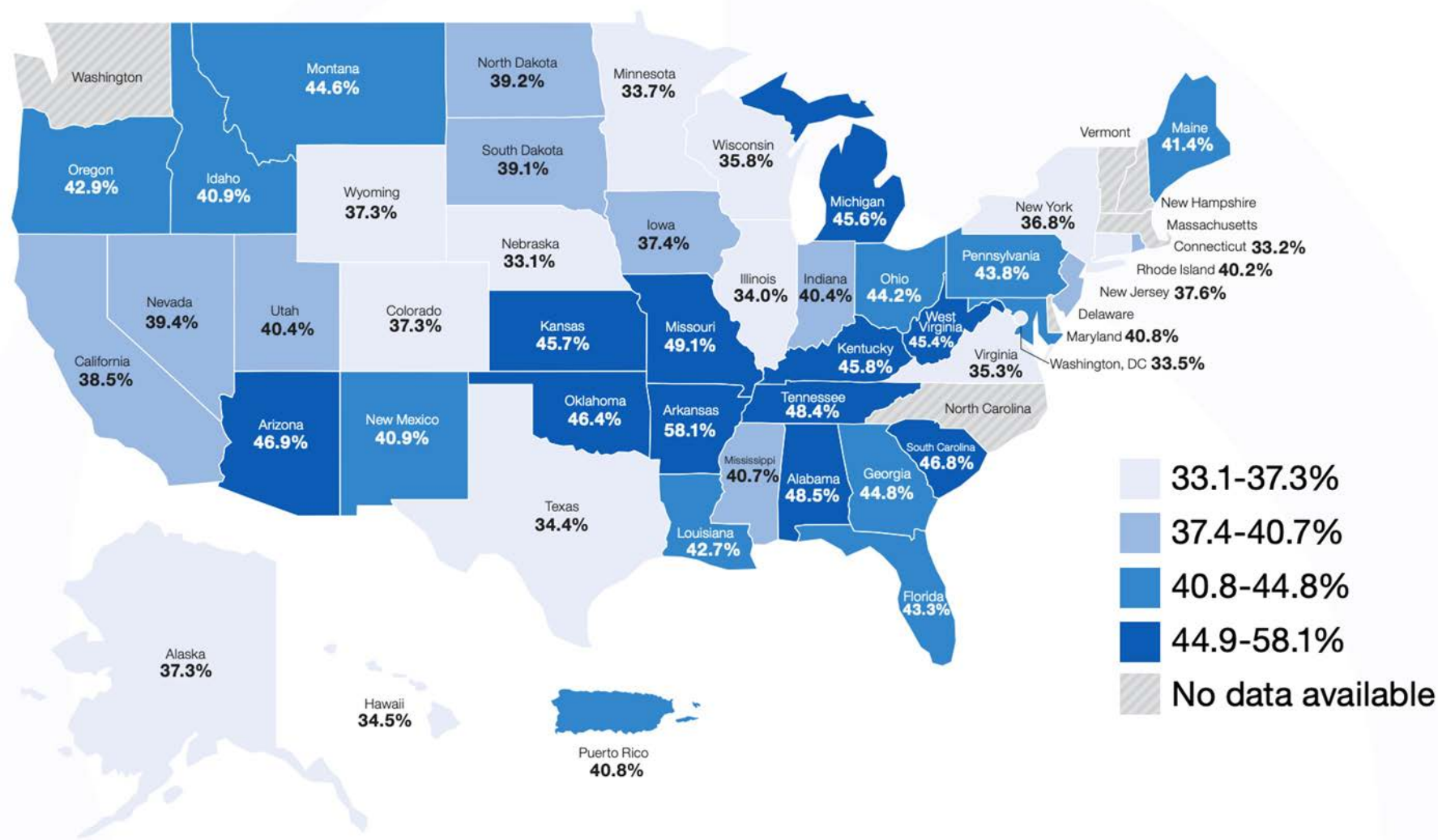
Health Status of Caregivers: Unhealthy Days and Insufficient Sleep

Figure 3: Caregivers aged 45 years or older who reported frequent mental distress

