Implementing Pragmatic Advance Care Planning Interventions in the Health System Context

Hillary Lum, MD, PhD
The Colorado Pragmatic Research in Health Seminar Series
March 3, 2021
Tweet: @Hdaylum
Collaborative Work

- Mentors
  Jean Kutner
  Cari Levy
  Rebecca Sudore
  Dan Matlock
  Bri Bettcher

- Clinical Partners
  Bennett Parnes
  CT Lin
  Ingrid Lobo
  John Scott
  Lisa Schilling

- Team
  Taryn Bogdewiecz
  Adreanne Brungardt
  Andrea Daddato
  Joanna Dukes
  Sue Felton
  Lierin Flanagan
  Kirbie Hartley
  Sarah Jordan
  Dana Lahoff
  Iliian Mino
  Elisabeth Montgomery
  Pat Schulof
  Prajakta Shanbhag

- Collaborators
  Russ Glasgow
  Bethany Kwan
  Dave Nowels
  Jenna Reno
  Allison Wolfe
Learning Objectives

Methods for Planning for Pragmatic Research: An Advance Care Planning Journey

- **Illustrate**: Illustrate options for multi-level stakeholder engagement
- **Compare**: Compare opportunities from diverse funders
- **Develop or refine**: Develop or refine plans for public goods
What Is Advance Care Planning?

Advance care planning is a process that supports people at any age or stage of health in understanding and sharing their personal values, life goals, and preferences for future medical care.

Why Does Advance Care Planning Matter?

• ~30% of older adults will need a decision maker to make decisions.

• Fewer in-hospital deaths and more hospice use.

• Decision makers often choose comfort care, especially if there was an advance directive.

Difficult Questions

• Where should conversations happen?
• Who should be involved?
• How can we engage others in advance care planning?
Levers of Culture Change for ACP

- General Public
- Healthcare systems
- Legal system

- Training of professionals
  - Public education

- Tools for conversations & documentation
- Policy & programs

- Data
  - Quality Metrics

NIH Stage Model

Pragmatic Considerations

- Stakeholder Experiences
- Research Questions
- Real-World Interventions
- Accessible Data
- Reflect and Adapt

Places & People of Culture Change

- Primary Care Group Visits
Science of ACP Group Visits

• Purpose:
  Develop an ACP Group Visit intervention to engage patients in ACP as a health behavior

• Theory:
  Group dynamic impacts attitudes and learning to influence behavior change, leading to ACP actions

ENgaging in Advance Care planning Talks (ENACT) Group Visits
Considerations for Multiple Funders

The Colorado Health Foundation
- Quality Improvement
- 5 Group Visits (Single Arm Feasibility)

National Palliative Care Research Center
- Refining Intervention with Stakeholders
- Implementation Manual

National Institute on Aging (NIA) K76
- Randomized Controlled Trial
- Recruitment Video

NIA Alzheimer’s Disease Supplement
- Adapting for Cognitive Impairment
ENACT Theoretical Framework

Collaborative Learning Theory
- Social Process
- Diverse Learners
- Individual Experience

Advance Care Planning Behavior Change Theory
- Maintenance
- Action
- Preparation
- Contemplation

Bruffee. Collaborative Learning. 1993
Advance Care Planning Group Visits

Intervention Components:

- Interactive conversations of advance care planning
- Education and support through group dynamics
- Patient goal setting for advance care planning actions
- Uses outpatient billing codes & documentation

Clinic Support:
What Does an ACP Group Visit Look Like?

Session 1

1 Month Apart

Session 2

8-10 Participants
Physician + Social Worker

CONTENT

- Check in, vital signs, medication review (30 min)
- Introductions, rapport building (15 min)
- Facilitated ACP discussion (60 min)
- Individualized goal setting (15 min)

RESOURCES

- ACP Handouts
- PREPARE video stories
- Easy-to-use advance directive forms

In Outpatient Clinic
Advance Care Planning Discussion Topics

- Values clarification
- Ongoing conversations (patients, family, decision makers, clinicians)
- Surrogate decision makers (flexibility)
- Advance Directives (medical power of attorney, living will)
- Common medical treatment options (risks, benefits, burdens)

Patient Experience: Acceptability & Usefulness

“They expressed their experiences and it put me at ease to realize that there are people out there who have the same thoughts as I do, and they are in the same situations that I am in where their loved ones cannot bear talking about the subject. ... It gave me more encouragement to find a way to encourage my loved ones to listen to what I have to say.”
Patient Engagement: ACP Behavior Change

Pre-Contemplation

• “I’m here primarily concerning the notifications of people in case of any type of emergency.”

