Family Caregiver Alliance®

Fighting For—Not With—Your Loved One's Healthcare Professionals

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MARCH 31, 2021

Today’s Talk

- Why families matter to healthcare
- Uneasy relationships
- Building trust
- Becoming part of the healthcare team

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- On a 1-10 scale in which 1 = very bad and 10 = very good, please rate your experience working with your loved one’s healthcare professionals

- Name 1 or 2 things that prevent family caregivers and healthcare professionals from being good partners

Family Caregiving In America

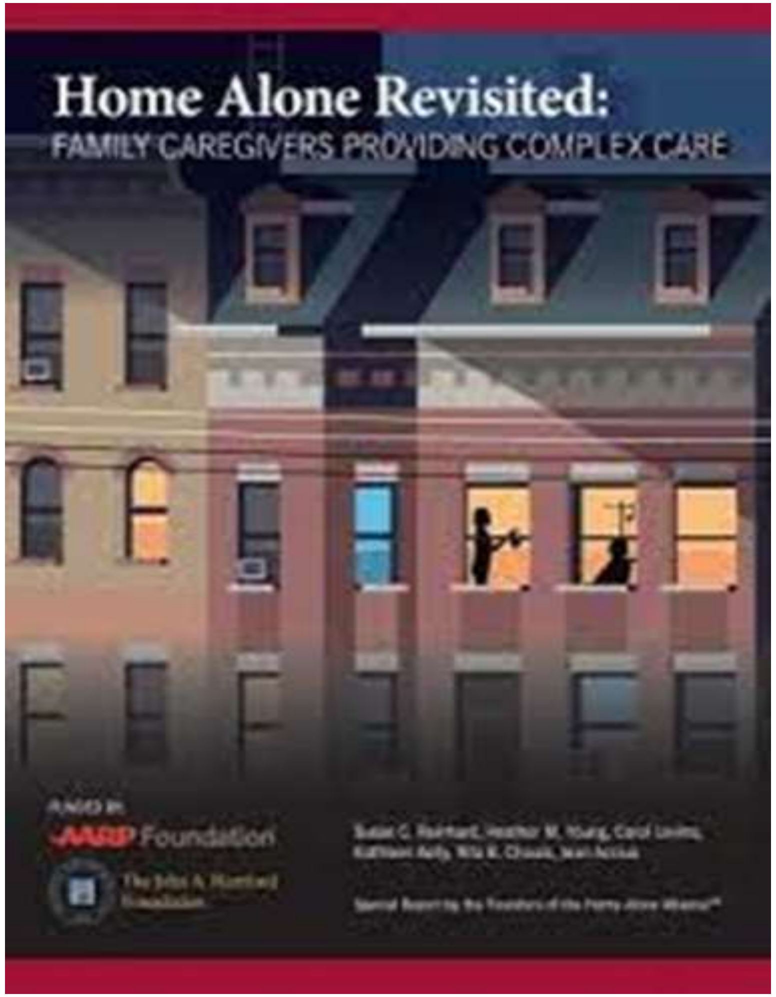
- 53 M Americans engage in some form of caregiving activity in a year (NAC/AARP, 2020)
- Numbers increasing because of demographics, medical advances

Family Caregivers’ Healthcare Roles (Wolff, Jacobs, 2015)

- Attendant
- Administrator
- Companion
- Driver
- Navigator
- Technical Interpreter
- Patient Ombudsman
- Coach
- Advocate
- Case Manager
- Healthcare Provider

Home Alone Revisited (2019)

- Half of the nation's 40 million family caregivers are performing complicated medical/nursing tasks for their family members, including giving injections, preparing special diets, managing tube feedings, and handling medical equipment"



Home Alone Revisited:
FAMILY CAREGIVERS PROVIDING COMPLEX CARE

AARP Foundation

Examples Of Effects Of Family Caregiving On Patients’ Clinical Outcomes

- **Family presence improves quality of medical visits (Wolff, 2008, 2011)**
- Family involvement can improve patients’ knowledge about diabetes (Kang, 2010)
- Caregiver availability lowers post-stroke costs (Roth, 2016)
- Telephonic caregiver support group **lowers costs** of care for veterans with dementia (Wray, 2010)

“It Takes Three To Tango”

Physician Attitudes

"A persistent tendency to equate families with <u>trouble</u> is evident in both the literature and practice of medicine."
—Levine & Zuckerman, Annals of Internal Medicine, 1999

