CARING FOR UNREPRESENTED OLDER ADULTS:
AN AGE-FRIENDLY PERSPECTIVE

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UTAH GERIATRICS SOCIETY
ANNUAL BUSINESS AND EDUCATION MEETING

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DISCLOSURES

• I have no relevant conflicts of interest to disclose.
OBJECTIVES

• Understand how to apply the 4Ms – What Matters, Medication, Mentation, and Mobility - to every clinical encounter with older adults
• Recognize that social isolation contributes to increased morbidity and mortality among older adults
• Appreciate how the complex needs of unrepresented older adults can be anticipated and addressed by Age-Friendly Health Systems
What is an Age-Friendly Health System?
ORIGIN OF AGE-FRIENDLY HEALTH SYSTEMS - 1

Age-Friendly Health Systems - Founding Organizations
• Institute for Healthcare Improvement
• The John A. Hartford Foundation
• American Hospital Association
• Catholic Health Association of the United States

Many evidence-based geriatric care models exist. However, implementation of these geriatric care models across US health systems is uneven.
Table 1. Seventeen Care Models with Level 1 or 2a Evidence of Impact.

1. ACE Unit
2. CM+
3. Care Transitions Program
4. Center to Advance Palliative Care
5. Geriatric Emergency Department
6. Geriatric Interdisciplinary Team Training
7. GRACE
8. Guided Care
9. HomeMeds
10. Hospital at Home and Mount Sinai’s MACT
11. HELP
12. IMPACT
13. NICHE
14. Patient Priority Care
15. PACE
16. TCM
17. University of California at Los Angeles Alzheimer’s and Dementia Care Program

Note: ACE = Acute Care for Elders; CM+ = Care Management Plus; GRACE = Geriatric Resources for Assessment and Care of Elders; MACT = Mobile Acute Care Team; HELP = Hospital Elder Life Program; IMPACT = Improving Mood—Promoting Access to Collaborative Treatment; NICHE = Nurses Improving Care for Health System Elders; PACE = Program for All-Inclusive Care of the Elderly; TCM = Transitional Care Model.

Distilled to 4 elements or “4Ms” that should be reliably provided to all older adults, regardless of the care setting or specialty.
THE 4MS OF AGE FRIENDLY HEALTH SYSTEMS

**What Matters**
Know and align care with each older adult’s specific health outcome goals and care preferences including, but not limited to, end-of-life care, and across settings of care.

**Medication**
If medication is necessary, use Age-Friendly medication that does not interfere with What Matters to the older adult, Mobility, or Mentation across settings of care.

**Mentation**
Prevent, identify, treat, and manage dementia, depression, and delirium across settings of care.

**Mobility**
Ensure that older adults move safely every day in order to maintain function and do What Matters.
WHAT MATTERS MOST TO YOU?
As of July 2022:

~2800 participating hospitals and practices

813, including University of Utah Health, achieved “Committed to Care Excellence” designation
DOES IT MATTER TO ASK “WHAT MATTERS MOST TO YOU”? 

JAMA Internal Medicine | Original Investigation

Association of Patient Priorities-Aligned Decision-Making With Patient Outcomes and Ambulatory Health Care Burden Among Older Adults With Multiple Chronic Conditions

A Nonrandomized Clinical Trial

Mary E. Tinetti, MD; Aanand D. Naik, MD; Lilian Dindo, PhD; Darce M. Costello, EdD, MPH, MBA; Jessica Esterson, MPH; Mary Gesla, BN, MSN, RN; Jonathan Rosen, MD; Kizzy Hernandez-Bigos, BA; Cynthia Daisy Smith, MD; Gregory M. Ouellet, MD; Gina Kang, MD; Yungah Lee, MD; Caroline Blaum, MD

Question
Is care for older adults with multiple chronic conditions that is aligned with their health priorities associated with improved patient-reported outcomes and reduced unwanted care?

