DYSFUNCTION JUNCTION: MANAGING COMPLEX PATIENTS AND COMPLEX FAMILIES

“BEST PRACTICES: Care for the Community Dwelling Older Adult”
Annual Conference of the Nebraska Geriatric Education Center

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PRESENTATION OBJECTIVES

1. Explain the significance to older adults of the environment and social supports, including the caregiver relationship.

2. Describe how and who becomes a caregiver and the impact of this process on the caregiving relationship.

3. Identify the effects of caregiving, including stress, burden, and risks.

4. Identify caregiver supports/resources that ensure quality of care and that maximize caregiving outcomes.

I have no conflicts of interest with respect to any product or commercial interest.
**SIGNIFICANCE OF ENVIRONMENT AND SOCIAL SUPPORTS**

(Donabedian, 1980; Gamroth, Semrak, & Tornquist, 1995; Hill, 2001; Keigher et al., 2000; Kelley-Gillespie, 2003; Lehman et al., 1991; Noelker & Harel, 2001)

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<th>CAREGIVING EXPERIENCE</th>
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<th>QUALITY OF LIFE</th>
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<td>• Socialization</td>
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CASE SCENARIO
Mrs. G.

• Patient Description

• Medical History

• Social History
CASE SCENARIO

“I know she shouldn’t be living alone anymore, but I am struggling with all the issues involved in moving her somewhere so she gets the care she needs. I don’t know what to do with her and she refuses to think about going into a nursing home. We moved her to Omaha a few years ago to be closer to me and my sisters, but my sisters don’t help me take care of her. It’s like they don’t see anything wrong with her. Sometimes they even accuse me of taking advantage of mom and stealing money from her. They just don’t see that she can’t even afford her own bills—my husband and I help her financially! They don’t contribute a dime! And they have their own issues—I guess…one is going through a divorce. The other has a sick kid. My brother is also no help. He has his own issues with drugs and alcohol—that’s one of the other reasons why we moved her to Omaha—to get away from him; he’s just a freeloader. But, my husband and kids are fed up with me and how much time I spend with my mother and taking care of things for her. They don’t give me a break—they don’t understand how exhausted I feel! I can’t sleep at night; I’ve gained weight; and, as if turning gray isn’t bad enough, now I’ve been losing my hair too! I feel extremely overwhelmed and am at my wits end!”
WHO IS A CAREGIVER?

(Family Caregiver Alliance, 2001)

A typical caregiver in the U.S. is female, approximately 46 years old, has at least some college experience, spends an average of twenty hours or more per week providing unpaid care to someone 50+ (most likely her mother), is married, is still raising children at home, has an annual income of less than $50,000, and has juggled work and family with caregiving responsibilities at some point during her role as a caregiver.
FAMILY DYNAMICS: DETERMINANTS AND PATTERNS OF CAREGIVING

(Carers Australia & National Centre for Social and Economic Modelling, 2004; Kelley-Gillespie, under review; McCallion, Toseland, Gerver, & Banks, 2004)
“Caregiving does not emerge with a life of its own, but takes place within an historical context. Both the aged relative and the caregiver enter the relationship with a history of interactions which may either facilitate or impede the caregiving relative in his/her attempts to fulfill caregiving responsibilities.”
CONSIDERATIONS OF FAMILIES AS SYSTEMS

(Mancini, 1989; Margles, 1995)

- each family member is interconnected with each other
- common values, beliefs, culture, behavioral patterns, shared experiences
- lines of communication, structure, and authority
- boundaries, expectations
IMPLICATIONS OF CAREGIVING

(Carers Australia & National Centre for Social and Economic Modelling, 2004; Estes et al., 1993; Kelley-Gillespie, under review; McCallion, Toseland, Gerver, & Banks, 2004; Scharlach & Kaye, 1997; Matras, 1990; Neysmith, 1999; Spillman & Black, 2005)
“NO CARE ZONE:” THE INFORMALIZATION OF CARE

(Estes et al., 1993)

Increased reliance on informal home-based caregiving
+ the process of transferring selected services out of the formal delivery system into the informal provision arena
+ the physical, intellectual, emotional, and economic responsibilities for that care are also transferred

= Results in a “No Care Zone”
IMPACT OF CAREGIVING: STRAIN AND STRESS

(Carers Australia & National Centre for Social and Economic Modelling, 2004; Estes et al., 1993; Kelley-Gillespie, under review; McCallion, Toseland, Gerver, & Banks, 2004; Scharlach & Kaye, 1997; Matras, 1990; Neysmith, 1999; Spillman & Black, 2005)

• Physical health
  – 1 out of 6 caregivers consider their health fair or poor
  – 15% say caregiving has made their health worse
  – 1 out of 4 caregivers say they exercise less than before they took on caregiving responsibilities

• Mental health
  – 1 out of 3 caregivers report emotional stress related to their caregiving responsibilities
  – Caregivers experience depression at higher rates than the general population (especially women), and are more frequently anxious, more likely to use psychotropic medications, and exhibit more symptoms of psychological distress
  – Family members of caregivers also experience high rates of depression
IMPACT OF CAREGIVING: STRAIN AND STRESS (cont’d)

• Family and leisure activities
  – Half of caregivers say they have less time for family and friends, including vacations, hobbies, and other social activities

• Work
  – 6 out of 10 caregivers report that caregiving responsibilities have affected their work and resulted in work-related adjustments

• Financial hardship
  – 54% of nonspousal caregivers contribute financially to the care of their recipient
  – Caregivers spend an average of $200 per month on care
  – 12% of caregivers experience considerable financial hardship
CAREGIVER STRESS

• 2 out of 3 need help with managing emotional and physical stress, balancing work and family responsibilities, and finding time for themselves.