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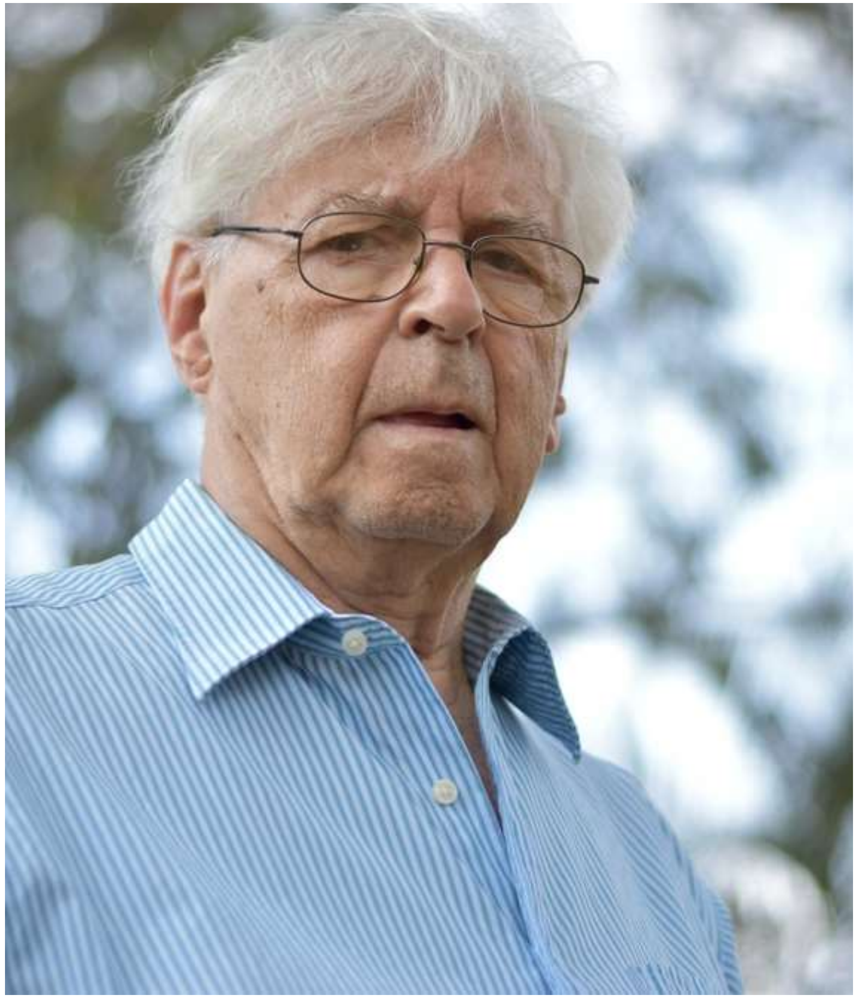
Physician Attitudes

- “Family caregiver involvement undermines patient autonomy and confidentiality”
- “It alters the quality of the patient-professional relationship”
- “Working with families takes additional time and is unreimbursed”

Patient Attitudes



- “I am capable of going to the doctor by myself”
- “I have a right to privacy with my doctor”
- “I resent it when my kids try to take over”

Family Caregiver Attitudes

- “I talk directly to the doctor and nurse about my mother’s condition. She doesn’t need to get upset.”

- “I don’t trust that the doctors understand my mother. I can figure out what’s best for her.”

My Caregiving Experiences

- Patchwork of healthcare and social service providers across multiple settings
- Poor communication
- PCP, neurologist, psychiatrist, neuropsychologist, psychotherapist, nursing, PT/OT, speech
- Home health aides
- Adult day care

My Caregiving Experiences

- Mother was angry; wanted to maintain control over her life, including her doctor's visits
- Arguing with me in front of doctor
- PCP perplexed
- Didn't want to exclude me
- Didn't want to alienate my Mom

- *What advice would you give family caregivers to work effectively with healthcare providers and care receivers?*

Forming Effective Partnerships

- Build trusting relationships among caregiver, care receiver and professional requires:

- Common goals
- Clear roles
- Means for timely communication
- Responsiveness
- Reliability
- Mutual respect
- Mutual support

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Preparation For A Better Partnership

- What are you willing and able to do?
- Observe, record and report symptoms?
- Manage a pill box?
- Handle medical procedures at home?
- Advocate for your loved one?

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Preparation For A Better Partnership

- Talk it over with the care receiver
- What role does he want you to play?
- What doesn't he want you to do?
- Will he give you access to all his medical information?
- Will he allow you to help make medical decisions?

“I Come In Peace”

- Make sure healthcare professional knows who are and what your relationship is with patient
- Get patient’s permission in front of professional to talk openly about his confidential medical information
- Offer yourself as a partner in care, helping professional help your loved one

“How Can I Best Help You?”