STUDY BACKGROUND: MULTIPLE CHRONIC CONDITIONS (MCCS)

• Older adults with MCCs receive much care with unclear benefit
• Clinical trials often exclude older adults with MCCs
• Focus on disease-specific outcomes can lead to treatment burden
  – People with MCCs spend an average of 2 hours per day on health care-related activities

METHODS

- 366 adults aged ≥65 with >3 chronic conditions and either 10 medications or visits to >2 specialists over the past year

- Exclusion criteria: Advanced dementia, hospice-eligible, receiving dialysis, or residing in a nursing home

- Patient Priorities Care intervention group
  - Included a primary care practice and a cardiology practice
  - Included discussion of health priorities by a facilitator and by clinicians
  - Identified “the one thing” that is the most important health outcome goal

PATIENT PRIORITIES CARE INTERVENTION

Figure 2. Steps in Patient Priorities Care

- **Step 1**
  - Facilitator helps patient
  - Clarify values
  - Identify health outcome goals
  - Elaborate care preferences
  - Engage with clinicians around health priorities

- **Step 2**
  - Patient’s health priorities are documented and transmitted to patient’s clinicians
  - Clinicians consider patient’s current health care and potential health care options within the context of patient’s health priorities and health trajectory

- **Step 3**
  - Patient and clinicians continuously work to align care and decisions with patient’s health priorities, by stopping, continuing or starting interventions
  - Clinicians translate patient’s health priorities into care options

PATIENT-REPORTED OUTCOMES

Table 2. Baseline Follow-up Differences in Patient-Reported Outcomes Among Older Adults With MCCs Receiving PPC or UC

<table>
<thead>
<tr>
<th>Patient-Reported Outcome</th>
<th>Least Squares Mean (SE)a</th>
<th>Usual Care</th>
<th>Baseline – Follow-upb</th>
<th>P Value</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Patient Priorities Care</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Treatment Burden Questionnaire</td>
<td>-12.4 (4.0)</td>
<td>-7.4 (4.0)</td>
<td>-5.0 (2.0)</td>
<td>.01</td>
</tr>
<tr>
<td>O-PACIC</td>
<td>-0.2 (0.2)</td>
<td>0.1 (0.2)</td>
<td>-0.06 (0.1)</td>
<td>.60</td>
</tr>
<tr>
<td>CollaborATE</td>
<td>-1.2 (5.3)</td>
<td>2.9 (5.2)</td>
<td>-4.1 (2.8)</td>
<td>.14</td>
</tr>
</tbody>
</table>

Abbreviations: MCCs, multiple chronic conditions; O-PACIC, Older Patient Assessment of Chronic Illness Care; PPC, patient priorities care; SE, standard error; UC, usual care.

a Treatment Burden Questionnaire (score range, 0-150; higher score indicates greater perceived burden of treatment); O-PACIC (score range, 1-5; higher score indicates better perceived experience of chronic disease care); and CollaborATE (score range, 0-100; higher score indicates greater perceived

b Parameter estimates from the propensity score-weighted, doubly robust linear regression analysis for the patient-reported outcome difference scores were adjusted for sex, age, race, educational level, marital status, living situation, insurance type, physical and mental health functioning, cognitive functioning, chronic conditions, number of medications, and duration of follow-up.

“Documentation by the PCPs or cardiologists of discussion or decision-making concerning patients’ health priorities were noted in 108 of 163 (66.3%) of the PPC participants versus none of the UC participants.”
<table>
<thead>
<tr>
<th>Health Care Use Category</th>
<th>Bivariate Analysis</th>
<th>Multivariable Analysis, Odds Ratio (95% CI)</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Weighted %a</td>
<td>(95% CI)b</td>
</tr>
<tr>
<td></td>
<td>PPC (n = 163)</td>
<td>Usual Care (n = 203)</td>
</tr>
<tr>
<td>Weighted No.</td>
<td>157</td>
<td>362</td>
</tr>
</tbody>
</table>

