Session # F2a

"Minding" the Family Caregiver: Systems-Based Approaches to Working with Dementia in Integrated Care

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Faculty Disclosure

Drs. Zubatsky and Vargish have NOT had any relevant financial relationships during the past 12 months.

Dr. Jacobs is paid for consultation and training for educational and/or healthcare organizations

Conference Resources

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

Slides and handouts are also available on the mobile app.

Learning Objectives

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

- Identify the burdens and challenges that family caregivers of dementia face in integrated care settings.
- Describe the ways that different interprofessional teams work to address challenges in family -centered dementia care
- Apply new biopsychosocial-spiritual strategies and interventions within family-based care for treating dementia patients and family members.

Bibliography / Reference

1. Mintz, S.G. (2014). The Double Helix: When The System Fails the Intertwined Needs of Caregiver and Patient, Health Affairs, 33(9):1689-1692.
2. Roth, D. L., Fredman, L., & Haley, W. E. (2015). Informal caregiving and its impact on health: A reappraisal from population-based studies. The Gerontologist, 55(2), 309-319.
3. Streater, A., Aguirre, E., Spector, A., & Orrell, M. (2016). Cognitive stimulation therapy for people with dementia in practice: A service evaluation. British Journal of Occupational Therapy, 79(9), 574-580
4. Zubatsky, M., Aragon-Prada, M., Muse, F., Rainey, P., & Martin, R. (2016). Navigating Without a Roadmap: Challenges of Early Alzheimer's Caregivers With Their Health Care Team. Global qualitative nursing research, 3, 2333393616673465.
5. Engel, P. A., Spencer, J., Paul, T., & Boardman, J. B. (2016). The geriatrics in primary care demonstration: integrating comprehensive geriatric care into the medical home: preliminary data. Journal of the American Geriatrics Society, 64(4), 875-879.

Learning Assessment

A learning assessment is required for CE credit.

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

A Psychosocial Approach to Help Caregivers and their Loved Ones

What Are We Not Catching Early on Regarding Caregiving?

The caregiver's **motivation** to be a competent caregiver to their loved one

Offering **appropriate respite care services** for caregivers after the diagnosis

Caregiver's **culture, values, beliefs, expectations**

Strengths and abilities that caregivers have to attend to loved one's

We Also Have a Lack of Dementia Care Services for Families in Primary Care

- **Services are often individualized around screenings and medication management follow-ups**
- **Caregivers miss important information about the diagnosis and a plan of care**
- **Families often are confused as to the next options in their care.**

Key Features of Cognitive Stimulation Therapy

14 psychosocial group sessions, usually twice a week

45 minutes to an hour, with exercise component will be longer.

Ideally 5-8 participants in a group, run by two therapists/facilitators.

Each session has a choice of activities, to cater for interests and abilities of group.

Group members should ideally be at similar stages of dementia, so activities can be pitched accordingly.

Attention should be paid to gender mix.

Spector et al., 2003

-**Mental stimulation**

- Getting people’s minds active and engaged

-**New ideas, thoughts and associations**

- Often with people with dementia, we tend to talk about things from the past
- The aim of CST is to continually encouraged new ideas, thoughts and associations

-**Opinions rather than facts**

- People will often be wrong with facts. If we ask people for their opinions, they cannot be wrong.