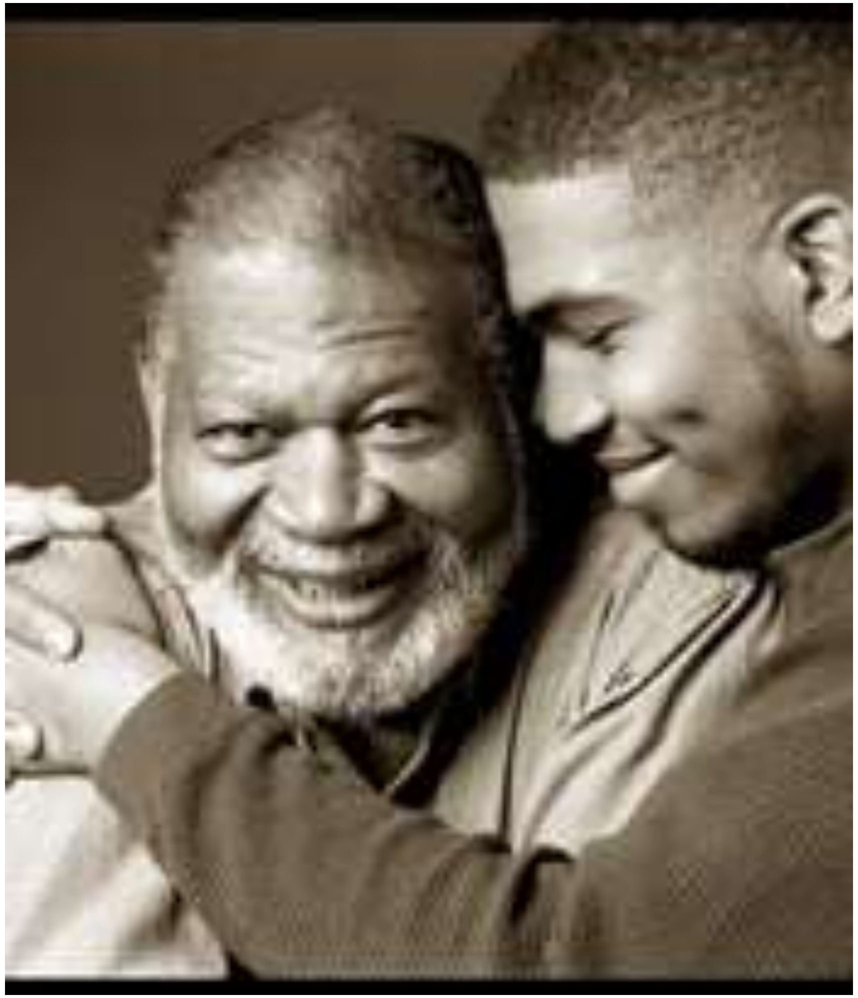
- Ask about preferred means of communication (e.g., portal message, text, email, phone call, just show up at the next medical appointment)
- Ask which type of information would be helpful to the clinical care (e.g., blood sugar or blood pressure readings, food diary, behavioral observations)
- Offer background information on what matters to patient (if patient can’t easily speak for himself)

“How Can You Best Help Me?”

- Ask for:
  - Easily understandable medical information about patient’s condition and treatments
  - Copies of all medical visit notes to share with other family members
  - Clear instructions for being a helpful care partner
  - Treatment options to weigh
  - Ability to provide input to treatment plan (with patient’s permission)

The Well-Planned Medical Visit

- Before: Talk with care receiver about agenda and questions
- During: Bring pad with questions. Take notes. Prompt patient to raise issues or raise them yourself
- After: Compare understanding of doctor’s suggestions with care receiver. Review instructions later



- ***Which of these ideas would or would not be helpful to you?***

- ***What other ideas for partnering with healthcare professionals do you have?***

Resolution

- Worked out compromise:
- I attended first few minutes of PCP visit to give report of medical changes and express my concerns
- My mother then had visit alone with PCP
- PCP then met briefly with me alone to share his impressions and plans

Summary

- Through identifying common goals and expressing interest in helping the professionals help your loved one, you can build trust and become a valued partner of the health care team

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Questions?

Comments?

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More Information About FCA

Family Caregiver Alliance offers education, services, research, and advocacy based on the real needs of family and informal caregivers. Founded in the late 1970s, FCA is the first community-based nonprofit organization in the United States to address the needs of families and friends providing long-term care for loved ones at home.

National Center on Caregiving (NCC) was established by FCA to advance the development of high-quality, cost effective programs and policies for caregivers in every state.

NCC sponsors Services by State, a state-by-state resource locator designed to help caregivers find support services in their communities.

Bay Area Caregiver Resource Center — operated by FCA for the six-county San Francisco Bay Area — provides support to family caregivers. FCA's staff of family consultants, through education programs and direct support, offer effective tools to manage the complex and demanding tasks of caregiving.

FCA CareNav is a secure online solution for quality information, support, and resources for family caregivers of adults with chronic physical or cognitive conditions such as Alzheimer's, stroke, Parkinson's, and other illnesses.

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