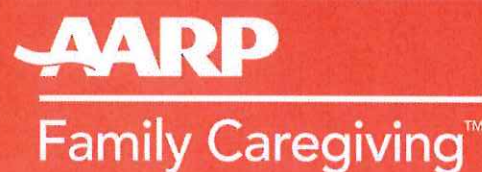


One Size DOES NOT Fit All: The Diversity of Family Caregivers

Rita B. Choula

AARP Public Policy Institute

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"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**."

Rosalyn Carter



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Family Caregiving: Then



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Family Caregiving: Now



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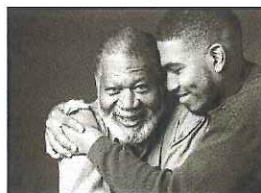
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Increasing Diversity of Family Caregivers

- There are 41 Million family caregivers in America
- Nearly 1 in 4 (24%) is a millennial
- 40% are men
- About 40% represent multicultural communities



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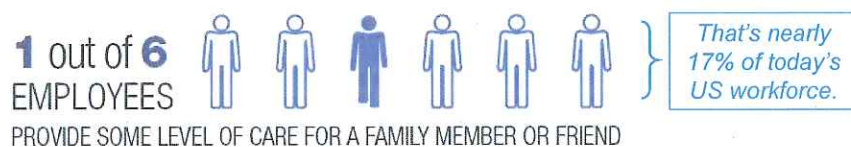
Family Caregivers Juggle Many Tasks



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Family Caregivers in the Workforce



- Number of employee-caregivers expected to grow exponentially over next decade
- Almost everyone will give or receive care at some point in their lives



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The Working Caregiver Experience



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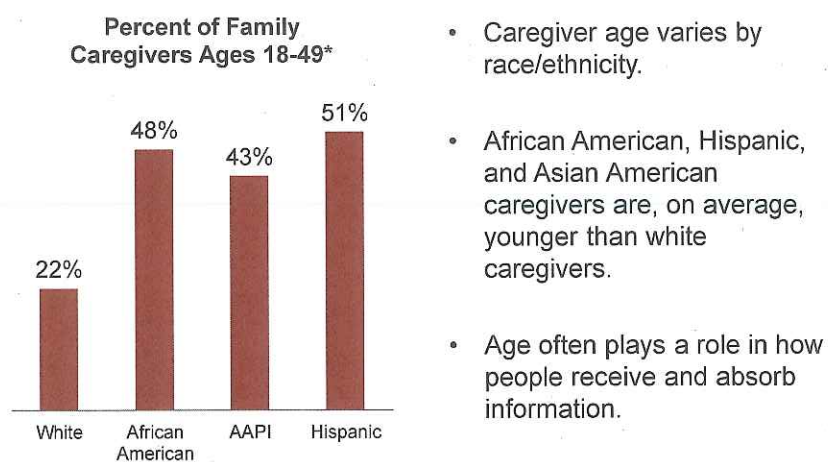
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The Financial Toll of Family Caregiving



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Multicultural Family Caregivers Tend to be Younger



*Includes family caregivers of adults 65+

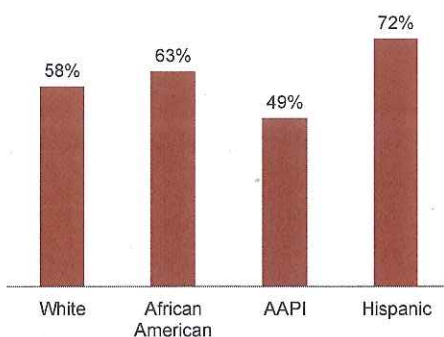
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Medical/Nursing Tasks

Family Caregivers Who Perform Medical/Nursing Tasks*



- Hispanic and African American family caregivers are more likely to perform medical/nursing tasks.

- These include:
 - Medication management
 - Wound care tasks
 - Mobility
 - Incontinence
 - Preparing Special Diets

*Includes family caregivers of adults 65+

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African-American Family Caregivers

- African American caregivers are more likely to care for a nonrelative (23 percent vs. 13 percent of all other race/ethnic groups).
- Along with Hispanic caregivers, more likely to report difficulty accessing local, affordable care services.
- Most likely of all groups for the caregiver to be a Veteran.

