

How to Engage, Support and Empower Family Caregivers

- Barry J. Jacobs, Psy.D., Principal, Health Management Associates
- Sara Honn Qualls, Ph.D., Kraemer Family Professor of Aging Studies, University of Colorado-Colorado Springs



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Faculty Disclosure

The presenters of this session currently have the following relevant financial relationships during the past 12 months.

As part of his role as a healthcare consultant, Barry J. Jacobs, Psy.D. works with a variety of provider, health system, insurer and governmental clients

Conference Resources

Slides and handouts shared by our conference presenters are available on the CFHA website at https://www.cfha.net/page/Resources_2019 and on the conference mobile app.



Learning Objectives

At the conclusion of this session, the participant will be able to:

- Review empirical findings on effects of caregiving on family caregivers and key components of caregiver support programs
- List necessary large systems changes in caregiver communication, documentation and shared decision-making to reduce patients' healthcare costs
- Describe current efforts of governments, health systems and insurers to engage, support and empower family caregivers

Bibliography / Reference

1. Qualls, S & Williams, AA (2013). Caregiver family therapy, Washington, DC: APA Books
2. AARP Public Policy Institute Brief (2017). Emerging innovation in managed long-term services and supports for family caregivers:
http://www.longtermscorecard.org/~media/Microsite/Files/2017/2017%20Scorecard/AARP1202_EI_EmerInnovationLTSS_Oct31v2.pdf
3. Jacobs, BJ (2018). Can families reduce patients' healthcare costs?, CFHA Blog, December:
<https://www.cfha.net/blogpost/689173/314205/Can-Families-Reduce-Patients-Healthcare-Costs?hhSearchTerms=%22barry+and+jacobs%22&terms=>
4. Roth, DL et. al. (2016). Medicare claims indicators of healthcare utilization differences after hospitalization for ischemic stroke: race, gender, and caregiving effects, Int J Stroke, 11(8):928-934.
5. Caregiving in the US 2015, a NAC/AARP report: <http://www.caregiving.org/caregiving2015/>

Learning Assessment

- A learning assessment is required for CE credit.
- A question and answer period will be conducted at the end of this presentation.

Family Caregiving in America

- 40 M Americans engage in some form of caregiving activity in a year (NAC/AARP, 2015)
- Numbers increasing because of demographics, medical advances



Why Family Matters (More Than Ever) in Healthcare

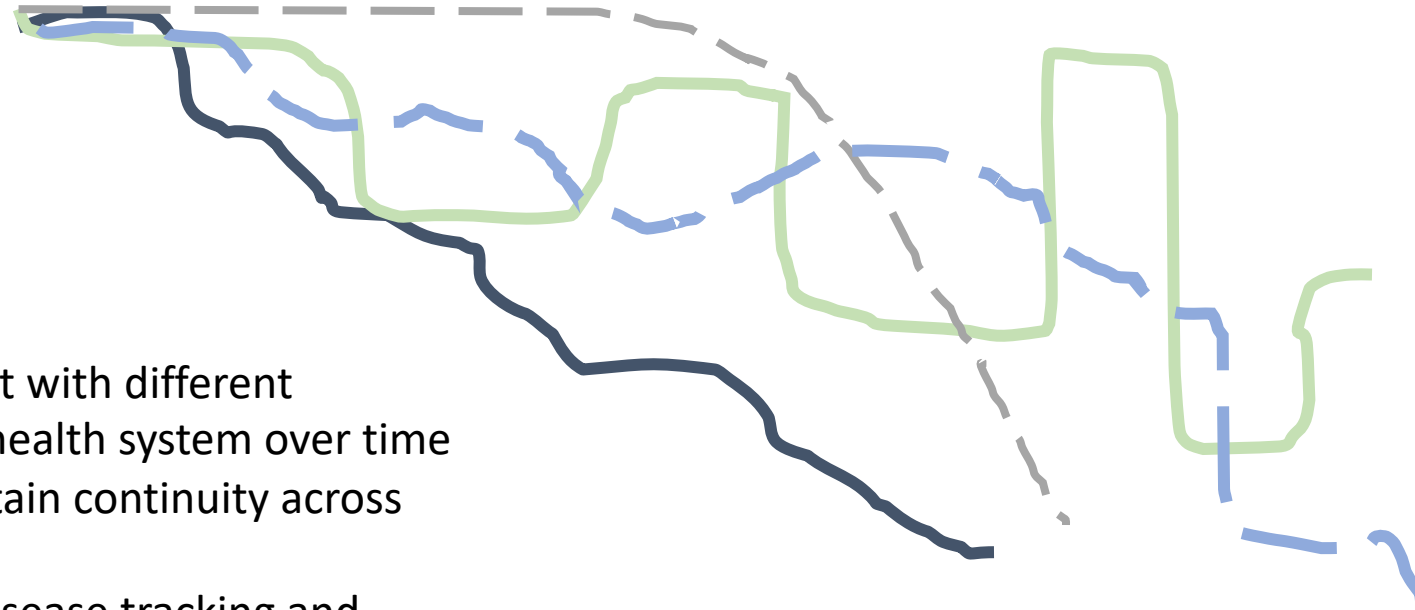
- Despite traditionally patient-centric American healthcare system, myriad factors → emphasis on families
- Rising incidence of chronic illnesses, functional limitations with rapidly aging population (20% over 65 by 2030)
- Decreased hospital lengths of stay and emphasis on preventing bounce-backs
- **Families seen as one key to implementing outpatient treatment plans, decreasing hospital utilization and lowering costs**



