



Session # 17

# Families and Health Research – A Critical Review

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CFHA 20<sup>th</sup> Annual Conference  
October 18-20, 2018 • Rochester, New York





# Faculty Disclosure

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The presenters of this session currently have had the following relevant financial relationships (in any amount) during the past 12 months.

Both Larry Mauksch and Barry J. Jacobs are paid for consultation and training to educational and/or healthcare organization.

# Conference Resources

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Slides and handouts shared in advance by our Conference Presenters are available on the CFHA website at [http://www.cfha.net/?page=Resources\\_2018](http://www.cfha.net/?page=Resources_2018)



Slides and handouts are also available on the mobile app.



# Learning Objectives

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

- Summarize the rationale for family-centered healthcare
- Review current evidence connecting family function and health care efforts
- Analyze next steps in research on families and health



# Bibliography / Reference

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1. McGoldrick, M., Preto, N. A. G., & Carter, B. A. (2015). *The expanding family life cycle: Individual, family, and social perspectives*. Pearson.
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4. Walsh, F. (2015). *Strengthening family resilience*. Guilford Publications.
5. Crane, D. R., & Christenson, J. (2014). A summary report of cost-effectiveness: Recognizing the value of family therapy in health care. In *Medical Family Therapy* (pp. 419-436). Springer International Publishing.



# Learning Assessment

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A learning assessment is required for CE credit.

A question and answer period will be conducted at the end of this presentation.

# (LM slides)

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Introduction

Rationale for F&H research

- Prevalence of chronic disease
- Living with someone with chronic illness
- Policy
- Workforce
- Payment
- Informatics

Funny joke

# Family Engagement in Primary Care

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# Format for Literature Review

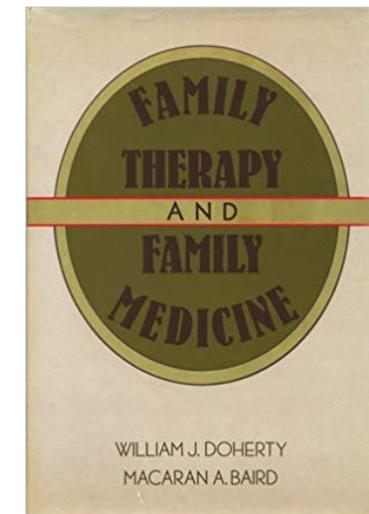
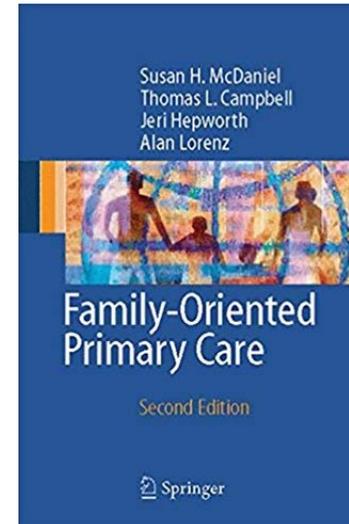
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1. Background
2. Search strategy
3. Research summary and synthesis
4. Critical analysis
5. Recommendations

# Background

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- Chronic disease rates are increasing, placing additional burden on caregivers (parents and spouses)
- Family-oriented care was discussed consistently from 1980s to early 2000s.
- Publications of the conceptual framework slowed down, but implementation research did not carry the momentum.
- Today, researchers are calling for evidence-based family engagement strategies



# Search Strategy

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1. Searched PubMed and CINAHL databases using search strings (Table 1)
2. Searched through reference lists of seminal articles
3. Used Google Scholar to find articles that cited seminal articles

Database search			
Search string	Database	Results	
(family engagement[Title/Abstract]) AND primary care[Title/Abstract]	PubMed	15	
(family engagement[Title/Abstract]) AND pediatric[Title/Abstract]	PubMed	32	
AB family engagement AND AB primary care	CINAHL	28	

# Greatest Hits: Evidence for FCC and CSHCN

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Karen Kuhlthau et al. (2011). Systematic review from 1986-2010

- Initial search=4886 articles. Final tally=24
- CSHCN: asthma, DS, TBI, CF, ADHD, generic
- Conclusion: FCC is associated with improved outcomes in several domains, among different populations and different operationalizations of FCC.
- Note: only a few studies reported nonsignificant or negative outcomes; no worse
  - Children with ADHD: manualized diagnosis & treatment with a team (parent, teacher, and PCP) showed NO EFFECT on behavioral symptoms, some short-lived effects on communication

