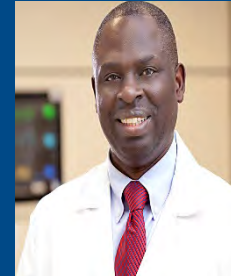# Caregiving Collaborations: Increasing Family and Community Capacity

Caregiver Conversations:
A Day of Learning, Support and Information Exchange
June 25, 2019

**Heather M. Young, PhD, RN, FAAN**
Professor and Founding Dean Emerita

**UCDAVIS**
**BETTY IRENE MOORE**
**SCHOOL OF NURSING**

# There are only four kinds of people in the world

❖ Those who have been caregivers

❖ Those who are current caregivers

❖ Those who will be caregivers

❖ Those who will need caregivers

Yet, caregivers are relatively invisible in our families, communities and health care systems

# Caregiving research/capacity building

- Caregiver physical and mental health
  - With Peter Vitaliano, PhD, (NIA & NIMH)
- Caregiving among Japanese-American families – attitudes, beliefs and choices about long term care
  - KAME project with Eric Larson, MD, (NIA)
  - Nikkei Project with Wayne McCormick, MD (NIA)
- Improving Behavioral Outcomes in Assisted Living
  - With Linda Teri, PhD (Alzheimer's Association)
- Latino Aging Research Resource Center (LARRC)
  - With Ladson Hinton, MD (NIA)
- Family Caregiving Institute (FCI)
  - With Terri Harvath, PhD, RN (Gordon and Betty Moore Foundation)
- Home Alone Revisited
  - With Home Alone Alliance: AARP and Family Caregiver Alliance

# Six Generations

Dorothy: 103
Margaret: 77
Lucy: 57
Natalie: 37
Hannah: 19
Lili-Mae: 1 month

# Health Care Trends

- Discharging older adults sicker and quicker
- Bundled payments with incentives to push to lowest cost setting (i.e., home)
- Hospitalists
- Greater range of options in care/services
- Preference to be at home
- Increasing consumer direction
- Higher acuity in assisted living and residential settings

# What do caregivers do?

- Household tasks, meals, transportation, laundry, managing money
- Self-care, supervision and mobility
- Emotional and social support
- Health care – encouraging healthy lifestyle, treatment adherence, direct care (medications, wound care), respond to acute needs/emergencies
- Advocacy and care coordination (with network and health care providers)
- Surrogacy - financial and legal matters, personal property, advanced planning, treatment decisions

# Who are the caregivers?

- 34.2 million adults in the US provided unpaid care to an adult in past 12 months
- 60% female caregivers, 65% female care recipients
- 85% are a relative, 49% parent, 10% spouse/partner
- On average, have been caring for 4 years, 24% >5
- On average, spend 24.4 hours/week providing care
- 53% have help from another unpaid caregiver
- 60% help with ADLs
- 57% help with medical/nursing tasks
- 56% work full time while caring
- 60% made change at work



RESEARCH REPORT                    JUNE 2015

2015 Report

**Caregiving in the U.S.**

Conducted by

AARP
Public Policy Institute

nac

# Diversity among caregivers

Relationship (partner, adult child, friend, and more)

Caregiving experience and skills

Care recipient(s) needs/strengths

Length of caregiving

Location on trajectory of care

Age, gender sexual orientation

Cultural background race/ethnicity

Religious affiliation

Employment status

Disease/ condition-specific issues

Communication and advocacy skills

Community connections/ strength of network

Financial resources

Housing situation/ proximity

Caregiver mental and physical health status

Motivation and relationship quality

Other family obligations

# Latino

Values of familial reciprocity (familismo) and decision making

Acculturation as a major factor

Preference for home care

Distrust of institutions

Expected intergenerational experience

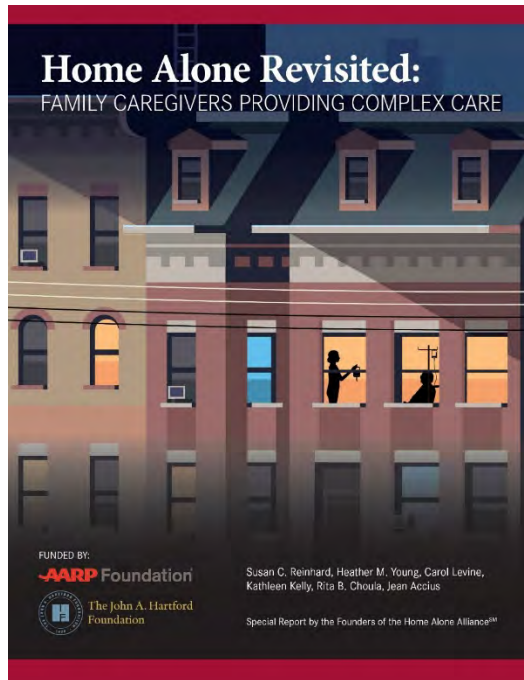Burden, family conflict, availability, personal costs



