Understanding Perceptions of Advance Care Planning by Race and Health Status

Hyunjin Noh, MSW, PhD, UA School of Social Work (PI)
Rebecca Allen, PhD, UA Department of Psychology (Mentor)
Kathryn Burgio, PhD, UAB School of Medicine (Mentor)
Kim Anderson, LCSW, UA School of Social Work
Cassandra Ford, PhD, UA School of Nursing
Yuqi guo, MSW, UA School of Social Work

Acknowledgement

- This study was supported by the Deep South RCMAR Pilot Grant Program (5P30AG031054-09).
- Mentors:
  - Rebecca Allen, PhD, UA Department of Psychology
  - Kathryn Burgio, PhD, UAB School of Medicine
- Participant recruitment was supported by FOCUS senior citizens, University of Alabama Medical Center (Dr. Anne Halli-Tierney), Beulah Baptist Church in Tuscaloosa, and Carrollton Senior Center in Carrollton, AL.

BACKGROUND

- Racial disparities in the use of life-sustaining treatments (LST) and advance directives (AD)
  - Cultural differences
  - Lack of knowledge about risks and burdens of life-sustaining treatments and about alternative end-of-life (EOL) options
  - Lack of reliable relationship with doctors to discuss advance care planning

Advance Directives

- documents individuals’ EOL preferences and wishes
- facilitates EOL discussions among patients, families and health care providers
- Equivocal evidence of effectiveness but still shows to decrease hospitalization and use of LST and increase use of hospice/palliative medicine
- Significantly lower completion rate among African Americans and other minorities

Significance

To address gap in our current knowledge about:

- Patients' and families' level of knowledge about risks and burdens of LST
- Informational needs for LST and other care options in advance care planning (ACP)
- Informational needs in completing advance directive (AD)

Aims of Study

1) to examine knowledge, attitudes, and beliefs regarding LST and EOL care options;
2) to identify perceptions of informational needs in ACP;
3) to explore perceptions of use of the advance directive form for documenting treatment preferences near the EOL

Research Questions

1) What is the *understanding* among African American and White older adults regarding the specific risks/benefits of LST and EOL care options?

2) What are *attitudes and beliefs* among African American and White older adults regarding the risks/benefits of LST and EOL care options?

3) What *information* about LST and EOL care options do African American and White older adults think they would need to be able to make decisions about appropriate care near the EOL?

4) What are African American and White older adults' *perceptions* about the use of the AD form?

Research Design

- A qualitative phenomenological approach using focus groups
  - Useful for exploring knowledge and experience and for examining what/how/why they think that way
  - Stimulates thinking process through sharing and comparing

Study Sample

- Participant eligibility:
  - current a resident of Alabama
  - 55 years of age or older
  - good cognitive status (self-appraised; “with good thinking skills”)
- Questions about race/ethnicity and self-rated health asked at the initial contact

Participant Recruitment

- Brief introductory talk before/after senior activities
- Posters and flyers posted in senior center rooms and medical center exam rooms
- Interested individuals directly talked to PI in person or via phone
- 4 Black (2 good health and 2 poor health) and 4 White (2 good health and 2 poor health) groups recruited (a total of 60 participants)

Data Collection

- Group meetings conducted from December 2015 until June 2016
- Black groups facilitated by a nursing faculty and white groups by a LCSW/social work doctoral student
  - Used a facilitator guideline developed by PI
- Field observation and note by PI and research assistant
- Written consent obtained
- Questionnaire about demographic/SES information
- Each meeting lasted 1hr 45 min to 2hr
- Each meeting audio-recorded and transcribed

Participant Characteristics

- 30 black and 30 white participants
- 13 years of school
- Mostly Baptists
- Mean age of 66 for black Groups (BG) vs. 73 for white groups (WG)
- Divorced (43%) or married (23%) in BG vs. married (43%) or widowed (37%) in WG
- Retired (53%) or disabled (27%) in BG vs. Retired (73%) or part-time (13%) in WG
- 8 black participants worked in health care vs. 2 white participants did
- Only 1 black participant had a living will vs. 10 white participants did

Focus Group Questions: *knowledge and attitudes*

- What would be some examples of medical care at end of life that are used to keep your life as long as possible when the illness is incurable? These are also called “life-sustaining treatment.”

- What would be some examples of EOL care used to ease your pain and suffering rather than to keep your life as long as possible?