# Greatest Hits: Current applications and future directions in Peds

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Kuo et al (2012) Commentary

- FCC: partnership approach to health care decision-making between family and health care provider
- Despite endorsement, FCC is insufficiently implemented in clinical practice
- Categories of principles
  - Information sharing
  - Respect and honoring differences
  - Partnership and collaboration
  - Negotiation
  - Care in context of family and community

# Greatest Hits: Childhood Obesity

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Nancy Butte et al (2017)

- RCT, 549 Hispanic and black children (BMI  $\geq$  85th percentile)
- Community-centered program (121 contact hours) versus primary care-centered program (8 contact hours)
- Results
  - Community program more efficacious for BMI reduction at 3 months but not 12 months
  - Family participation was irregular, highlighting the need for greater scheduling flexibility and accommodation
  - Researchers conclude need for research in sustaining family engagement in low-income populations

# Greatest Hits: Family Companion Contributions to PC visits

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- Jennifer Wolff et al., (2011) Meta-analysis
- 17 studies (10 observational and 7 surveys)
- Findings
  - Accompaniment to routine adult physician visits was 38%
  - Most companions were spouses (54%) or adult children (32%)
  - Accompanied visits were 20% longer
  - Physicians engaged in more biomedical information giving when a companion was present
  - Companion verbal activity was favorably related to patient outcomes, but evidence is weak
  - Patients (38%), companions (46%), and physicians (65%) endorsed accompaniment

# Greatest Hits: Family Companion Contributions to PC visits

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- Jennifer Wolff et al., ( 2017)
- 2017: Audio tapes of 30 dyads (PC visits of older patients with family companion)
  - Family companions predominantly facilitated doctor and patient information exchange
  - More than half of companion communication behaviors were directed at improving doctor understanding of patient
  - Companions were more verbally active during visits of patients who delegated the management of their health to others than visits of patients who co-managed or self-managed their health
  - Companions were rated as more helpful by patients who preferred active involvement of family in medical decision-making
- Next: Need to understand effects of and strategies for clarifying patient and family expectations for PC visits

# Research Summary and Synthesis

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- Patient and family engagement are **not** distinguished clearly in the literature
- Researchers seem to mainly examine family engagement at the pediatric and geriatric life phases
- Researchers are interested in family engagement for ethnicity minority and low-income populations
- Family engagement is crucial for intervention compliance
- Family-based lifestyle interventions provide clinically meaningful reductions in obesity relative to standard care.
- Families are willing to enroll kids in child weight management programs from primary care practices

# Critical Analysis

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- Very few studies looking at family engagement for life phases between pediatric and geriatric
- There is little implementation research on family engagement in primary care
- There is little research on FE and IBH

# Family Caregiving

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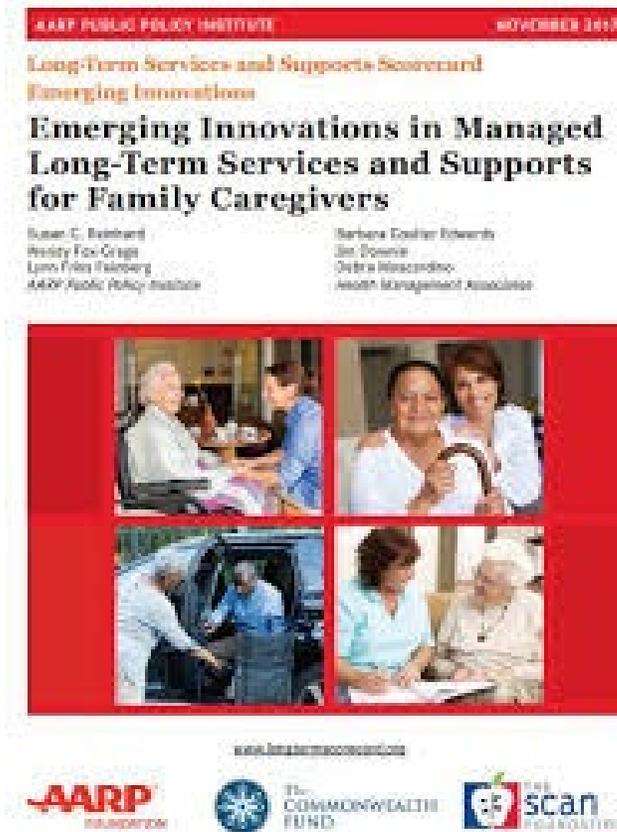
# Family Caregiving Research