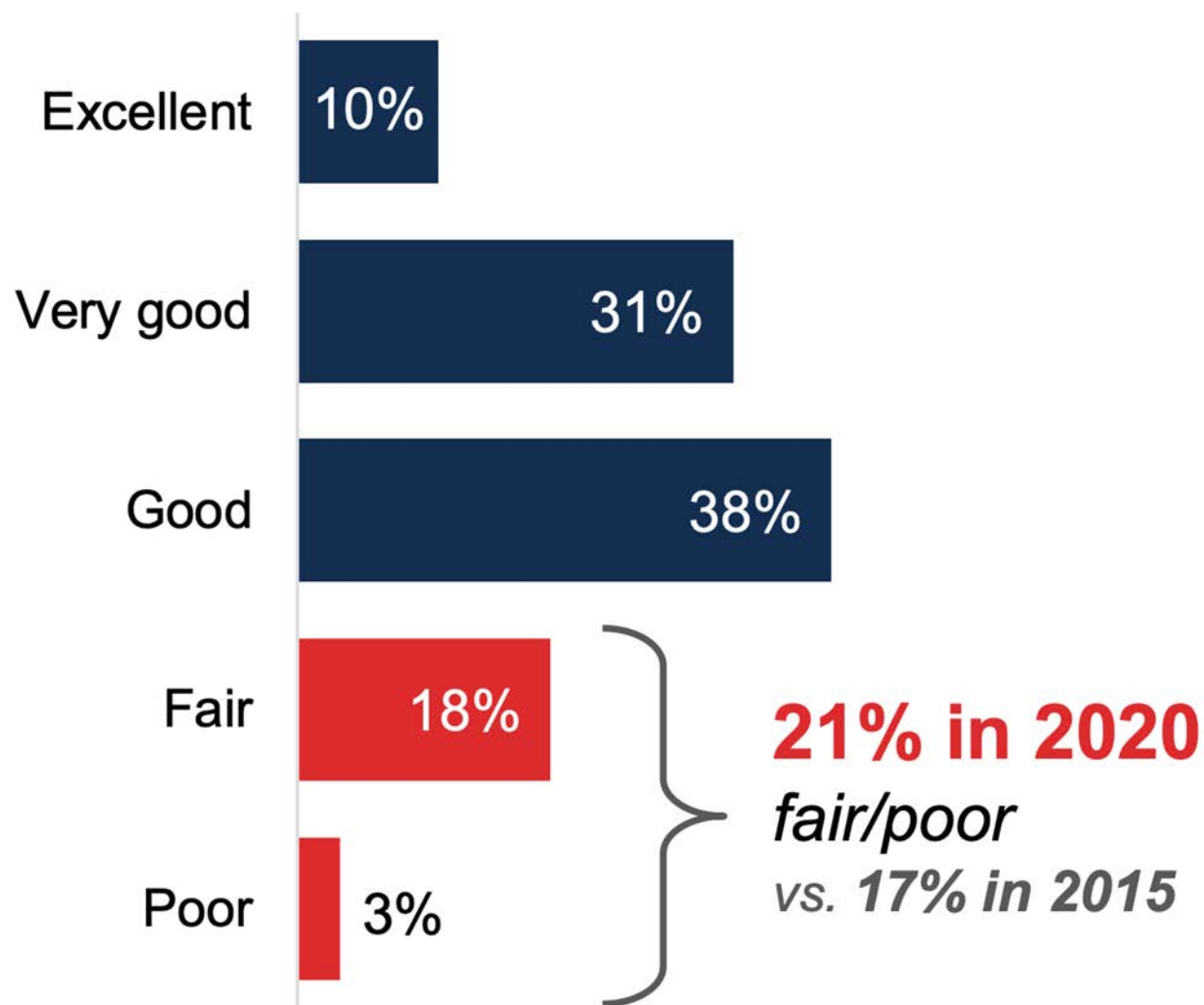


Health Status of Adult Caregivers: Prevalence of Chronic Diseases and Disability Status

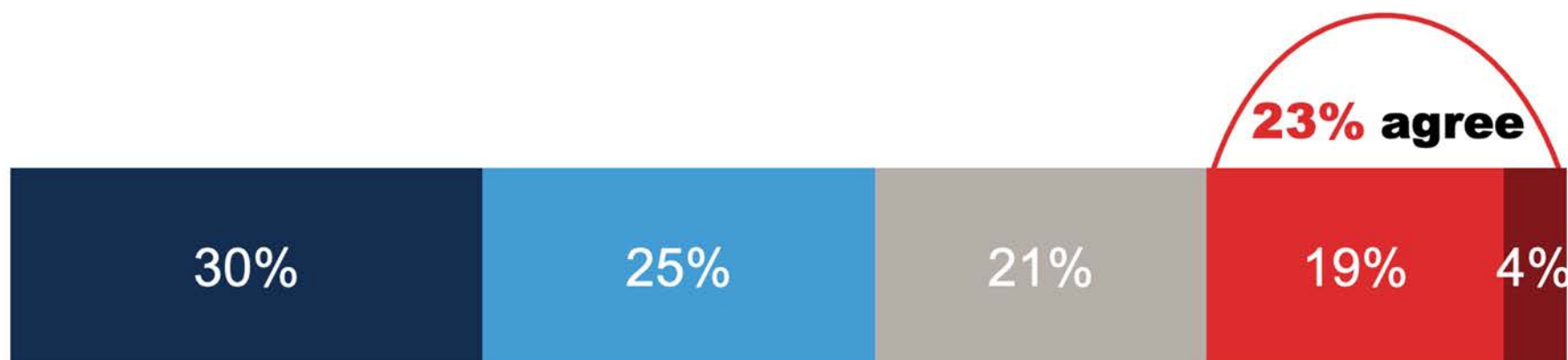
Figure 4: Caregivers aged 45 years or older who reported having 2 or more chronic diseases