- What type of care would you prefer when medical care to cure an illness no longer works?
  - All life support
  - Limited medical care
  - Comfort care only

Focus Group Questions:

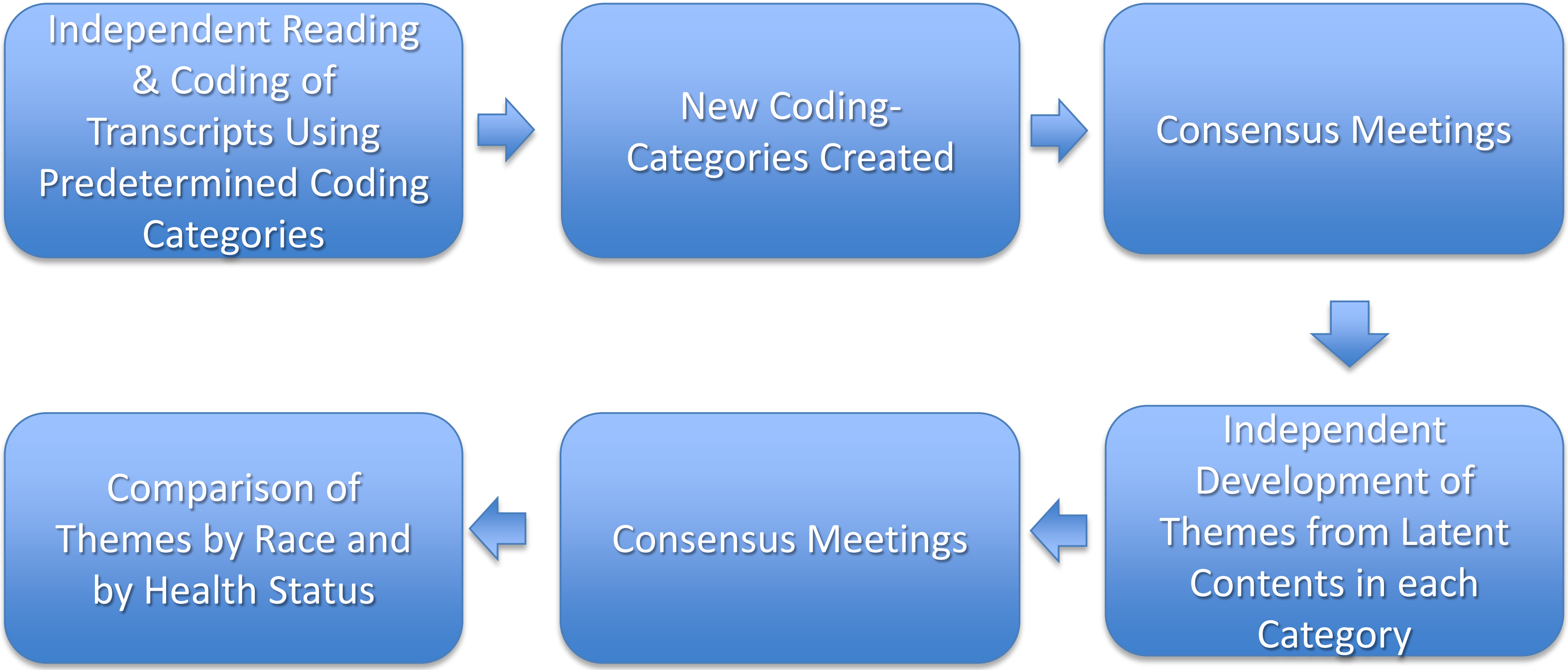
Advance Directives

- What are some things you would like to know or you need to think about so that you can meaningfully answer the questions in each section of AD?

Willingness for EOL Discussion and AD Completion

- Would you be willing to use this form to have your end-of-life care wishes in writing?
- Would you have discussion about your wishes with your family?
- Would you have discussion with your doctor about it and file it in your medical record in the doctor's office?

Data Analysis:
Directed Thematic Analysis



Independent Reading & Coding of Transcripts Using Predetermined Coding Categories

