Caring for the Caregiver Across Time

Ann S. Morrison PhD, RN
Johns Hopkins School of Medicine
Alzheimer’s Disease Research Center
amorris@jhmi.edu
The Copper Ridge Institute
Radlick Nurse Scholar
Caregiver Stress

- Caregivers face similar stressors with very dissimilar outcomes.
- Caregivers possess a unique constellation of characteristics that influence their ability to take on the role.
Caregiver Stress Proliferates Across Time

- Becoming a caregiver is an unplanned career
- AD has a relentless, debilitating course
- As the patient loses function, caregiving responsibilities increase
  (inverse relationship)
There Are Stages of Caregiving

Caregiving Changes Over time

I. The Beginning

II. Learning to be a caregiver

III. Full Time Caregiver

IV. Veteran Caregiver
The Beginning

Noticing that memory problems move from occasional to a distinct pattern

1. Experience a quiet panic, fear
2. Use denial until an indisputable event occurs
3. Worry about impact of becoming a caregiver
The Beginning

Noticing that memory problems move from occasional to a distinct pattern

4. May have little physical care
5. Has a large psychological adjustment
6. Lots of planning needed
Learning to be a Caregiver (Early Stage Dementia)

Goals for this stage

- Learn to manage care
- Plan for later stages
- Understand limitations
- Strengthen support mechanisms
Learning to be a Caregiver (Early Stage Dementia)

Goal is to educate yourself and prepare for months ahead

- Dispel myths you may have
- Learn primarily stage specific information
- Learn the difference between STM and LTM
- Remember family members at different points of understanding and acceptance
Learning to be a Caregiver (Early Stage Dementia)

- Learn reasons for changes seen (problems other than memory)
- Get a list of available resources (Alz Assoc)
- Think about trips, future choices such as moving
Learning to be a Caregiver (Early Stage Dementia)

Tasks

1. Create a schedule for patient (calendar, recorders, speed dial)
2. Use “memory places”
3. Have care recipient write and rehearse for important phone calls
4. Use a spiral bound notebook for chores and phone numbers, important conversations
Learning to be a Caregiver (Early Stage Dementia)

5. Organize important papers, doctors phone numbers, medicine lists, relatives phone numbers
6. Learn when to call for help
7. Strengthen friendships and social ties
8. Extra effort for pleasurable activities
9. Buy the expensive bottle of wine!
Full time Caregiver (Middle Stage Dementia)

Repatterning of Care - Wuest, 2000

1. Caregiver struggles to respond to care demands
2. Work and family relationships altered
3. Becoming difficult to address competing responsibilities

Full time Caregiver
(Middle Stage Dementia)

4. Experience care dilemmas
5. Recognize altered prospects for the future
6. Experience ambivalence
Full time Caregiver
(Middle Stage Dementia)

Goals

- Reduce expanding stress by learning advanced care skills and problem solving skills
- Contain stress by reinforcing support systems and maintenance of self-interests
- Accept limitations
Objective Primary Stressors
Direct result of the disease process

Patients Needed Care
- Degree of Cognitive Impairment, Functional Loss
- Problematic Behavior, Resistance to Care

Caregivers Response to Needed Care
- Based upon what you know
- Willingness to take on role
- Emotional response to the disorder and secondary life changes
Secondary Stressors

Direct caregiving stressors give rise to stressors outside the boundaries of caregiving. These stressors arise as a consequence of caregiving:

- Constriction of social life /leisure time
- Financial Concerns
- Family Conflict
- Isolation
- Role overload
- Loss of self (loss of self-validating experiences)
Full time Caregiver
(Middle Stage Dementia)

Reduce expanding stress

- Therapeutic processing
  - Expressing feelings and concerns
  - Learning concrete problem solving
  - Understanding feelings of others
- Accepting limitations of care recipient
  - Decrease resistance to the situation
  - Reframing perceptions
Full time Caregiver (Middle Stage Dementia)

Reduce expanding stress

- Accept relief with care
  - Day care, in home help, temporary respite
- Have a realistic appraisal of care recipient functioning
- Learn about the non-memory symptoms of AD
Full time Caregiver (Middle Stage Dementia)

Contain proliferation of stress

- Learn advanced care skills
  - Reading body language, managing agitation
- Problem solving skills
  - Learn sources of problems and set priorities
- Seek crisis intervention as needed
- Attention to personal needs and wants
- Ask for anticipatory guidance or what to be concerned with in the near future
Full time Caregiver
(Middle Stage Dementia)

Contain proliferation of stress

♦ Comfort and emotional support
♦ Daily structure and organization
♦ Assistance with decision making
♦ Meticulous medical care social networks
  ✿ Maintain hobbies, roles, interests

Rabins, Lyketsos, Steele. Practical Dementia Care, Oxford Press, 1999
Full time Caregiver (Late Middle Stage)

Goal/Care plan
Progressively work to accept transition of care to others
  - Round the clock care
  - Assisted living or nursing homes
  - Hospitalization
    - Have an emergency plan for caregiver OR care recipient hospitalization
Moderating Factors for the Caregiver Experience

- Age
- Gender
- Occupation
- Marital Status
- Type of relationship to pt.
- Quality of relationship to pt.
Moderating Factors for the Caregiver Experience

- Social Support (Ease of contact)
- Medical Support (MD, RN, Therapist)
- Use of Services (Day care, Counseling)
- Coping Skills
- Self-efficacy
- Caregiver Mastery
Moderating Factors for the Caregiver Experience

- Frequency of visits
- Financial Status
- Employment Status
- Duration of Care
Outcomes of Caregiving

Positive outcomes of caregiving

- Competence
- Self-worth
- Satisfaction
- Repayment
Outcomes of Caregiving

Negative outcomes of caregiving
- Depression
- Anger
- Anxiety
- Poor physical health
- Mortality
Veteran Caregiver
(Late Stage Dementia)

Interventions

Think of placement as an option throughout late stages of care

Red Flags for Caregiver burnout

- role captivity
- depression
- feelings of futility
- lack of satisfaction with CG role
Veteran Caregiver (Late Stage Dementia)

◆ Interventions
  - Monitor your health and effect caregiving has on it
  - Inquire about need for financial assistance for at home care or placement
  - Contact Department of Aging, Social Services for evaluation
  - Prepare for adjustment to placement
Veteran Caregiver (Late Stage Dementia)

- Interventions
  - Letting go of caregiver role
  - Social readjustment
  - Renew social contacts or networks
Summary

- Caregiving usually involuntary and long-term
- Responsibilities increase over time
- Success associated with flexibility and non-resistance
- Each caregiver has a unique set of strengths, weaknesses, and concerns
Conclusion

- There are predictable stages of caregiving across time.
- Early stage caregivers benefit from education and planning.
- In later stages caregivers benefit from concrete problem solving, respite, and maintenance of outside interests.
Thank You