

High Value Care: Supporting the Family Caregiver Workforce

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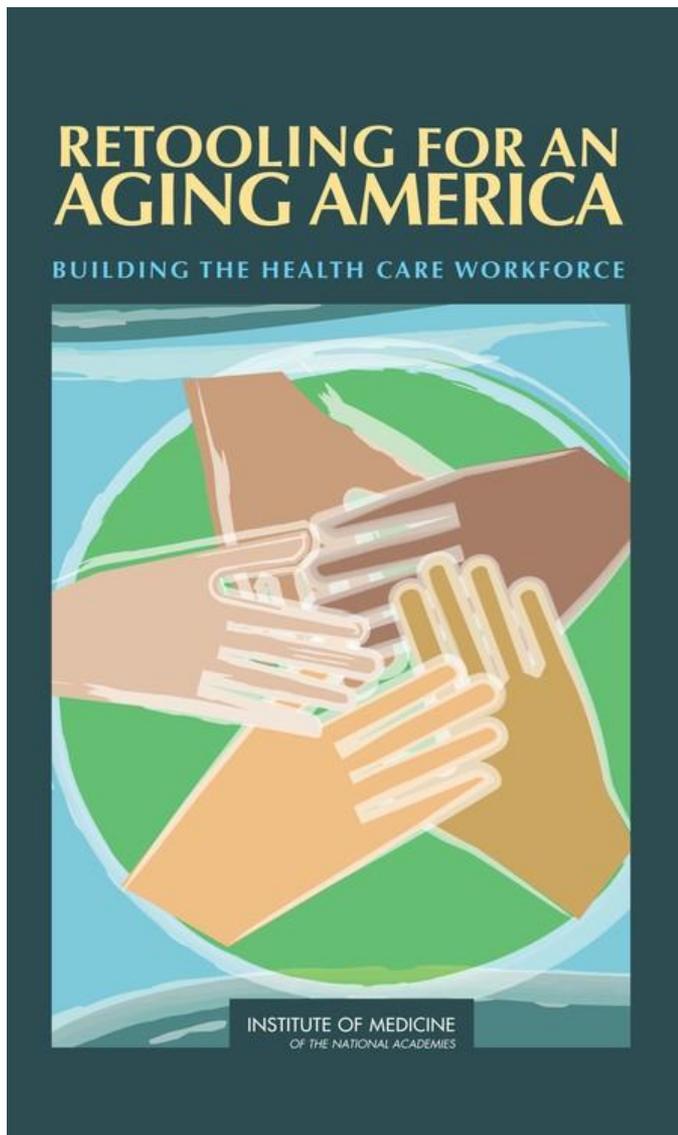
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Health-Related Responsibilities Assumed by Family Caregivers	
Role	Function
Attendant	Provide personal care
Administrator	Manage household
Health Provider	Deliver medical care
Companion	Provide emotional support
Driver	Facilitate transportation
Advocate	Request services
Navigator	Coordinate care across providers and care settings
Coach	Encourage patient self care activities
Technical Interpreter	Facilitate patient understanding
Patient Extender	Facilitate provider understanding

From: Wolff J. Supporting and sustaining the family caregiver workforce for older Americans: Commissioned Paper. 2007:35. Located at: Background Paper for IOM Report: Retooling for an Aging America.

Unpaid. Unappreciated. Untrained.
Undercounted. Exhausted. But vital.

“America’s stealth weapon against chronic illness is a 46-year-old woman with a family, a high-school degree, a full-time job and a household income of \$35,000. She has no particular training in health care. And, to tell you the truth, sometimes she doesn’t feel that great herself...”