### Medications

- **Any medication**
  - Added: 65.0 (58.9)
  - Stopped: 52.0 (33.8)
- **Cardiovascular medication**
  - Added: 20.8 (15.7)
  - Stopped: 25.9 (8.9)
- **Psychotropic medication**
  - Added: 18.7 (11.2)
  - Stopped: 11.0 (7.0)

### Diagnostic/laboratory tests

- **Any ordered**
  - 80.8 (86.4)
  - 5.0 (3.6)
- **Any avoided**
  - 48.9 (44.4)
  - 5.5 (2.6)

### Referrals/consults

- **Any ordered**
  - 29.2 (21.5)
  - 12.3 (7.1)
- **Any avoided**
  - 57.5 (62.1)
  - 6.4 (8.6)

### Procedures

### Self-management tasks

- **Any added**
  - 0.71 (0.52-0.97)
- **Any stopped**
  - 0.69 (0.39-1.22)

**Abbreviations:** MCCs, multiple chronic conditions; PPC, patient priorities care; UC, usual care.

STUDY LIMITATIONS

• Not randomized
  – Clinicians were not blinded to group assignment
  – Outcome assessors were blinded

• Single practice with relatively homogenous population (White, female)

• Involvement of only 2 specialties may underestimate effect

• Impact on clinic revenue is unclear
STUDY STRENGTHS

• Feasible for patients
• Readily incorporated into clinic workflow
• Modest time required for Patient Priorities Care
  – Training: 8 hours over 15 months
  – Clinical practice: 30 min distributed across 3 office visits
PRACTICAL IMPLICATIONS: MANAGING COMPLEXITY

• What is the most common chronic condition experienced by older adults? Having > 1 chronic condition (i.e. multimorbidity)*

• The 4Ms provide a useful framework to focus what can be an overwhelming visit for the patient and clinician

• Conversations about What Matters can be relatively brief

• Addressing What Matters may reduce treatment burden for older adults and improve communication among clinicians about What Matters to patients

THE 4MS OF AGE-FRIENDLY CARE: FINDING THE SWEET SPOT

What Matters

Clinical Guidelines

Medications, Mobility, Mentation
UNREPRESENTED OLDER ADULTS AND THE 4MS
UNREPRESENTED OLDER ADULTS AND THE 4MS

What happens when it is difficult – or impossible – to find out What Matters most to an older adult?
CASE STUDY: PATIENT R.G.

- 67 year old gentleman with type 2 diabetes, hypertension, macular degeneration, frequent falls, and cognitive impairment thought related to TBI
- Inconsistent medication adherence leading to uncontrolled blood pressure and A1c
- Accompanied to some visits by an aide from Volunteers of America
R.G.’s capacity to make his own medical decisions is in question
  - Montreal Cognitive Assessment (MOCA) score is 5/30 (normal ≥ 26/30)

The aide is not his guardian and is therefore is unable to make health care decisions on his behalf

He lacks an advance health care directive

He has no known family or friends
A TYPICAL OFFICE VISIT WITH R.G.

• He has only a vague idea of what medications he takes and why he takes them
• He leaves medication bottles on the transit bus
• Social worker states that “little can be done to provide him with more resources until a crisis occurs”
VIEWING R.G. THROUGH THE 4MS LENS

**What Matters:** Unclear given cognitive deficits and lack of family, friends, or a surrogate decision maker

**Mobility:** Several ED visits related to falls

**Mentation:** History of traumatic brain injury and MOCA score <10 suggests that he may lack medical decision-making capacity

**Medications:** High risk for an adverse medication event
LONELINESS & SOCIAL ISOLATION: A PUBLIC HEALTH CRISIS

ADVERSE HEALTH IMPACTS OF LONELINESS & SOCIAL ISOLATION

• Loneliness is a more powerful predictor of adverse health outcomes than obesity, sedentary lifestyle, and air pollution*

• Adverse health impact of social isolation is equivalent to smoking 15 cigarettes per day**

