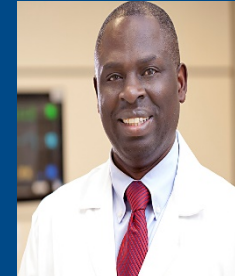# Caregiving Collaborations: Increasing Family and Community Capacity

6th Annual Elder Friendly Futures Conference
September 14 2017

Heather M. Young
Dignity Health Dean's Chair for Nursing Leadership
Associate Vice Chancellor for Nursing
Founding Dean and Professor, School of Nursing

UCDAVIS
BETTY IRENE MOORE
SCHOOL OF NURSING

There are only four kinds of people in the world

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

(Rosalyn Carter)

Our time together

- So what are the problems we are trying to solve - where are some of our challenges and opportunities?
- How might we think about approaches to build family, community and system capacity?

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

Oldest Person Alive Today

Violet Brown

Lives in Jamaica

117 years old

Oldest son is 97

Has been going to her church for over 100 years

"I have six children, one died. Five alive, but them all sick. Them sick more than me," she said, bursting out in infectious laughter.
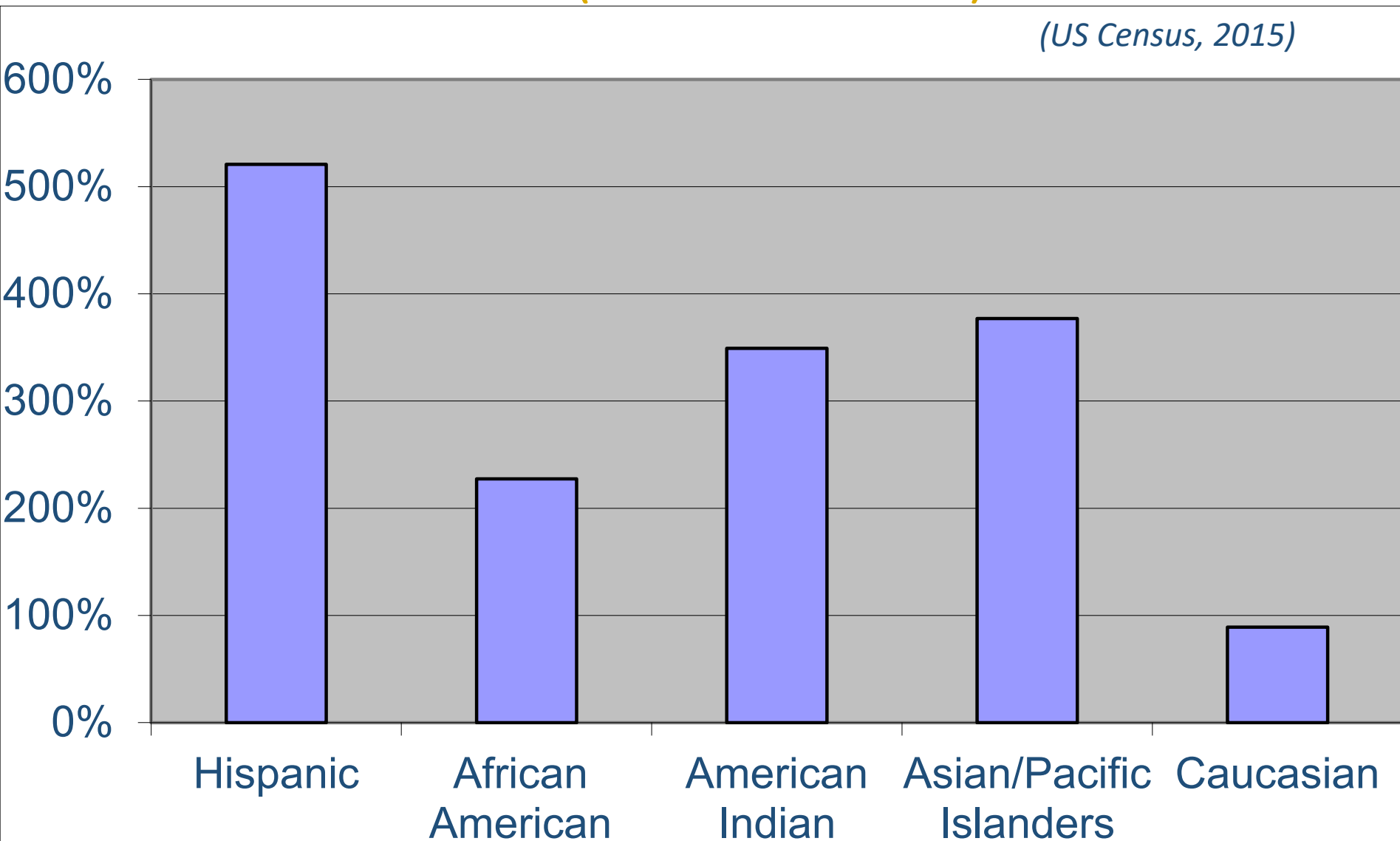