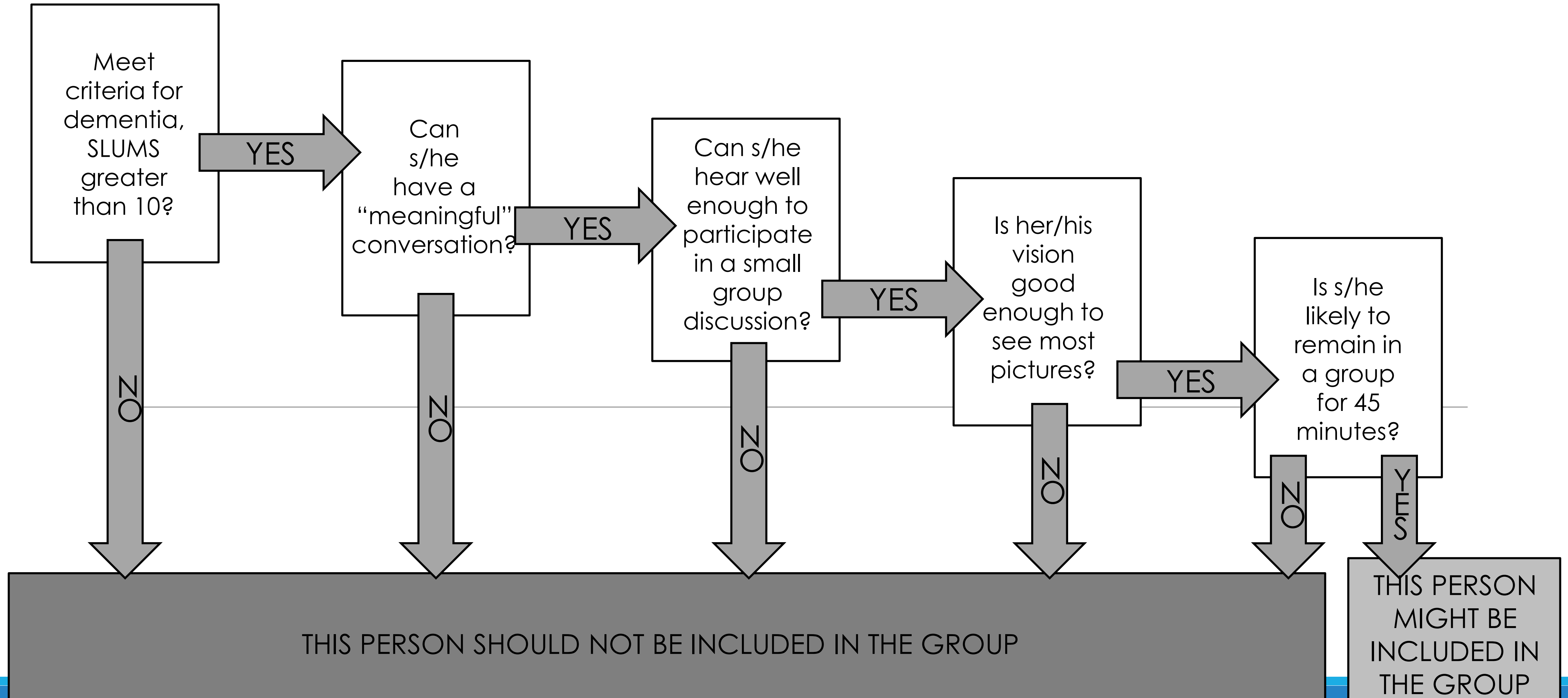
-**Using reminiscence as an aid to the here-and-now**

- A powerful tool towards orientation

-**Using orientation, both sensitively and implicitly**

- Orientation needs to be done in a subtle, implicit way

Who is appropriate for CST?



Assessments Throughout the Program

SLUMS
- http://medschool.slu.edu/agingsuccessfully/pdfsurveys/slumsexam_05.pdf

QOL-AD
- http://www.dementia-assessment.com.au/quality/qol_handout_guidelines_scale.pdf

Cornell Scale for Depression in Dementia
- http://www.amda.com/resources/2005_updates_ltc_teaching_kits/dementia.pdf

Rapid Caregiver Well-Being Scale (Caregivers)

TUGS
- http://www.cdc.gov/homeandrecreationalsafety/pdf/steadi/timed_up_and_go_test.pdf

Perryville Memorial Hospital

- A model for how to incorporate a family-centered dementia protocol in a medical setting
  - Ways to bill services for CST under OT codes
  - Respite care services for caregivers who have loved ones in the group (Groups running simultaneous to CST)
  - Buy-in from administrators and directors on the benefits of a family-centered approach
  - Intern training for new professionals who help facilitate groups

