CREATING SUSTAINABLE FAMILY CAREGIVING RELATIONSHIPS

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TODAY’S TALK

- Family caregiving in America
- Research overview
- A conceptual model of family stress
- Identifying meanings/beliefs that facilitate and obstruct family caregiving efforts
- The sibling meeting
- Working with couples in caregiving families
FAMILY CAREGIVING IN US

- NAC/AARP 2009 study: 65 million Americans providing care during the course of a given year (49 M for adults over age 50)
- 31% of all US households
- Most typical: 48-year-old woman taking care of a parent for about 4 years as well as working part-time
US CAREGIVING (cont.)

- Great heterogeneity—every family has its story (and community and culture)
- 66% female; 34% male
- 72% white; 13% African-American; 12% Latino
- 2.4 M grandparents; 1.3 M children as caregivers
- Range of emotional reactions: 31% highly stressed; 25% not at all stressed
THE DESCENDANTS (2011)
ROBOT & FRANK (2012)
AMOUR (2012)
Numbers of family caregivers growing because of demographics, medical advances

More than 5 M Alzheimer’s patients today; by 2050, 11.5-16 M (Alzheimer’s Association)—70% cared for at home

Average life-span of Alzheimer’s pt at diagnosis: 7-8 years

Most common answer caregivers give when asked (at pt’s diagnosis) how long they think they’ll have to care: 2 years
RESEARCH ON CAREGIVING’S EFFECTS ON CAREGIVERS

- Long-term caregiving (Schulz & Martire, 2004) linked with:
  - Insomnia
  - Depression and anxiety
  - Musculoskeletal problems (e.g., back pain)
  - Decreased immune system functioning
  - Decreased use of preventative medical services
  - Increased mortality (Schulz, JAMA, 1999)
RESEARCH (cont.)

- Worse for spouses (6 times greater risk of depression) than adult children (2 times)
- Key variables for dementia caregiving: agitation; patient’s inability to perform ADLs; perception that loved one is suffering
Examples of other factors studied:
- Race/ethnicity: (African-Americans, Latinos cope better than whites)
- Gender (females more likely to become depressed/anxious)
- Education (less education, less burden)
BUT: Not all effects of caregiving are negative.

Caregiving brings "strains and gains"; latter includes spiritual growth, personal growth, feelings of mastery.

Death of loved one brings relief but also, for some, increased degree of grief and depression.
THE CAREGIVING CAREER

Aneshensel et al., 1995
Chronic Stress Trajectory

Schulz, 2010

Psychologic\al Appraisal

Initiate IADL CG

Benign

Distress

Psychiatric/Physical Morbidity

Death

Continued Depression/Reengagement

Recovery

Health Effects

Minor

Expand ADL CG

Placement

Death

Health Effects

CG/CR Trajectory

Initiate IADL CG

Expand ADL CG

Placement

Death

Relief
QUESTIONS

What, if anything, surprises you about these findings?

How do they square with your personal and professional experiences?
INTERVENTION RESEARCH

- Rosalynn Carter Institute: Elements of evidence-based support programs:
  - **Frequent contact** with helping professional over extended period of time who has specific intervention protocol of **higher intensity**
  - Provision of **multi-components** including knowledge, skill-building, problem-solving, counseling
  - Use of **multiple means of contact** including in-person, telephone, Internet
Noted example: Mary Mittelman’s NYU Caregiver Intervention—increases caregiver well-being, forestalls nursing home placement of Alzheimer’s patients for nearly 2 years (2006)

Also: REACH II, Savvy Caregiver, Environmental Skill-Building, FOCUS, COPE
QUESTION

What have you found to be the key elements to your clinical success with family caregivers?
A CONCEPTUAL MODEL OF FAMILY STRESS (1958)

Reuben Hill’s ABC-X Model

A Stressor Event
Normative-developmental or Exceptional; Acute or Chronic

B Family Resources

C Interpretation of Stressor

X Crisis

01/18/2000 Chapter 14
McCubbin’s Double ABC-X Model (1982)
ABC-X of CAREGIVING

- A—functional decline due to physical, cognitive and/or behavioral impairments
- Different illnesses and disabilities pose different challenges to families, depending on severity and course of condition and developmental stage of family
- B—family’s material resources (money, insurance, availability of local programs)
- External psychological resources (support from extended family members, neighbors, social service/healthcare professionals)
- Internal psychological resources (capacities to communicate, agree on decisions, solve problems, take concerted actions, tolerate emotions, etc.)
C—Meaning (personal, spiritual, cultural, community-sanctioned) that family members attribute to loved one’s illness/disability and to caregiving endeavor