www.JamaicaObserver.com

Age Wave is Hitting the Shore

- Population >65 will increase from 14.9% in 2015 to 22.5% in 2050
- In US between 1980 and 2010, >90 tripled, >100 increased by 65.8%
- First baby boomer turned 70 January 2016 and someone turns 70 every 8 seconds for the next 30 years
- Dependency ratio 21 in 2010 will increase to 30 by 2030

US Census, 2015

Bronzing (Browning of the Graying) of America 2012-2060 (% increase in >65)

(US Census, 2015)

Chart showing percent increase in population over 65, 2012-2060:
- Hispanic: ~520%
- African American: ~228%
- American Indian: ~350%
- Asian/Pacific Islanders: ~378%
- Caucasian: ~90%

Societal Trends

- We have more grandparents than grandchildren
- Fewer children, more adults without children
- Geographic mobility, changing migratory patterns
- Growing population of rural older adults
- More blended families
- Higher rates of divorce for adults > 65

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

Demand Driven by Common Chronic Conditions
(# individuals > 65 years old in millions)
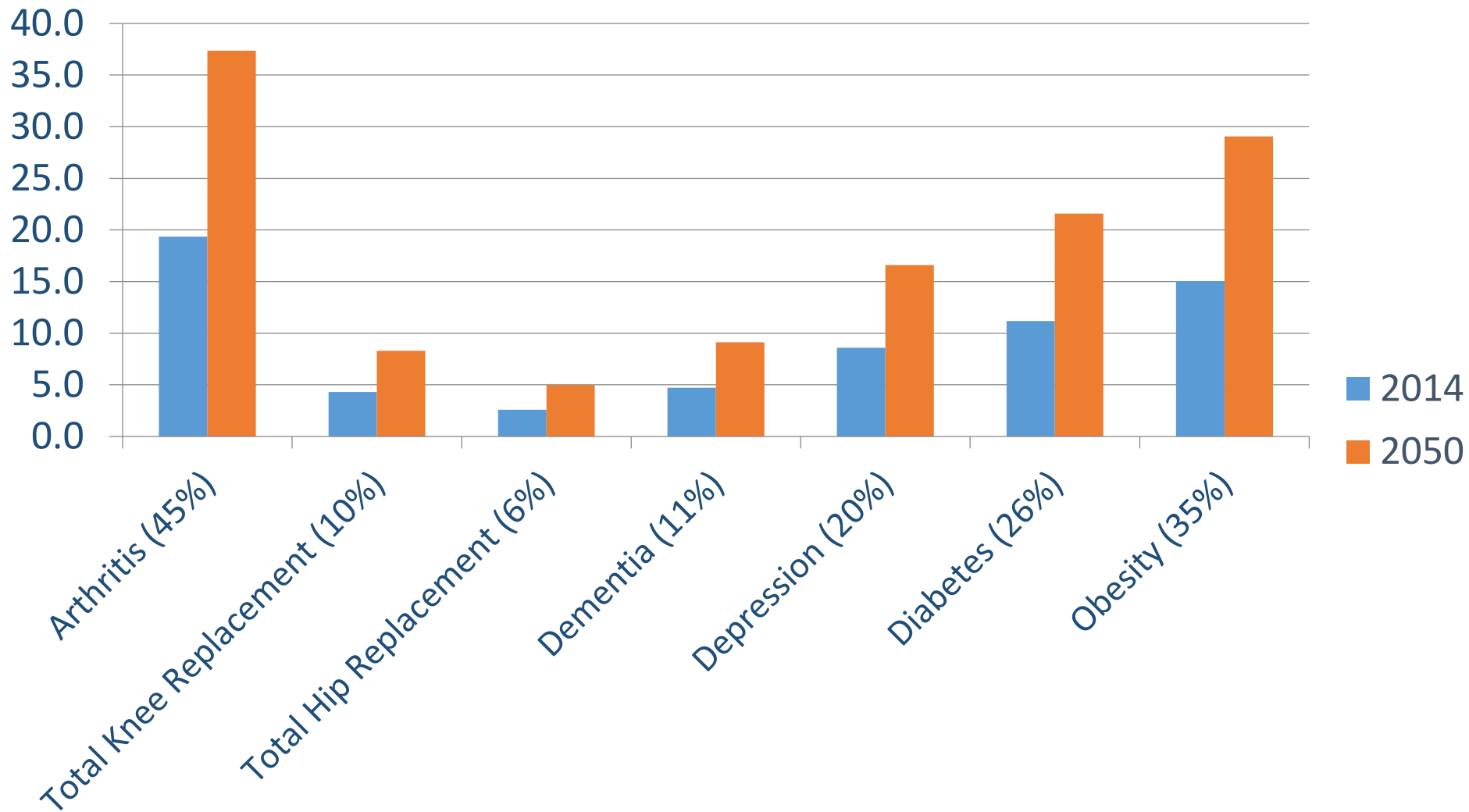
What do caregivers do?