• Loneliness and social isolation are independent predictors of ASCVD risk***

• ↑morbidity and mortality from social isolation is found across all age groups¶

***Valtorta et al. Heart 2016.
TERMINOLOGY THAT MAY DESCRIBE PATIENT R.G.

• “Adult without advocate” or “adult orphan”

• “Unrepresented” or “unbefriended”
### DEFINITIONS

<table>
<thead>
<tr>
<th></th>
<th>Has medical decision-making capacity?</th>
<th>Has a completed advance health care directive?</th>
<th>Has family, friends, or a legally authorized surrogate who is willing and able to assist with medical decisions?</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Adult without advocate or adult orphan</strong></td>
<td>Yes</td>
<td>No</td>
<td>No</td>
</tr>
<tr>
<td><strong>Unrepresented or unbefriended</strong></td>
<td>No</td>
<td>No</td>
<td>No</td>
</tr>
</tbody>
</table>
CONTINUUM OF VULNERABILITY

Older adult without advocate

CRISIS OCCURS

Loss of medical decision-making capacity

Unrepresented

"Best interest" standard

Guardianship

What matters most is unknown
But, we do know that Baby Boomers are at high risk of becoming unrepresented since >10 million live alone, and 20% are childless.*

*AARP, 2016.*
PREVALENCE OF UNREPRESENTED PATIENTS IN HEALTHCARE SETTINGS

• 16% in the intensive care unit*
• 4% in long term care†
• Unknown in primary care

†American Bar Association 2004.

It is estimated that there are 70,000 to 330,000 unrepresented older adults in the US.¶
How often do geriatrics health care providers encounter the unbefriended?

CLINICAL CONCERNS REGARDING THE UNBEFRIENDED

- Prolonged hospital stay
- Delay in transition to end of life care
- Lack of quality of life
- Physical or psychological pain
- Delay in treatment or surgery
- Loss of Rehab potential

Had distress because of an inability to act

Had to continue medically non-beneficial care

Had delay in authorizing charges for care
QUALITATIVE COMMENTS: DELAY

• “We could not find an appropriate place to transfer an adult with frontotemporal dementia who had no family or friends. No psychiatric facility would take him due to his wandering behavior and due to lack of staff for 1:1 supervision. He remained several months in the hospital.”

• “I also think that there is a gray category where somebody is essentially unbefriended because it is nearly impossible to get ahold of the designated decision maker.”

HELPFUL APPROACHES TO CARING FOR THE UNBEFRIENDED

- Involving leadership
- Consultation with neuropsych
- Transition to another type of care
- Patient values
- Team approach
- Consulting with a 3rd party
- Ethics committee
- Locate/reach out to family
- Home visit/home care
- Procedural approach
- Guardian or court or legal
- Case/nurse manager
- Community resources
- Adult protective
- Social work

MY PATIENT LACKS MEDICAL DECISION-MAKING CAPACITY...NOW WHAT?

• Search for any existing advance directives
• Refer to your state’s priority order of surrogate decision makers
• Consider initiating guardianship proceedings in the absence of an advance directive, available surrogate, or patient objection to finding of incapacity
IF THERE ARE NO AVAILABLE SURROGATES:
LEGAL GUARDIANSHIP

• Pros:
  – Court oversight
  – Appropriate for permanent incapacity

• Cons:
  – Slow and expensive
  – Removal of some or all constitutional rights
  – Difficult to reverse
  – “Stranger” guardians
AGS Position Statement: Making Medical Treatment Decisions for Unbefriended Older Adults

Timothy W. Farrell, MD, AGSF,¹,² Eric Widera, MD,³,⁴ Lisa Rosenberg, MD,⁵ Craig D. Rubin, MD, AGSF,⁶ Aanand D. Naik, MD,⁷,⁸ Ursula Braun, MD, MPH,⁷,⁸ Alexia Torke, MD, MS,⁹ Ina Li, MD,¹⁰ Caroline Vitale, MD, AGSF,¹¹,¹² Joseph Shega, MD,¹³,¹⁴ for the Ethics, Clinical Practice and Models of Care, and Public Policy Committees of the American Geriatrics Society
SELECTED AGS CLINICAL RECOMMENDATION

• Assess medical decision-making capacity in a systematic fashion
  
  – RATIONALE: Evidence suggests that unstructured capacity assessments are often performed poorly. Cognitively impaired patients may still retain capacity to make some or all decisions.

