CREATING SUSTAINABLE FAMILY CAREGIVING RELATIONSHIPS

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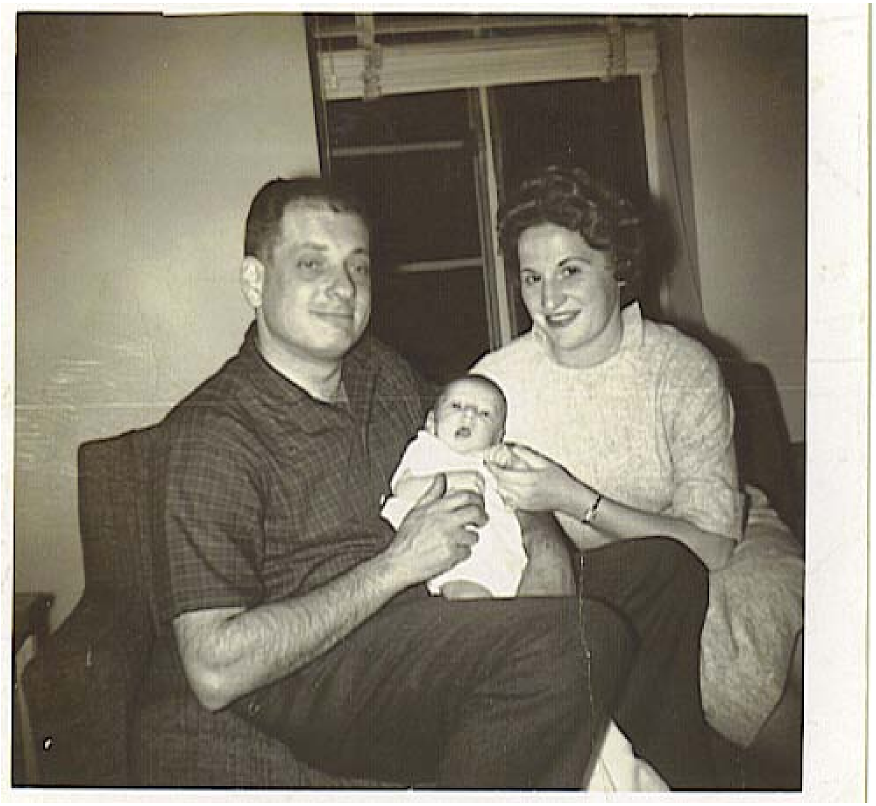
TODAY’S TALK

- 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 SAVAGES (2007)

THE DESCENDANTS (2011)

ROBOT & FRANK (2012)

AMOUR (2012)

US CAREGIVING (cont.)

- 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 caregive: 2 years

RESEARCH ON CAREGIVING'S EFFECTS ON CAREGIVERS

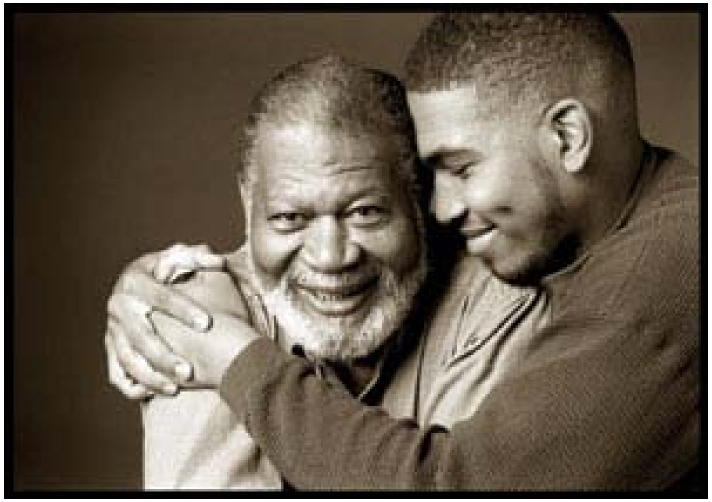
- Long-term caregiving (Schulz & Martire, 2004) linked with:
- Insomnia
- Depression and anxiety
- Musculoskeletal problems (e.g., back pain)
- Decreased immune system functioning
- Decreased use of preventative medical services
- Increased mortality (Schulz, JAMA, 1999)

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

RESEARCH (cont.)