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Hispanic/Latino Family Caregivers

- More likely to live in the same household as the person for whom they care.
- More often perform 21+ hours of caregiving per week than the general population (41 percent vs 32 percent).
- Compared with all caregivers, less likely to have internet access at home (76 percent vs 85 percent).
- More likely to seek resources available in languages other than English (22 percent).
- Fifteen percent are LGBT- a higher rate than other groups.

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Asian American Pacific Islander (AAPI) Family Caregivers

- Reported greater need for information on key topics:
 - Keeping the someone safe at home (57 percent vs 42 percent).
 - incontinence/toileting problems (19 percent vs 11 percent)
- More likely to seek resources available in languages other than English (19 percent)
- More likely to believe their caregiving role will continue during the next 5 years (66% vs. 52% all other racial/ethnic groups)

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Family Caregiver Providing Complex Care

- 50% of family caregivers perform medical/nursing tasks for individuals with challenges in physical, cognitive, and behavioral health.
- They carry a heavier responsibility than those who do not perform these tasks, spending more than twice as many hours per week providing care.



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. www.aarp.org/homealone

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Multicultural Family Caregivers Providing Complex Care

- Multicultural family caregivers are performing M/N tasks at rates similar to Whites
- The impact of income and experience with strain and worry differs quite strikingly by racial and ethnic group:
 - Multicultural family caregivers are more likely to experience strain and worry about making a mistake, regardless of their income level
 - For Whites, the level of strain and worry about making a mistake decreases as their income increases

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. www.aarp.org/homealone

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Social Isolation

- Millennials more likely to be disconnected from friends – 20% do not see any of their friends in a given month
- Blacks/African Americans are most at risk of being socially isolated and less satisfied with the quality of their social relationships

"I feel bad about venting to my friends, so I end up just keeping it all inside."



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. www.aarp.org/homealone

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Negative Effects on Quality of Life

- Added stress and vigilance
- Worry about making a mistake
- Worry about paying for care
- Negative effects on employment
- Chinese caregivers face more challenges:
 - 2/3 worry about paying for care, making a mistake and worrying about something going wrong
 - Twice as likely to say that performing tasks causes problems in relationships with care recipient

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. www.aarp.org/homealone

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Positive Effects on Quality of Life

- Feeling about making an important contribution (greatest for Hispanic/Latino and Black/African American caregivers)
- Feeling closer to the care recipient
- Performing tasks also eases worry
- Gives the caregiver new skills (particularly Hispanic/Latino, Black/African American, and Chinese family caregivers and Generation X and Millennial caregivers)

Reinhard, SC, Young, HM, Levine, C, Kelly, K, Choula, R and Acclius, J (2019). Home Alone Revisited: Family Caregivers Providing Complex Care. Washington DC; AARP Public Policy Institute. www.aarp.org/homealone

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stereotypes

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Real Possibilities

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More Action is Needed to Help Caregiving Families

- Make certain that a broad, national strategy sets strategic direction
- Provide financial help to ease the financial costs of caregiving
- Strengthen workplace flexibility policies and enact paid family leave programs
- Ensure that family caregivers are routinely identified and that their needs are assessed and supported in health care and community services
- Promote common terminology and standard definitions of family caregiving in surveys

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Takeaways



- While significant federal and state policy changes have occurred since 2015 to support family caregivers, **more work needs to be done**
- The aging of the population and its impact on families **can no longer** be viewed as a private, family-only issue
- America's public policies have **not kept pace** with changing demographics and social trends
- Investments in family caregiver supports now will **build a more caring society** for our families and ourselves

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A Call to Action

What is your why????



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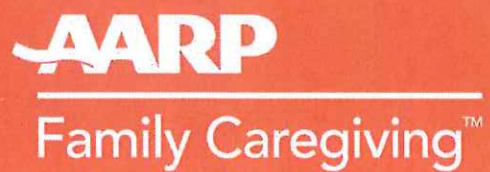


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THANK YOU!



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