SELECTED AGS POLICY RECOMMENDATION

• Proactively prevent older adult orphans from becoming unbefriended
  – RATIONALE: Adult orphans are one crisis away from becoming unbefriended.
COULD THE 4MS HELP PREVENT PATIENTS FROM BECOMING UNREPRESENTED?
4MS APPROACHES TO PREVENT PATIENTS FROM BECOMING UNREPRESENTED

**What Matters:** Identify adults without advocates, conduct proactive advance care planning, engage in court/stakeholder partnerships

**Mobility:** Assess gait speed (correlates with life expectancy)

**Medications:** Arrange for medication blister packs, electronic medication dispensers, or supervised medication administration

**Mentation:** Assess medical decision-making capacity
COULD THE EHR HELP IDENTIFY ADULTS WITHOUT ADVOCATES?
EHR: DEMOGRAPHICS AND FINANCES

Demographics

- Marital Status:
  - Other
  - Single
  - Married
  - Divorced
  - Widowed
  - Legally Separated

- Life Partner/Domestic Partner

- Spouse Name:

- Number of Children:

- Years of Education:

- What is the highest level of school you have completed or the highest degree you have received?

Financial Resource Strain

- How hard is it for you to pay for the very basics like food, housing, medical care, and heating?
  - Not hard at all
  - Not very hard
  - Somewhat hard
  - Hard
  - Very hard
  - Patient refused
When a patient is socially isolated, think not only of depression, but also consider whether she could be unrepresented or at risk of becoming unrepresented.
PROACTIVE ADVANCE CARE PLANNING
PROACTIVE ADVANCE CARE PLANNING (ACP)

• Do not wait for a crisis to conduct ACP

• ACP is a reimbursable service under Medicare*
  – ICD-10 code 99497 (first 30 minutes)
  – ICD-10 code 99498 (each additional 30 minutes)

• ACP can be implemented flexibly
  – Not limited by location or specialty

PREPARE™ FOR YOUR CARE

A program to help you make medical decisions for yourself and others

https://www.prepareforyourcare.org
EVIDENCE SUPPORTING PREPARE™

Simple Tools for Patients Increase Advance Care Planning Documentation

- 6 months before baseline: 1%
- Easy-to-Read Advance Directive (AD): 25%
- AD + PREPARE Website: 35% (*p = 0.04)

http://www.geripal.org/2017/05/rebecca-sudore-on-advance-care-planning.html
WINGS PROGRAMS

• About half of states have WINGS or similar programs
• Stakeholders include courts, AAAs, APS, bar associations, social services programs, and guardians
• Functions include educating the public, supporting guardians, and advocating for strong court oversight

final-wings-brochure.pdf (americanbar.org)
PATIENT R.G.: THE REST OF THE STORY

• ED visit after an unexplained fall
• Discharge from ED at 4 AM without a plan for transportation home
• He wandered and was nearly hit by a car
• This was the crisis that led to action - placement in a long term care facility and initiation of guardianship proceedings
FUTURE DIRECTIONS: ADULTS WITHOUT ADVOCATES AND THE UNREPRESENTED

• Determine the prevalence of older adults without advocates in outpatient primary care settings
• Assess the effectiveness of proactive interventions to prevent older adults without advocates from becoming unrepresented
• Quantify health outcomes and costs when unrepresented older adults have prolonged hospitalizations
FULFILLING THE PROMISE OF AGE-FRIENDLY HEALTH SYSTEMS

- Health systems are only as good as the care they provide for the most vulnerable patients, such as R.G.

- Everyone – patients, caregivers, staff, and clinicians from virtually all specialties – can and should adopt a 4Ms approach to caring for older adults.