Caregiving: Anticipating & Managing Family Conflict

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Definitions

• The term **caregiver** refers to anyone who provides assistance to someone else who is, in some degree, incapacitated and needs help:
  o a husband who has suffered a stroke;
  o a wife with Parkinson’s disease;
  o a mother-in-law with cancer;
  o a grandfather with Alzheimer’s disease;
  o a son with traumatic brain injury from a car accident;
  o a child with muscular dystrophy;
  o a friend with AIDS.
Definitions (continued)

• **Informal caregiver** and **family caregiver** are terms that refer to unpaid individuals such as family members, friends and neighbors who provide care. These individuals can be primary or secondary caregivers, full time or part time, and can live with the person being cared for or live separately.
• **Formal caregivers** are volunteers or paid care providers associated with a service system.
Caregiving Population

• More than 50 million people, provide care for a chronically ill, disabled or aged family member or friend during any given year

• Caregiving is no longer predominantly a women's issue. Men now make up 44% of the caregiving population.

Caregiving Population

- Caregivers providing care for a family member over the age of 50 routinely underestimate the length of time they will spend as caregivers - only 46% expected to be caregivers longer than two years. In fact the average length of time spent on caregiving was about eight years, with approximately one third of respondents providing care for 10 years or more.

Caregiving Population

• Most women will spend 17 years caring for children and 18 years helping an elderly parent.

Source: 101 Facts on the Status of Working Women produced by business and Professional Women's Foundation
ECONOMICS OF CAREGIVING

• The value of the services family caregivers provide for "free" is estimated to be $257 billion a year. That is twice as much as is actually spent on homecare and nursing home services.

ECONOMICS OF CAREGIVING

• Caregiving families tend to have lower incomes than non-caregiving families. Thirty-five percent of average American households have incomes of under $30,000. Among caregiving families the percentage is 43%.

ECONOMICS OF CAREGIVING

• Of the estimated 2.5 million Americans who need assistive technology such as wheelchairs, 61% can't afford it.

ECONOMICS OF CAREGIVING

• Out of pocket medical expenses for a family that has a disabled member who needs help with activities of daily living (eating, toileting, etc.) are more than 2.5% greater (11.2% of income compared to 4.1%) than for a family without a disabled member.

Source: Drs. Altman, Cooper and Cunningham, 'The Case of Disability in the Family: Impact on Health Care Utilization and Expenditures for Non-disabled Members' Milbank Quarterly 77 (1) pages 39 - 75, 1999
ECONOMICS OF CAREGIVING

• Women who are family caregivers are 2.5 times more likely than non-caregivers to live in poverty and five times more likely to receive Supplemental Security Income (SSI).

Study conducted by researchers at Rice University and data compiled from the Health and Retirement Study funded by the National Institute of Aging and conducted by the University of Michigan, 1992-2004
ECONOMICS OF CAREGIVING

- Caregiving families (families in which one member has a disability) have median incomes that are more than 15% lower than non-caregiving families. In every state and DC the poverty rate is higher among families with members with a disability than among families without.

ECONOMICS OF CAREGIVING

• During the 2009 economic downturn, 1 in 5 family caregivers had to move into the same home with their loved ones to cut expenses.

Evercare Survey of the Economic Downturn and Its Impact on Family Caregiving; National Alliance for Caregiving and Evercare. March 2009
ECONOMICS OF CAREGIVING

• 47% of working caregivers indicate an increase in caregiving expenses has caused them to use up ALL or MOST of their savings.

Evercare Survey of the Economic Downturn and Its Impact on Family Caregiving; National Alliance for Caregiving and Evercare. March 2009
ECONOMICS OF CAREGIVING

• The average family caregiver for someone 50 years or older spends $5,531 per year on out of pocket caregiving expenses in 2007 which was more than 10% of the median income for a family caregiver that year.

Valuing the Invaluable: The Economic Value of Family Caregiving, 2008 Update. AARP
IMPACT ON FAMILY CAREGIVER'S HEALTH

• 23% of family caregivers caring for loved ones for 5 years or more report their health is fair or poor.
  Caregiving in the United States; National Alliance for Caregiving in collaboration with AARP; November 2009

• 20% of employed female caregivers over 50 years old report symptoms of depression compared to 8% of their non-caregiving peers.
Stress of family caregiving for persons with dementia has been shown to impact a person's immune system for up to three years after their caregiving ends thus increasing their chances of developing a chronic illness themselves.