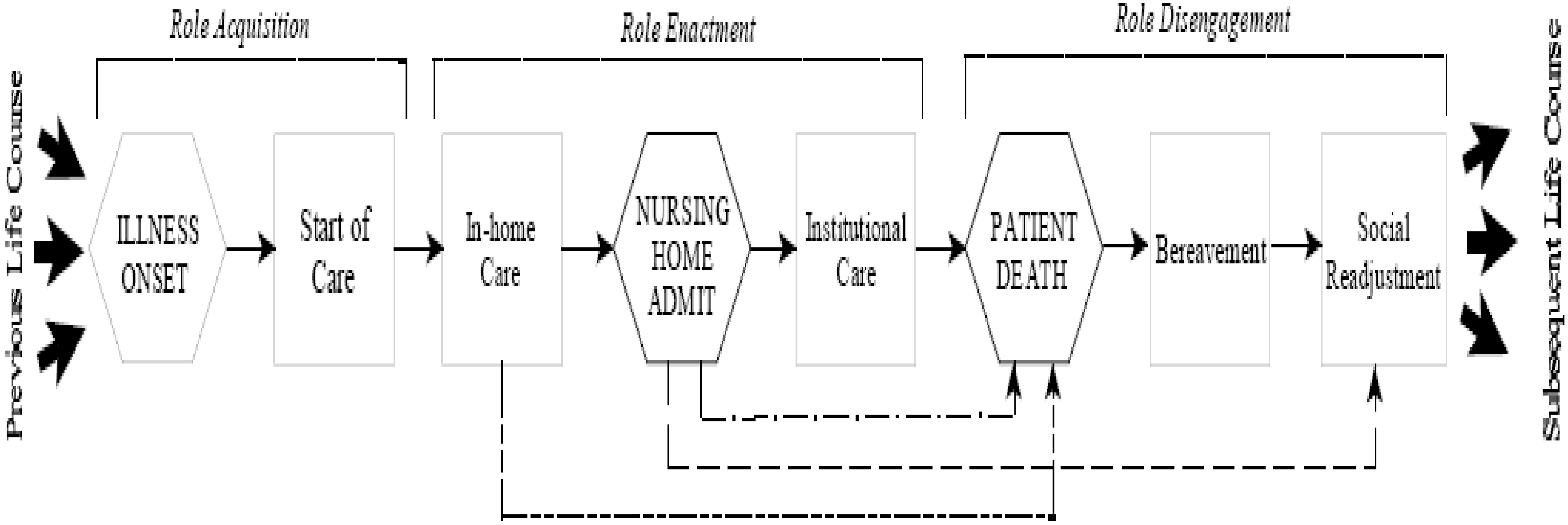
- Examples of other factors studied:
- Race/ethnicity: (African-Americans, Latinos cope better than whites)
- Gender (females more likely to become depressed/anxious)
- Education (less education, less burden)



RESEARCH (cont.)