# African American

Traditional family values – reciprocity, family integrity, role modeling

Caregiving as an expression of love, respect and spirituality

Centrality of maintaining cohesion, control and stability of family and community

Complex web of support

Racism/discrimination



# Experiences of Caregiving

# Asian American

Traditional norms of filial piety, changing with new generations

Socio-cultural expectations

Strained interpersonal relationships and role strain

Values and expectations of family and formal systems do not always align

Pride/shame in asking for help





# Native American

Cultural expectation to care despite limited resources

Collective (communal) care orientation and complex exchange

Anxiety re complex medical problems and ensuing family conflicts

Multi-dimensional experience: high rewards (reciprocity, enjoyment) and burdens (role conflict, negative feelings, low efficacy)

Dearth of formal supports

# Home Alone Revisited: Major Findings



Home Alone Revisited:
FAMILY CAREGIVERS PROVIDING COMPLEX CARE

FUNDED BY:
AARP Foundation
The John A. Hartford Foundation

Susan C. Reinhard, Heather M. Young, Carol Levine, Kathleen Kelly, Rita B. Choula, Jean Accius

Special Report by the Founders of the Home Alone Alliance
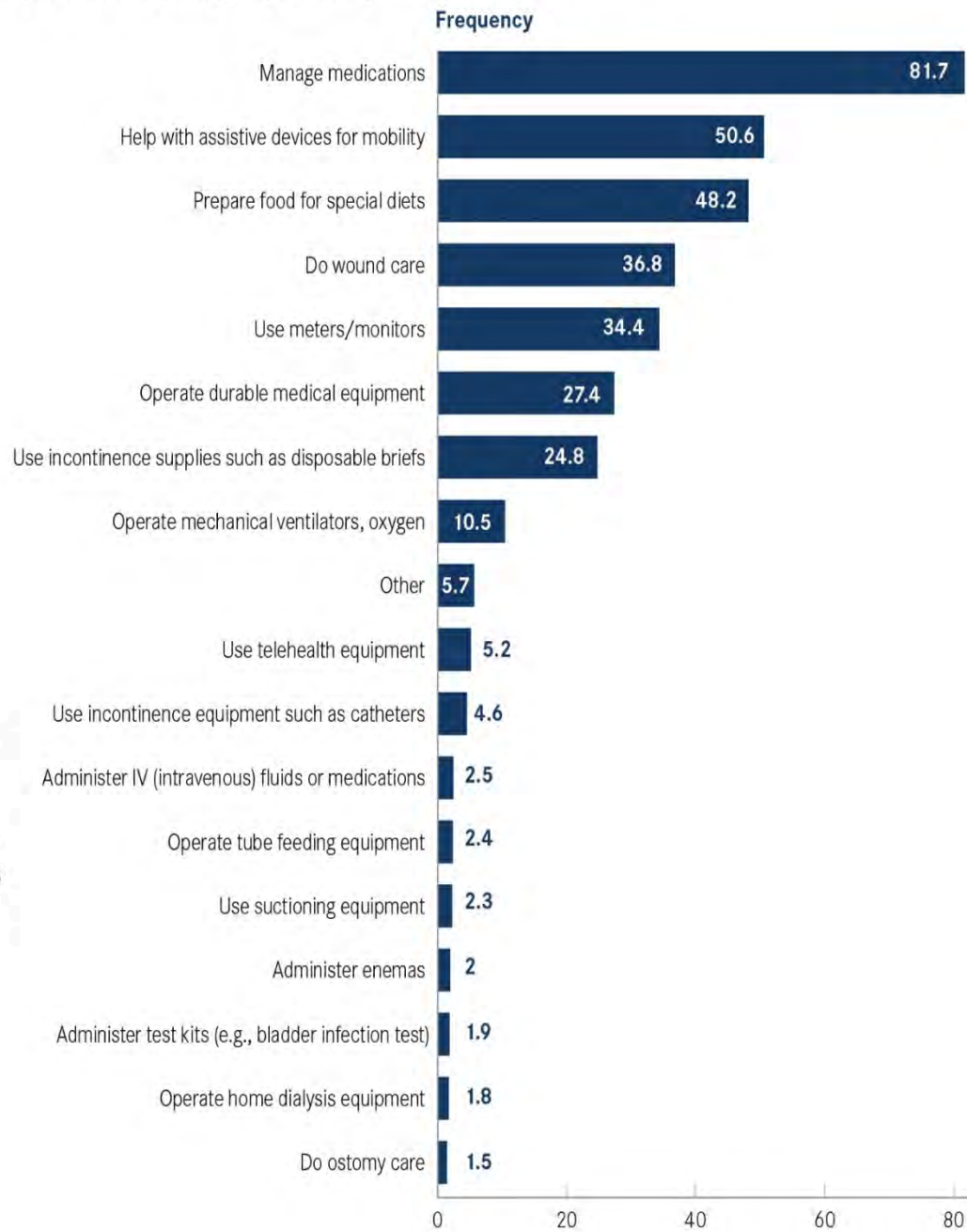
*Reinhard, SC, Young, HM, Levine, C, Kelly, K, Choula, R and Accius, J (2019). Home Alone Revisited: Family Caregivers Providing Complex Care. Washington DC; AARP Public Policy Institute*
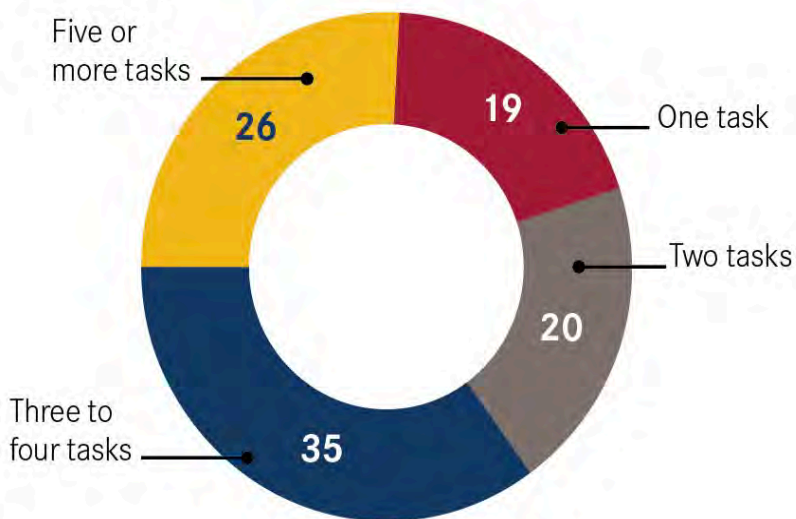