- 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
- Caregiving households: 21% Hispanic, 20.3% African American, 19.7% Asian American, 16.9% White
- 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
- 60% help with ADLs
- 57% help with medical/nursing tasks
- 53% have help from another unpaid caregiver
- 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
National Alliance for Caregiving

Diversity among caregivers

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

Age, gender sexual orientation

Cultural background race/ethnicity

Religious affiliation

Employment status

Financial resources

Caregiving experience and skills

Care recipient(s) needs/strengths

Length of caregiving

Location on trajectory of care

Disease/ condition-specific issues

Communication and advocacy skills

Community connections/ strength of network

Housing situation/ proximity

Caregiver mental and physical health status

Motivation and relationship quality

Other family obligations

The Caregiving Trajectory
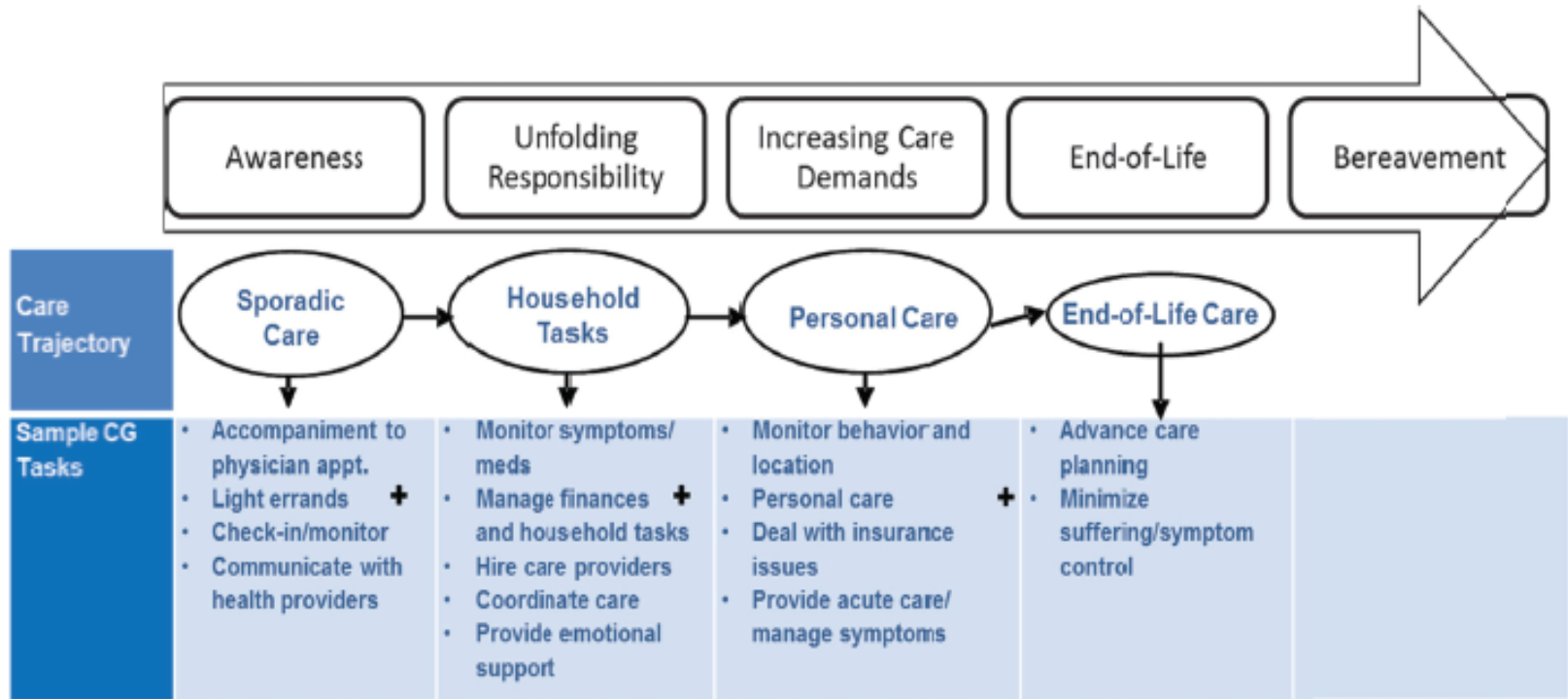
FIGURE 3-1 An example of a dementia care trajectory.
SOURCES: Adapted from Gitlin and Schulz (2012) and Schulz and Tompkins (2010).

$6,954

Average Out of Pocket Expenses for Family Caregivers in 2016

Family Caregivers Provide $470 Billion in Unpaid Care

Source: Valuing the Invaluable 2015 Update: Undeniable Progress, but Bigs Gap Remain, AARP Public Policy Institute

$11,923

Average Out of Pocket Expenses for Long-Distance Caregivers in 2016

More than three in four family caregivers (78%) are incurring out-of-pocket costs as a result of caregiving
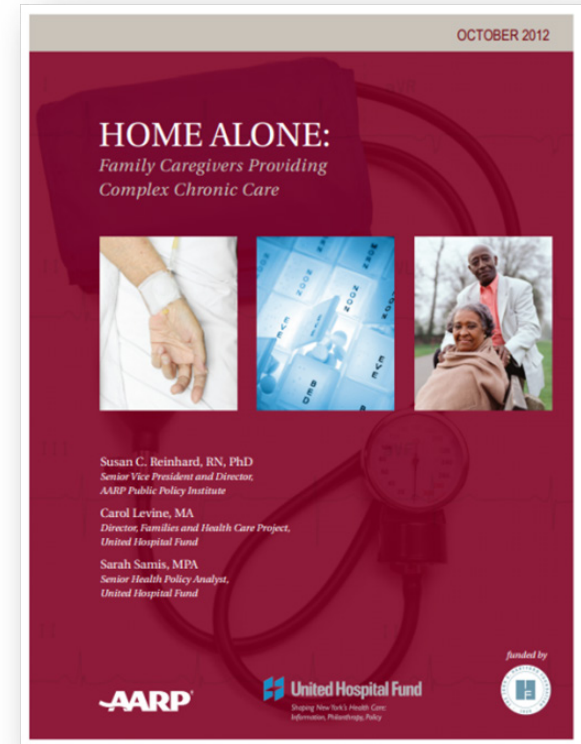
78%

