Family Caregiving Issues and Demands

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Issue: Family Caregiving
(Hooymann & Kiyak, 2011)

Caregiving:
- Attending to another’s health needs
- Often includes assistance with ADLs

Informal Caregivers:
- Family
- Friends, neighbors, acquaintances

Older adults in the community:
- Over 80% of older adults with 3+ limitations able to live in community because of unpaid caregivers
Issue: Caregivers as Support Systems for Older Adults
(Alzheimer’s Association, 2013; McInnis-Dittrich, 2014)

- In 2012, 15.4 million caregivers provided:
  - 17.5 billion hrs of unpaid care
  - valued at $216+ billion dollars

- 80% of care provided in the community is mostly by family members

- Less than 10% of older adults receive all of their care from paid caregivers

- 22.4 million households rely on unpaid family caregiver(s)

- Demand for formal and informal caregiving expected to rise
Issue: Shrinking Pool of Potential Caregivers
(Census 2010; Hooyman & Kiyak, 2011)

- **Availability** of "natural helpers/caregivers" **declines dramatically with age**

- **Availability** of caregivers **determine** if older adult’s with long-term care needs remain at home
Issue: Impact of Demographic and Social Changes on Families
(Hooymann & Kiyak, 2011)

Intensified demands on families to provide more complex care for longer periods of time and for multiple family members

1. Rapid growth of oldest-old
2. Women employed
3. More complex family structures
4. Racial and economic inequities
5. Managed care
6. Cost-cuts to Medicaid Pts
7. Rapid hospital discharge
Issue: Spouses and Partners
(McInnis-Dittrich, 2014)

Spouses:
- 75% of men compared to less than 50% of women over age 65 live with a spouse

Life partners:
- Essential part of gay/lesbian support
  - Lack benefits
  - Lack adult children
Issue: Older Couples/Partners Face Unique Challenges

- Changing marital roles
- Retirement
- Shifting dependency roles

(McInnis-Dittrich, 2014)
Issue: Characteristics of Caregivers

(ADAMS, 2011; BRFSS, 2010; NAC/AARP, 2009; Stoukides, Holzer, Ritzau & Burbank, 2006)

Most caregivers are family members:
- 42% adult children
- 25% spouses

Caregivers for persons with AD & Other Dementias:
- 71% female
- 23% age 65+
- 50% some college education
- 59% currently employed, a student, or homemaker
- 70% married or in a long-term relationship
- 30% have children under 18
Issue: Gender as a Factor in Caregiving and Care Receiving (ADAMS, 2011)

Women as Caregivers
- 71% of caregivers are women

Women as Care-Receivers
Issue: “Graying” and Browning” of America
(Census, 2010)

“graying of America”:  
- 2010: 13% of population
- 2030: 26% of population (estimated)
- 70 million (projected),

“browning of America”:  
- 2010: 25% of 65+ ethnic/minority population
Ethnic and Racial Diversity in Caregiving
(Alzheimer’s Association, 2013; NAC/AARP, 2009)

- 54% white caregivers assist a parent; 38% other racial/ethnic groups

- Hispanic and African-American caregivers (30 hrs/wk); non-Hispanic white (20 hrs/wk); Asian-American (16 hrs/wk)

- Caregivers experiencing a high burden from caregiving:
  - 57% African-American
  - 45% Hispanic
  - 33% White and Asian-American
Types of Care Provided to People with AD and Other Dementias

(Alzheimer’s Association, 2013:30)

- ADLs
- IADLs
- Medications
- Treatment adherence
- Managing behaviors
- Finding and using support services
- Arranging for paid in-home, nursing home or assisted living care
- Other family issues, decision-making
Demand: Forms of Care Provided by Families

(Hooyman & Kiyak, 2011)

- Emotional support
- Instrumental activities (IADLS)
- Personal care (ADLS)
- Contacting and monitoring
Demand: Caregiver Strain
(McInnis-Dittrich, 2014)

Risk factors:

1. **Mortality:**
   - 63% higher

2. **Depression:**
   - 40-60%

3. **Physical illness:**
   - 25-30%
Demand: Caregiver Stress
(Family Caregiver Alliance; Hooymann & Kiyak, 2011)

1. Primary Stressors
   - derived from older adult’s illness

2. Secondary Stressors
   - Objective burden
     - Daily demands of caregiving
   - Subjective burden
     - Feelings/emotions aroused in caregiver

*Caregiver’s individual appraisal of the situation (subjective burden) more salient than objective burden (actual tasks performed)*
Stress of Caregiving: Level of Care Index
(NAC/AARP, 2009)

High Caregiving Stress Levels:
- 61% emotional stress
- 56% financial stress
- 53% family relationship issues
- 39-44% suffer from depression

Caregivers most likely to experience stress:
- Women
- Older caregivers
- Residing with care recipient
- White or Hispanic
- Believed there was no choice in taking on the role of caregiver

End-of-life care stress:
- 59% felt “on duty” 24 hrs/day
- 72% experienced relief when pt died

Causal Factors contributing to high stress levels:
- Lack of Reciprocity in Relationships
- Social Isolation
- Dynamics of Adult Child/Parent Relationship
Areas of Caregiver Burden
(Family Caregiver Alliance; Hooyman & Kiyak, 2011)

1. Poor physical and mental health outcomes
2. Financial burdens
3. Emotional burdens
1. Poor Physical and Mental Health Outcomes
(Alzheimer’s Association, 2013; Family Caregiver Alliance; Hooyman & Kiyak, 2011)