Example: “Caregiving is an opportunity for growth” vs “Caregiving is a trap”
Some beliefs act as barriers to caregiver coping (Losada et al, 2006)

“I should set aside my interests and dedicate myself completely to the care of my relative”

“A caregiver should only seek help from others when she doesn’t know how to solve a problem”
C (MEANING) INTERVENTIONS

- Exploring attributions about cause of loved one’s disability
- Identifying goals (prospective retrospection); hierarchy of care recipient needs
- Honoring the Mission
- Marathon metaphor
- Normalizing ambivalence
- Challenging perfectionism
- Receiving with grace
- Challenging negative spirituality
Overarching goals:

Assess meanings

Make subconscious/unspoken perceptions, beliefs and goals more visible and modifiable

Foster conscious, intentional, realistic decision-making to increase sustainability
4 CATEGORIES OF MEANINGS/BELIEFS

- Beliefs about nature and cause of loved one’s illness (attributions)
- Beliefs about one’s sense of purpose and responsibility in making sacrifices on behalf of a loved one (“Why?”)
- Beliefs about setting limits and receiving help
- Beliefs about healthcare and social service professionals
EXPLORING ATTRIBUTIONS

- Assumption: A caregiver’s belief about cause of a loved one’s behavior or dysfunction will affect her willingness to caregive (e.g., Wadley, Haley, 2001) and her capacity for coping

- “The care recipient is engaging in disruptive behavior to spite me” (Burgio et al, 2003)

- Transcripts of wife, siblings
ATTRIBUTIONS (cont.)

- Interventions:
- Avoid confrontation between yourself and caregiver or between primary caregiver and other family members
- Increase scope of information that is available to all family members
- Suggest beliefs are rooted in past experiences
- Separate past from disease
CHALLENGING NEGATIVE SPIRITUALITY

- Some caregivers of strong faith will believe that care recipient’s illness and caregiving are punishments from God or that God has abandoned them (Pargament et al, 1998)
- Will increase passive acceptance, depression
SPIRITUALITY (cont.)

- Interventions:
  - Question whether illness/caregiving are punishment or test from God
  - Advise seeking religious counsel
  - Encourage continued fellowship with spiritual community
  - Bolster spiritual practice, even when belief falters
BELIEFS ABOUT PURPOSE: NORMALIZING AMBIVALENCE

Assumptions: 1) Many caregivers have mixed feelings about their caregiving tasks (if not about their missions to care)

2) They feel guilty about their negative feelings toward caregiving

3) To assuage guilt, they redouble their efforts at caregiving tasks—leads to increased rigidity about routines as well as heightened reluctance to accept support
AMBIVALENCE (cont.)

- Interventions:
  - Identify negative feelings as normal, expectable
  - Distinguish between hating caregiving tasks and hating caregiving or care recipient
  - Give permission to hate and to set limits on caregiving tasks
CHALLENGING PERFECTIONISM

- Assumption: Many caregivers try to be “perfect” to decrease ambivalence, guilt
- Interventions: Most loved ones need “good enough” caregiver, not perfection
- Foster comparisons with others’ beliefs (e.g., support group, books, websites)
ALLIANCE-BUILDING BY HONORING THE MISSION

- Solicit the story of giving care
- Avoid premature advice-giving
- Inquire about meaning of caregiving in caregiver’s life
- Identify and honor caregiver’s sense of mission
- Raise issue of sustainability
- Inquire about sources of sustenance
- Transcript of daughter
BELIEFS ABOUT LIMITS: IDENTIFYING GOALS

- Assumption: Many caregivers fling themselves into caregiving with no clear goals or unspoken, unrealistic ones

- “I’ll do whatever it takes”

- “If I’m a good enough caregiver, I can restore him to who he was (and prove the ‘experts’ wrong)” (e.g., Jacobs, 1997, 1999)
Interventions:

- Increase information over time
- Develop sense of range of options within goals (see “Hierarchy”)
- Encourage caregiver to define her own commitments and limitations
- Discuss multiple means (i.e., outside supports) to same goals
Prospective retrospection: “When you look back at this time 5 years from now, how do you think you’ll regard what you accomplished as a caregiver?”

Regrets? Appreciation of commitments upheld?
HIERARCHY OF (CARE RECIPIENT) NEEDS

ABRAHAM MASLOW
HIERARCHY OF NEEDS

Maslow, A. Motivation and Personality (2nd ed.)

