# Uncertainty About Advance Care Planning Treatment Preferences Among Diverse Older Adults

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# Background

- Advance care planning asks patients to make treatment decisions in advance
  - E.g., CPR and mechanical ventilation
- Low rates of engagement in advance care planning among racial/ethnic minorities
- Aggressive treatments more often requested by
  - Racial/ethnic minorities
  - limited health literacy

# Background

- Hypothetical scenarios are often used in advance care planning
  - E.g., “Imagine you were in a coma…”

- Patients may have difficulty extrapolating current treatment preferences to unknown future circumstances

# Background

- When patients articulate their treatment preferences in advance based on scenarios
  - we assume they are certain about their choices
  - place a great deal of weight on the decisions

- If patients are not completely certain about their choices
  - we may misrepresent their preferences in a medical crisis

# Objectives

- To assess advance treatment preferences among diverse, older adults in response to a hypothetical scenario
- To assess patients' uncertainty about these treatment preferences
- To assess associations between uncertainty and patient characteristics
  - race/ethnicity and literacy level.

# Methods

- **Design:** Cross sectional, descriptive
- **Participants:** 205 English/Spanish-speakers, aged ≥ 50 years
- **Setting:** Outpatient clinic, San Francisco General Hospital
- **Intervention**: Scenario
  - read to participants by bi-lingual research assistants
  - reassured that the scenario did not pertain to them
  - asked to imagine situation and care they may want

# Hypothetical Scenario: Poor Outcome

*"Imagine your doctor told you that you have a serious disease that does not have a cure and that you may die within the next 6 months.*

*Then imagine you get very sick and have to go to the hospital. You and your doctor have to decide what to do.*

*Your doctor thinks that life-support treatments are NOT LIKELY to help you live longer and will not cure your serious disease.*

*Some examples of life support treatments are: shocks to the heart, pressing on the chest to keep the heart pumping, and a tube placed in the lungs to help with breathing."*

# Methods: Outcome Variables

- **1. Treatment Preferences:**

*"Imagine you were in this situation. Would you choose:"*

  - All life-support treatments
  - To try life-support treatments, but stop if not helping
  - No life-support treatments

- **2. Uncertainty:**

*"How certain are you about your decision?"*

  - very sure, somewhat sure, not so sure, not sure at all

- Because life/death decisions may be based on preferences:
  - Uncertainty defined as: somewhat sure, not so sure, not sure at all

# Methods: Predictor Variables

- Demographics: race/ethnicity, SES, education
- Health status
- Religiosity
- Prior exposure to end-of-life issues
  - Advance directive
  - ICU
  - Surrogate decision maker
- Literacy:
  - s-TOFHLA, scores 0-36
  - limited literacy defined as score ≤ 22

# Results

| PATIENT CHARACTERISTICS, n = 205 | Mean / % |
|---|---|
| Mean Age (years) | 61 (± 8) |
| Women | 52 |
| Race/Ethnicity: White, Non-Hispanic | 25 |
| White, Hispanic (Latino) | 31 |
| Black, Non-Hispanic | 24 |
| Asian/Pacific Islander | 9 |
| Multi-racial/ethnic, Other | 10 |
| Education: < High school education | 31 |
| Limited Literacy | 40 |
| Spanish-speaking | 29 |
| Fair-to-poor self-rated health | 69 |
| Very to extremely religious | 46 |
| Prior exposure to EOL issues | 76 |

# Results: Preferences & Certainty

| PREFERENCES AND CERTAINTY, n = 205 | % |
|---|---|
| **Life Support Preferences Based on Scenario** | |
| All life support treatments | 20 |
| Try life support, but stop if not working | 28 |
| No life support treatments | 45 |
| Do not know | 7 |
| **Degree of Certainty** | |
| Very sure | 55 |
| Somewhat sure | 32 |
| Not so sure | 8 |
| Not sure at all | 5 |
| **Uncertainty about treatment decisions*** | **45** |

* Uncertainty did not vary by treatment preference (p=0.35)

# Patient Characteristics Assoc. w/ Uncertainty

| PATIENT CHARACTERISTICS<br>*Only statistically significant results shown | Uncertain %<br> | P-value<br> |
|---|---|---|
| Race/Ethnicity: | | |
| **Asian/Pacific Islander** | **74** | <.001 |
| **White, Hispanic (Latino)** | **62** | |
| Black, Non-Hispanic | 37 | |
| White, Non-Hispanic | 31 | |
| Multi-racial/ethnic/Other | 24 | |
| Education: | | |
| **< High school education** | **55** | .05 |
| ≥ High school education | 41 | |
| Literacy | | |
| **Limited** | **61** | <.001 |
| Adequate | 34 | |
| Language | | |
| **Spanish** | **63** | <.001 |
| English | 38 | |
| Health Status | | |
| **Fair-to-poor** | **51** | .01 |
| Good-to-excellent | 31 | |

# Race/ethnicity, Literacy, & Health Status Independently Associated with Uncertainty

| Characteristics Associated with Uncertainty — Multivariate* | OR (95% CI) |
|---|---|
| Asian/Pacific Islander vs. White | 4.90 (1.42-16.90) |
| Latino vs. White | 2.45 (1.04-5.81) |
| Limited vs. Adequate Literacy | 1.91 (1.00-3.70) |
| Fair-to-poor vs. good-to-excellent health status | 2.03 (1.00-4.15) |

*Adjusted for age, race, gender, literacy, religiosity, health status, and prior end-of-life experiences

Education and language excluded due to high correlations with literacy and race/ethnicity

# Limitations

- Only one hospital
- Only one scenario
- Cannot disentangle uncertainty about preferences and the question
- Decisions in research study may differ from clinical care

# Conclusions

- ~50% of diverse older adults who reported a treatment preference based on a hypothetical scenario were uncertain about their decision

- Uncertainty was more common among
  - Minorities
  - participants with limited literacy
  - and poor health status

# Implications

- Patients may not be ready or able to make definitive advance treatment decisions based on hypothetical scenarios
- By assuming these advance treatment preferences represent truth:
  - may misrepresent patients' preferences
  - esp. among minorities & limited literacy
- Assess certainty and re-assess over time

# Implications for Advance Care Planning

- Move away from asking patients to make advance treatment preferences based on "what ifs"

- Move to preparing patients and surrogates to talk to one another, identify their values, and make appropriate decisions in the face of serious illness
  - To this end, need culturally sensitive, literacy-appropriate decision support tools

# Multivariate Results

| Characteristics Associated with Preferences (All LS) | OR (95% CI) |
|---|---|
| Asian/Pacific Islander vs. White (5/19 = 26%) | 5.6 (1.2-25.5) |
| Latino vs. White (22/64 = 35%) | 7.9 (2.3-27.8) |

*Adjusted for age, race, gender, literacy, religiosity, health status, and prior end-of-life experiences

Education and language excluded due to high correlations with literacy and race/ethnicity