- Today's caregivers provide intense and complex care: 50% perform medical/nursing tasks and manage multiple health conditions that are often accompanied by pain.
- Today's caregivers are diverse and so are their experiences.
- Caregivers who are socially isolated or have no choice about caregiving are more at risk for experiencing difficulties with complex care.
- Caregivers performing more medical/nursing tasks experience both positive and negative impact.
- Many family caregivers are still on their own—health systems should do more to prepare these vital members of the team.

https://www.aarp.org/ppi/info-2018/home-alone-family-caregivers-providing-complex-chronic-care.html

# Medical/Nursing (M/N) Tasks

## M/N Tasks Frequency, % (*n* = 1,084)

**Frequency**

| Task | % |
|---|---|
| Manage medications | 81.7 |
| Help with assistive devices for mobility | 50.6 |
| Prepare food for special diets | 48.2 |
| Do wound care | 36.8 |
| Use meters/monitors | 34.4 |
| Operate durable medical equipment | 27.4 |
| Use incontinence supplies such as disposable briefs | 24.8 |
| Operate mechanical ventilators, oxygen | 10.5 |
| Other | 5.7 |
| Use telehealth equipment | 5.2 |
| Use incontinence equipment such as catheters | 4.6 |
| Administer IV (intravenous) fluids or medications | 2.5 |
| Operate tube feeding equipment | 2.4 |
| Use suctioning equipment | 2.3 |
| Administer enemas | 2 |
| Administer test kits (e.g., bladder infection test) | 1.9 |
| Operate home dialysis equipment | 1.8 |
| Do ostomy care | 1.5 |