20%

Family caregivers are spending, on average, nearly 20% of their income on caregiving activities

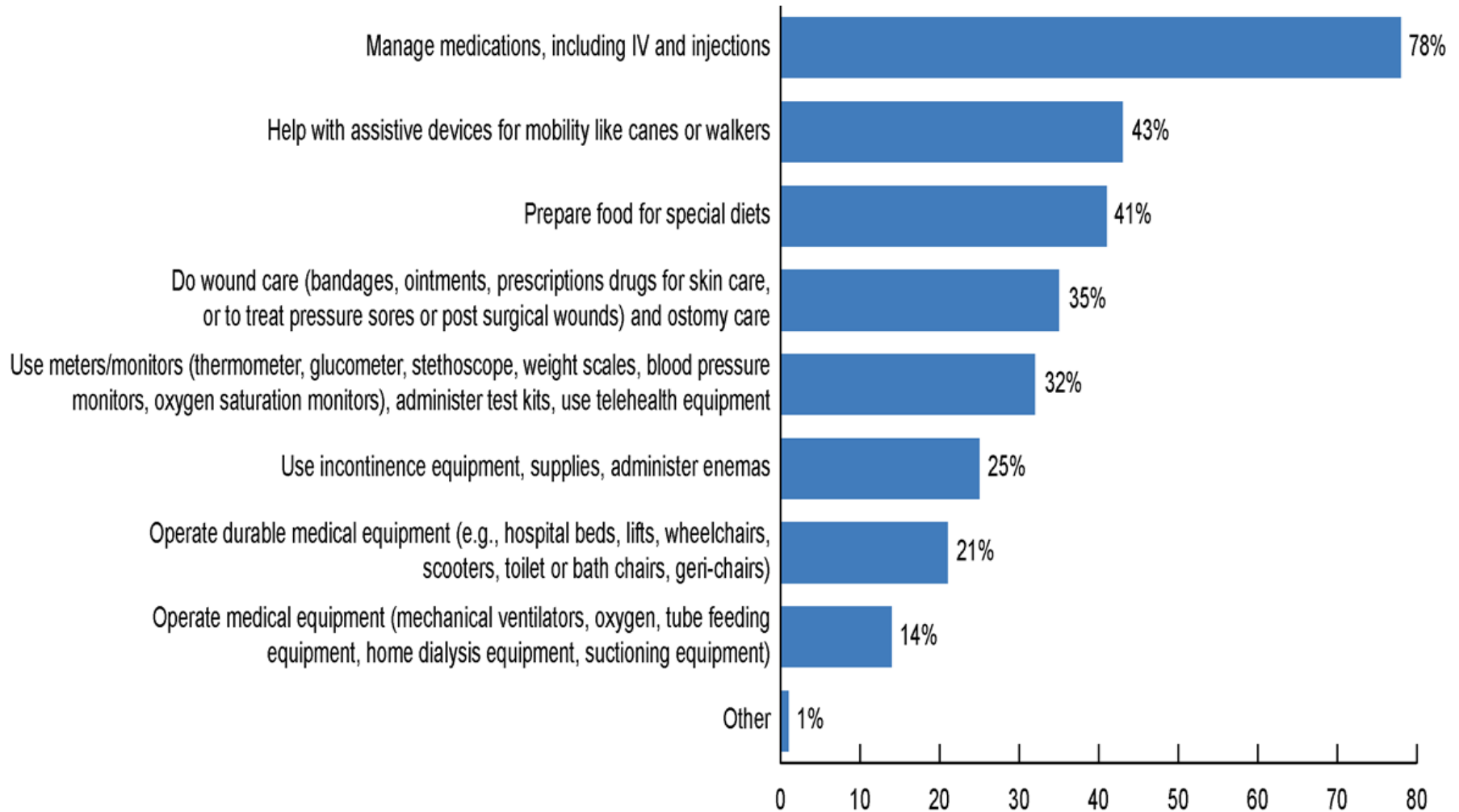# Caregivers provide ~90% of long term care