Engage, Support, Empower

- Many family members don't identify themselves as caregiver
- *How do we engage them?*
- Many family caregivers feel isolated and unsupported
- *How do we risk stratify them and provide tailored services?*
- Many family caregivers feel marginalized by integrated healthcare teams
- *How do we embrace and empower them as partners in care?*

Chronic Illness Trajectories



- Patients intersect with different components of health system over time
- Families can sustain continuity across systems
- Family skills in disease tracking and management need to be systematically supported and enhanced

Key Questions for Caregiver accompanying a patient with chronic disease

- What is the hardest decision you are facing in how to care for your loved one?
- Checklist of Activities of Daily Living with which you provide assistance

Effects of Caregiving on family caregivers

- Risks of Stress
 - Significant in long-term, high demand caregiving such as dementia care
 - For some, negative effects on health
 - Varies substantially by cultural identity and social class
- Positive Impact
 - Added meaning and purpose
 - Protective health effects on vast majority

Screening for Burden

1-Question Screener for Burden (Schulz and Beach, 1999)

- *How much of an emotional strain is it on you to provide the help directly or arrange for help to be provided for your relative?*

3-Question Screener for Burden (Liew et al, 2019)

- *Are you afraid what the future holds for your relative?*
- *Do you feel your health has suffered because of your involvement with your relative?*
- *Do you feel you have lost control of your life since your relative's illness?*

Line in the Sand

- *Everyone has limits about what they are willing and able to do. What part of caregiving will be especially hard for you? What are your limits?*

Assessment of Self-Care/Coping

- **What do you need to do to get from start to finish?**
- **What do you do to relax when you're stressed out?**
- **How have you and your family managed other difficult times?**

360° Screening

- Objective Burden
 - Length of time in role
 - Amount of ADL/IADL
- Subjective Burden
- Positive Meaning – *To what extent have you grown as a person or found meaning in this caregiving role?*
- Rigid norms of obligation – *To what extent do you feel trapped by your relative's illness?*
- Low perceived support – *To what extent do you feel supported by family and friends in your caregiving role?*

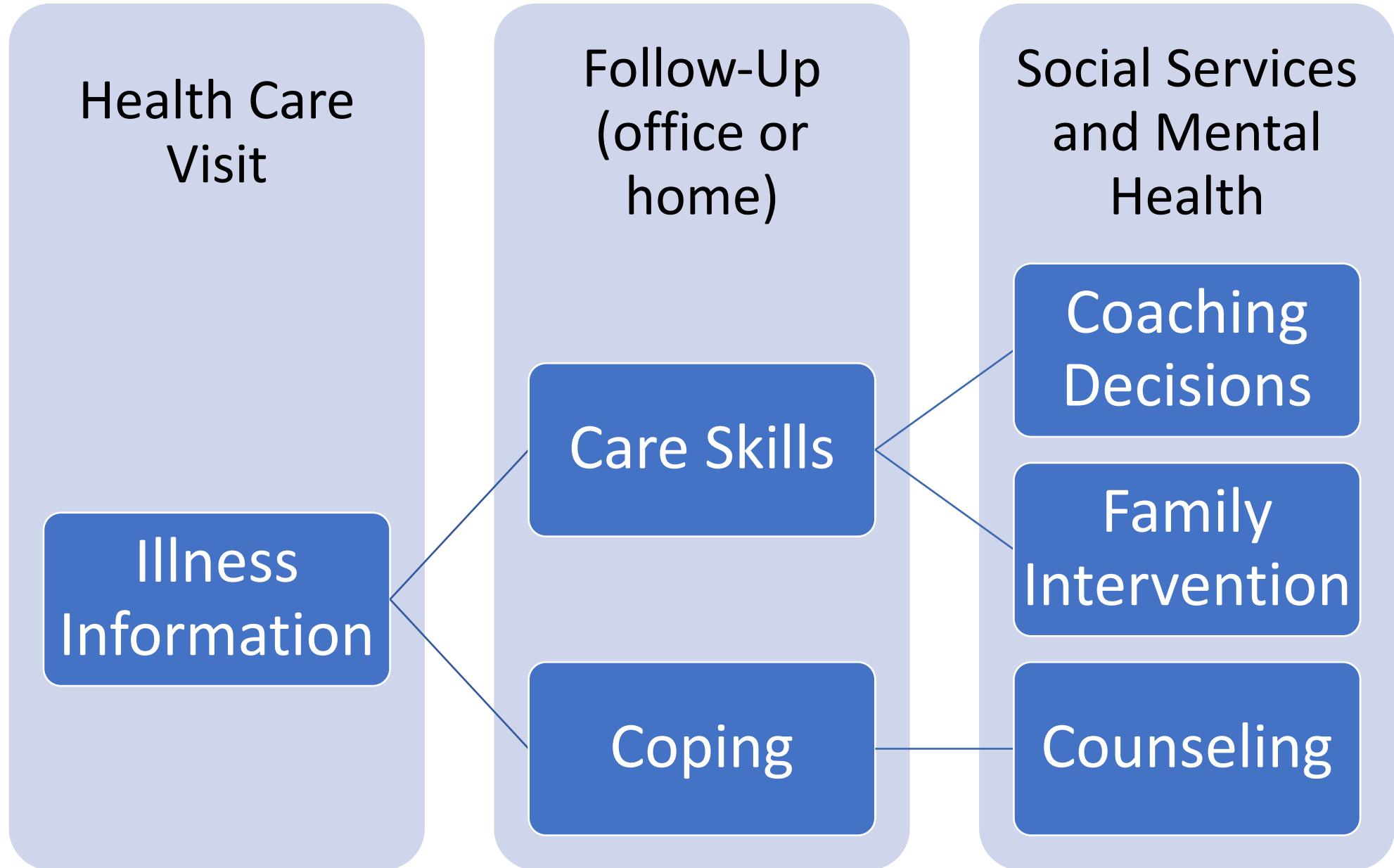
Fuller assessment option: Caregiver Reaction Scale