Caregiver self-rated health



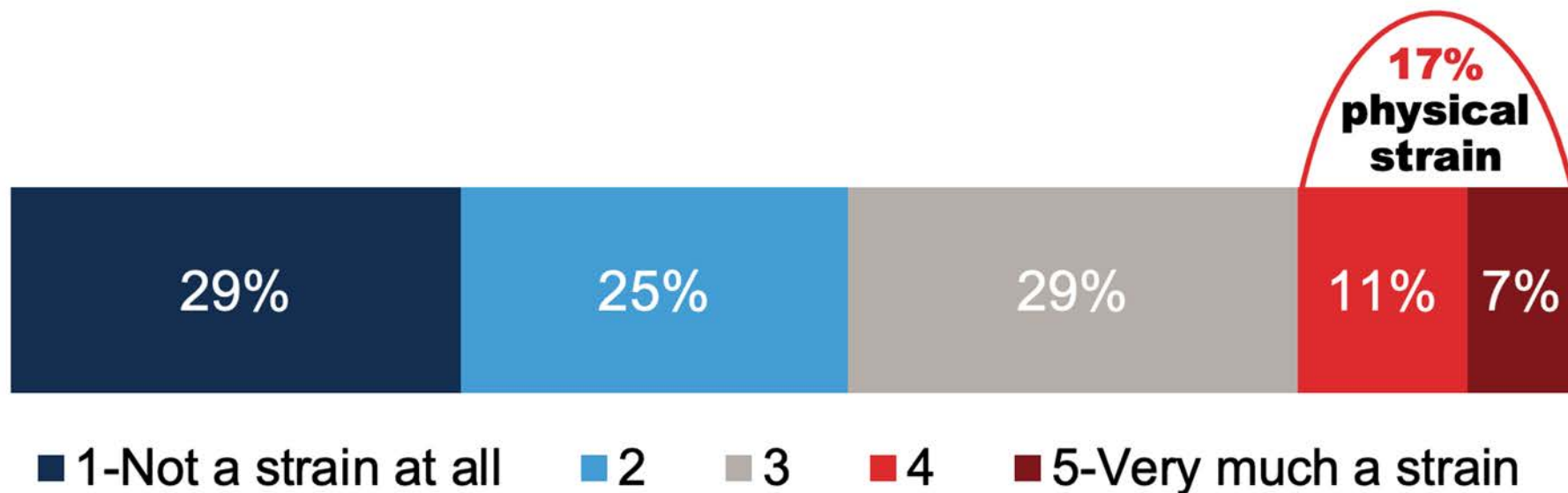
Difficulty caring for own health



■ 1-Strongly disagree ■ 2-Disagree ■ 3-Neither ■ 4-Agree ■ 5-Strongly agree

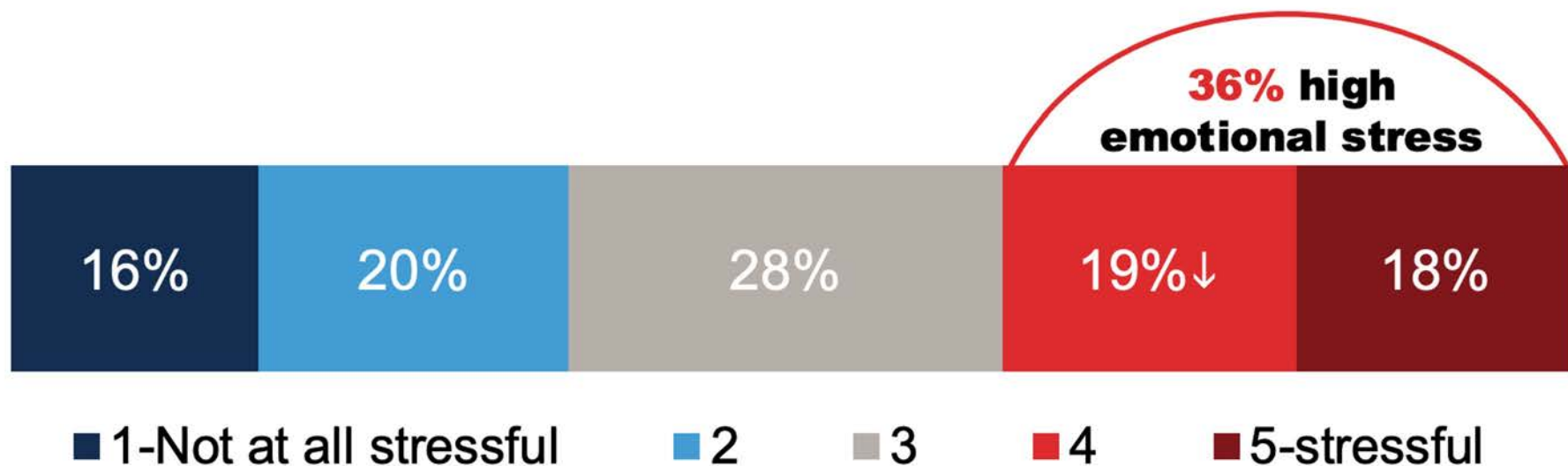
Physical strain of caregiving

MEAN 2.4