## Performing Multiple M/N Tasks, % (*n* = 1,084)

Five or more tasks — 26
One task — 19
Two tasks — 20
Three to four tasks — 35

# Preparation to perform M/N tasks

❖ Most commonly, caregivers learn on their own

❖ Health care professionals more involved in complex, skilled tasks

❖ Millennials and men less likely to receive instruction

**M/N Tasks Learned on Own, % (n = 1,084)**

| Task | % |
|------|---|
| Incontinence—disposable briefs | 76.4 |
| Special diets | 71.4 |
| Enemas | 70.4 |
| Assistive devices for mobility | 60.3 |
| Durable medical equipment | 56 |
| Medications | 53.6 |
| Meters/monitors | 46.2 |
| Telehealth equipment | 33.9 |
| Wound care | 33.5 |
| Test kits | 30 |
| Ostomy care | 29.9 |
| Mechanical ventilators, oxygen | 21.4 |
| Incontinence—catheters | 19.1 |
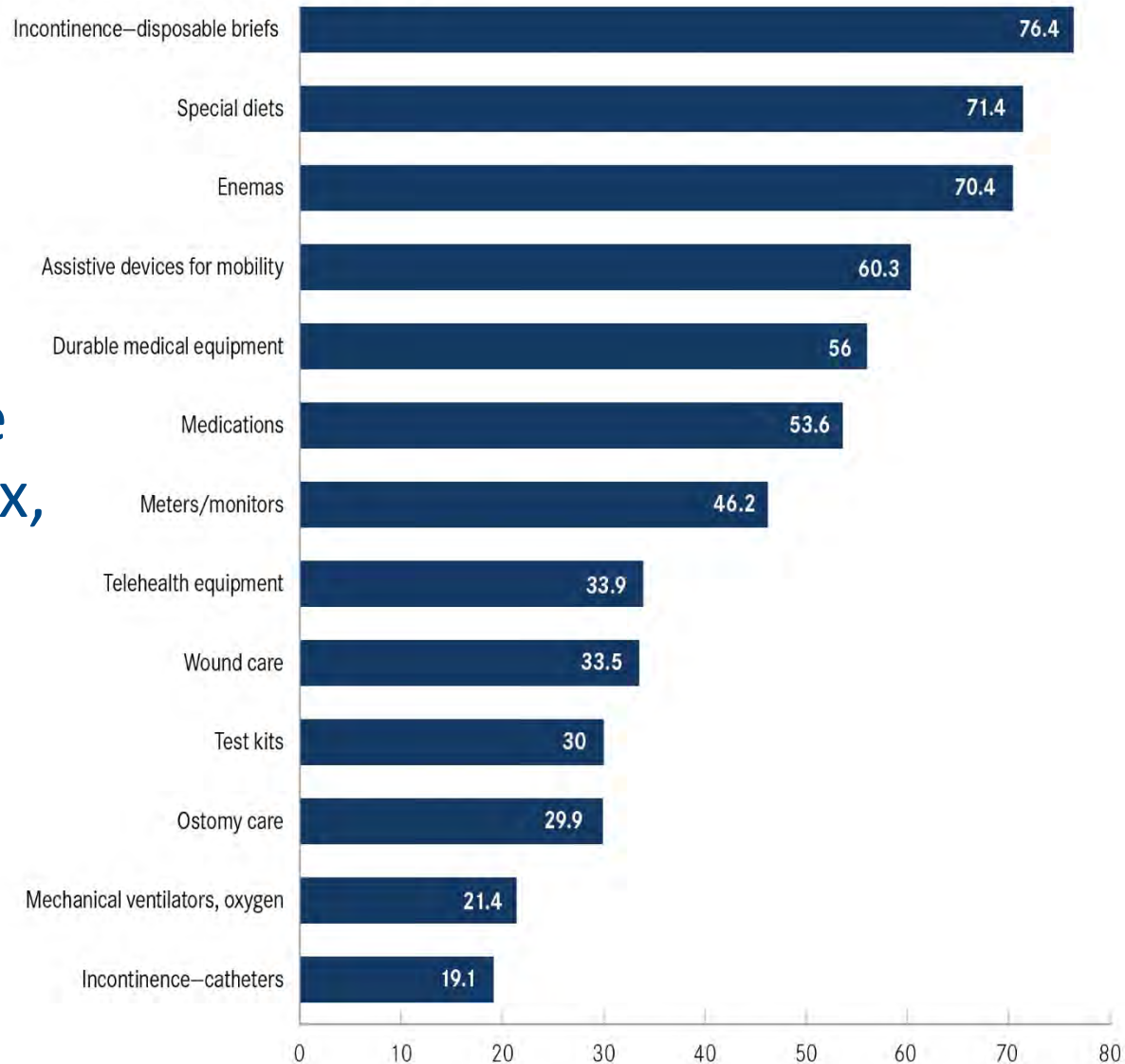
# Outcomes of caregiving

