The Family Caregiver Perspective: Intersections Among Health Disparities, Disabilities, Health Equity & Health Literacy

National Academies of Sciences, Engineering and Medicine
Roundtable on Health Literacy & Roundtable on the Promotion of Health Equity and the Elimination of Health Disparities

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Our Inspiration

- Legendary account of a tree blossoming at the sound of monsoon thunder
- Empowering individuals to “blossom” during caregiving challenges

Our Work

- Nonprofit offering education and support programs to family and friend caregivers
- Serving people who provide personal care, emotional, financial and other support to aging loved ones and loved ones with long-term illnesses and disabilities.
- Evidence-based caregiver interventions & other evidence-informed programs
- Small group programs and stress management education tailored to individual needs

Helping Family Caregivers Blossom During Life’s Challenges...
Family Caregivers At-A-Glance

• “Typical” family caregiver: 49-year-old woman caring for a relative (However, caregiving is performed by people across the lifespan, such as minor children caring for parents or grandparents.)

• 60% female; 40% are male

• 82% care for someone living with or within 20 miles of them

• 34% employed full-time; 25% employed part-time; Caregivers employed outside the home work on average 34.7 hours per week

• 32% provide ≥21 hours of unpaid care per week; On average, caregivers provide 62.2 hours weekly

• Typical higher hour caregiver (≥21 hours/week) has provided care for 5-1/2 years and expects to do so for another 5 years

• Vulnerable to emotional stress as well as physical and financial strains

• Want resources and tools to assist with managing stress

Selected Demographic Data On Race & Ethnicity of Family Caregivers

• Approximately unpaid 43 million family/friend caregivers in the U.S.

• Individual adult caregiver identify their race/identity as follows:
  • White: 62%
  • African-American: 13%
  • Hispanic (non-White, non-African-American): 17%
  • Asian-American: 6%

• Reported prevalence of caregiving by racial/ethnic group:
  • Hispanic (non-White, non-African-American): 21%
  • African-American: 20%
  • Asian-American: 19.7%
  • White: 16.9%

Sources:
National Alliance for Caregiving and AARP. Caregiving in the U.S. 2015.
The Roles of Family/Friend Caregivers

• Assisting with activities of daily living, transportation, medication management and, often, skilled care
• Communicating on loved one’s behalf with professional members of the care team
• Coordinating care with professional caregivers
• Ensuring continuity of care between medical appointments and after hospital discharge
• Providing emotional support
• Providing financial support
• Advocating on behalf of loved one (e.g., accessing benefits)
• Acting as information gatekeepers (e.g., accessing reliable health information)
• And much, much more ....
Creating an *Effective* Care Team

Building Cooperative Relationships

Care Receiver

Professional Caregiver

Family Caregiver

Studies have found professional and family caregivers need:
- information about their roles;
- support from peers;
- linkage to other caregivers.

(Slide adapted from “Caring for You, Caring for Me,” a program of the Rosalynn Carter Institute for Caregiving)
Selected Observations from Research on Racially/Ethnically Diverse Family Caregivers:

• Race and ethnicity can influence how a caregiver perceives the relative rewards and burdens of caregiving.*

• “Socioeconomic status may override culture for purposes of predicting behavior related to caregiving because poverty rates are higher among minority cultures....” (citing U.S. Census Bureau 2000)*

• “Caregiver reactions, coping strategies, distress levels, acceptance of symptoms and attitudes toward clinicians and outside help may vary considerably across different cultures....” (citing “Culture and Caregiving,” 1992)**

• “All ethnic minority caregiving groups reported worse physical health than the White caregivers experienced.” (citing Pinquart & Sörensen, 2005)**

Sources:


As an advocate, a family/friend caregiver’s role involves navigating cultural or socioeconomic factors that may impact the care recipient’s access to quality health information and health care.

Addressing cultural and socioeconomic disparities can potentially improve a family/friend caregiver’s experience of caregiving and result in better health outcomes for both caregivers and their loved ones.
Additional Resources Featuring Voices of Diverse Family Caregivers

• National Alliance for Caregiving’s “Caregiving Champions” video series:
  “What Motivates You” (available at: https://www.youtube.com/watch?v=tutHYfd3Viw);
  “Why We Need Champions- Karen Marshall” (https://www.youtube.com/watch?v=u3NWgGMjGi0);
  “Why We Need Champions- Steven Vieser” (https://www.youtube.com/watch?v=qO1fY92BHXc); and
  “Why We Need Champions – Mauretta Copeland” (https://www.youtube.com/watch?v=1i1zvbCRY2U).

• The Color of Autism Foundation, http://www.thecolorofautism.org/