- 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

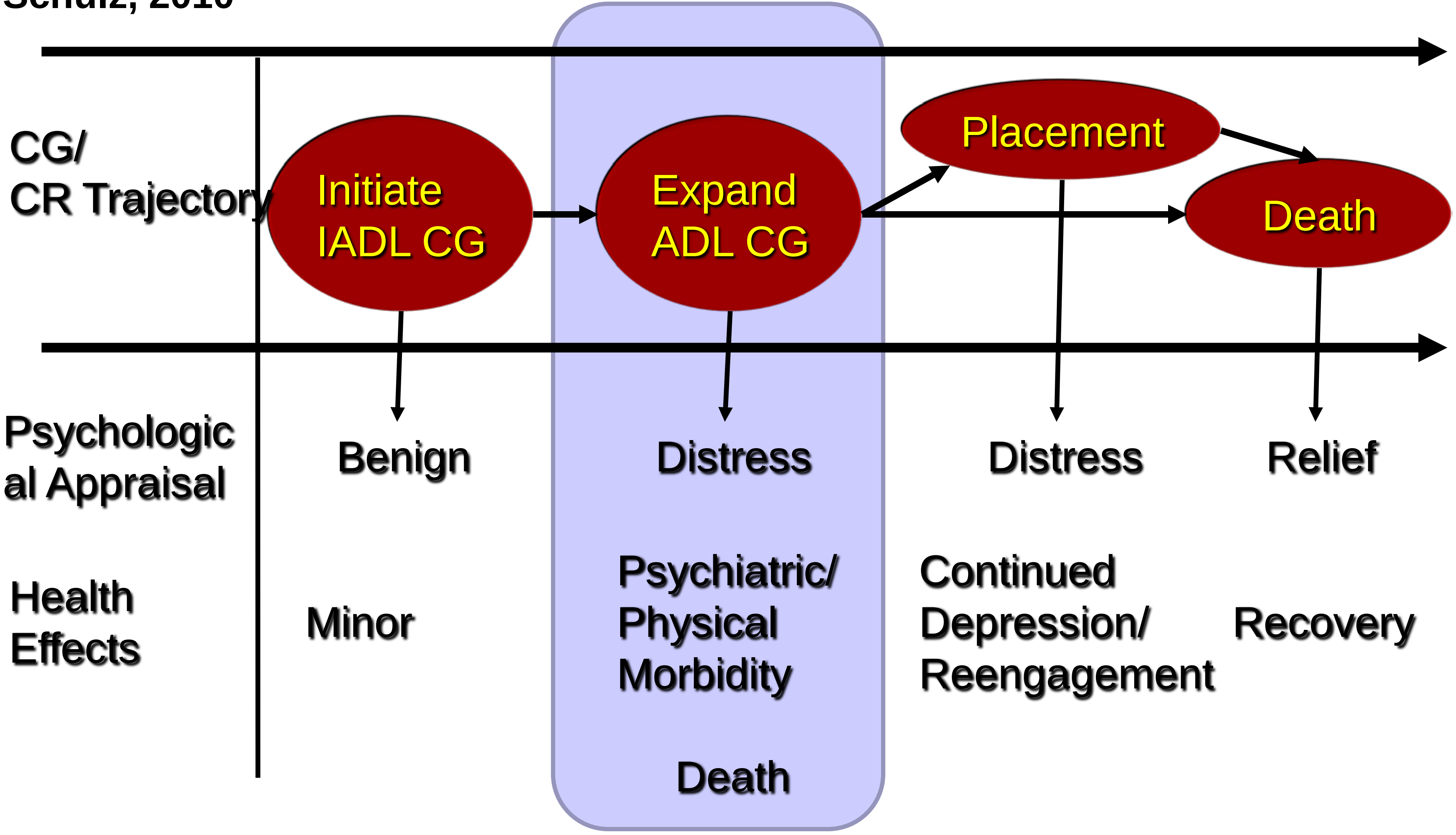
THE CAREGIVING CAREER



Aneshensel et al., 1995

Chronic Stress Trajectory

Schulz, 2010



CG/ CR Trajectory	Initiate IADL CG	Expand ADL CG	Placement	Death
Psychological Appraisal	Benign	Distress	Distress	Relief
Health Effects	Minor	Psychiatric/ Physical Morbidity Death	Continued Depression/ Reengagement	Recovery

