The Experience of Caregiving

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Presentation Objectives

- Understand the prevalence and experience of family caregivers who assist older relatives with chronic conditions
- Discuss the effects of caregiving for caregivers
- Explain interventions that lessen the negative effects of caregiving and strengthen its positive aspects
- Provide information on policy changes affecting caregivers
Prevalence and Economic Value of Caregiving

- In 2009, 42.1 million US caregivers assisted an adult with ADL limitations at any given time, and 61.6 million provided help at some time during that year (Feinberg et al., 2011)

- Economic value: $450 billion or $1,500 for everyone in US and approaching total Medicare expenditures of $509 billion (NCA, 2009)

- Economic value of caregivers assisting PswAD: $200+ billion (over 17 billion hours of unpaid care)

Prevalence in Ohio (2009)

- Total population: 11.5 million
- 2.4 million caregivers at any time during the year (20%)
- 1.6 billion hours of care
- Total value: $17.5 billion
**Future Availability of Family Caregivers?**

- Increasing number of older persons; greater rates of chronic conditions and disability in old age
- “Rebalancing” long term care away from nursing homes and to home- and community-based care
- Shrinking pool of family caregivers due to smaller families, high divorce rates, no children (10% of women in 1970s & 20% today)
- Geographically dispersed families
- Growing reliance on two-income households

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**Seeing Shift in Types of Assistance Given**

- Supervision and cueing
- Help with Instrumental Activities of Daily Living
- Help with Personal Care Assistance
- Help with *Medically complex care* (Moorman & MacDonald, 2012)
Medically Complex Care

- Provided by 46% of family caregivers (Reinhard et al., 2012)
- Medication management (78%), wound care (35%), special diets, IV therapy, monitoring specialized medical equipment
- Only 31% reported home visits by a health care professional
- Most caregivers believe this care avoided institutionalization of the care receiver

Importance of Practitioners’ Assessment of Caregivers

- Consensus panel of 54 experts on family caregiving, health & LTC developed a resource inventory of assessment measures for practitioners (practical, reliable, valid, cited in the research literature)
- Purpose: systematically determine caregivers’ needs and strengths as the basis for care planning
- Measures cover 7 domains: care context, perceptions of care receiver’s health and functioning, caregiver’s values & preferences, caregiver’s well-being, caregiving consequences, caregiver’s skills, knowledge, and abilities, and potential resources

www.caregiver.org/caregiver/jps/content/pdfs/SelCGAssmtMeas_ResInv_FINAL_12.10.12.pdf
Importance of Caregiver Assessment

- Initial assessment to establish baseline
- Reassess at point of care transitions for care receiver (e.g., hospitalization and discharge, move to AL or NH)
- Reassess at point of change in caregiver’s status (e.g., health change, retirement)
- Reassess at specific intervals to examine change in selected outcomes of interest

Caregiving’s Negative Financial Effects

- 27% reported moderate to high financial hardship (NCA & AARP, 2009)
- 24% cut back on care-related spending due to the recession
- 60% concerned about their personal savings
- 51% said the recession increased their care-related stress
- 42% spend more than $5,000 yearly for care-related expenses
Caregiving’s Negative Effects on Employment and Income

- 69% make work accommodations (flex time, cut back hours, change shifts or jobs)
- Age 50+ leaving the workforce: projected loses are $115,900 in wages, $137,980 in SS benefits, and $50,000 in pension benefits
- 43% had work hours or pay cut since the recession
- US businesses: $33.6 billion per year in lost productivity from full-time caregiving employees

Caregiving’s Negative Effects on Health

- 25% to 50% meet diagnostic criteria for major depression
- 17% to 35% report fair or poor health
- At higher risk for hypertension, heart disease, stroke, immune system dysfunction, slower wound healing, sleep problems, and psychotropic drug use (especially those caring for someone with AD)
The Experience of Caregiving

Caregiving’s Benefits

- Shift from conceptual models of caregiving as stress and burden to ones incorporating the Positive Aspects of Caregiving (Dooley et al., 2007)
- New construct: “exemplary care” (communicating that CR is loved, respected and worthy of special consideration) (Harris et al., 2011)
- Findings show caregivers of PswAD who saw themselves as giving more exemplary care reported better emotional outcomes (e.g., less depression)
- African-American caregivers had more positive perceptions of caregiving and less burden due in part to higher religiosity, lower anxiety, and less upset about problem behaviors

