The Impact of Caregiving in America

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WHO ARE OUR CAREGIVERS?
44MILLION + FAMILY CAREGIVERS IN THE USA
PROFILE OF CAREGIVERS IN AMERICA

- 82% care for 1 adult
- 15% care for 2 adults
- 3% care for 3+ adults

On average, caregivers help with 4.2 Instrumental Activities of Daily Living

49% felt they had no choice in taking on this role

85% provide care to a relative

28% of caregivers have a child or grandchild living with them

Caregivers by Race:
- 16.9% White
- 19.7% Asian American
- 20.3% African American
- 21% Hispanic

$28+ billion in lost productivity for full/part-time employed caregivers

8.4 million provide care to an adult with an emotional or mental health issue

17.9 billion hours of unpaid care for people with Alzheimer’s & related dementias

600,000-700,000 families have an adult with I/DD living with aging family members with no future planning

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Self-Identification

- Unpaid individual involved in assisting others with activities of daily living and/or medical tasks.

- Are you currently or have you been in the last year a caregiver for a family member or friend?

- Do you currently provide or have you provided in the last year unpaid help to a relative or friend who has a disability or chronic disease?
19% of caregivers self-identify.
A CULTURAL LENS

- The term ‘caregiver’ is not universal
  - USA – Caregiver
  - UK – Carer
  - Nigeria – Family

- However, there are 80 translations available for ‘caretaker’
The REAL QUESTION

- How do we (the health care system, social service agencies, employers) help you the moment we see you in your role of caring for a loved one?
The Story of Caregiving in America

17% of caregivers feel their health in general has gotten worse as a result of their caregiving responsibilities.

17-35% of family caregivers view their health as fair to poor.

11% of family caregivers report that caregiving has caused their physical health to deteriorate.

40% to 70% of family caregivers have clinically significant symptoms of depression.

25% of caregivers say it is very difficult to get assistance that is both affordable and helpful.
The Impact on Mental Health

- 80% of caregivers are not healthcare professionals
- Caregiving is not something we ‘prepare’ for
- 1 in 5 family caregivers suffer from depression
- Post-Caregiving - mourning the loss of a loved one
  - 41% of former caregivers of a spouse with Alzheimer’s disease or another form of dementia experienced mild to severe depression up to three years after their spouse had died
“When all else fails, go get the therapy and help you need. I did, I went to counseling and it’s been so helpful, and (Insurance) pays for it. It’s wonderful to share things and not be judged.”

- Sharon, Caregiver
www.healtheo360.com

Healtheo360 is a caring community for Patients with chronic conditions, their Caregivers, Family Members and Friends to share their stories of inspiration, motivation and support.
Care 2 Caregivers

www.care2caregivers.com

Care2Caregivers is staffed by peer counselors who have cared for family members with dementia and also worked as dementia professionals in the health care industry. They have seen dementia from both sides and offer free, ongoing peer support.
County-Based Caregiver Coalitions

www.njcaregivers.org
Community-based providers collaborate to identify gaps in services experienced by caregivers and determine solutions.
Respite

Respite care provides short-term relief for primary caregivers. It can be arranged for just an afternoon or for several days or weeks. Care can be provided at home, in a healthcare facility, or at an adult day center.

- Respite Care Relief/Assistance:
  - Area Agency of Aging (county-specific)
  - MLTSS Health Plans
Health Literacy

Health literacy barriers experienced by caregivers when navigating the healthcare system can have a negative impact on the health of the loved one they are caring for.

- Health Literacy Resources:
  - EdLogics – [www.edlogics.com](http://www.edlogics.com)
  - Chronic Disease Self Management Courses
Resiliency

- Caregivers often experience the stress-burn out cycle which can impact their personal life, employment, and caregiving capacity

- Stress Management Resources:
  - Stress Busting for Family Caregivers
  - Mindfulness Training
  - General Self-Care
Building an Inclusive Culture of Healthy Caregiving

- Awareness
- Advocacy
- Action
Awareness

- Caregiving has been slated as a public health issue
- November is National Caregiver Awareness Month
- Increased focus on the identification and support of family caregivers
Advocacy

- Federal
  - RAISE Family Caregiver Act - HHS will create a national family caregiver strategy by bringing together federal agencies and representatives from the private and public sectors

- State
  - NJ CARE (Caregiver, Advise, Record, Enable) Act -
  - NJ Caregiver Taskforce Bill - Pending
Advocacy

- Hawaii
  - Kupuna Caregivers Act - Hawaii is the first state in the nation to offer money to caregivers who also work full-time.

- United Kingdom
  - Short Term Carer Leave
  - Appointed Minister of Loneliness
Action

Using an equity lens, it is our responsibility to identify and implement culturally appropriate best practices for supporting ‘caregivers’, ‘carers’, or ‘family’ in their role of caring for a loved one and beyond

Share the journey & the stories
"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."

Rosalynn Carter
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