Contemplation

• “How do you get there though? You may have all these preconceived ideas about I just want to go when I’m ready, and then at the last minute, it is sort of like, hmmm…”

Preparation

• “At this point, it seems like the next step is really on me, on us.”
Pilot RCT of ENACT Group Visits

Pilot RCT timeline:
- Recruit, randomize, baseline data
- 3 month outcomes
- 6 month outcomes

Outcomes:
- EHR review
- ACP readiness
- Stakeholder interviews

Seniors Clinic
- Referrals (n = 835)
- Patients (n = 110)
- Recruitment rate = 13%
- Group size: 3-11 patients
- First session patients (n=41)
- Second session patients (n=34)
- Retention/completion rate = 83%

N=110
Mean age 77 years
60% female
79% white
63% married
22% caregivers
Efficacy: ACP Documentation

ACP DOCUMENTS

Rate of ACP Documents

<table>
<thead>
<tr>
<th>Mailed ACP Arm</th>
<th>ENACT Group Visits Arm</th>
</tr>
</thead>
<tbody>
<tr>
<td>0%</td>
<td>40%</td>
</tr>
<tr>
<td>3 months</td>
<td>44%</td>
</tr>
<tr>
<td>6 months</td>
<td>70%</td>
</tr>
<tr>
<td>12 months</td>
<td>76%</td>
</tr>
</tbody>
</table>

DECISION MAKER DOCUMENTATION

Rate of Decision Maker Documentation

<table>
<thead>
<tr>
<th>Mailed ACP Arm</th>
<th>ENACT Group Visits Arm</th>
</tr>
</thead>
<tbody>
<tr>
<td>0%</td>
<td>69%</td>
</tr>
<tr>
<td>3 months</td>
<td>71%</td>
</tr>
<tr>
<td>6 months</td>
<td>76%</td>
</tr>
<tr>
<td>12 months</td>
<td>83%</td>
</tr>
</tbody>
</table>

p<0.01 at 3, 6 and 12 months
<table>
<thead>
<tr>
<th>Readiness Questions (Sudore et al)</th>
<th>6 months, N=100</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Control Mean (SD)</td>
</tr>
<tr>
<td>Sign official papers naming a medical decision maker to make medical decisions for you?</td>
<td>4.39 (0.99)</td>
</tr>
<tr>
<td>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?</td>
<td>4.28 (1.22)</td>
</tr>
<tr>
<td>Talk to your doctor about the kind of medical care you would want if you were very sick or near the end of life?</td>
<td>3.59 (1.30)</td>
</tr>
<tr>
<td>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?</td>
<td>4.26 (1.05)</td>
</tr>
</tbody>
</table>
Patient: “Being there, being able to ask the questions, hearing the other participants share was very meaningful. It was a significant advantage. I think it brought up some things that I hadn’t considered.”

Primary care practitioner: “Even though I may be good at having those conversations with my patient and making sure we're establishing those goals, I need them to talk to other people about it… I think it's easier for some people to talk about it with strangers, initially. It can help set the stage for them to go talk about it in the real world.”
Engaging Multiple Stakeholders

Practice Implementation Manual

Online Facilitator Training Modules

Social Workers

Patients

Family Members

Primary Care Practitioners

Medical Assistants

Schedulers

Patient Recruitment Video

Peer Partners in Groups

CPC+ Comprehensive Primary Care Plus
Public Good: Patient Awareness
Inclusion Criteria
• ≥ age 70
• English- or Spanish-speaking
• At least one clinic visit in past year

Eligibility Screening
Informed Consent (demonstration of decision making capacity)
Enrollment
Baseline Assessment

Exclusion Criteria
• Lack of phone, inability to travel to clinic, moving out of the area within 6 months,
• Hearing impairment that limits participation

Intervention Arm
• Send Colorado easy-to-use advance directive and PREPARE pamphlet by mail
• Two 2-hour group visits with facilitated ACP discussion and goal setting

