Designing a Pragmatic Advance Care Planning Group Visit Intervention for Individuals with Mild Cognitive Impairment

Andrea E. Daddato, PhD, MS
Prajakta Shanbhag, MPH
Brianne M. Bettcher, PhD
Hillary D. Lum, MD, PhD

Division of Geriatric Medicine
SCHOOL OF MEDICINE
UNIVERSITY OF COLORADO **ANSCHUTZ MEDICAL CAMPUS**

Alzheimer's and Cognition Center
UNIVERSITY OF COLORADO
ANSCHUTZ MEDICAL CAMPUS

BACKGROUND

- Among older adults without cognitive impairment, a novel Engaging in Advance Care Planning Talks (ENACT) Group Visits intervention increased ACP documentation and readiness to engage in ACP.
- For individuals with mild cognitive impairment (MCI), planning for their future medical wishes and values before further cognitive decline is important.

OBJECTIVE: As a pragmatic intervention, can the ENACT Group Visits be adapted to support people with MCI and their family care partners?

SETTING/POPULATION

- Individuals with MCI and partners recruited as dyads from the UCHealth Seniors Clinic and a longitudinal study of MCI at the University of Colorado Alzheimer's Disease Center.
- **Inclusion:**
  1. Documented or self-reported diagnosis of MCI, early dementia, or cognitive concerns
  2. Age 60 years or older
  3. Family care partner who can participate
- **Exclusion:**
  1. 3 or more errors on the Short Portable Mental Status Questionnaire (SPMSQ)
  2. Hearing issues that would make it difficult to participate in group discussions
  3. Inability to travel to the study site
  4. Inability to demonstrate capacity to consent

REFERENCES
1. Sudore, R. L., Landefeld, C. S., Williams, B. A., Barnes, D. E., Lindquist, K., & Schillinger, D. (2006). Use of a modified informed consent process among vulnerable patients: a descriptive study. *J Gen Intern Med, 21*(8), 867-873. doi:10.1111/j.1525-1497.2006.00535.x
2. Onken, L., Carroll, K., Shoham, V., Cuthbert, B., & Riddle, M. (2014). Reenvisioning clinical science: Unifying the discipline to improve the public health. *Clinical Psychological Science*, *2*, 22–34.
d.school bootcamp bootleg.
3. Institute of Design at Stanford. https://static1.squarespace.com/static/57c6b79629687fde090a0fdd/t/58890239db29d6cc6c3338f7/1485374014340/METHODCARDS-v3-slim.pdf Accessed on March 12, 2020.
4. Sudore, R. L., Heyland, D. K., Barnes, D. E., Howard, M., Fassbender, K., Robinson, C. A., . . . You, J. J. (2017). Measuring Advance Care Planning: Optimizing the Advance Care Planning Engagement Survey. *J Pain Symptom Manage, 53*(4), 669-681 e668. doi:10.1016/j.jpainsymman.2016.10.367

METHODS

To design for pragmatic implementation, we used a human-centered design process, rapid-cycle prototyping, and qualitative methods guided by the NIH Stage Model for Behavioral Intervention Development to adapt an ENACT group visits intervention to individuals with MCI and their study partners.[2,3]

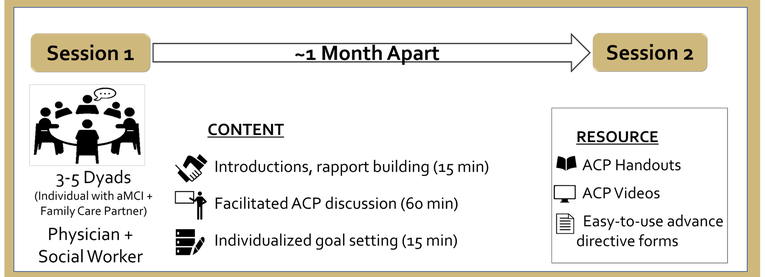
- ✓ Stage 0 – Basic science
- ✓ Stage I – Intervention generation, refinement, modification, and adaptation and pilot testing
- ✓ *Stage III – Efficacy testing with real-world providers (not done)*
- ✓ Stage IV – Effectiveness research
- ✓ *Stage V – Dissemination and implementation research (not done)*

