



COLLEGE OF NURSING

THE UNIVERSITY OF ALABAMA IN HUNTSVILLE



Home Health Nurses' Knowledge and Beliefs of Suffering, Artificial Nutrition and Hydration in People with Late Stage Dementia

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Acknowledgements

- Elaine J. Amella, PhD, RN, FAAN, FGSA
- Barbara Edlund, PhD, APRN-BC, ANP
- Martina Mueller, PhD
- Lynne Nemeth, PhD, RN, FAAN
- Betty Ferrell, PhD, RN, FAAN, FPCN



Dissertation Work

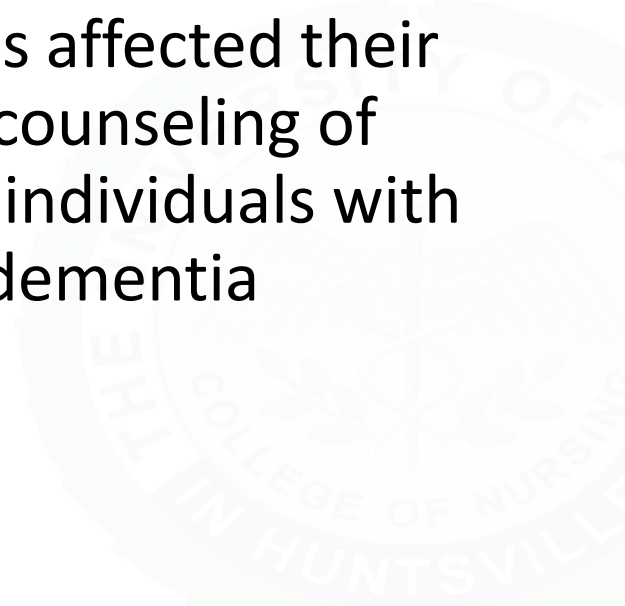
- Dimensional analysis of concept (suffering in people with late stage dementia)
- Pilot study to validate instrument
- Mixed methods study for final dissertation work