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

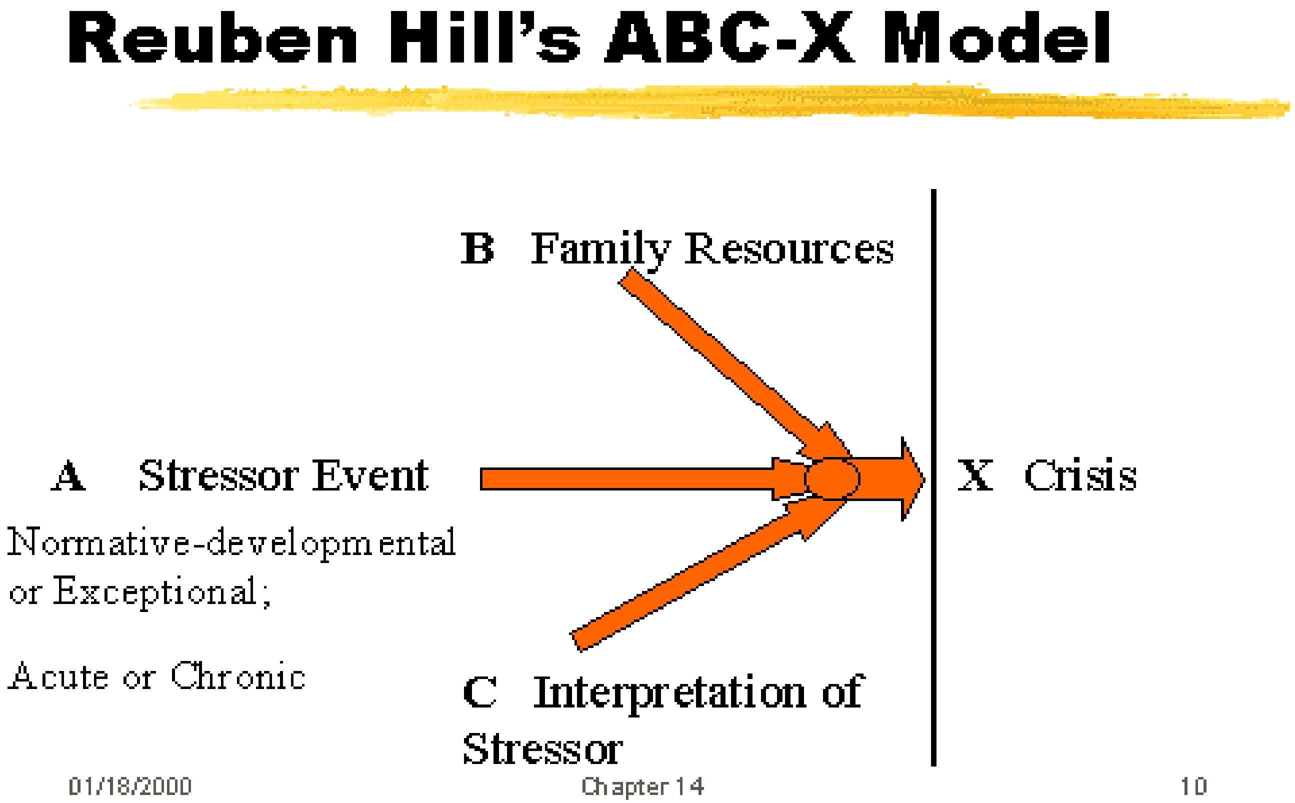
INTERVENTION RESEARCH (cont.)

- 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

B Family Resources

A Stressor Event

Normative-developmental
or Exceptional;