**Physical Health Problems:**
- 25-30% of caregivers
- Increased risk of cardiovascular disease:
  - High levels of stress hormones
  - Reduced immune function
  - Slow wound healing
  - Increased hypertension, coronary heart disease, impaired endothelial function in blood vessels

**Emotional Distress/ Mental Health Problems**
- Clinical Depression: 40-60%
- Major depression: 25-50%
- Increases with length of caregiving/amount of time (36+/wk)
2. Financial Burdens
(Hooymann & Kiyak, 2011; National Alliance for Caregiving and AARP)

Direct costs of care
- Financial contributions
- Home care equipment/medicine
- Hired help
- Travel costs

Indirect opportunity costs
- Reduced hours/income at work
- Early retirement
- Absenteeism/disruptions at work
- Reduced productivity at work
- Missed opportunities in career
- Inadequate accommodations
- (e.g., flex time, etc.)
- Women caregivers experience higher rates of poverty in old age
3. Emotional Burdens
(Hooyman & Kiyak, 2011; National Academy; National Alliance for Caregiving and AARP)

**Subjective burdens:**
- Worry, anxiety, feeling alone, isolated, disconnected
- “erosion of self” with identity submerged in care role
- Grief, loss, hopelessness, depression
- Negative attitudes/behaviors toward care recipient (anger)
- Guilt, anger, resentment, denial

**Objective burdens:**
- Loss of time for oneself, family, friends;
- Giving up vacations, hobbies, social life
- Strained social and family relationships
- Getting less exercise than before assuming caregiving role
Demand: Characteristics of Care-Receiver (McInnis-Dittrich, 2011)

*Degree of disability in care-receiver a key determinant of caregiver stress

- Disability
- Dementia
- Depressed
- Dependent
- Difficult
Caregiving for Relatives with Dementia
(Alzheimer’s Association; Hooyman & Kiyak, 2011)

- 70% of pts with Alzheimer’s disease (AD) are cared for at home for entire duration of the disease

- Families provide 80% of the care for pt with AD
Depression among Caregivers of Older Adults with Dementia

(McInnis-Dittrich, 2011)

- 43-52% of caregivers are depressed
  - Depression rates twice that of non-caregivers

- Rates highest among white caregivers

- Caregivers of color
  - Express depression somatically (develop health problems)
Benefits of Caregiving
(Family Caregiver Alliance; Hooyman & Kiyak, 2011)

Caregiving is multidimensional and includes both negative and positive experiences

- Personal benefits: “self-efficacy”; sense of purpose; opportunity to “work through” conflictual relationships
Caregiver Assessment
(Family Caregiver Alliance; Hartford: How to Try This; Hooyman & Kiyak, 2011)

1. Helps identify issues that might be overlooked
2. Gives the family a defined role in the treatment process
3. Validates family’s experiences
4. Reduces risks to caregivers’ well being

- Caregiver Burden Interview (CBI)
- Revised Memory and Behavior Problems Checklist (RMBPC)
- Modified Caregiver Strain Index
Moderators of Caregiver Stress

1. Emotional Support
2. Instrumental Support
3. Other Moderating Factors
Type and Focus of Caregiver Interventions
(Alzheimer’s Association, 2013)

Psychoeducational:
- Lectures, discussions and written materials

Supportive:
- Building support through caregiver group membership

Psychotherapy:
- Skill development: self-monitoring; challenging negative thoughts and assumptions; problem-solving; time management; emotional regulation

Multicomponent:
- Combinations of interventions: psychoeducational, supportive, psychotherapy, technological
Interventions with Caregivers

1. Caregiver Support Groups
   (McInnis-Dittrich, 2014)

Goals

Group Membership

Promote sensitivity to specific cultural concerns of caregivers

Support Group Activities

Role of the Leader
Interventions with Caregivers

2. Improving Caregiver/Care-Receiver Relationship

(McInnis-Dittrich, 2014)

Spousal or Partner Relationship

Adult Child/Parent Relationship
Interventions with Caregivers

3. Promoting Self-Care for the Caregiver

(McInnis-Dittrich, 2014)

- Realistically assess their abilities to provide caregiving services
- Ask for help when they need it
- Identify personal resources and mobilize other caregiver support
- Anticipate future demands and take corrective action
- Maintain their own personal sense of well-being
Tips for Family Caregivers  
(McInnis-Dittrich, 2005:341)

1. Take charge of your life
2. Be good to yourself
3. Watch for signs of depression
4. Accept help and suggest specific things to do
5. Keep informed as information is empowering
Tips for Family Caregivers
(McInnis-Dittrich, 2005:341)

6. Be open to technologies and ideas that promote independence

7. Trust your instincts

8. Grieve for your losses

9. Stand up for your rights as a caregiver

10. Seek support from other caregivers.
Formal Supports for Caregivers

- Adult day care
- Respite care
- Home health care
- Counseling in person or by phone
- Family Therapy
- Psychoeducational groups
- Training programs/skill development
- Self-care techniques
- Support groups
- Internet resources, chat rooms
References


Websites

- Caregivers:  www.caregivers.com

- Metropolitan Area agency on Aging of Minneapolis/St. Paul, MN:  www.tcaging.org

- National Alliance for Caregiving:  www.aoa.dhhs.gov/caregivers/FamCare.html

- National Family Caregivers Association (NFCA)  www.nfcacares.org