• Health of the caregiver and *level of choice* in taking on the caregiving role are the two greatest predictors of perceived *physical strain*.

• Level of burden and *level of choice* in taking on the caregiving role are the two greatest predictors of perceived *emotional strain* and *financial hardship*. 
CASE SCENARIO

• Mrs. G. does not currently utilize any community care services other than MoW.
• Family voices concern that she is no longer able to live independently and seeks help from us in determining the appropriate level of care and types of alternate living arrangements needed and/or resources available.
• What would you do first? What recommendations would you make?
ASSESSMENTS

• Health/mental health—r/o delirium, dementia/Alzheimer’s, depression, anxiety, suicide, eating disorder/nutritional issues, adverse medication effects; obtain dental check; assess fall risk
  • http://www.hartfordign.org/resources/education/tryThis.html
  • http://www.nursing.umn.edu/CGN/ResourcesEducators/AssessmentDementia/home.html
• Caregiver stress assessment
  • http://www.ama-assn.org/ama1/pub/upload/mm/433/caregiver_english.pdf
• Elder Abuse/Neglect assessment
  • http://www.hartfordign.org/publications/trythis/issue15.pdf
COMMUNITY RESOURCES/SOLUTIONS

Caregiver Support
- Caregiver Support Groups
- Respite Care
- Alanon
- National Caregiver Organizations/Websites
- Disease-Specific Organization (e.g., NAMI, Alzheimer’s Association)
- Family Medical Leave, Dependent Care Benefits
- Grandparents Raising Grandchildren Support Groups/Services/Resources

Information and Referral Sources
- 2-1-1, Answers4families, CHIRS, AAA, Elder Services Community Resource Directory
- Benefits Checkup

Legal
- Advanced Directive
- R/O Need for Guardian/Conservator
COMMUNITY RESOURCES/ SOLUTIONS (cont’d)

In-Home Resources
- Home Care Worker, Home Health Nurse; Homehealth Compare
- PT; OT; ST; Nutritionist/Dietician (Depending on Nutritional Assessment/Eating Disorder Issue)
- Mobile Medical Care
- In-Home Fall/Safety Assessment—Make Arrangements for Suggested Modifications Via Community Services Assistance (Durable Medical Equipment, Adaptive Equipment, Assistive Technology)
- Lifeline Medical Alert System
- Friendly Visiting/Companion Programs
- Church Supports-- Pastoral Care/Counseling, Stephen’s Ministries, Parish Nursing

Community Resources
- Adult Day Care
- Senior Center
- Transportation/Escort Services
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<th>Mental Health</th>
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<td>Medicaid, Including Medicaid HCBS Waiver</td>
<td>Grief/Bereavement Services/Support Groups (e.g., LADOS, WDS)</td>
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<td>SSI Eligibility</td>
<td>Hobbies/Interest Groups</td>
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<td>Medicare Part D</td>
<td>Recreational/Leisure/Entertainment Opportunities</td>
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<td>Medicare Supplemental Insurance</td>
<td>Creativity Programming</td>
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<td>Pharmaceutical Assistance Programs and Pharmacy Copay Plans (e.g., Walgreens, Hyvee, Walmart)</td>
<td>Leaving A Legacy</td>
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<td>MedicareRx Compare</td>
<td>Arts/Poetry/Writing</td>
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<td>Life Long Learning</td>
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<td>Computer Classes</td>
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<td>Volunteer Opportunities (e.g., RSVP, Foster Grandparent)</td>
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<td>Outpatient and/or Home-Based Mental Health Programs</td>
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<td>Housing</td>
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<td>Subsidized Senior Housing Programs/Rental Subsidy</td>
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<td>Utility Assistance Programs</td>
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<td>Assisted Living</td>
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<td>Nursing Home; Nursing Home Compare</td>
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EXAMPLES OF HELPFUL WEBSITES AND RESOURCES

- Benefits and Rx CheckUp
  https://ssl4.benefitscheckup.org/
- UNMC CHIRS: Consumer Health Information Resource Services
  http://www.unmc.edu/library/consumer/
- Answers4Families
  http://www.answers4families.org/
- 2-1-1
  http://www.ne211.org/index.php
- ElderCare Locator
  http://www.eldercare.gov/Eldercare/Public/Home.asp
- Medicare (Nursing Home Compare, Hospital Compare, Prescription Plan Compare, Home Health Compare, Compare Dialysis Facilities, Health Plans and MediGap Policies Compare)
  http://www.medicare.gov/

- NE DHHS: State Office on Aging
  http://www.hhs.state.ne.us/ags/agsindex.htm
- Full Circle of Care
  http://www.fullcirclecare.org/index.shtml
- National Family Caregiver Support Program
  http://www.aoa.gov/prof/aoaprog/caregiver/careprof/state_by_state/state_contact.asp
- Strength for Care
  http://www.strengthforcaring.com/util/resources/states/state/nebraska.html#State_/County_Caregiving_Resources35
- AARP
  http://www.aarp.org/
- ElderCare Resource Handbook
  http://www.careconsultants.com/handbook.html
Take Away Points

• End goal = maximize Quality of Care

• Be careful about “assigning” family members as caregivers

• QoL $\neq$ HRQoL

• No premature decisions about patients not being able to “age in place”
IT'S HER HEART AGAIN, ISN'T IT?
She has no energy. She can't breathe.

THEY'VE DONE EVERYTHING THEY CAN DO.
Is mom in the hospital?

NO. SHE'S AT HOME. I'VE BEEN TAKING CARE OF HER.
Dad, that's too much for you!

STRANGE ... I THOUGHT I WASN'T DOING ENOUGH.