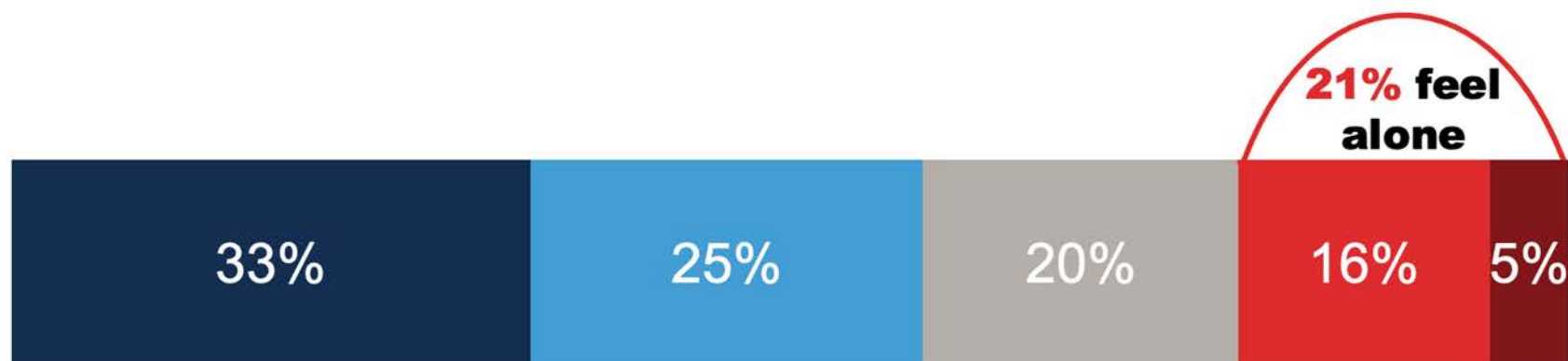


Emotional stress of caregiving

MEAN 3.0

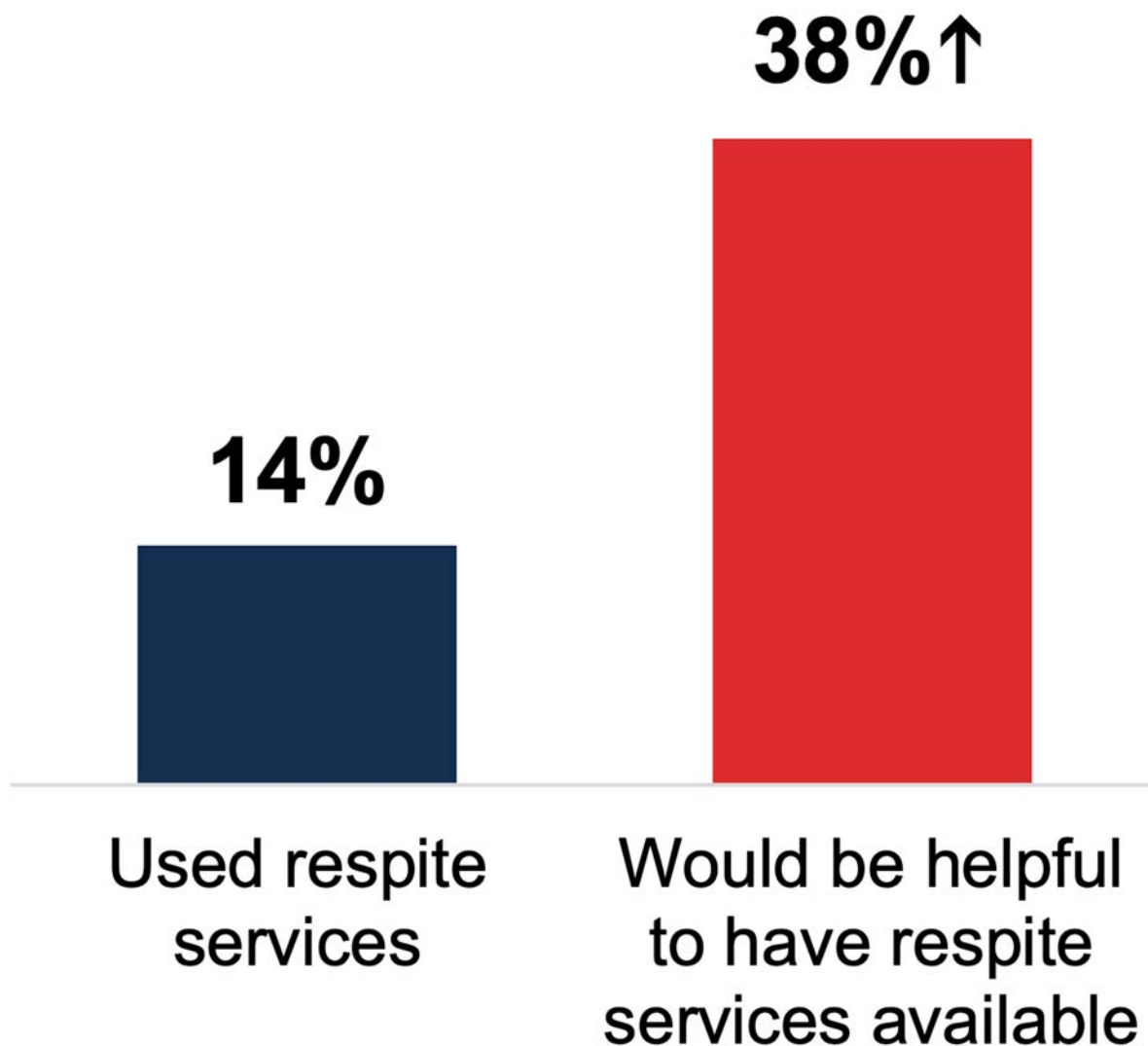


Feeling alone



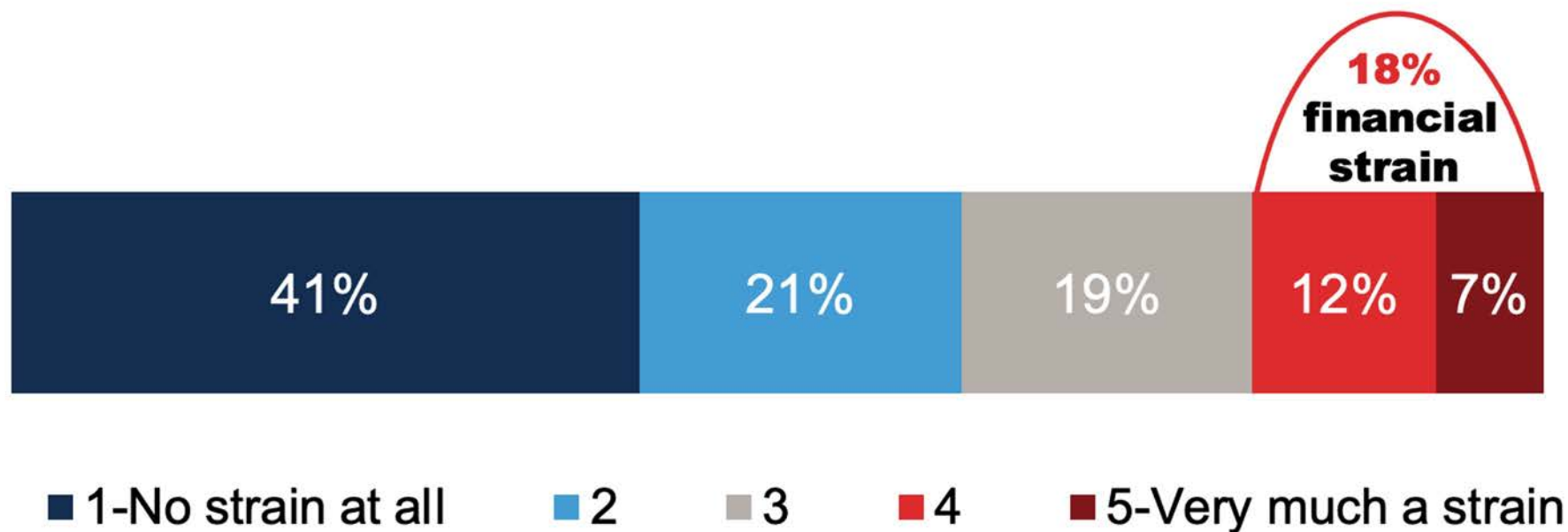
■ 1-Strongly disagree ■ 2-Disagree ■ 3-Neither ■ 4-Agree ■ 5-Strongly agree