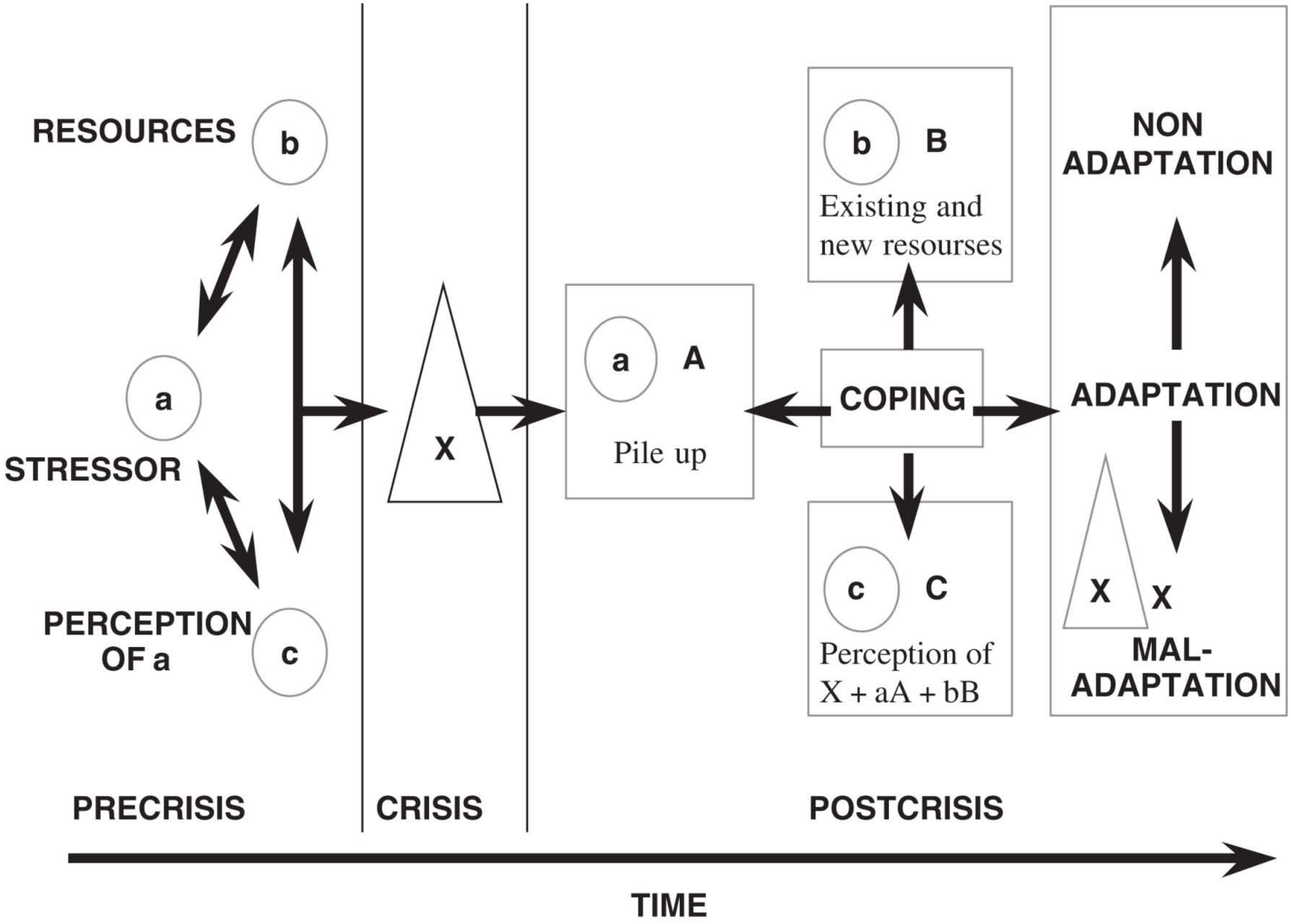
Acute or Chronic

C Interpretation of Stressor

X Crisis

01/18/2000 Chapter 14 10

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

A**B**C-X

- 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.)

AB**C**-X

- 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”

AB**C**-X

- 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

MEANING (cont.)