Control Arm
• Send Colorado easy-to-use advance directive and PREPARE pamphlet by mail

6-month follow up
• Chart review to assess ACP documentation
• Phone calls to assess patient-reported outcomes
• Acceptability interviews with participants from each arm

Location – Denver Metro Area
5 Primary Care Clinics
500 patients
Goal of 15% with cognitive impairment, defined by MOCA <26
5-6 facilitators, including advanced practice providers
Adaptations

- Spanish Group Visits
  - Partnering with Denver Health
- Virtual Group Visits
  - Partnering with Dr. Allison Wolfe
- Cognitive Impairment Group Visits
  - Partnering with Dr. Bri Bettcher
Adapting for Cognitive Impairment

- Longitudinal Patient and Care Partner Stakeholder Input
- Iterative Refinement
- Multi-method evaluation

Study Timeline

**Aim 1**
- Convene 3 Stakeholder Meetings
- Focus Group 1.1
  - February 2019
  - 6 dyads
- Group Visit 2.1
  - Session A only
  - 4 dyads
- Debrief Evaluate Iterate

- Focus Group 1.2
  - June 2019
  - 4 dyads
- Group Visit 2.2
  - Sessions A & B
  - 3 dyads
- Debrief Evaluate Iterate

- Focus Group 1.3
  - October 2019
  - 4 dyads
- Group Visit 2.3
  - Sessions A & B
  - 3 dyads
- Debrief Evaluate Iterate

**Aim 2**
- Conduct 4 Unique ENACT Group Visits Interventions

<table>
<thead>
<tr>
<th>January</th>
<th>February</th>
<th>March</th>
<th>April</th>
<th>May</th>
<th>June</th>
<th>July</th>
<th>August</th>
<th>September</th>
<th>October</th>
<th>November</th>
<th>December</th>
</tr>
</thead>
</table>

2019
Places & People of Culture Change

• Primary Care Group Visits
• mHealth Approach – Patient Portal
Rationale for Engagement via Patient Portal

In 2017, My Health Connection had no information for advance care planning.

Colorado law for the Medical Durable Power of Attorney does not require witnesses or notary.

Example from the literature:
A portal process resulted in filling in advance directive forms, which were printed, signed, brought to clinic.
**Input from stakeholders and partners: Designing for Clinical Use**

<table>
<thead>
<tr>
<th>Patients and Family Advisors</th>
<th>Clinical Operations</th>
<th>Healthcare Team Members</th>
</tr>
</thead>
<tbody>
<tr>
<td>• ACCORDS Research Patient Advisory Committee</td>
<td>• Computer analysts</td>
<td>• Healthcare Providers</td>
</tr>
<tr>
<td>• Family Medicine Clinic</td>
<td>• Legal Counsel</td>
<td>• Care Managers</td>
</tr>
<tr>
<td>• Seniors Clinic</td>
<td>• Health Information Management</td>
<td>• Social Workers</td>
</tr>
<tr>
<td>• UCH Patient and Family Advisory Committee</td>
<td>• Health Literacy</td>
<td>• Medical Assistants</td>
</tr>
<tr>
<td></td>
<td>• Population Health Leadership</td>
<td>• Nurses</td>
</tr>
<tr>
<td></td>
<td>• Marketing</td>
<td>• Palliative Care Teams</td>
</tr>
</tbody>
</table>
Patient Stories & Leadership Testimonials

- “All of our providers and staff are focused on ensuring patients receive the very best care and experience.

- I’ve personally seen how important these conversations and documents are”

  – Liz Concordia, UCHealth CEO
Design and Implementation of Patient Portal–Based Advance Care Planning Tools

Hillary D. Lum, MD, PhD, Adreanne Brungardt, MM, MT-BC, Sarah R. Jordan, MA, Phoutdavone Phimphasone-Brady, PhD, Lisa M. Schilling, MD, MSPH, Chen-Tan Lin, MD, Jean S. Kutner, MD, MSPH

Three Implementation Phases

Phase 1 (May 2017)
- New Webpage
- Online Message for ACP questions to centralized team

Phase 2 (July 2017)
- Electronic Medical Durable Power of Attorney (includes messages to provider and patient)

Phase 3 (Oct 2017)
- Display advance directives to patient via patient portal
“Being able to go online and kind of do a little research myself, it made me more comfortable with it, and then I could bring up that kind of conversation. So I think it’s absolutely a necessity to have it online to at least get people started.”