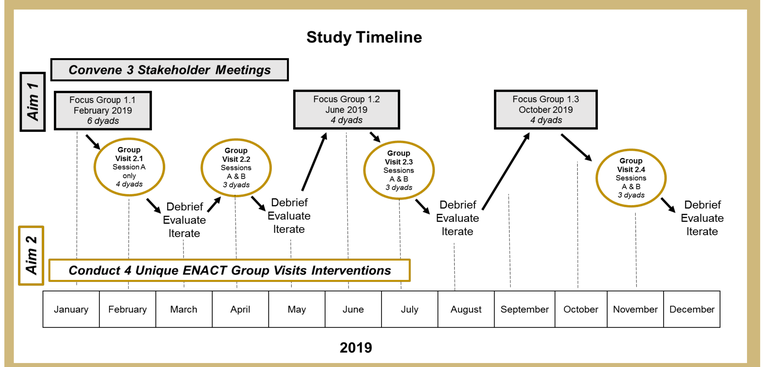
Aim 1: Longitudinal cohort of six dyads met three times to suggest adaptations to an evidence-based ENACT Group Visits model.

Aim 2: Single arm study of four ENACT group visits prototypes that were iteratively refined with adaptations from the longitudinal cohort and participant feedback.

To measure **effectiveness** and **implementation outcomes**:

1. Effectiveness: 4-item questionnaire for ACP readiness (pre and post)[4]
2. Appropriateness: Surveys after ENACT group visits
3. Acceptability, Feasibility & User Input: Qualitative telephone interviews





RESULTS

Table 1. Demographics of Participants with MCI

	Focus Group (n=6)	ENACT Group Visit Interventions (n=13)
Age	76.2 (±6.62)	78.7 (±5.81)
Female	3 (50%)	3 (23%)
Family Care Partner's Relationship to Participant with MCI		
Spouse	4 (67%)	9 (69%)
Partner	1 (17%)	1 (8%)
Child	1 (17%)	3 (23%)

Table 2. Appropriateness of ENACT Group Visit (n=13 participants; 13 family care partners)

On a scale of 1-5 (1=strongly disagree, 5=strongly agree)	Total M (SD)
1. The group visit setting is better for talking about advance care planning than a normal visit with my doctor.	4.46 (0.86)
2. The group discussion gave me useful information.	4.81 (0.40)
3. I felt comfortable talking about advance care planning in the group setting.	4.73 (0.53)
4. Talking with other people about advance care planning was helpful.	4.62 (1.02)
5. I feel the group visit addressed my specific questions.	4.38 (0.70)
6. I feel able to discuss advance care planning with my regular healthcare provider.	4.50 (0.58)
7. I would recommend these group visit sessions to a friend.	4.65 (1.06)

Acceptability of ENACT Group Visits for Individuals with MCI – Longitudinal Cohort:

- The stakeholders reported ACP as a priority for individuals with MCI and described the need for ACP in a group setting.

Human-centered design process:

- Use of rapid prototyping and stakeholder engagement allowed iterative user-input to test different ACP resources and tools aimed at helping individuals with MCI and their partners discuss ACP, across four group visit prototypes.

Feasibility and User Input:
(n=10 participants with MCI; 10 family care partners):

- Group visit setting was helpful to hear others' stories related to ACP
- Two sessions is important to build rapport (3 would be excessive)
- Discussion of how to start a conversation about ACP with loved ones was most helpful topic
- Need more explicit discussion of MCI
- Having a care partner attend with the participant was helpful to the person with MCI
- Unclear what to expect from a group visit, but glad they did
- Group size: 4 dyads would be ideal - allows for intimate conversations (recruitment challenges)

CONCLUSIONS

- Despite stakeholder acceptability and appropriateness, adaptations to the ENACT Group Visits to specifically reach dyads affected by MCI may have limited feasibility for implementation into usual care (primary care or neurology care).

Table 3. ACP Readiness (n=13 participants)

	Pre-Group Visit Mean(SD)	Post-Group Visit Mean (SD)	p-value
How ready are you to sign official papers naming a medical decision maker to make medical decisions for you?	1.9 (1.1)	1.8 (0.9)	0.71
How ready are you to talk to your decision maker about the kind of medical care you would want if you were very sick or near the end of life?	1.5 (0.9)	2.4 (1.0)	**0.03***
How ready are you to talk to your doctor about the kind of medical care you would want if you were very sick or near the end of life?	2.8 (1.4)	2.0 (0.9)	0.10
How ready are you to sign official papers putting your wishes in writing about the kind of medical care you would want if you were very sick or near the end of life?	2.0 (1.2)	2.1 (1.2)	0.86