Respite services

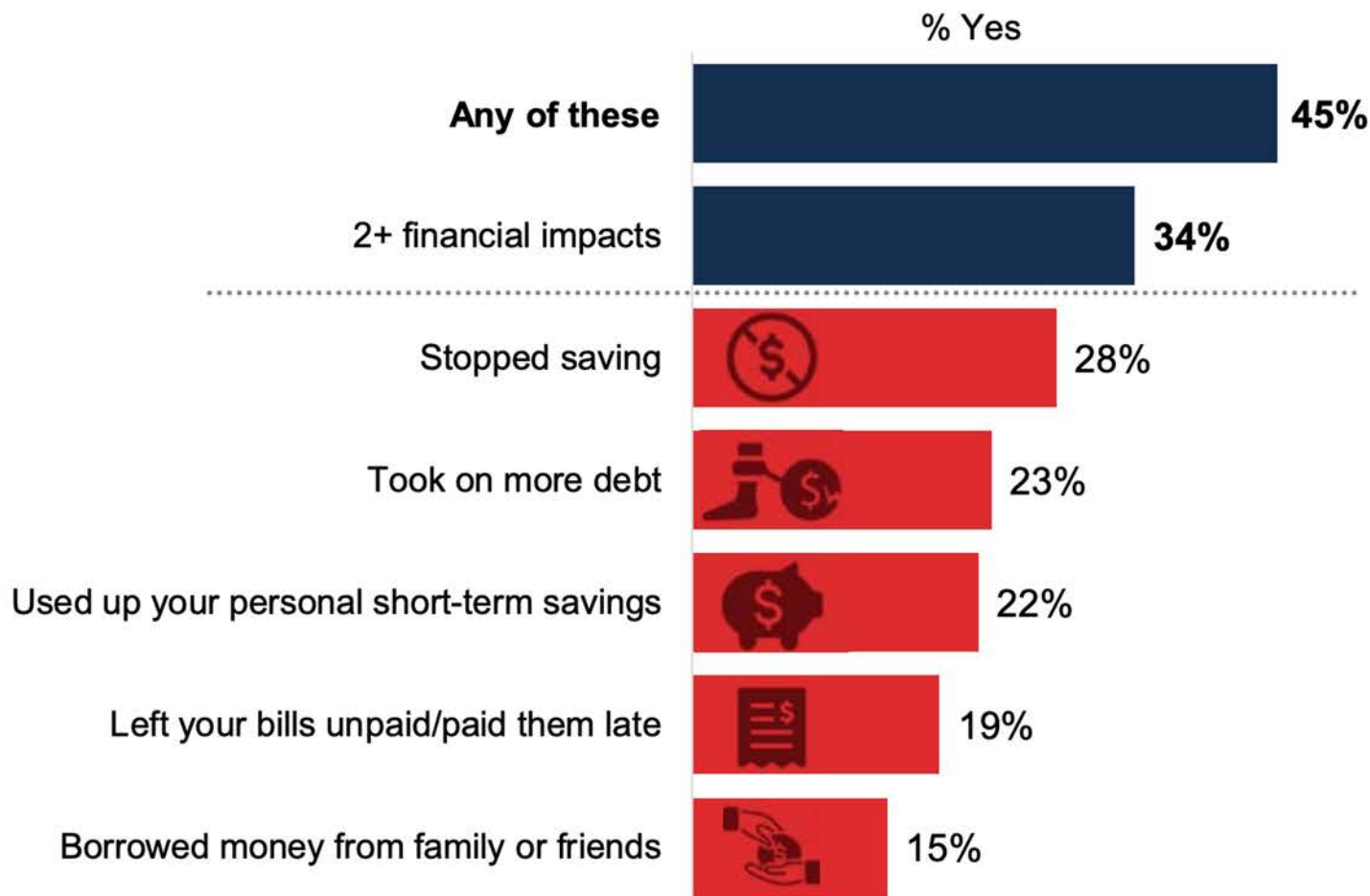


Financial strain of caregiving

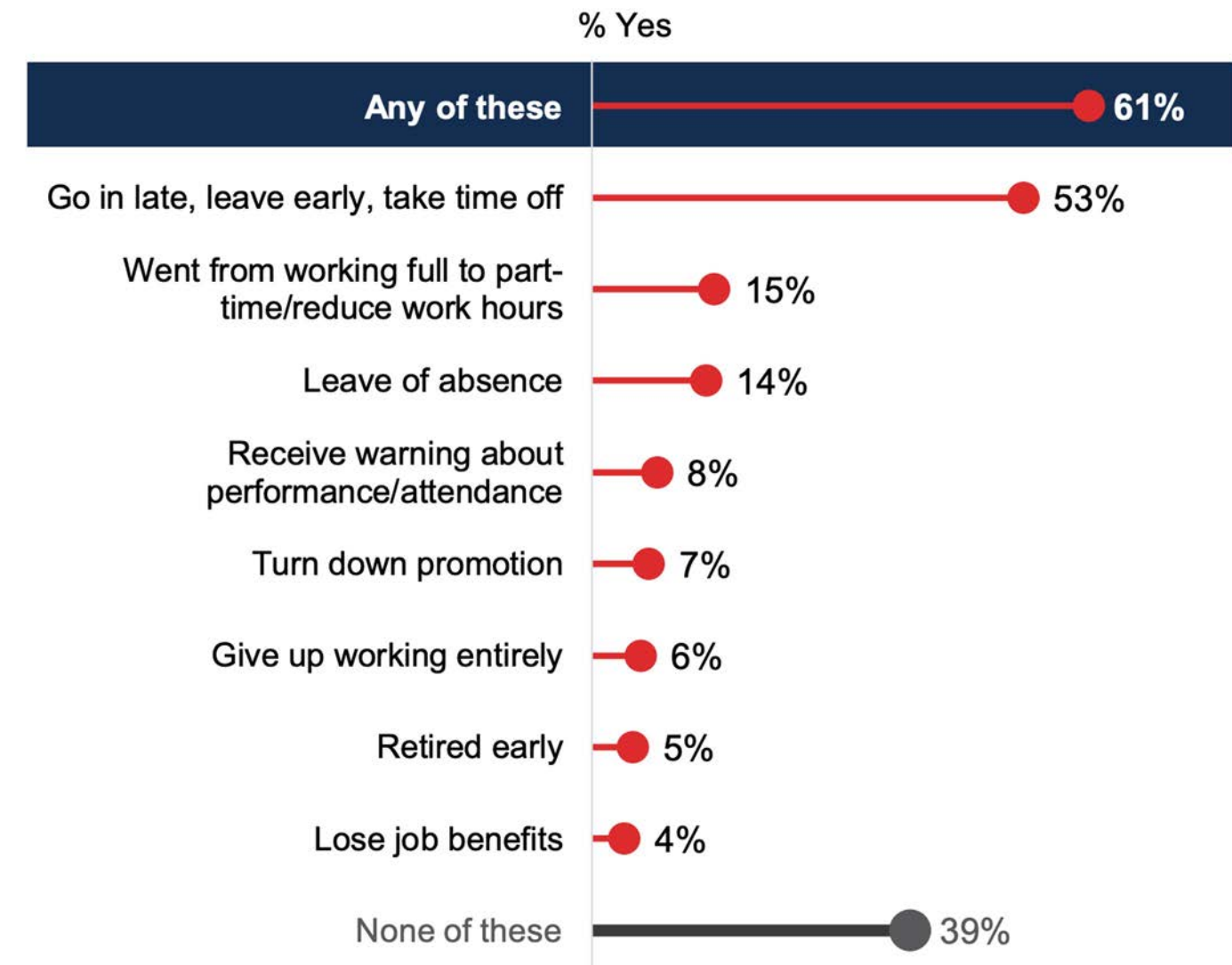
MEAN 2.2



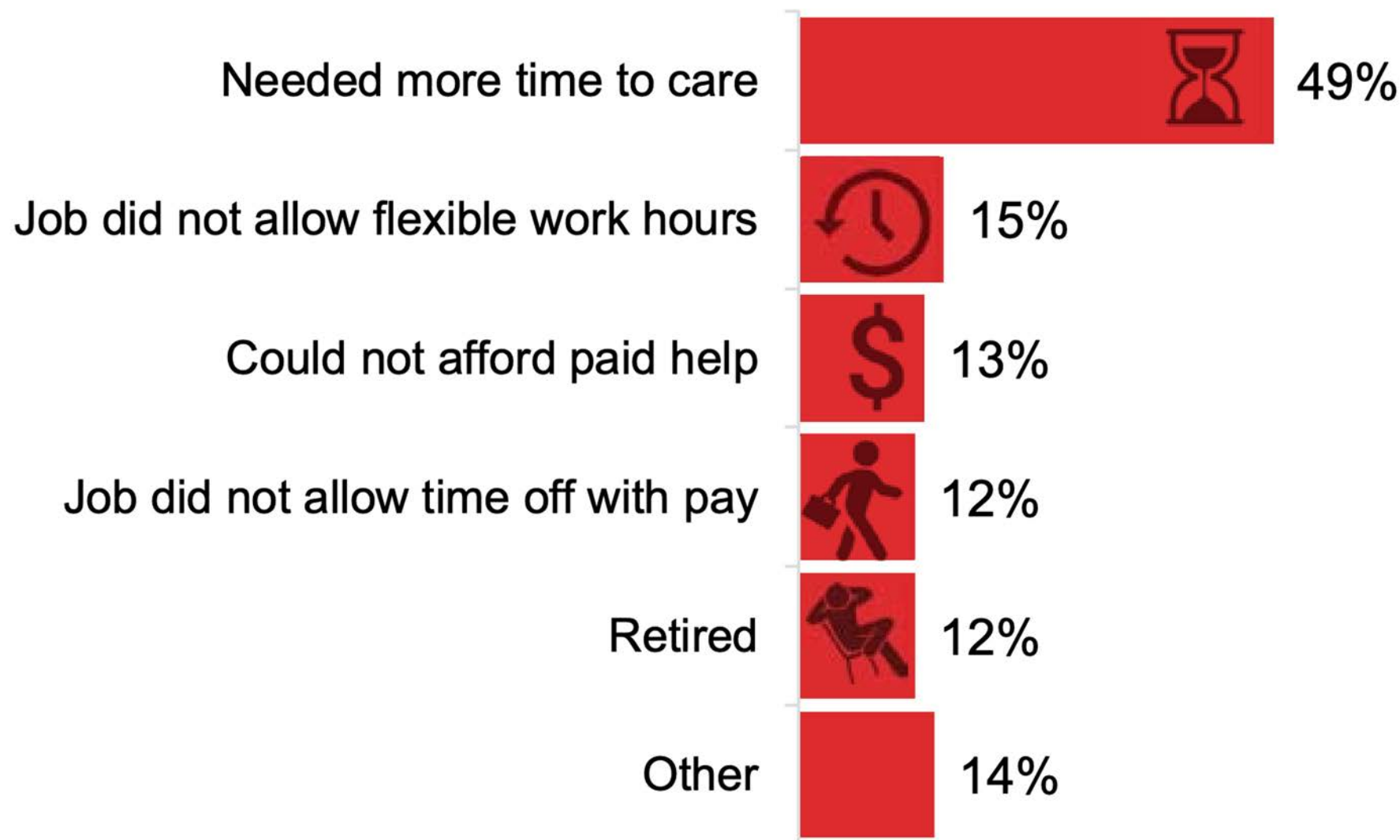