Supporting family caregivers has potential for reducing healthcare costs for our aging population by decreasing hospital readmissions and nursing home placements

November 2017 AARP/HMA survey of innovative practices by MLTSS insurers to better engage and support family caregivers:

[http://www.longtermscorecard.org/~media/Microsite/Files/2017/2017%20Scorecard/AARP1202\\_EI\\_EmerInnovationLTSS\\_Oct31v2.pdf](http://www.longtermscorecard.org/~media/Microsite/Files/2017/2017%20Scorecard/AARP1202_EI_EmerInnovationLTSS_Oct31v2.pdf)

*But what does the research say is actually possible?*



# History

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50 years of diverse research in psychology, nursing, social work, medical, epidemiological, etc. literatures

Much of the research is disease-specific—e.g., stroke, cancer, schizophrenia—and solely involves primary caregiver, not whole family

Focused primarily on caregiver issues--psychological (burden/depression) and physical morbidity as a result of caregiving; effects of caregiver support programs (including education, skills training, support, counseling) on caregiver well-being and functioning

Less emphasis on effects of family caregivers support programs on care recipient functioning and clinical outcomes

# PubMed (# of citations)

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Family caregiving = 6359

Family caregiving AND healthcare = 3555

Family caregiving AND healthcare outcomes = 239

Family caregiving AND healthcare costs = 158

Family caregiving AND healthcare utilization = 120

Family caregiving AND hospital readmissions = 7

# Greatest Hits: Schulz's Self-Neglecting Dementia Caregiver

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**Dementia caregiving linked with 63% increased mortality among elderly co-residing spouses in convenience sample (Schulz & Beach, JAMA, 1999)**

Schulz & Martire, 2004 (increased morbidity):

Insomnia

Depression and anxiety

Musculoskeletal problems (e.g., back pain)

Decreased use of preventative medical services

# Greatest Hits: Roth's Purpose-Driven and Resilient Caregiver

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Roth et al (2013) did population-based study of over 3500 caregivers and found that, rather than suffering increased mortality, they had **16.5% reduced rate of death** compared to non-caregivers

# Greatest Hits: Mittelman's Institute Delaying Protocol

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NYU Caregiver Intervention—increases caregiver well-being, forestalls nursing home placement of Alzheimer's patients for nearly 2 years (2006)



# Gitlin & Hodgson Overview (2015)

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Looked at 7 meta-analytic and 17 systematic reviews of RCTs of dementia caregiver interventions (2001-2013) and 15 intervention studies (2013-2014)

6 broad types of interventions: professional support; psychoeducation; behavior management skills-training; counseling; self-care/relaxation training; and multi-component

Outcome variables: caregiver knowledge, burden, self-efficacy, psychological morbidity (depression/anxiety)

**Results: Overall weak to moderate effect**

Best: Multi-component—improved caregiver well-being and care receiver functioning and rate of nursing home placement

# Gitlin & Hodgson (cont.)

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5 key characteristics of effective dementia caregiver interventions:

- \* Active involvement of caregiver, rather than didactic approach
- \* Tailored to specific needs identified by caregiver
- \* Addressing multiple areas of need
- \* For longer periods of time or with multiple episodes of intervention
- \* Intervention dose, intensity and specific is adjusted for caregiver risk profile

# Research Summary & Synthesis

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- Family caregiver interventions have some mild positive effects—more so if dosed at greater intensity for longer duration with multiple components
- Impact of family caregiver interventions on care recipient functioning or clinical outcomes is less well-established
- It is assumed that dementia caregiving research findings are generalizable to caregivers dealing with different diseases
- Much of caregiver research has been conducted in non-clinical settings. There is a strong need for translational research
- Family caregiving research is only now becoming more systemically focused—i.e., on whole family and its dynamics, taking into account disease trajectory, rather than just on primary caregiver

# Critical Analysis

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- Too little family caregiver research is tied to rates of hospital readmission or nursing home placement. As a consequence, family caregiver interventions are not adequately linked to decreased healthcare and social service costs
- Too little translational caregiver research is currently being undertaken

# Recommendations and Discussion

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# Recommendations

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- (LM) Next steps in research

# Discussion

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# References

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# Session Evaluation

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

Thank you!