- 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

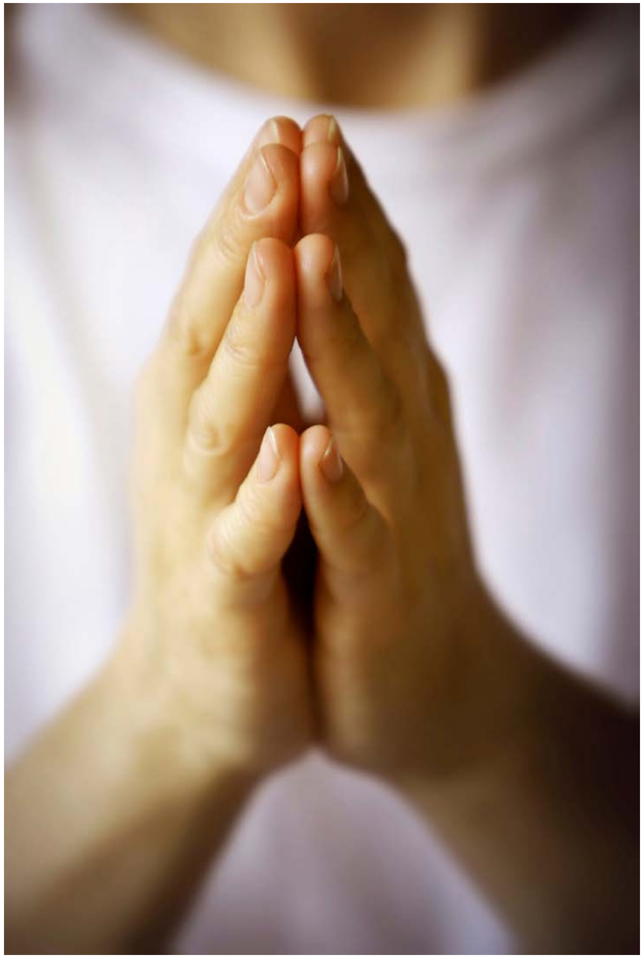
- Assumption: A caregiver’s belief about cause of a loved one’s behavior or dysfunction will affect her willingness to caregive (e.g., Wadley, Haley, 2001) and her capacity for coping
- “The care recipient is engaging in disruptive behavior to spite me” (Burgio et al, 2003)
- Transcripts of wife, siblings

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 caregive)
- 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)