IMPACT ON FAMILY CAREGIVER'S HEALTH

• Nearly three quarters (72%) of family caregivers report not going to the doctor as often as they should and 55% say they skip doctor appointments for themselves. 63% of caregivers report having poor eating habits than non-caregivers and 58% indicate worse exercise habits than before caregiving responsibilities.

IMPACT ON FAMILY CAREGIVER'S HEALTH

• 40% to 70% of family caregivers have clinically significant symptoms of depression with approximately a quarter to half of these caregivers meet the diagnostic criteria for major depression.

IMPACT ON FAMILY CAREGIVER'S HEALTH

• More than 1 in 10 (11%) of family caregivers report that caregiving has caused their physical health to deteriorate.
  How Do Family Caregivers Fare? A Closer Look at their Experiences. Center on Aging Society. 2005.

• A wife's hospitalization increased her husband's chances of dying within a month by 35%. A husband's hospitalization boosted his wife's mortality risk by 44%.
  Nicholas D. Christakis, Professor, Health-care Policy, Harvard Medical School, Boston and Suzanne Salamon, M.D., Associate Chief, Geriatric Psychiatry, Beth Israel Deaconess Hospital, Boston, New England Journal of Medicine, Feb. 16, 2006
IMPACT ON FAMILY CAREGIVER'S HEALTH

- Family caregivers experiencing extreme stress have been shown to age prematurely. This level of stress can take as much as 10 years off a family caregiver's life.

The total estimated cost to employers for full-time employees with intense caregiving responsibilities is $17.1 billion.

The average cost per employee for those with intense caregiving responsibilities is $2,441.

The total estimated cost to employers for all full-time, employed caregivers is $33.6 billion.
The total estimated cost to employers for all full-time, employed caregivers is $33.6 billion.

The average cost per employee for all full-time, employed caregivers is $2,110.
2030 CAREGIVING PROJECTIONS

• By the year 2030, nearly 150 million Americans will have some type of chronic illness, a 50% increase since 1995.
  

• Based on projected USA census, 150 million Americans with chronic illnesses will be 41% of the population or higher.
The World of Caregiving

- Skills Required for Success
  - Collaboration
  - Community

- Storytelling as a Tool

- Caring: The External & Internal World of Caregiving

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Mixed Emotions

Negative

Positive
The Irrational World of Caregiver

- Strengths
- Weaknesses
- Family value patterns
- Dysfunctional
- Difficulties
- Patient centered
- Unspoken levels of permission
Caregivers as Partners

• How can healthcare professionals collaborate with caregivers to achieve better outcomes?

• What do caregivers need to know to enhance medical outcomes?
Prospectus on Caregiving

When will this ordeal be over?  What can I learn from this experience?
A Holistic View of the Healing Process

More hospitals & medical schools researching the relationships between medicine and emotion.
“That initial feeling in the pit of your stomach is familiar to everyone who discovers a loved one is ill. Foreboding washes over the soul, and a flush passes through the body. You respond to the news both physically and emotionally.”

“Enrich Your Caregiving Journey”
Margery Pabst
“I still can’t believe it! Yesterday, we were grilling our favorite steaks on the back patio and today we are eating TV dinners, stunned to our cores. He faces chemo and radiation treatments. I don’t want to tell him how frightened I am, so I’ve been putting a positive face on it. I feel so alone. We exist in our own two-person cocoon.”

“Enrich Your Caregiving Journey”
Margery Pabst
Anticipating & Managing Family Conflict

• Often a caregiver role

• Critical to patient well-being & healing
MANAGING FAMILY CONFLICT
OVERALL PURPOSE

Patient Care

Focus on What’s Important: The Patient

You/Caregiver

Others
THREE COMMON AREAS OF CONFLICT

- Finances
- Control
- Family History

You
Caregiver

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1. What conflicting feelings do I have?