Home Alone: Family Caregivers Providing Complex Chronic Care

- National survey of 1,677 family caregivers), mean age = 53
- 68% provided care for > 1 year
- 47% working, 27% retired
- 40% lived in the same house as the care recipient
- 55% of care recipients lived with multiple chronic conditions, mean age = 71
- In past year:
  - 64% visited an emergency department
  - 57% had inpatient hospital stay

OCTOBER 2012

HOME ALONE:
Family Caregivers Providing Complex Chronic Care

Susan C. Reinhard, RN, PhD
Senior Vice President and Director,
AARP Public Policy Institute

Carol Levine, MA
Director, Families and Health Care Project,
United Hospital Fund

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Senior Health Policy Analyst,
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AARP

United Hospital Fund
Shaping New York's Health Care:
Information, Philanthropy, Policy

funded by

Home Alone: Medical Nursing Tasks

N=777

Task	Percentage
Manage medications, including IV and injections	78%
Help with assistive devices for mobility like canes or walkers	43%
Prepare food for special diets	41%
Do wound care (bandages, ointments, prescriptions drugs for skin care, or to treat pressure sores or post surgical wounds) and ostomy care	35%
Use meters/monitors (thermometer, glucometer, stethoscope, weight scales, blood pressure monitors, oxygen saturation monitors), administer test kits, use telehealth equipment	32%
Use incontinence equipment, supplies, administer enemas	25%
Operate durable medical equipment (e.g., hospital beds, lifts, wheelchairs, scooters, toilet or bath chairs, geri-chairs)	21%
Operate medical equipment (mechanical ventilators, oxygen, tube feeding equipment, home dialysis equipment, suctioning equipment)	14%
Other	1%

Outcomes of caregiving

- ❖ Depression/anxiety

- ❖ Affect/mood

- ❖ Health

- ❖ Life satisfaction

- ❖ Social isolation

- ❖ Financial loss

- ❖ Gain – enrichment, meaning

Caregiver Health: Negative Outcomes

- Higher levels of depression and mental health problems *(Vitaliano, et al; Schulz, et al; Zarit, et al)*
- Higher stress with lower income
- Increased blood pressure, insulin levels, metabolic syndrome *(Vitaliano et al.)*
- Depressed immune function *(Kiecolt-Glaser)*
- Higher risk for morbidity and mortality *(Schulz & Beach)*
- Depressed caregivers more at risk to abuse care receiver *(Beach; Williamson)*
- Pessimism as predictor of depression and poorer health *(Lyons)*

Caregiver Mental Health: Positive Outcomes

- Sense of mastery, competence *(Lawton; Orbell; Archbold; Stewart)*
- Preparedness *(Archbold and Stewart)*
- Self-efficacy *(Haley)*
- Caregiver satisfaction *(Albert; Lawton)*
- Enriched relationships *(Archbold; Braithwaite)*
- Enjoyable aspects of caring/Uplifts *(Cohen; Logsdon; Kinney)*
- Meaning in caring *(Farran; Perry; Young)*
- Feeling appreciated *(Archbold; Kramer; Kinney; Ryff)*

Gender differences

- Women tend to spend more time caregiving, and perform the more difficult tasks
- Women report more uplifts
- Women more likely to <u>report</u> anxiety, worry, and depression
- Men exhibit poorer health (cardiovascular, metabolic, and stress hormones)

Thinking about approaches

- Intra and interpersonal issues
- Person-environment fit
- Community capacity building
- Systems of care
- Technology