Top financial impacts of caregiving



Work impacts as a result of caregiving



Reasons caregivers stopped working

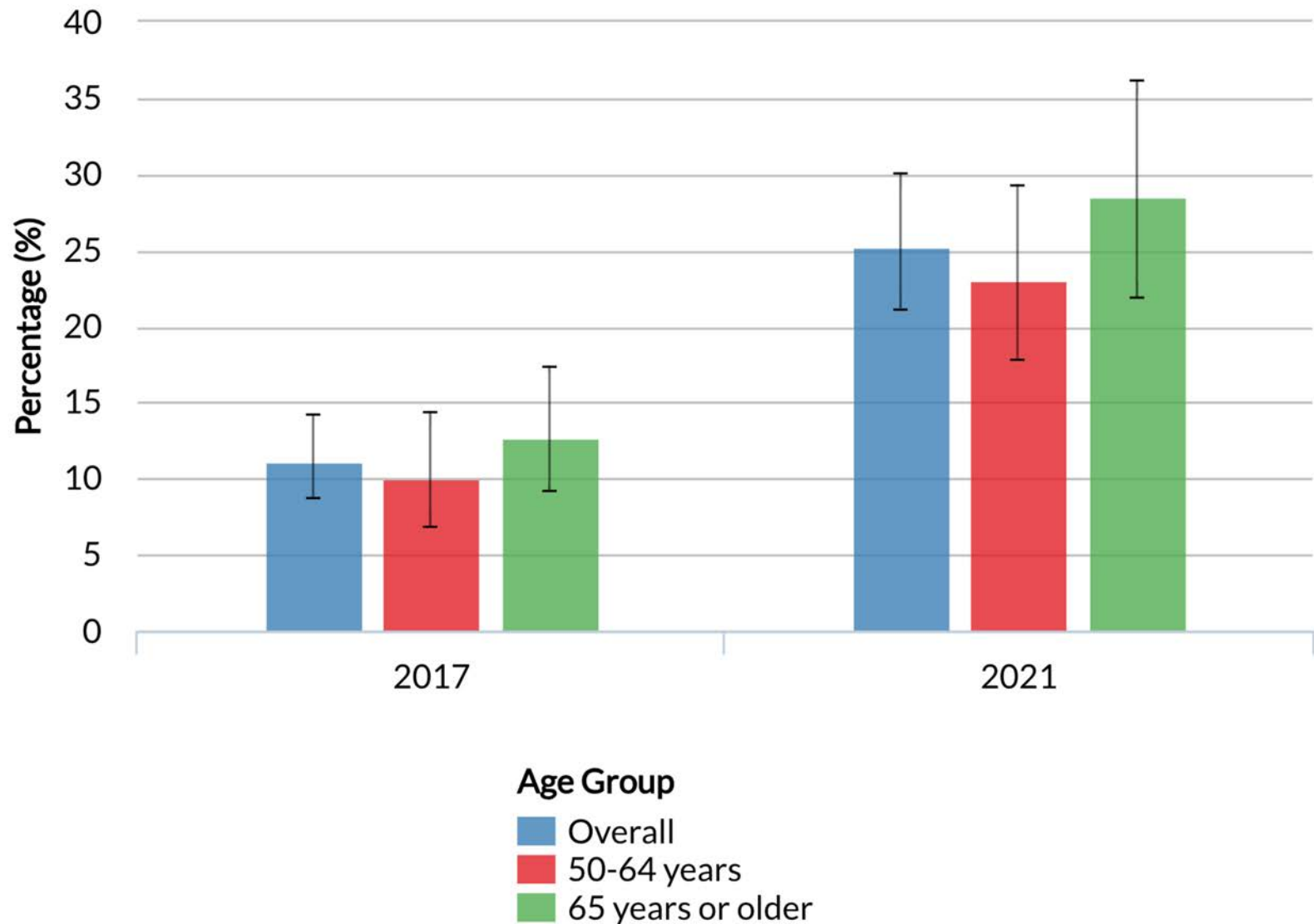