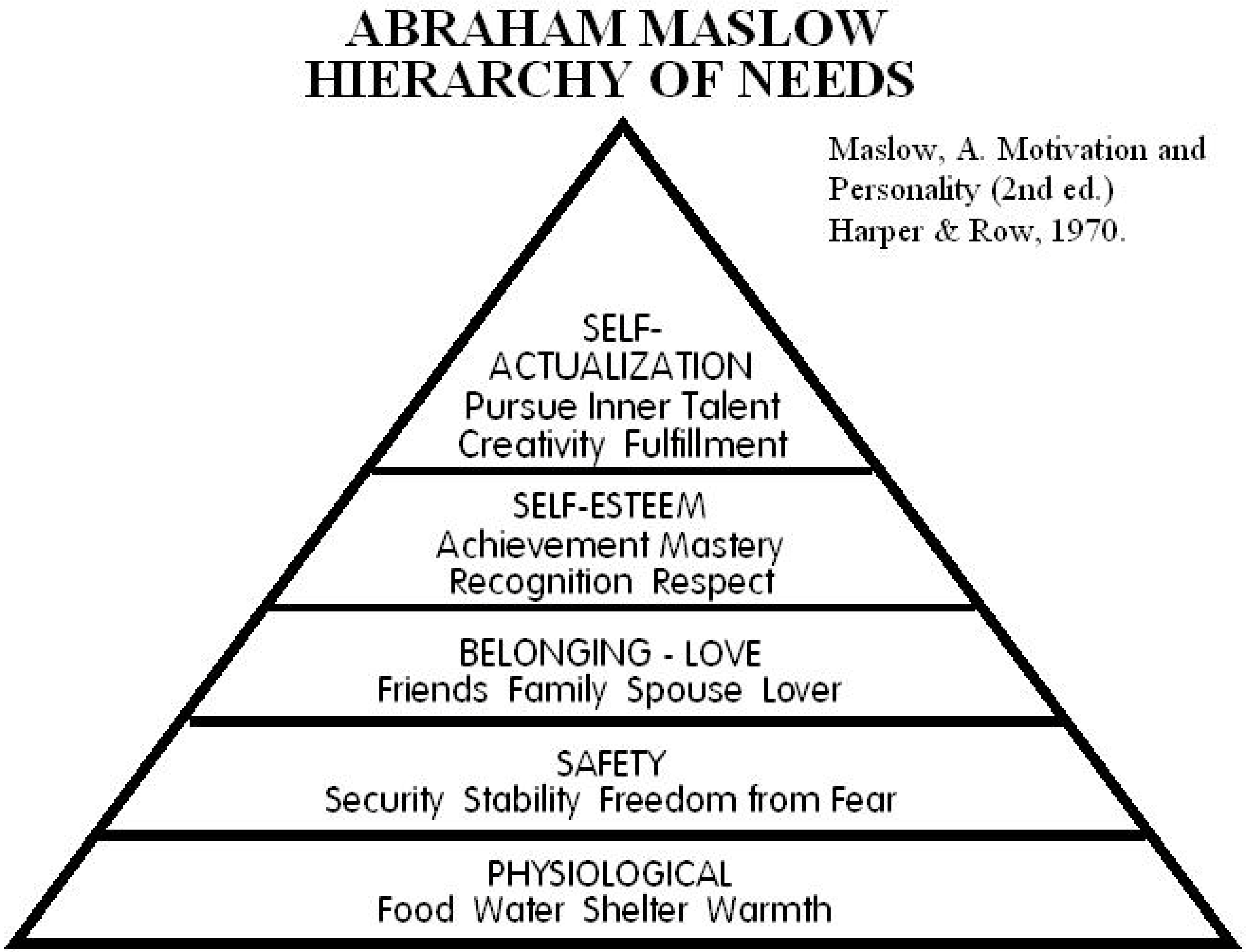
GOALS (cont.)

- 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

GOALS (cont.)

- 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.) Harper & Row, 1970.

SELF-ACTUALIZATION
Pursue Inner Talent
Creativity Fulfillment

SELF-ESTEEM
Achievement Mastery
Recognition Respect

BELONGING - LOVE
Friends Family Spouse Lover

SAFETY
Security Stability Freedom from Fear

PHYSIOLOGICAL
Food Water Shelter Warmth

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

QUESTION

- How do you encourage clients to accept help?

BELIEFS ABOUT PROFESSIONALS

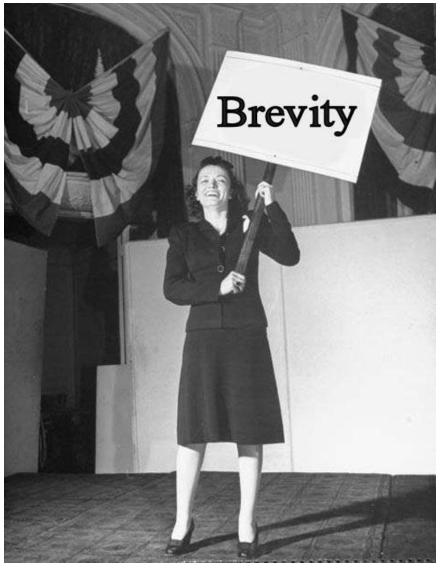
- Lack of comfort with healthcare and social service systems leads to perception that pros don’t understand or care
- Lack of trust
- Unwillingness to partner
- Under-utilize services

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

PROGRAMMATIC IMPLICATIONS

- 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?”

PROGRAMS (cont.)

- 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 caregive 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

MARITAL (cont.)

- 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

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RESOURCES

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- Well Spouse Association: www.wellspouse.org
- National Family Caregivers Association: 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.)

- <u>The Emotional Survival Guide for Caregivers</u> by Barry J. Jacobs, Psy.D. (Guilford, 2006)