The National Academies of SCIENCES · ENGINEERING · MEDICINE
REPORT
Families Caring for an AGING AMERICA
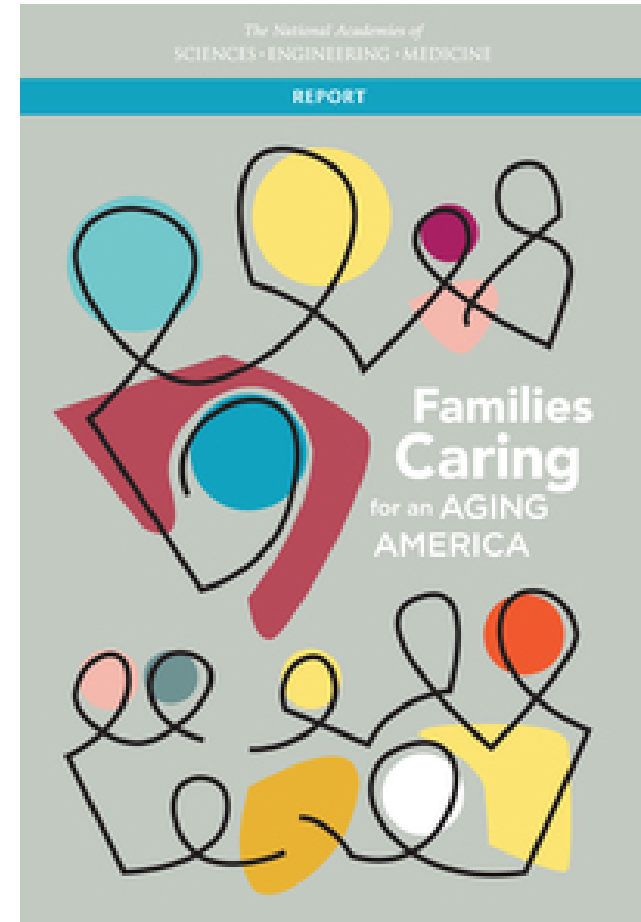
Conceptual models

- Atheoretical
- Stress/appraisal/coping *(Zarit; Pearlin; Vitaliano; Lawton)*
- Family stress *(Pruchno; Kramer)*
- Transitions *(Schumacher; Young)*
- Role strain/quality *(Archbold; Stephens; Lyons)*
- Social exchange *(Picot; Walker)*
- Symbolic interaction *(Perry)*
- Existential models *(Farran)*
- Feminist models *(Hooyman)*

Caregiving intervention research

Early studies: psychosocial, skills training, respite, counseling

- PREP (Preparedness, Enrichment, and Predictability) *(Archbold, Stewart)*
- REACH (psychosocial, skills, environmental modification, technology) *(Schulz, Burgio)*
- STAR (antecedents, behaviors, consequences) *(Teri)*
- Physical activity *(King)*

Systematic Review of multi-cultural caregiving 1980-2013 (n=238)

Apesoa-Varano, Feldman, Choula, Reinhard and Young, 2015

	Formative	Intervention	Cross-sectional	Longitudinal	Qualitative	Quantitative	Mixed-methods
African American (n=36)	33	3	34	2	22	4	10
Asian American (n=25)	23	2	25	0	20	2	3
Latino (n=40)	37	3	39	1	31	0	9
Native American (n=6)	5	1	6	0	1	1	4
Cross-Ethnic (n=131)	120	11	116	15	86	0	45
Total	218	20	220	18	160	7	71

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

Experiences of Caregiving

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

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

Impressions

➢ Limited longitudinal studies - limited understanding of caregiving trajectory

➢ Interventions of multicultural caregivers use the Stress-Appraisal-Coping model applied to Caucasians

➢ Clear importance of community/culture – yet individual approaches dominate

➢ Dearth of interventions to mobilize and sustain caregiving network, communications, conflict resolution or advance planning

➢ Limited studies addressing influence and potential of technology

Recommendations

➢ Address heterogeneity of groups (Latinos, Asian Americans, Native Americans)

➢ Expand conceptual models for research (i.e., reciprocity, family development/dynamics, feminist ideology, stigma/discrimination, sociological theories, etc.)

