



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

- AARP: Public Policy Institute. (2006). Valuing the invaluable: A new look at the economic value of family caregiving.
- Ayalong, L. (2004). Cultural variants of caregiving or the culture of caregiving. *Journal of Cultural Diversity*. 11(4) 131-138.
- Belle, S.H., Burgio, L., Burns, R., Coon, D., Czaja, S.J., Gallagher-Thompson, D...Zhang, S. (2006). Enhancing the quality of life of dementia caregivers from different ethnic or racial groups: A randomized control trial. *Annals of Internal Medicine*. 145(10), 727-738.
- Callahan, C.M., Boustani, M.A., Unverzagt, F.W., Austrom, M.G., Damush, T.M., Perkins, A.J.,...Hendric, H.C. (2006). Effectiveness of collaborative care for older adults with Alzheimer Disease in primary care. *Journal of the American Medical Association*. 295(18), 2148-2157.
- Given, B., Sherwood, P.R. & Given, C. (2008). What knowledge and skills do caregivers need? *American Journal of Nursing*. 108(supp9), 28-34.
- Etters, L., Goodall, D & Harrison, B. (2008). Caregiver burden among dementia patient caregivers: A review of the literature. *Journal of the American Academy of Nurse Practitioners*. 20, 423-428.
- Montgomery, R.J. & Kosloski, K. (2009). Caregiving as a process of changing identity: Implications for caregiver support. *Journal of the American Society on Aging*. 33(1), 47-52.
- National Alliance for Caregiving. (2009). Caregiving in the U.S. Washington, D.C.: Naiditch, L. & Weber-Raley, L.
- Pinquart, M. & Sorensen, S. (2006) Helping caregivers of persons with dementia: which interventions work and how large are their effects? *International Psychogeriatrics*. 18(4), 577-595.
- Savundranayagam, M.Y. & Montgomery, R.J. (2009). Impact of role discrepancy on caregiver burden among spouses. *Research on Aging*. 32(2), 175-199.
- Scharlach, A.E., Kellam, R., Ong, N., Baskin, A., Goldstein, C. & Fox, P.J. (2006). Cultural attitudes and caregiver service use: Lessons from focus groups with racially and ethnically diverse family caregivers. *Journal of Gerontological Social Work*. 47(1/2), 133-156.
- Wisniewski, S. R., Belle, S.H., Marcus, S.M., Burgio L.D., Coon, D.W., Ory, M.G., Burns, R. (2003). The Resources for Enhancing Alzheimer's Caregiver Health (REACH): Project Design and Baseline Characteristics. *Psychology and Aging* 18(3), 375-384.
- Yedidia, M.J. & Tiedemann, A. (2008). How do family caregivers describe their needs for professional help? *American Journal of Nursing*. 108(supp9), 35-37.
- Zarit, S. & Femia E. (2008). Behavioral and psychological interventions for family caregivers: Characteristics of effective approaches and flaws in study design. *American Journal of Nursing*. 108(supp9), 47-53.