2. Have I acknowledged those feelings?

3. How do I usually deal with conflict?

4. What do I need to do as or before I help others?
HOW TO THINK ABOUT CONFLICT

- Finances
- Control
- Family History
- You/Caregiver
How is anger shown?
Is control gender/age based?
How are disagreements resolved?
Is control shared?
Are family/friends developing skills for caregiving, financial issues, health literacy, etc.?
What alliances exist?
Who usually has the decision making role /roles?
Other:
HOW TO THINK ABOUT CONFLICT

What long term alliances exist?
What communication patterns exist in the family?
How do patterns emerge during stress?
How does conflict usually get resolved?
What disagreements persist?
What feelings do family members have toward each other? (ex. concern, jealousy, anger, love?)
What events in family history made negative/positive impact?
Other:
What are the financial priorities?
Do we have a budget?
How do/will we handle the unexpected?
Did we get the best deal?
Who will make budget changes?
Who communicates with banks/brokers?

• Other:
HOW TO CONSIDER CONFLICT

Questions to Consider:

TIP: Begin with the easiest area to build personal skill and confidence

• Where does conflict exist within the family or with friends: Finances? Control? Family History?

• What are the most important questions for me and my family to answer?

• What area is the easiest to resolve? The hardest to resolve?

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Conversations

Red Flags

- “Joe always got to make the decisions.”
- “I want Mother to have the best. After all, she always took care of us.”
- “Susan always leaves when Dad starts shouting.”
- “I wish I knew why Alex and Tessa decided to see another doctor.”

Possible Responses

Other:

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Conflict Scale

1. Little or no conflict
2. One difficult family member in conflict with everyone
3. Conflict confirmed between two family members
4. Conflict among more than two family members
5. High conflict among family members

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GOAL: ESTABLISH AGREEMENT ON MIDDLE GROUND

What can we agree on?

Middle Ground

What we can’t agree on now?
Meeting Goals

• **Before** - Identify red flags
  • Communicate one-on-one with family
  • Ask for their help at the meeting

• **During** – Identify outcome desired
  • Ask for opinions
  • Listen to each person
  • Ask for middle ground

• **After**...
Conversations

Red Flags

Possible Responses

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MY GOALS FOR MIDDLE GROUND:
CONVERTING DISAGREEMENTS

What can we agree on?

List disagreements that can be converted to “middle ground”

What we can’t agree on now?
COMMUNICATION TIPS FOR MANAGING / RESOLVING CONFLICT

• Use open ended questions (Avoid questions that begin with words like ‘could’, ‘should’, ‘would’, ‘do’.)

• Check to make sure you understand by saying “Tell me more about _______” or “So you think_______” or “So you want _________ to happen.”

• Use “I” messages

• Ask “What can we begin to agree on?” or “If we change _____, can you agree to what ____ is suggesting?”

• Other:
Increasing Social Capital & Continuum of Care

- Strengths
- Giving
- Receiving
- Interdependence
SOCIAL CAPITAL

+ Makes sense – “right thing to do”
- Makes cents – “economic thing to do”

= Win/Win
Who Will Be Your Caregiver?

Values?

Interests?

Knowledge?
Emotional wellness can’t be exactly calculated, but all of us know that stress and distress affects body & mind, leading to dysfunctional and antisocial behavior. The skillful and thoughtful caregiver will attend to both physical & emotional needs of themselves and others.
Where are we?

Research <-> Administration

Focus on humanity, dignity, community, and collaboration
Health Literacy

- Empowering your advocacy for yourself and others
- Managing transitions
- Becoming a partner in care
Margery Pabst holds the M.A. in English from the University of Wisconsin, Madison. Her career has spanned both the public and private sectors as a writer, facilitator, and consultant. Margery led 500 language arts instructors in the Norfolk [VA] Schools, won top sales honors at Development Dimensions International, and served as Vice President of HBJ Leadership. She founded MLP Enterprises in 1988 and specialized in writing and facilitating leadership curriculum for Fortune 100 companies. Margery is the author of Team Speak™, a presentation skills program, and three e-books on life transitions. In the past few years, she experienced the intensely emotional role of caregiving firsthand. Enrich Your Caregiving Journey is the result of that experience, one that Margery views as holding potential for great personal growth.