Caring for the Caregivers

Background
1. Burden of caring for the elderly can be enormous
   o Caregivers are "hidden patients"
2. Caring for elderly and caregiver requires a team approach with physician as access point and resource guide
   o Being aware of local and national resources is essential
3. There will not be enough geriatric specialists to provide for all the elderly and their families thus putting the burden on primary care provider
4. >50 million people provide care for chronically ill, disabled or aged family member or friend during any given year
   o 60% of family caregivers are women
   o 17% of family caregivers provide >40 hours/week of care
5. Women who are family caregivers are 2.5x more likely than non-caregivers to live in poverty and 5x more likely to receive Supplemental Security Income (SSI)
6. Stressed elderly spousal caregivers with a history of chronic illness themselves have a 63% higher mortality rate than their non-caregiving peers
   o Stress in caring for persons with dementia impacts a caregiver's immune system for up to 3 years after caregiving ends

Caregiver's Assessment
1. Defining the situation and anticipating demands
   o Patient's present and expected functional and cognitive disabilities and emotional status
   o Patient's current self-care and personal needs including Activities of daily living and Instrumental activities of daily living (IADLs)
   o Treatments and procedures that need to be carried out
   o Hours per day and type of skills necessary for home care
   o Period of time that assistance is required and predictability of care needed
   o Components of home care that cause the patient and caregiver difficulty or distress
2. Knowledge
   o Expected course of disease including treatment cycles as appropriate (disease specific)
   o Patient/family expectations of disease process, including likely outcome
   o Expected side effects and symptoms from therapy and long-term effects from the disease, including potential complications
   o Symptom management
   o A working knowledge of a formal care plan
3. Skills
   o Monitoring the care situation
   o Interpreting the care situation and patient's status
   o Making decisions and problem solving
   o Taking action
   o Making adjustments
   o Accessing and accepting resources
   o Negotiating the health care system
   o Providing direct care
4. Family roles
   - Usual family, social, emotional, and work role of each family member, including who is the primary wage earner for the family and who is responsible for carrying the patient’s and family’s health insurance
   - Patient and caregiver roles that will be altered because of care requirements

Giving Help

1. Providing information and education
   - Symptom management (including pain control)
   - Medical care procedures and equipment
   - Evaluation and monitoring of disease and treatment
   - Coordination of care
   - Assistance with self-care
   - Assistance with cooking, cleaning, and household tasks
   - Patient household or family roles
   - Emotional support
   - Transportation
   - Financial aspects of care
   - Communication with the patient and health care providers
   - How to ask for help
   - Self-awareness of stress level and stress reduction
   - Personal time and leisure
   - Time management and priority setting
   - Problem solving
   - Social Support Services-local, regional, or national (see below) including respite services
   - Alternative Living Arrangements

2. Developing critical thinking skills
   - Creativity: Step back and view situation from new perspective
   - Optimism: realistic optimism
   - Planning
   - Expert information

3. Employing coping behaviors
   - Implement as early in the care situation as possible
   - Common strategies:
     - Praying
     - Talking with friends and relatives
     - Pursuing hobbies
     - Exercising
     - Getting help from a counselor/ professional
     - Respite care

4. Utilizing resources and finding social support
   - Health care resources- respite care, chore services, home health aides, support groups, skilled home care
   - Social resources
     - Health care
     - Family member
     - Totally unrelated to care situation
5. Warning signs of distress - Questionnaire

- Do you feel that you are currently under a lot of stress?
- What aspects of your day are more stressful?
- Have you been feeling down or blue lately?
- Have you been feeling more anxious and irritable lately?
- Do you family and friends visit often?
- Do your friends and family watch your relative for you so that you have time for yourself?
- Do you have any outside help?
- Is your relative with dementia having any behaviors, such as wandering, that are difficult to manage?
- What do you do to relieve your stress and tension?

Resources

1. Readings
   - Caring for Your Aging Parents: A Planning and Action Guide (Cohen & Eisdorfer, 1993)
   - How to Care for Aging Parents (Morris, 1996)
   - The Caregiver Survival Series (Sherman, 1994)
   - Preventing Caregiver Burnout (Sherman, 1997)

2. Web sites
   - National Family Caregivers association: http://www.nfcacas.org/
   - Alzheimer's Association: http://www.alz.org
   - American Cancer Society: http://www.cancer.org/
   - Caregiver Survival Resources: http://www.caregiver911.com/
   - Family Caregiver Alliance: http://www.caregiver.org/

References

   http://www.aafp.org/afp/20001215/2613.html and


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