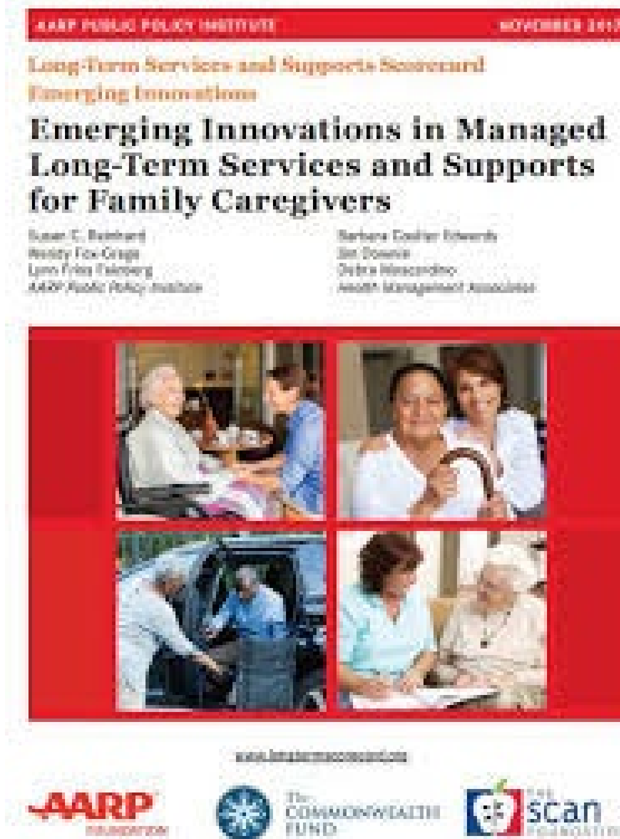
http://www.pchmo.org/services-CST.aspx

A Surge In Interest in Enhancing Family Caregiver Supports

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



Opportunities

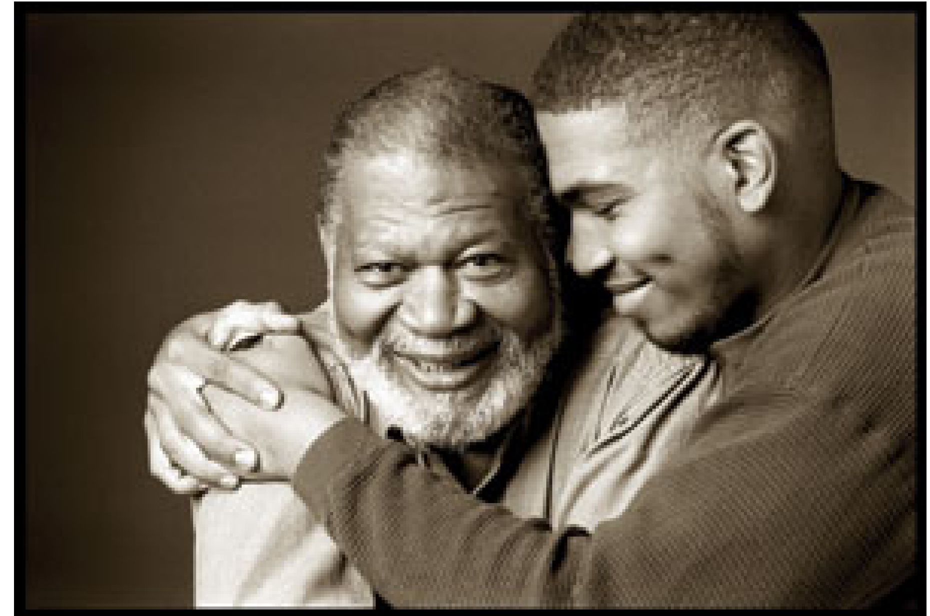
MLTSS

D-SNPs

Medicare ACOs

Medicare Advantage plans

Complex care management programs



Need For More Formal and Comprehensive Caregiver Assessment

"Assessing and addressing both the individual's and the family caregivers' information, care, and support needs and their experience of care" (Feinberg)

Willing and able to perform care tasks?

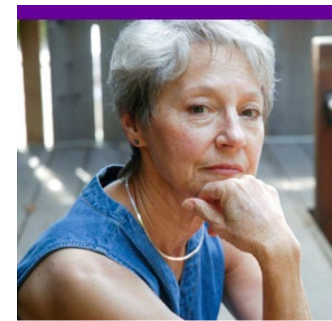
Honoring the Mission

- 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

"Why do you do what you do for your loved one?"

What are the values underlying your <u>choice</u> to give care?

Karen



"Shortly after I was pregnant I left my husband. And then after the child was born, I decided I was going to go back with him. And my parents knew it wasn't going to work. And my mother kept saying, 'You'll go back and have another baby.' And my father said to me, 'You can always come home. I don't care if you have 10 babies. You can always come home.' He left that door open for me. And I did just that. I went back and had another baby and came back with two babies. And, I'll never forget that. I always knew I could go home."