Resiliency Model of Family Adaptation for Caregiving Grandmothers

- Research on transitions in caregiving for 485 Ohio grandmothers over 2 years (Musil et al., 2010)
- Older grandmothers with increasing responsibilities raising grandchildren fared worse on most outcome measures
- While resiliency or learned resourcefulness was found to improve affect and cognition for elders with chronic illnesses, no significant differences in this measure were found among the caregiving groups (Zauszniewski et al., 2007)
Evidence-based Caregiver Interventions

Cognitive, Behavioral, Psychosocial
(www.rosalynncarter.org/caregiver_intervention_database)

- Anger, depression, and anxiety management
- Modeling caregiving behaviors
- Communication skills training
- Caring for a dying person
- Counseling and social support
- Family-based interventions
- Disease-specific: stroke, osteoarthritis, dementia, developmental disabilities, spinal cord, TBI

REACH: Resources for Enhancing Alzheimer’s Caregiver Health

- Longitudinal, multi-site evaluation of the effectiveness of in-person and telephone social and behavioral interventions (Elliott et al., 2010)
- Multi-component intervention to alleviate caregiver stress
- Identifies risk levels (depression, burden, self-care, social support, problem behaviors) and related interventions (education, behavioral management skills, increase social support, cognitive reframing, increase healthy behaviors)
- Findings show improved self-reported health and decreased burden in white, black and Hispanic populations
Care Consultation

- Establishes ongoing, long-term relationship with clients using telephonic counseling and care coordination (http://www.benrose.org/Research/EBP_CareConsultation.cfm)
- Provides health- and care-related information; organizes family caregivers; increases awareness and use of community services; and provides coaching and emotional support
- Targets adults with chronic health conditions or disabilities and their caregivers

Dyadic Intervention: SHARE Supporting Health, Activities, Resources, and Education

- Targets those with early stage dementia and the primary caregiver (Whitlatch et al., 2006)
- 7 sessions: to increase knowledge of dementia, improve communication skills and support in the dyad, and increase understanding of care values & preferences
- Goal: to develop a realistic plan of care involving the primary caregiver, other informal helpers and paid helpers populating circles of care with various helpers in relation to care tasks
Reducing Disability in Alzheimer’s Disease

- In-home education program by trainers (Terri et al., 2003)
- Teaches caregivers how to manage problem behaviors
- Delivers exercise training for the care receiver to improve strength, balance and flexibility
- Findings show care receivers had better physical function, less depression, and were less likely to be institutionalized

Respite Services

- Lifespan respite
- National Respite Network and Resource Center
- Ohio Respite Coalition
Affordable Care Act: New Support for Family Caregivers

- Law mentions caregivers 46 times and family caregiver 11 times (Feinberg & Reamy, 2011)
- References caregivers as decision makers about care options
- Addresses need for caregiver assessment and consideration of their experience in quality improvement of health care services
- Promotes new care models with family caregiver as key partner
- Promotes better preparation of caregivers to perform their tasks

Affordable Care Act

- Expands home- and community-based services and support to caregiving families
- Health/medical homes: required to offer families support
- Accountable Care Organizations: required to do caregiver assessments
- Geriatric Education Centers: must offer two courses annually to caregivers; practical training on giving care
References


Feinberg, L., & Reamy, A.M. Health Reform Creates New Opportunities to Better Recognize and Support Family Caregivers, AARP Public Policy Institute, Fact Sheet 239, October, 2011.


References


Rosalynn Carter Institute for Caregiving, 2012, Caregiver Assessment:

www.caregiver.org/caregiver/jps/content/pdfs/SelCGAssmtMeas_ResInv_FINAL_12.10.12.pdf


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Resources

ARCH National Respite Network
www.archrespite.org

National Alliance for Caregiving
www.caregiving.org

Family Caregiving 101
www.familycaregiving101.org/

Family Caregiver Alliance
www.caregiver.org

Thank you!

Questions or comments
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