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# Caregiving in the United States: Results of a National Survey

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# Caregiving in the US – Where Have We Been?

- Traditionally, the purpose of survey was to present a current picture of family caregivers and compare it to family caregivers in the past.
- Surveys were conducted in 1997, 2004, 2009 and now 2014

# Caregiving in the US – Highlights from 2009 Study

- Caregivers predominately female (66%), typically caring for a relative, such as a parent or spouse
- Reasons for care were: old age, Alzheimer's, mental/emotional illness, cancer, heart disease, and stroke
- Children needed care for ADD/ADHD, autism, mental/emotional illness, and developmental delays
- Key Takeaway: Caregivers needed support managing their own stress and health, and in the workplace, in addition to help caring for a loved one

# Caregiving in the US – Where We Are Going?

- 2014 Methodology
  - Transition from phone survey to online panel (recruited by phone)
- Why?
  - Survey research is changing
  - Companies are moving to the use of online panels
  - Costly to conduct phone surveys
  - Less people have landlines
    - See, e.g., *Family Caregivers are Wired for Health*, Pew Research Center

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## **The New Normal – Focus of 2014 Study**

- High-Intensity Caregivers (21+ hours)
- “Oldest Old” – Caregivers Age 75+
- Medical/Nursing Tasks
- Family Caregivers in the Workplace
- New Policy Solutions

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# The New Normal – Focus of 2014 Study

- Oversampling
  - African-American/Black, Asian-American Pacific Islander, Hispanic/Latino
  - Age 75+ Caregivers

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## New Questions from 2014 Study

- **Medical/Nursing Tasks**
  - {Do/Did} you help your \_\_\_\_ with any medical/nursing tasks?
    - This might include giving medicines like pills, eye drops, or injections, preparing food for special diets, tube feedings, or wound care. You could be monitoring things like blood pressure or blood sugar, helping with incontinence, or operating equipment like hospital beds, wheelchairs, oxygen tanks, nebulizers, or suctioning tubes.

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## New Questions from 2014 Study

- **Medical/Nursing Tasks, cont...**
  - You said earlier in the survey that you {help/helped} your \_\_\_\_\_ by giving medicines, like eye drops, pills, or injections for his/her condition. Is that correct?
  - How difficult {is/was} it for you to do the medical/nursing tasks that {are/were} required to help your \_\_\_\_\_?

## New Questions from 2014 Study

- **Medical/Nursing Tasks, cont...**
  - Did anyone prepare you to do these tasks?
  - Who prepared you to do the medical/nursing tasks needed to help your \_\_\_\_\_?
  - How well do you feel that person prepared you to take on these medical/nursing tasks?

# New Questions from 2014 Study

- **Hospitalization**

- In the last 12 months that you were caring for him/her, how many times was your \_\_\_\_\_ hospitalized overnight?
- When your \_\_\_\_\_ was in the hospital, were you included by health care workers, like nurses, doctors, or social workers, in discussions about your \_\_\_\_\_'s care?
- Before your \_\_\_\_\_ left the hospital or was discharged, did you receive clear instructions about any medical/nursing tasks you would need to perform for your \_\_\_\_\_?

# New Questions from 2014 Study

- **Working Caregivers**

- Does your supervisor know that you are caring for your \_\_\_\_\_ ?
- For employees in your position, which of the following does your employer offer?
  - Flexible work hours
  - Telecommuting or working from home
  - Programs like information, referrals counseling, or an employee assistance program, to help caregivers like yourself
  - Paid leave, where you could take paid time off from work for several weeks to care for a family member

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## New Questions from 2014 Study

- **Working Caregivers, cont...**
  - Have you ever been fired from any job as a result of being a caregiver for your \_\_\_\_\_ or any other loved one?
  - Would you support banning workplace discrimination against workers who have caregiving responsibilities?

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## New Questions from 2014 Study

- **Policy Solutions**

- How difficult {is/was} it to get affordable services in your \_\_\_\_\_'s local area or community that {could help/would have helped} you care for your \_\_\_\_\_, like delivered meals, transportation, or in-home health services?

# New Questions from 2014 Study

- **Policy Solutions, cont...**

**Various organizations are thinking about ways to help caregivers like you. Which of the following do you think would {be/have been} helpful to you?**

- Requiring health care providers to include your name on your \_\_\_\_\_'s medical chart, so you {are/were} part of conversations or decisions about his/her care
- Requiring hospitals to {keep/have kept} you informed about major decisions, like transferring or discharging your \_\_\_\_\_
- Requiring hospitals or facilities to instruct or demonstrate any medical/nursing tasks you might {need/have needed} to do

# New Questions from 2014 Study

- **Policy Solutions, cont...**

**Various organizations are thinking about ways to help caregivers like you. Which of the following do you think would {be/have been} helpful to you?**

- Having respite services available, where someone would {take/have taken} care of your \_\_\_\_\_ to give you a break
- Requiring a doctor, nurse, or social worker ask you about what you {need/needed} to help care for your \_\_\_\_\_
- Requiring a doctor, nurse, or social worker ask you what you {need/needed} to take care of yourself
- None of the above

## New Questions from 2014 Study

- **Policy Solutions, cont...**
  - {Does/Did} your \_\_\_\_\_ have plans in place for his/her future care, such as instructions for handling financial matters, healthcare decisions, or living arrangements?
  - Do you have your own plans for your own future care, such as handling financial matters, healthcare decisions, or living arrangements?

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## Launch Plans

- Release in June 2015 at Capitol Hill Briefing
- Webinar for State/Local Caregiving Advocates
- Reports and materials archived online
- Infographics and Fact Sheets on special populations, including ethnic caregivers
- Online social media and blog discussions

# 2015 Caregiving Activities -- AARP

- Valuing the Invaluable
  - State Caregiving Data
- Caregiver Video Project
- Survey on Financial Caregivers
- Caregiver, Advise, Record, Enable (CARE) Act
- Assisting Caregivers Today (ACT)  
Congressional Caucus
  - Supporting the new bipartisan, bicameral caucus

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## **2015 Caregiving Activities – National Alliance for Caregiving (NAC)**

- Caregivers of Persons with Mental Illness
- International Alliance of Carer Organizations
- Caregiving Champions
  - [www.caregiving.com/champions](http://www.caregiving.com/champions)
- Caregiving and Technology

# Questions?

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