An Interprofessional Team Approach to Identifying Caregivers' Needs: UR Geriatric Assessment Clinic

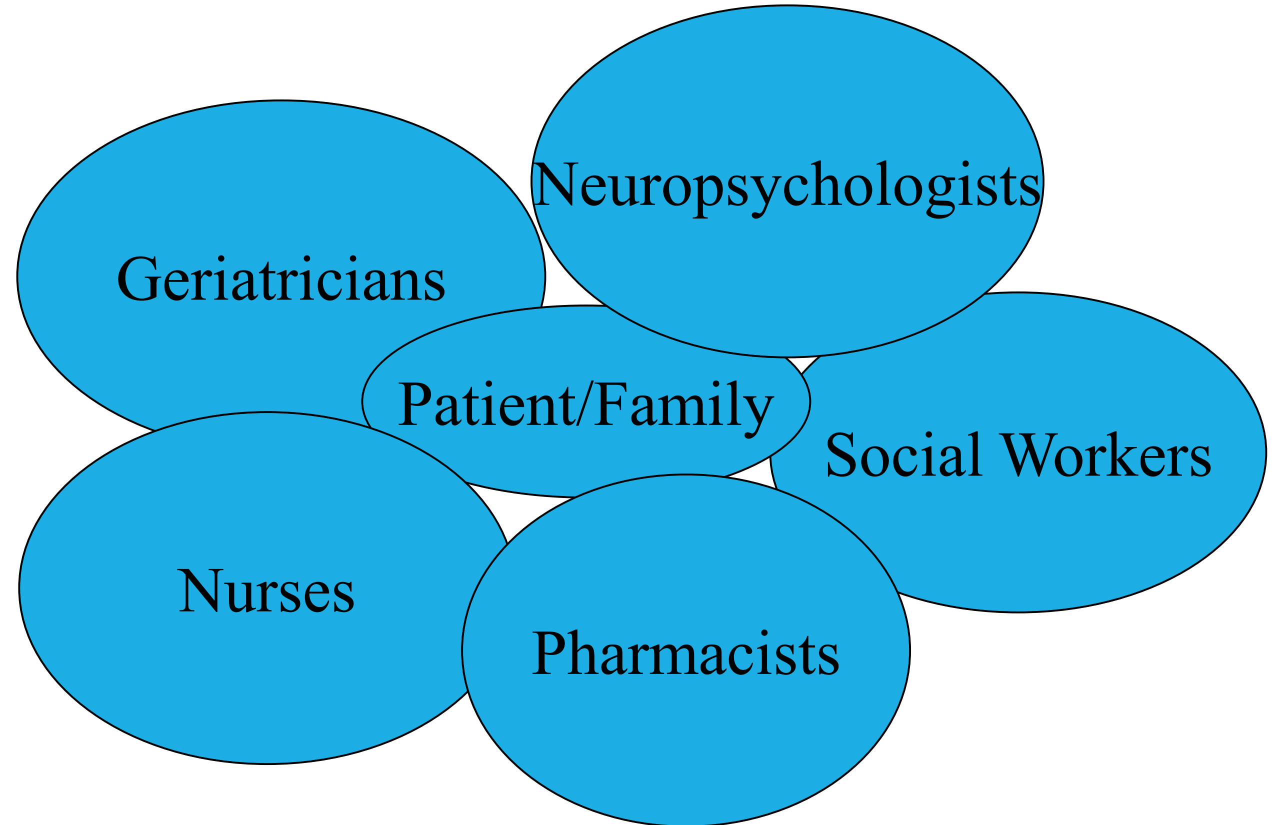
Established in 1980 by Dr. T. Franklin Williams and has since become known a national model for subsequent clinical programs.

Goals:

1. maintain frail older adults in the community at the most independent level through an interdisciplinary approach of comprehensive geriatric assessment
2. Main teaching site for the University of Rochester and other local health professional schools for training in geriatrics.

Interprofessional Team Interface

- Each team member's professional domain knowledge is recognized.
- Collaborative team practice central to model.
- Allows for contextual understanding of complex issues.



The Geriatric Assessment Model

- Comprehensive assessment done by interdisciplinary team
- Personalized recommendations provided to patients, families, caregivers, and primary care physicians
- Information shared regarding community resources and service agencies to assist older adults in the Greater Rochester area.

Components of Geriatric Assessment

- Medical
- Functional
- Psychological
- Cognitive
- Social
- Economic
- Family Dynamics

Caregiver Assessment Tools

- Zarit Burden Scale (Zarit, 1983)
  - 22 items (scale: 0 never – 4 nearly always)
  - >21mild-mod burden
- Behav 5+ (Sadak, Borson et al 2014)
  - 6 items (YES/NO)
  - > 2 suggests need for psychosocial supports

Interprofessional Team Recommendations

- Team members acknowledge and validate caregivers' needs
  - Problem solve together
- Resources in community are shared with both caregiver and Primary Care Provider
  - Ensure follow-up

Final Reflection Question

What are existing barriers for those in integrated care trying to attend to caregiver health?

Session Evaluation

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

Thank you!