Future of caregiving

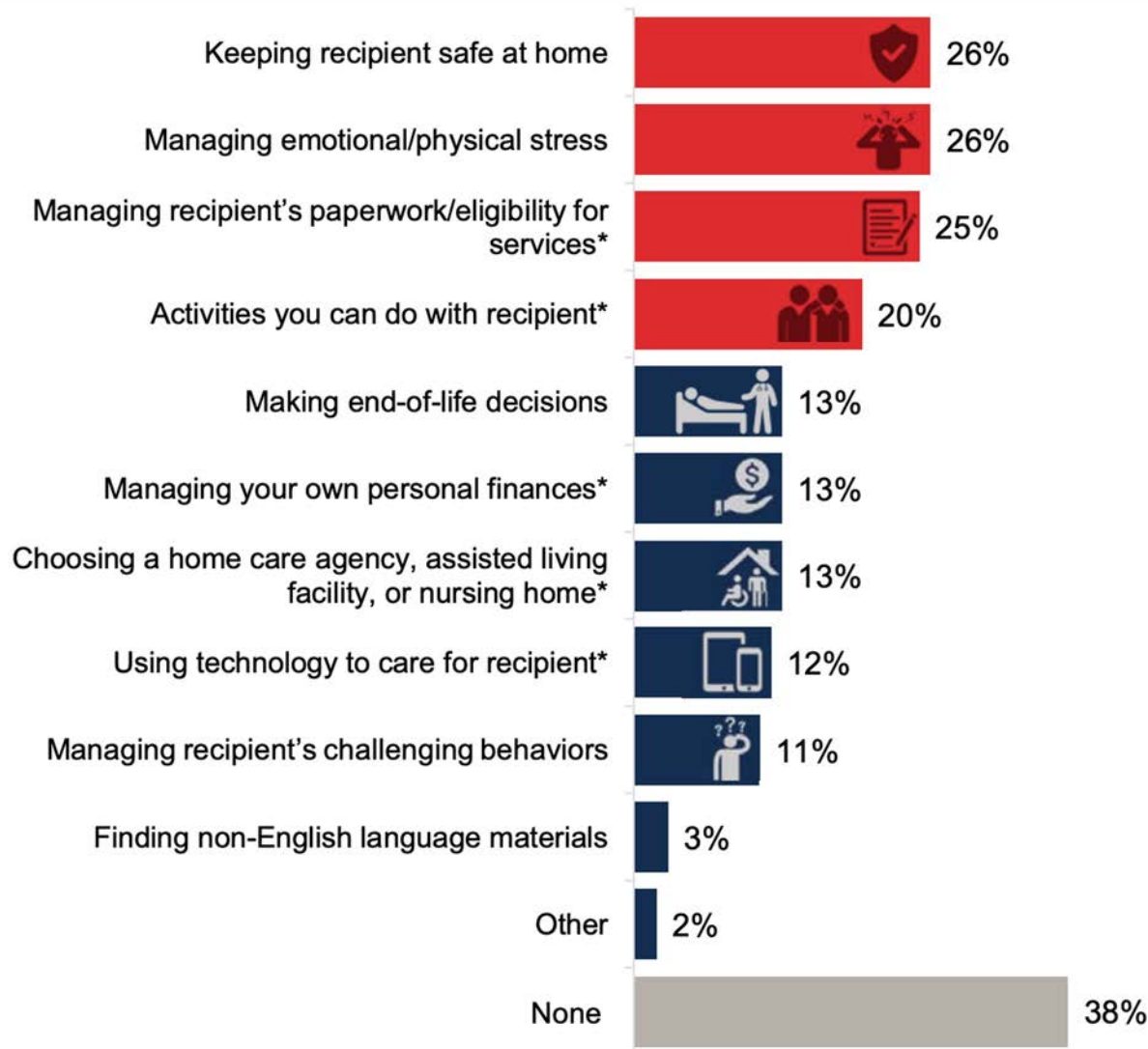


Percentage of older adults who provided care for someone with dementia or other cognitive impairment within the past month