- Physiological
  Food, Water, Shelter, Warmth

- Safety
  Security, Stability, Freedom from Fear

- Belonging - Love
  Friends, Family, Spouse, Lover

- Self-Esteem
  Achievement, Mastery, Recognition, Respect

- Self-Actualization
  Pursue Inner Talent, Creativity, Fulfillment
QUESTIONS

- Is it acceptable or guilt-inducing for a caregiver to commit to providing for a loved one’s Physiological and Safety needs but not higher needs?
- Does your program support a caregiver’s commitment to providing for a loved one’s needs for Belonging and Self-Esteem?
MARATHON METAPHOR

- Assumption: Many caregivers jump into caregiving pursuit without knowing its length or requirements
- Caregiving as marathon, not sprint:
  - Have to learn the up-hills and down-hills of the lay of the land (disease)
  - Have to learn to pace oneself
  - Have to learn to replenish along the way
- All are essential—or don’t finish race
RECEIVING WITH GRACE

- Assumption: Most of us would rather give than receive
- But running best race means taking in sustenance, utilizing support
- Spiritual traditions of seeing giving in receiving—offering others the blessing of doing good
How do you encourage clients to accept help?
BELIEFS ABOUT PROFESSIONALS

- Lack of comfort with healthcare and social service systems leads to perception that pros don’t understand or care
- Lack of trust
- Unwillingness to partner
- Under-utilize services
PROS (cont.)

- Interventions:
- Education is necessary but not sufficient
- Caregiving families need to feel heard, understood and cared for before they are willing to fully allow pros into their lives
HOW TO PARTNER WITH PHYSICIANS

- Develop long-standing relationships
- Adopt their preferred modes of communication; establish means of rapid response and *feedback loops* (e.g., fax, email, very short phone calls)
PARTNERING WITH PHYSICIANS (cont.)

- Keeping them informed with latest data respects their central relationship as client and family guide and counselor
- Provide your observations/opinions
- Work within their constraints
- Don’t win points with clients and family caregivers by scapegoating physicians; recognize blame as serving emotional needs
Assessment: Add exploration of beliefs to intake:

“Why do you do what you do for your loved one?” (see “Honoring the Mission”)

“What will/does it mean to you to accept help for caregiving from others”

“Do you have spiritual views that affect your decision to be a caregiver?”
Interventions:
- Continue to explore caregivers’ meanings
- Offer alternative explanations, attributions
- Put caregivers in contact with people who have alternative explanations, attributions
THE SIBLING MEETING

- Family meeting goals:
  - Raise stakes—"How you caregiving together will affect your relationship with one another long after your parent dies"
  - Promote consensus about diagnosis, prognosis, and parent's needs
  - Devise caregiving plan to which everyone contributes (though not equitably)
SIBLING (cont.)

- Frequently updated listserv
- At least quarterly scheduled meetings
- In vivo, phone/video conference
- Fine-tune plan at each meeting to take into account changing care needs, family members’ shifting commitments, emotions
MARITAL THERAPY

- Illness creates relationship skews, can result in dyad of over-functioning caregiver, under-functioning care-receiver
- Relationship dynamic can compound disability beyond medical reality
- Can lead to decreased intimacy (e.g., nurse or lover, not both), increased depression
Goal is to rebalance differentials in power and functioning as much as possible through empowering care-receiving to contribute, instructing caregiver to play role of coach (if appropriate)

Transcript of couple dealing with stroke
REFERENCES

REFERENCES (cont.)

- For info on Reuben Hill and Hamilton McCubbin: http://www.sagepub.com/upm-data/38638_Chapter4.pdf
REFERENCES (cont.)

- For info on Abraham Maslow’s Hierarchy of Needs: http://en.wikipedia.org/wiki/Maslow’s_hierarchy_of_needs
- Jacobs, BJ (2006). Honoring the mission—don’t be too quick to ease the caregiver’s burden, Psychotherapy Networker, May/June, 29-30
**RESOURCES**

- Well Spouse Association: [www.wellspouse.org](http://www.wellspouse.org)
- National Family Caregivers Association: [www.thefamilycaregiver.org](http://www.thefamilycaregiver.org)
- *Medical Family Therapy* by SH McDaniel, J Hepworth, W Doherty (Basic, 1992)
- *Families, Disability & Illness* by J Rolland (Basic, 1995)
- *Beliefs & Illness—A Model for Healing* by LM Wright & JM Bell (4th Floor Press, 2010)
RESOURCES (cont.)