Female, 30 years old
Sharing Program Highlights to Key Leaders

My Health Connection (MHC)
ADVANCE CARE PLANNING TOOLS

Hillary Lum, M.D., PhD
hillary.lum@cuanschutz.edu
V2.1.2021

Since January 2020, there has been a huge surge in electronic MDPOAs submitted through MHC due to COVID-19.

Electronic MDPOA Features:
- DECISION MAKER & MEDICAL PREFERENCES
- VIEWABLE & DOWNLOADABLE
- PATIENT & PROVIDER COMMUNICATION

2017-2021
18,000 Patients have used the ACP Tools

Every day, about 50 UCH Health patients
Choose a Medical Decision Maker thru MHC

Available Across UCH Health and Affiliates

Regional Use
Patients from 28 States
1 In Germany
Extraordinary Partners in Care: Five-year goal

Every person who receives care through UCHealth will have their goals of care assessed and documented at least annually to include relevant changes in health, functional status or social situation.

- This documentation will be accessible to and may be updated by all care team members.
- Patients and their care teams will engage in shared decision making that takes into account the person’s personal expertise about their goals and preferences, and also acknowledged provider's belief/value system.
- Supports and options are in place that make care in the patient’s preferred location the default (rather than ED or hospital admission).

Courtesy of Dr. Jean Kutner, Chief Medical Officer, University of Colorado Hospital
Places & People of Culture Change

• Primary Care Group Visits
• mHealth – Patient Portal
• A Community Website
Colorado Care Planning Website

- A public-facing website of Colorado advance care planning information using iterative, diverse stakeholder input.

Here’s a roadmap for future medical planning in Colorado. Start exploring!

Think About Your Values
Choose A Decision Maker
Write Down Your Wishes
Make Medical Choices
Share Your Wishes

ROADMAP
Follow this roadmap for guidance through the advance care planning process. Each step along the way provides you with information to help you choose which steps and documents are right for you.

WHAT IF I...
Everyone has their own personal journey, and often our journeys have different needs. Check out this page for tailored resources on what makes you you. For example, “What if I am a Veteran” and “What if I need an Advance Directive in Spanish”.

COLORADO COMMUNITY RESOURCES
Advance care planning may bring up additional topics such as housing, caregiving and insurance. Use this page to find resources near you such as housing, caregiving and insurance.

READ MORE
READ MORE
READ MORE
Resources & Websites

§ Advance Care Planning – Center for Improving Value in Health Care (CIVHC): https://www.civhc.org/programs-and-services/advance-care-planning/

Kari Degerness, MBA, LNHA
  ◦ kdegerness@civhc.org

§ The Conversation Project – Boulder County http://theconversationprojectinboulder.org/

§ Easy to Read Advance Directive www.prepareforyourcare.org
Key Pragmatic Approaches

Multiple Voices
- Ongoing formal and informal input from stakeholders to refine ACP approaches

Multiple Funders
- Leveraging different funding to address scientific and stakeholder needs

Multiple Deliverables
- Developing implementation tools, practical resources, and community resources
<table>
<thead>
<tr>
<th>Reflections</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Be creative</strong></td>
<td>Create things that people can use</td>
</tr>
<tr>
<td><strong>Partner</strong></td>
<td>Collaborate with different people, especially patients and community members</td>
</tr>
<tr>
<td><strong>Listen</strong></td>
<td>Seek to understand what others need, incorporate their input</td>
</tr>
<tr>
<td><strong>Persist</strong></td>
<td>Highlight important things, sometimes funders, health care systems, payors and policy makers will agree</td>
</tr>
</tbody>
</table>
Patient: “It was a little bit tight, I think if they had a little bit more room between people, that might help a little bit.”

Medical Assistant: “We need to have the patients in the room on time and also we need to take the vitals, so it’s been kind of stressful. A little bit more help, that would make it a little bit different.”

Social Worker: “The only weakness I can think of is the rooming process. Typically on Friday afternoons have some less staff for check in. We have gotten started a couple minutes late. Our medical assistants have gotten a little overwhelmed.”