UNDERSTANDING AND MANAGING FAMILY DYNAMICS WHEN MAKING BIG DECISIONS

Nebraska Long Term Care Partnership Renewal
“Someday is TODAY”

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TODAYS 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. Portray the experiences of role reversal among family members.
4. Identify ways families cope with changing roles, relationships, and expectations.
5. Identify the effects of caregiving, including stress, burden, and risks.
6. Identify supports/resources that ensure quality of care and maximize caregiving outcomes.

FAMILY DYNAMICS, CAREGIVING, QUALITY OF CARE, AND QUALITY OF LIFE
WHO IS A CARE RECEIVER?

- 65% of care recipients are female
- 52% of older care recipients are widowed
- 8 out of 10 care recipients are aged 50+ (average age = 75)
- 55% of care recipients live in their own home; 53% of older care recipients live alone
- 25% of care recipients have Alzheimer’s or another form of dementia
- 9 out of 10 care recipients 50+ take prescription medications

WHAT IS “CAREGIVING?”

WHO IS A CAREGIVER?

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/mother-in-law), 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

CONSIDERATIONS OF FAMILIES AS SOCIAL SYSTEMS
• Varied configurations of families
• Each family member is interconnected with each other
• Common values, beliefs, culture, behavioral patterns, shared experiences
• Lines of communication, structure, boundaries, hierarchy, and authority
• Expectations, roles, relationships

TYPES OF FAMILIES
1) Tight-knit
2) Sociable
3) Intimate but distant
4) Obligatory
5) Detached
DETERMINANTS OF CAREGIVING

- Geography/location
- Frequency of contact
- Level of communication
- Level of affection/attachment
- Family structure/position/gender
- Filial responsibility/obligation
- Merits/debts
- Employment
- Perceived skill, capacity, resources
- Cultural values

DIVISION OF RESPONSIBILITY

- greater division of responsibility among multiple children
- loose sibling relationships facilitate parent-caring process, as those who are close are most likely to share the care

IMPLICATIONS OF FAMILY DYNAMICS AND CAREGIVING

- Responsibilities
- Roles
- Expectations
REVERSAL OF PARENTING ROLES

- “Role Reversal” – a shift in the roles, responsibilities, and balance of power in which adult children assume increasing responsibility for a parent, while the roles of the parent change accordingly.

- “Filial Maturity” – the ability to accept the parents’ dependency as appropriate and to take whatever responsibility is indicated by the situation of the person with dementia and the situation of the total family.
  ~ “You know what’s right, but it’s still your mother.”

“NEW” STAGES OF GRIEF

1) Crisis
2) Unity
3) Upheaval
4) Resolution
5) Renewal

A MODEL FOR FAMILY COPING ACROSS THE TIME PHASES OF ILLNESS/DISEASE

Crisis  Chronic  Terminal

Pre-Dx  Dx  Initial  “Long Haul”  Pre-terminal  Death  Morning & Resolution of Loss
IMPLICATIONS OF CAREGIVING

"NO CARE ZONE:" THE INFORMALIZATION OF CARE

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 & STRESS

• Physical health
• Mental health
• Family and leisure activities
• Work
• Financial hardship
CHOICE AND STRESS

- Health of the care partner 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.

ONE LAST THING: DID YOU KNOW?

WHAT IS ELDER ABUSE?

**Definition:** Intentional or neglectful acts by someone with an ongoing relationship and duty toward that elder leading to harm of a vulnerable adult age 60 or 65 or older.

- 1 in 10 are reported.
- Can occur anywhere: home, nursing home, or other institutions.
- Women and “older” adults are more likely to be victimized.
- The perpetrator is 90% likely to be a family member.
- Dementia (51%), Mental Health and substance abuse issues of both abuser and victim is a significant risk factor.
WHY DOES IT HAPPEN? WHY IS IT INCREASING?

- Family dynamics
- Caregiver issues
- Cultural issues
- Advanced Age
- Emergence of Earlier Abusive/ Traumatic Events

WHERE TO GO FOR HELP?

- Adult Protective Services: (800) 652–1999 in Nebraska and (800)362-2178 in Iowa
- Long term Care Ombudsman 1-800-942-7830. If calling from outside Nebraska, telephone 1-402-471-2307
- Office on Aging www.enoa.org
- Geriatric Assessment Clinic (UNMC, Methodist, VA, Pender, NE)
- Primary Care Providers and Case Managers
- Home Care Agencies: Home Safety Assessment

Other community resources:
- www.unmc.edu/homeinsteadcenter (Community Resource Guide)
- www.Alz.org
- www.aarp.org
- Family Caregiver Alliance: www.caregiver.org
- National Center for Elder Abuse: www.elderabusecenter.org

COMMUNITY RESOURCES/ SOLUTIONS

Caregiver Support
- Caregiver Support Groups
- Respite Care
- Al-a-non
- 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
**CONTINUED**

### 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
- Adult Day Care
- Senior Center
- Transportation/Escort Services

### CONTINUED

### 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

### CONTINUED

### Housing
- Subsidized Senior Housing Programs/Rental Subsidy
- Utility Assistance Programs
- Assisted Living
- Nursing Home; Nursing Home Compare

### Financial/Insurance
- Medicaid, Including Medicaid HCBS Waiver
- SSI Eligibility
- Medicare Part D
- Medicare Supplemental Insurance
- Pharmaceutical Assistance Programs and Pharmacy Copay Plans (e.g., Walgreens, Hyvee, Walmart)
- MedicareRx Compare
CONTINUED

Mental Health

– Grief/Bereavement Services/Support Groups (e.g., LADOS, WDS)
– Hobbies/Interest Groups
– Recreational/Leisure/Entertainment Opportunities
– Creativity Programming
  • Leaving A Legacy
  • Arts/Poetry/Writing
  • Life Long Learning
  • Computer Classes
  • Volunteer Opportunities (e.g., RSVP, Foster Grandparent)
– Outpatient and/or Home-Based Mental Health Programs

COPING STRATEGIES

• Education/training
• Peer support/support groups
• Telephone reassurance
• Professional guidance
• Counseling
• Self-care practices
• Access resources
• Family conference
• Prayer/faith connections

ASSESSMENT OF THE FAMILY DYNAMICS

• In general, without referring to individuals, how would you describe your family’s functioning?
• How has the family handled past challenges (homeostasis)?
• Think about your role in the family. How is this alike or unlike your view of yourself in other settings?
• Ask each family member about his/her role in the family & the role historically with the care receiver.
QUESTIONS TO CONSIDER

• What are the family rules articulated by family members?
• What are the roles?
• What relationship dynamics/patterns have been described?
• What do you need to assess further?
• Who should be at the family meeting?
• What are the priority areas?
• Community referrals?

TAKE AWAY POINTS

1. Caregiving takes place within an historical family context.
2. Types of families and relationships among family members determine caregiving responsibilities, roles, and expectations.
3. Role reversal is challenging for all family members and is an ongoing process as the disease progresses.
4. Families can effectively grieve losses.
5. Families can effectively cope with changing roles, relationships, and expectations and the stresses of caregiving.
6. End goal = maximize Quality of Care in order to maximize Quality of Life.
7. Be careful about “assigning” family members as caregivers.
8. QoL ≠ HRQoL
9. No premature decisions about patients not being able to “age in place.”

REFERENCES

REFERENCES (CONTINUED)


REFERENCES (CONTINUED)