➢ Consider network and dynamics (extended family and non-kin)

➢ Incorporate longitudinal view of caregiving (caregiving trajectory)

➢ Address context of caregiving in intervention research (socio-cultural barriers and facilitators)

LGBT Caregivers

- Diversity within the community, multiple identities
- Attention to societal context and caregiving network –"families of choice"
- Social isolation and high rate of living alone among older adults
- Limited longitudinal studies – research field is relatively young
- Discrimination and discriminatory policies pose barriers at multiple levels – from interpersonal to systems –health insurance, health care, social services and housing

Fredriksen-Goldsen and Hooyman, 2007
Stein, Beckerman, Sherman, 2010

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

Care receiver: 61 year old man living in a rural community with Parkinson's Disease, early cognitive impairment, sensitive to meds, uses a walker, needs help with ADLs, judgment issues, loses track of medications and timing

Caregiver issues: Spouse who has heavy job responsibilities, also caring for mother in assisted living, two sons who live 90 minutes away

Family issues: Coordinating care and communication, assuring back up and coverage, training for tasks, emotional support, home safety, financial planning

Community issues: In-home help, neighbor involvement, home remodel, safe walking, broadband internet access

Health System issues: coordination among specialties, recognition of primary caregiver expertise, transition planning

Aging is a Family Issue

- We live in the context of connections and ties
- Families make the greatest caregiving contribution
- We have expectations of each other and of ourselves – sometimes unrealistic
- Families have histories and established dynamics
- Our choices affect others
- Many family members want to avoid a crisis, and want to help

Needs of families who are caring: Communication

- Decide process for decisions: who, what, when, how
- Identify shared values and goals, expectations, and areas of disagreement
- Project likely trajectory—health, finances, preferences
- Consider what each member can contribute and how they might coordinate and share the load
- Identify and evaluate salient options and back up plans

Help Families Can Use

- Health care professionals—to help with health assessment and projections, identifying options, provide support through transitions
- Legal and financial advisors to assist with estate planning, guardianship, real estate transactions
- Facilitated family meetings/conflict resolution
- Community and web-based resources to provide information about options and considerations

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

Priority 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

Targets for Health Care Systems

- Recognition of caregivers as part of the team – assess, include, support, educate
- Consumer preferences – advance planning and communication
- Episodic and chronic management – awareness of trajectory
- Integration across systems of care (acute, long-term care, informal)
- Health disparities and health equity
- Emphasis on transitional care/care coordination
- Financial incentives for managing across systems
- Cultural safety and inclusion

Technology can help

- Cuing, reminding
- Communication with care providers, family
- Remote monitoring/care
- Telehealth
- Medication management – organizers, dispensers, pumps
- Home monitoring – security, lights, temperature
- Electronic health records
- On-line support and education

Health Care Professional Capacity

- Workforce preparation in gerontology and care of older adults – professionals and unlicensed staff
- Family caregiving – how can health care professionals support family/friend care
- Full practice authority/delegation
- Interprofessional collaboration
- Health system innovation
- Diversity of the workforce

Policy and Leadership Opportunities

- Advocacy, public outreach, broad 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

AARP®
Real Possibilities

A State Scorecard on Long-Term Services and Supports for Older Adults, People with Physical Disabilities, and Family Caregivers

WA state rankings:
#1   Overall
#11 Affordability and access
#2   Choice of setting and provider
#15 Quality of life/care
#5   Support of family caregivers
#3   Effective transitions

The Care Act:
Caregiver Advise, Record, Enable

Under the CARE Act, hospitals will:

- Allow patients to designate a family caregiver
- Notify the family caregiver when the patient is going to be discharged
- Give the family caregiver an opportunity for instruction and demonstration of the medical tasks required when their loved one returns home

Now law in 39 states

The Home Alone Alliance^{SM}

Caregiving Resources

- School of Nursing partnership with AARP and the Home Alone Alliance
- Series of online video tutorials with accompanying articles in AJN – medications, mobility, wound care
- Leverages accessibility of the Internet
- Reaches people when and where they can receive information

Caregiving Video

Family Caregiving Institute

- Discover and disseminate knowledge needed to improve systems that support the capacity of family caregivers to advance health and well-being for older adults with serious illness and for themselves
- Enhance capacity of family caregivers to thrive while enacting their vital role safely and effectively
- Increase capacity of health care professionals to deliver person-family-centered care by partnering effectively with family caregivers.