(O'Malley, K.A. & Qualls, S.H. (2016). Preliminary evidence for the validity and reliability of the Caregiver Reaction Scale. *Clinical Gerontologist*, 40, 281-294. <http://dx.doi.org/10.1080/07317115.2016.1198858>)

Key Components of CG Interventions

- Professional Support
- Psychoeducation
- Behavior management
- Counseling
- Self-care/relaxation training
- Multi-component interventions, typically engaging family members in increasing their support of primary caregiver

Gitlin & Hodgson, 2015



Warm hand-off – pushing through resistance

- You are running a marathon, not sprint. Let's keep you in shape.
- You deserve support.
- If not you, who? We must prioritize your strengths to sustain you for the patient.
- At some stages of care, big decisions must be made that really change your relationships in important ways. These are hard. I encourage you to get some good ideas from a counselor about how to talk with your loved one(s) about the challenges and decisions you face.
- Even if you aren't ready today to make big changes, I hope you will learn now about the options for getting help providing care, for that point in the future when you need it.

Rising Tide

- Government
- Healthcare Insurers
- Health Systems
- **Necessary steps for institutionalizing family-engaged care**

Government

- **Caregiver Advise, Record Enable (CARE) Act:**
- Passed by 46 states in past 4 years
- Requires identification of primary family caregiver in patient's hospital chart
- Family caregiver to be notified when patient is discharged
- Requires in-person instructions about medical tasks that family caregiver will provide for patient at home

- **Federal:** RAISE Family Caregiver Advisory Council: 3-year, blue ribbon committee to inform all federal policies regarding family caregiving for all age-related and other disabilities
- **States:** New Jersey and Rhode Island have passed legislation in last 12 months to set up similar advisory groups to inform state policies

Health Insurer (esp. MLTSS) Efforts

- AARP/HMA (2017) report on “Emerging Innovations...”:
- http://www.longtermcorecard.org/~media/Microsite/Files/2017/2017%20Scorecard/AARP1202_EI_EmerInnovationLTSS_Oct31v2.pdf
- Assessment
- Respite
- Direct Engagement
- Instruction and Support
- Partnership with CBOs



Health Systems

- Implementation of CARE Act in hospitals
- Care transitions programs (including use of community health workers and peers)
- Palliative and hospice care
- Geriatric, pediatric and physical medicine rehabilitation care
- Complex care programs
- Home care—especially with rise of “self-directed care”



- Focus on older adults transitioning from hospital to home
- Home-based social work navigation
- Stress mgmt course (“Powerful Tools for Caregivers”)
- Use of *promotores*
- Link to community agencies
- Decreased caregiver depression
- Decreased patient hospital and ER utilization

Necessary Steps

- **Solid research base for interventions:**
 - Best Practice Caregiving website—being created by Benjamin Rose Institute and Family Caregiver Alliance with extensive grant funding.
Expected fall of 2019???
- **Brief family caregiver clinical protocols with proven ROI:**
 - Stanford University School of Medicine current efforts to review family caregiving literature and create feasible protocols. Led by Nirav Shah, MD with 6 physician research fellows

Session Survey

Use the CFHA mobile app to complete the survey/evaluation for this session.



Join us next year in Philadelphia, Pennsylvania! Thank you!