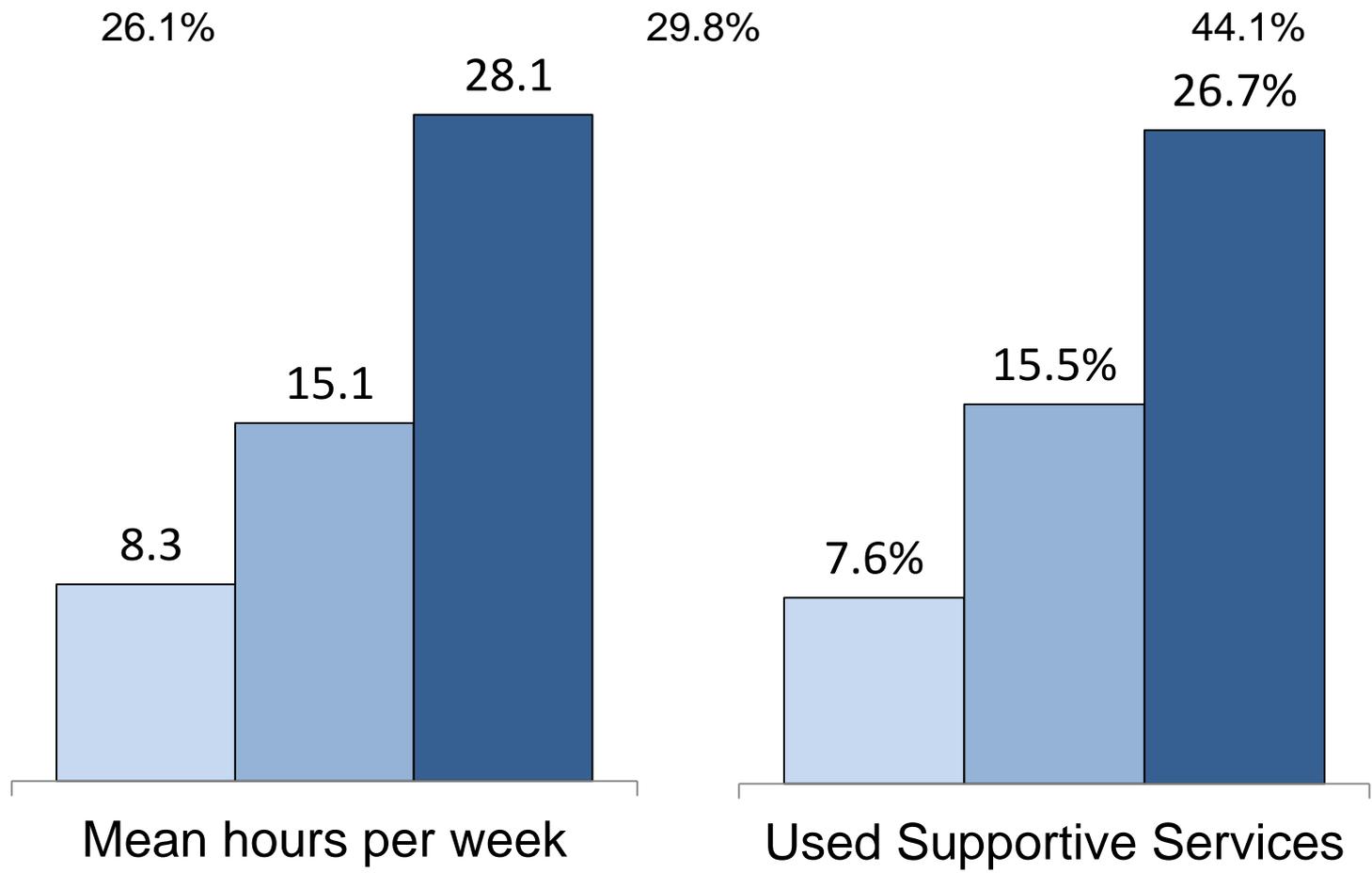
-- AMA Medical News, 2001

JAMA Internal Medicine

A National Profile of Family and Unpaid Caregivers Who Assist Older Adults With Health Care Activities

Jennifer L. Wolff, PhD; Brenda C. Spillman, PhD; Vicki A. Freedman, PhD; Judith D. Kasper, PhD

□ No Help (3.8 million) □ Some Help (4.4 million) ■ Substantial Help (6.5 million)



Source: 2011 National Health and Aging Trends Study and National Study of Caregivers.