View by: Age Group; Overall - Overall

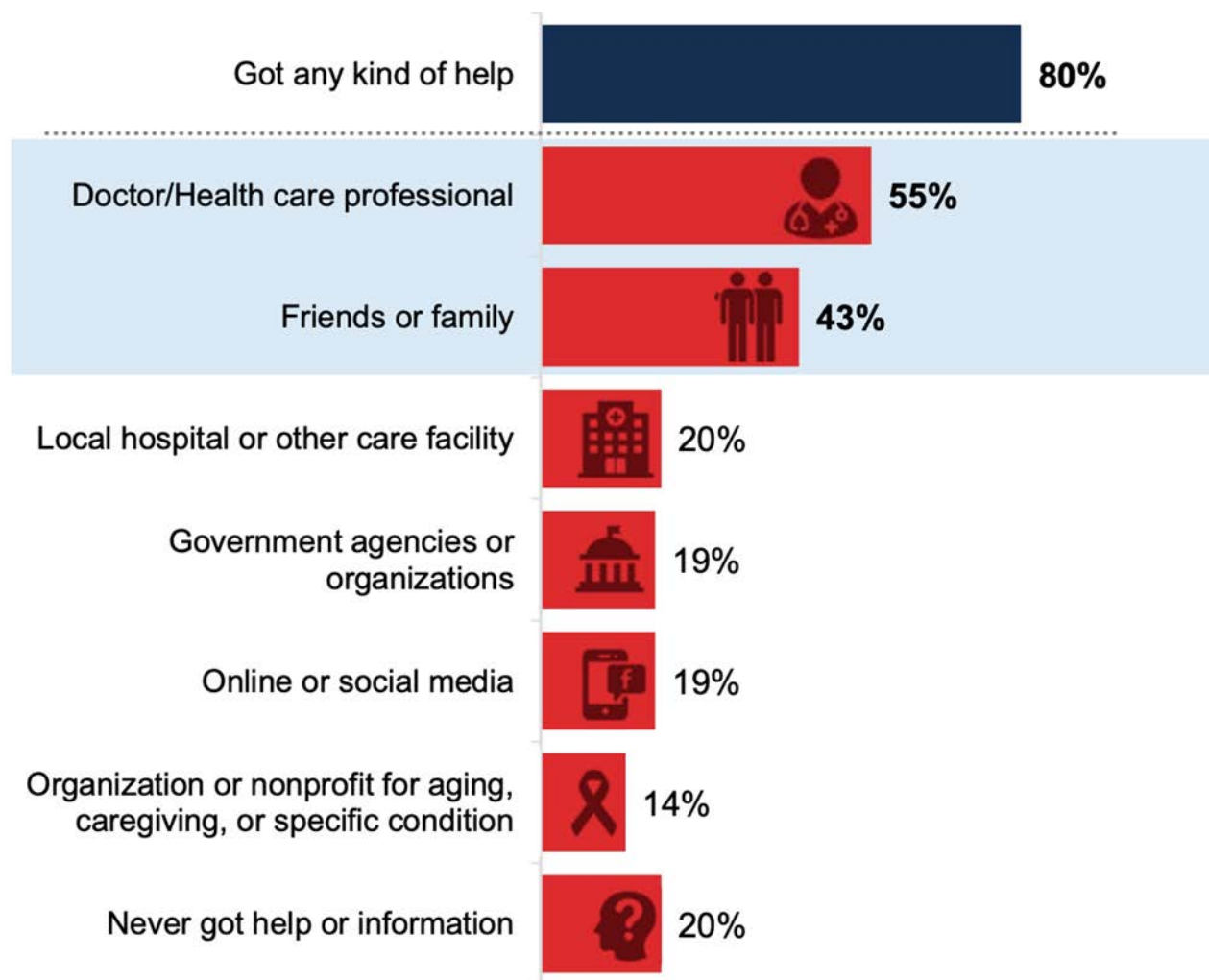


Caregiver Training and Information Needs



*New in 2020

Sources of Help or Information used by Caregivers



Conversations with healthcare providers

13%↓



Had a doctor, nurse, or social worker ask you about what you need/needed to help care for yourself

29%



Had a doctor, nurse or social worker ask about what you need/needed to help care for your care recipient

Resources for Caregivers

There are only four kinds of people in the world.

Those who have been caregivers.

Those who are currently caregivers.

Those who will be caregivers, and
those who will need a caregiver.

- Rosalynn Carter

What can I do as a PCP?

Patient care

Early discussion of future planning for medical, financial, and legal POA

Early detection and diagnosis of caregiving needs

- Ask about ADLs

- Ask about IADLs

- Perform a baseline cognitive screen, repeat as needed

- Fill out a **MOST form** with your patient

Learn how to do a **decisional capacity assessment**

What can I do as a PCP?

Caregiver care

Make sure you're providing physical mental health support to caregivers

Allow of more care modalities (televisits, home visits)

If possible provide social work or community health worker support to caregivers

Paperwork!!!

- FMLA paperwork
- Medicare waiver
- ALF admissions

If placement is needed, know the difference between and price range of unskilled home care, ALF, SNF, memory care

Make plans for what happens if primary caregiver is sick/hospitalized

Printed resources

sage | Advocacy &
Services for
LGBT Elders
We refuse to be invisible

Caregiving in the LGBT Community



**A Guide to Engaging
and Supporting LGBT
Caregivers through
Programming**

"Still the gold standard."—Lisa Genova, author of *Still Alice*

Over
3 Million
Copies Sold
Worldwide

The 36-Hour Day

6TH EDITION
*Revised and
Updated*

**A Family Guide to
Caring for People Who Have
Alzheimer Disease,
Other Dementias,
and Memory Loss**

**NANCY L. MACE, MA
PETER V. RABINS, MD, MPH**

Online resources

Caregiver.org Family Caregiver Alliance

Alz.org NM Chapter - Calendar of activities in-person & virtual posted Jan-Mar

caregiveraction.org Caregiver Action Network

aging.nm.gov New Mexico Aging & Long-Term Services Department

aarp.org/caregiving/ AARP Caregiving section

www.sageusa.org SAGE: Advocacy & Services for LGBTQ+ elders

Aacy.org American Association of Caregiving Youth (Florida based)
Links to other websites for youth caring for persons with ALS, cancer, early-onset dementia or veteran/wounded warrior

www.csusm.edu/youthcaregivers/ info for children as young as 4, can also be used by adults

Videos

Family Caregiver Alliance Caregiver College Video Series (8)

UCLA Alzheimer's and Dementia Care Videos (15) Caregiver Training

Teepa Snow Positive Approach to Care

- Dementia Care Partner Talk Show (podcast)

Dementia Careblazers (also a podcast)





November is
**NATIONAL
FAMILY CAREGIVERS
MONTH**

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<https://www.genworth.com/aging-and-you/finances/cost-of-care/cost-of-care-trends-and-insights.html>
<https://www.genworth.com/aging-and-you/finances/cost-of-care.html>

CDC Alzheimer's Disease and Healthy Aging Data https://nccd.cdc.gov/aging_data/

Caregiving in the LGBTQ+ Community. <https://www.sageusa.org/resource-posts/caregiving-in-the-lgbt-community/>

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