FAMILY CAREGIVER SUPPORT PROGRAM

LITERATURE REVIEW

Seattle Human Services Department Aging and Disability Services
OVERVIEW

- Introduction
- Caregiver’s needs
- Effective interventions
- Culture/Race/Ethnicity
- Summary
WHO ARE THE FAMILY CAREGIVERS?

- 30-38 million CG*, 48 YO Female
- About 20-21 hours per week
- Average of 4.6 years
- Implications of caregiving
  - Economic value of $350 billion*
    - Help long-term care and health care system
  - Out of pocket expenses
  - Lost wages and retirement income
  - Lost productivity
  - Health effects

*2006 data
WHERE DO THEY GET THEIR INFO?

- Health or caregiving provider (36%)
- Internet (25%)
- Family, friends, other caregivers (20%)
Caregivers Needs – Caregivers Perspective

- Keeping the care recipient safe at home
- Managing their own stress
- Easy activities to do with care recipient
- Finding time for themselves
- Balancing work/family responsibilities
- Talking to doctors/other professionals
- Choosing home care agency
- Making end of life decisions
- Choosing assisted living facility
- Managing challenging behaviors
- Choosing nursing home
- Moving, lifting CR
- Managing incontinence

- Information about available services
- Stress management and coping strategies
- Help with financial issues and insurance coverage
- Help with communicating professionals
- Information on disease
- Help with recruiting competent help
- Help with learning care tasks
- Help with communicating with person with dementia
- Legal advice
- Information about drugs
- Help with addressing end-of-life issues
- Advice on moving recipient to a facility
- Help with dealing with family
CAREGIVERS NEEDS – PROFESSIONAL PERSPECTIVE

• Lack of confidence and feel unprepared
  - How to manage CR symptoms, cognitive stimulation, supervision, monitoring, medication administration, communication, memory enhancement, problem solving.
  - Increase knowledge for goal directed behaviors and priority-setting, decision-making, and problem-solving.
  - Deal with difficult situations – anger, depression, rehabilitation, disruptive behaviors, incontinence.
**Effective Interventions**

- Psychoeducational or psychotherapeutic
  - Applying general information to specific situations
- Multidimensional or multicomponent
  - Addressing various stressors that affect caregivers health and wellbeing
  - Combining different forms of interventions such as education, support groups, and respite
- Interventions need to be flexible
  - Tailoring individual needs of the caregiver
- Dosage of treatment varies
LIMITATIONS TO RESEARCH

- Mismatch treatment goals to caregiver needs
- Measurement of outcomes to problems that do not exist – intervention may not be “effective”
- Culture/Race/Ethnicity may influence treatment goals
CULTURE/RACE/ETHNICITY

- Measurement of outcomes
  - Caregiver burden/depression may not be recognized or reported as readily

- Cultural norms and traditions
  - Cultural value of caregiving
    - Personal satisfaction and fulfillment
    - Sense of filial piety – respecting and taking care of parents as they age
CULTURE/RACE/ETHNICITY - BARRIERS

• Reliance on informal support network
  – May provide misinformation
• Lack of knowledge of available services
• Mistrust of formal service providers
  – Distrust of dominant culture
• Services unavailable or inappropriate
  – Language barrier
  – Not culturally-specific or tailored to cultural traditions
**Conclusion**

- "One-size fits all" approach does not work
  - Interventions must be tailored to caregiver needs and situation
  - Multidimensional/multiple component – not just one type of intervention
- Education with active role-playing
- Family-centered approach
- Culture/Race/Ethnicity appropriate providers
FOR MORE INFORMATION

Contact:
Doug Ricker, Lead Planner
Aging and Disability Services
Seattle Human Services Department
Doug.Ricker@Seattle.Gov
206-684-0292
REFERENCES