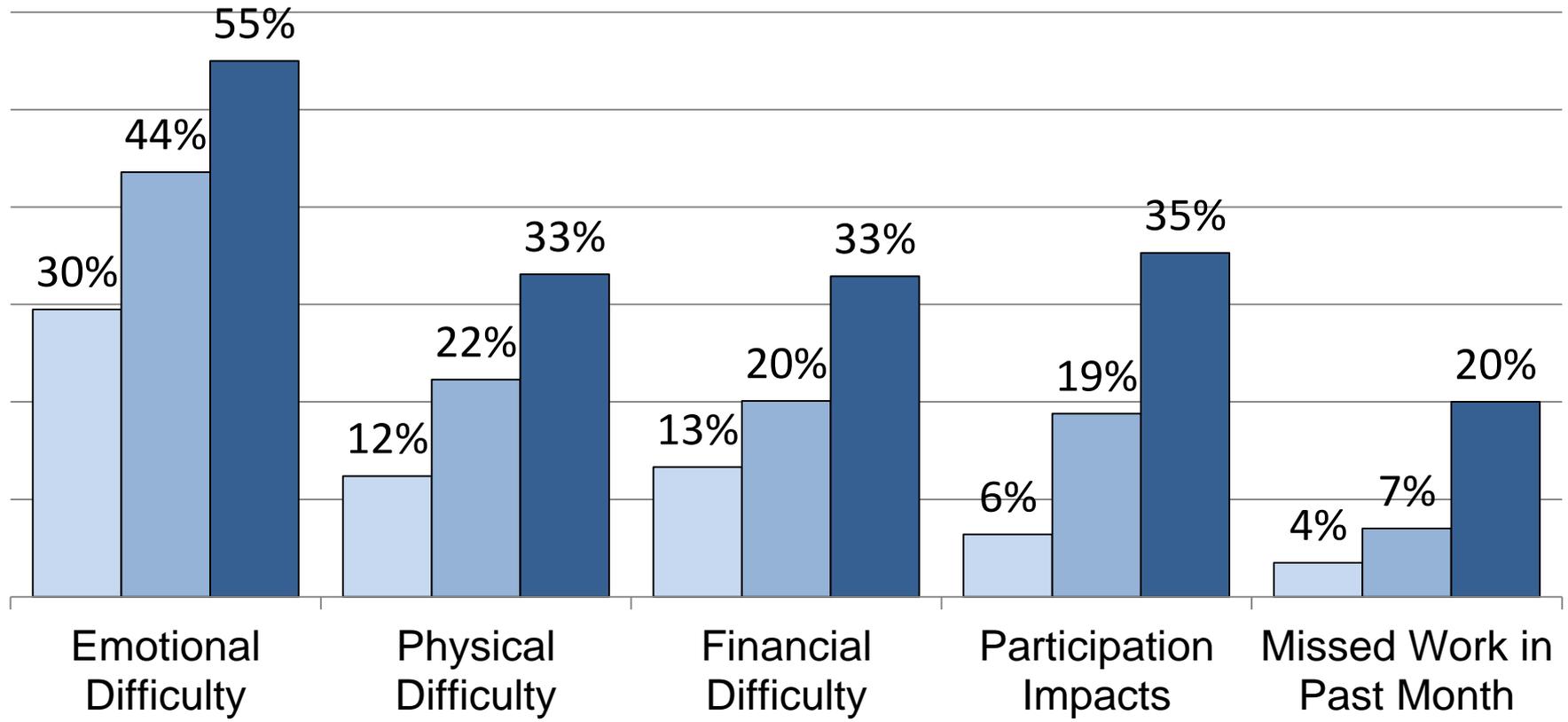
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Caregiver Helps Older Adult with Health Care Activities:

□ No Help □ Some Help ■ Substantial Help



Source: 2011 National Health and Aging Trends Study and National Study of Caregivers.

“If a doctor wants some alone time with [Patient], that’s fine. But the fact of the matter is he’s not going to remember what was talked about...The other big problem is that doctors ask questions and he doesn’t know the answer. What medications are you on and for why? Those kinds of questions he can’t answer. I can, and then sometimes the doctor gets angry when I answer and they say, “Let him answer,” but the problem is he doesn’t have the answer. The fact of the matter is he’s not going to remember what to ask, and if I write a note he might not remember to look at it. You can’t pin a note to an intelligent, grown man’s sweater. And you’ve been to two doctors, three doctors in the week, and they ask you the exact same question, and they go over the medications in incredible, excruciating detail and it’s all networked because it’s [Provider System] and it certainly didn’t change since yesterday or earlier today. It’s just like are you kidding me? There are things we would rather be doing than sitting here.”

--Wife of 87 year-old man with mild cognitive impairment

NATIONAL QUALITY STRATEGY AIMS AND PRIORITIES



Moving Toward Person & Family Centered Care

Face-to-Face Communication:

- Build on patient-directed strategies (*Kinnersley BMJ 2008*) to elicit & align patient-family goals and expectations for care (*Wolff JAGS 2014*)

Electronic Communication:

- Facilitating transparency, respecting patients' preferences though shared access to the patient portal (*Zulman Annals Intern Med 2011; Sarkar JAMA 2014; Wolff JAMIA 2016*)

Care Delivery & Population Health:

- Rationalizing family caregivers' involvement, minimizing risk: understanding capacity and providing appropriate support (*FCA 2006 Consensus Conference on Family Caregiver Assessment; Gitlin TG 2015; Sorenson The Gerontologist 2002*)

“Without considering the patient in his or her family context inadvertently eliminates both a wider understanding of illness and a broader range of solutions...Including family members means the clinician has enlisted his or her most potent allies.”

--Susan McDaniel, “Family-Oriented Primary Care”

Thanks!

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