- ❖ Depression/anxiety
- ❖ Affect/mood
- ❖ Health
- ❖ Life satisfaction
- ❖ Social isolation
- ❖ Financial loss
- ❖ Gain – enrichment, meaning
- ❖ Sense of mastery

# What do caregivers need?

- 32% say a health care provider asked about what they need to care
- 16% say a health care provider asked what they need to take care of themselves
- 84% could use more information or help on caregiving topics (safety, managing stress, dealing with behaviors or incontinence, nursing tasks)
- 15% have used respite
- 30% would appreciate being paid or tax credit
- 49% would like their name in the EHR
- 22% want help with end of life decisions

# Implications for Communities

- Identifying health priorities and actions at the community level
- Building community capacity
- Breaking down silos, democratizing resources
- Health system design – across settings
- Imaginative partnerships
- Enabling technology

# Potential areas for community solutions

- Community level planning – gaps in services, accessibility, livability, transportation, opportunities for activity and engagement
- Supports for family care/distance caregiving
- Health promotion and respite
- Mobility – home and community design
- Bring people together – address isolation
- Improve systems of care and coordination among systems
- Role of technology in health
- Emergency preparedness

# How can Health Care Systems Help

- Recognize caregivers as part of the team – assess, include, support, educate
- Address consumer preferences – advance planning and communication
- Episodic and chronic management – be aware of trajectory
- Integrate across systems of care (acute, long-term care, home)
- Address health disparities and health equity
- Emphasize transitional care/care coordination
- Cultural safety and inclusion

# Technology can help

- Cuing, reminding
- Communication with care providers, family
- Remote monitoring/care
- Telehealth
- Medication management—organizers, dispensers, pumps
- Home controls and sensors
- Less invasive surgery
- Electronic health records
- Online support and education
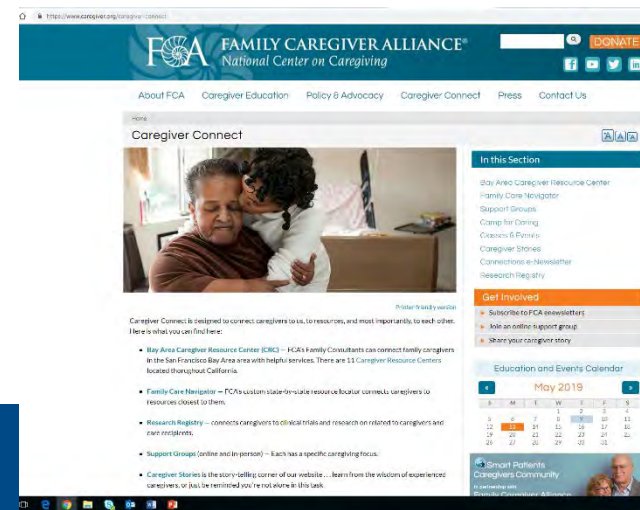
# Policy and Leadership Opportunities: Your voice matters!

- Advocacy, public outreach, communication
- Caregiver-friendly work environments
- Housing, transportation, community resources
- Universal design, urban planning
- Federal and state policies to support caregivers: family leave, nurse delegation, home care referral registry, Family Caregiver Support Program

# The Home Alone Alliance℠

# Caregiver Resources



- Caregiver assessment through Family Caregiving Alliance or Area Agency on Aging
- Family Caregiving Alliance resources on web-site
- Series of online video tutorials – medications, mobility, wound care, special diets, incontinence on AARP website

# Problems to solve – challenges and opportunities

- Increasing demand with less supply of caregivers
- Diverse strengths and needs among caregivers
- Communication and coordination among all the moving parts
- Availability of supports, services and information
- Building capacity – family, community, workforce
- Policies that support family caregiving