New Coding-Categories Created

Consensus Meetings

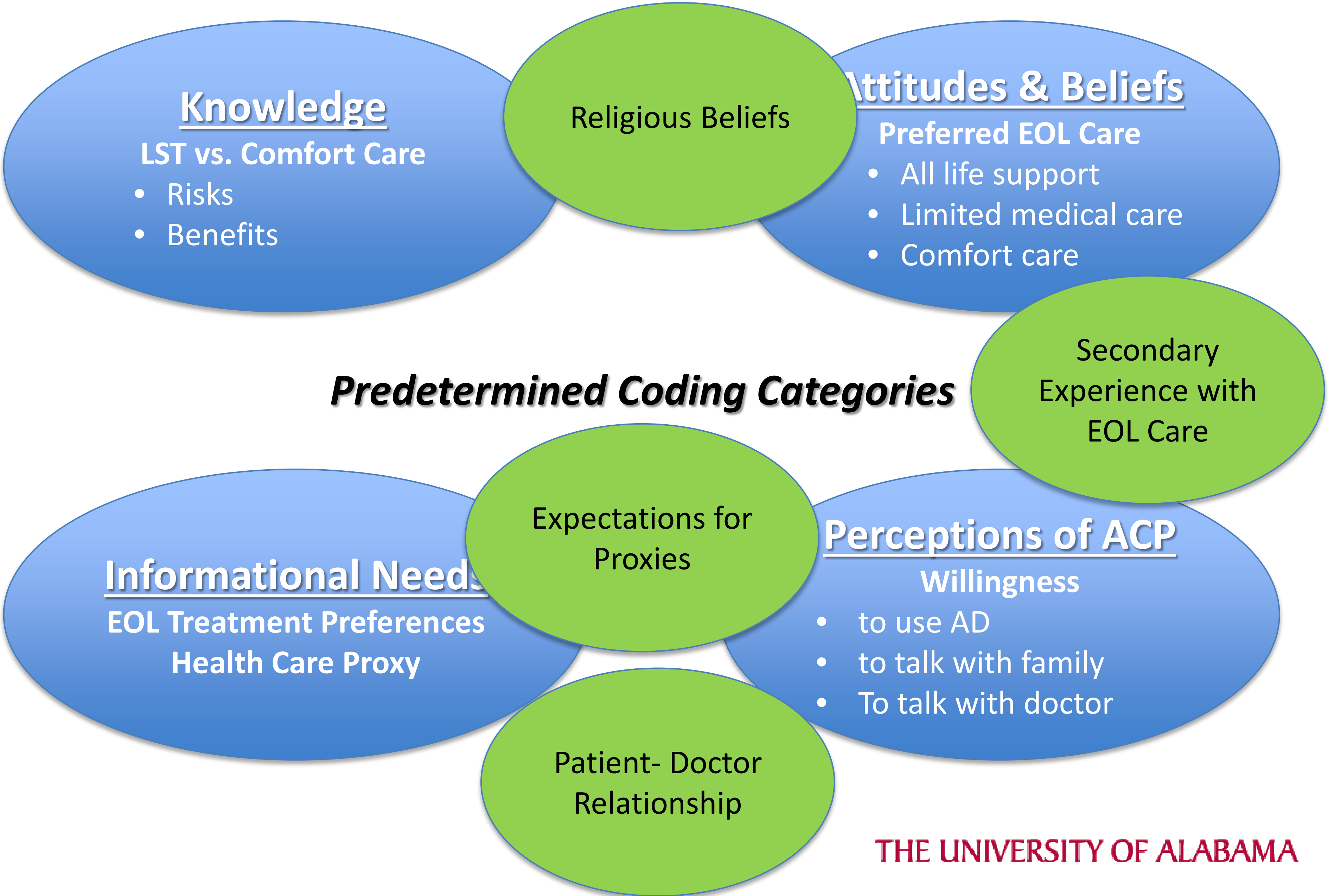
Independent Development of Themes from Latent Contents in each Category

Consensus Meetings

Comparison of Themes by Race and by Health Status

Findings

Predetermined Coding Categories



Knowledge

LST vs. Comfort Care

- Risks
- Benefits

Religious Beliefs

Attitudes & Beliefs

Preferred EOL Care

- All life support
- Limited medical care
- Comfort care

Secondary Experience with EOL Care

Expectations for Proxies

Informational Needs

EOL Treatment Preferences

Health Care Proxy

Perceptions of ACP

Willingness

- to use AD
- to talk with family
- To talk with doctor

Patient- Doctor Relationship

Knowledge & Attitudes

- WG more knowledgeable about risks and potential harms of LST
- Neither group aware of use of antibiotics as LST purpose
- *Previous or secondary experience* with hospice critical to hospice knowledge in both groups
- Majority in WG prefer comfort care only or comfort care & limited medical care
- Mix of all three options in BG
- *Religiosity* expressed more often in BG and in WG with poorer health

Informational Needs

- WG expressed wanting further clarifications of wording in AD:
  - “Terminally Ill”, “near future”, “long enough”
  - “default” comfort measures provided along with LST
  - “at least two doctors”
  - extent of healthcare proxy’s authority?
- Both groups wanting specific information on logistics of completion but more so in BG
  - Notarize?
  - Safety box?
  - Transferrable?

Expectations for Healthcare Proxy

- WG wanted exact execution of their wishes by proxies
- BG relied on their children's judgment even if it means going against their original wishes
- Both groups concerned about family's feeling regarding who gets to be appointed as proxy and other potential family conflicts

Patient-Doctor Relationship

- BG discussed lack of continuity in patient-doctor relationship and resulting mistrust
  - “They don’t stay…”
  - “Move on to the next victim.”
  - “Kept alive for organ harvesting”
- BG more concerned about breach of confidentiality/privacy
- WG also discussed some mistrust in the context of doctor’s financial motivation
- More trust in doctors expressed in poorer health groups

Conclusion & Implications

- Lack of knowledge about risks/burdens of LST
- Further explanations or elaborations needed in AD for its meaningful use
- Religiosity as a critical factor in deciding preferred EOL treatment
- Support needed for EOL discussions, including proxy designation, with family members
- Mistrust issue persists, particularly rural African American communities

Questions?
Comments?