Purpose

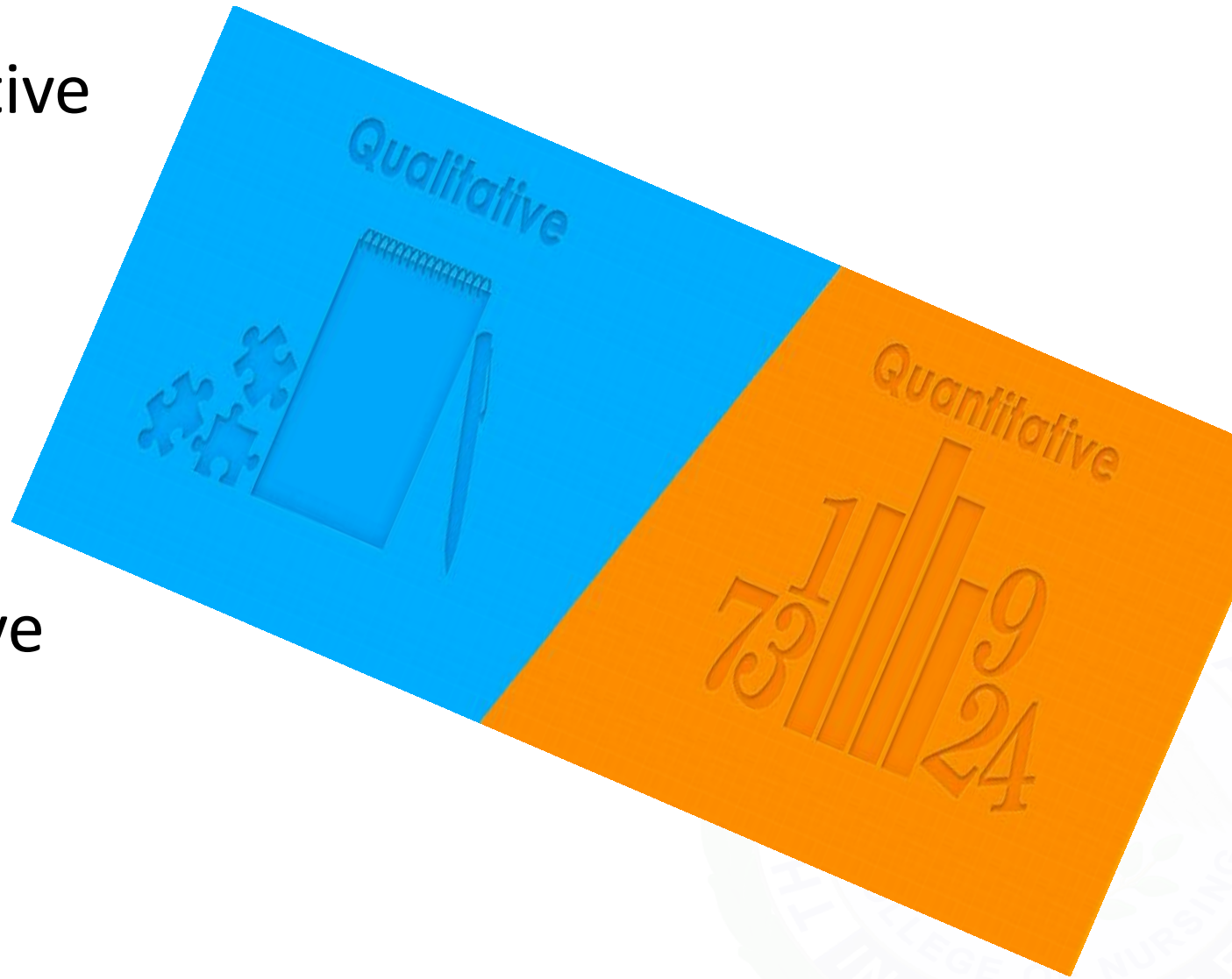


To determine home health nurses' knowledge and beliefs or perceptions about suffering, artificial nutrition and hydration (ANH) and to examine whether their knowledge, beliefs or perceptions affected their actions or counseling of families of individuals with late stage dementia



Mixed Methods Study

- Quantitative



- Qualitative

Quantitative

- Questionnaire adapted from Ke, et al (2008) 'Knowledge of Provision of ANH in Terminal Cancer Patients'
- Changed items into 2 sentences based on content expert suggestions
- Added scenario at end of questionnaire with 5 open-ended questions (suffering piece)
- N = 17
- Cronbach's alpha 0.71



Questionnaire

- 29 Questions
 - 1st 6 questions were demographics
 - 7-29 were questions regarding ANH
- Questions
- Scenario
 - An elderly man with a diagnosis of dementia was experiencing weight loss and the daughters asked five questions of the home health nurse regarding pain, suffering, and the benefits and risks of ANH for their father.



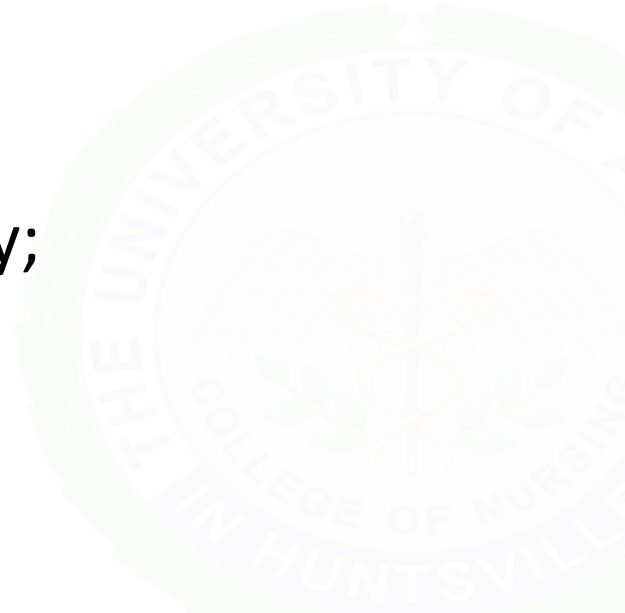
Focus Group Questions

1. What does the 'word' suffering mean to you?
2. What do you know about the positive and negative affects of ANH in persons with LSD?
3. Tell me your thoughts on suffering individuals with LSD. Do you believe PWD suffer as the disease progresses and how?
4. Describe a time in your career when you felt a person with dementia was suffering. What happened and how did it make you feel?
5. Describe your thoughts on families' perceptions of ANH in individuals with LSD?
6. How would you measure suffering in individuals with LSD?
7. Describe a conversation you have had with either a patient or family member regarding ANH. What information did you give him/her about ANH?
8. If you believe that suffering is more than physical symptoms, how would you expect to know that someone is suffering?
9. What are your thoughts and experiences about ANH prolonging life in persons with LSD?

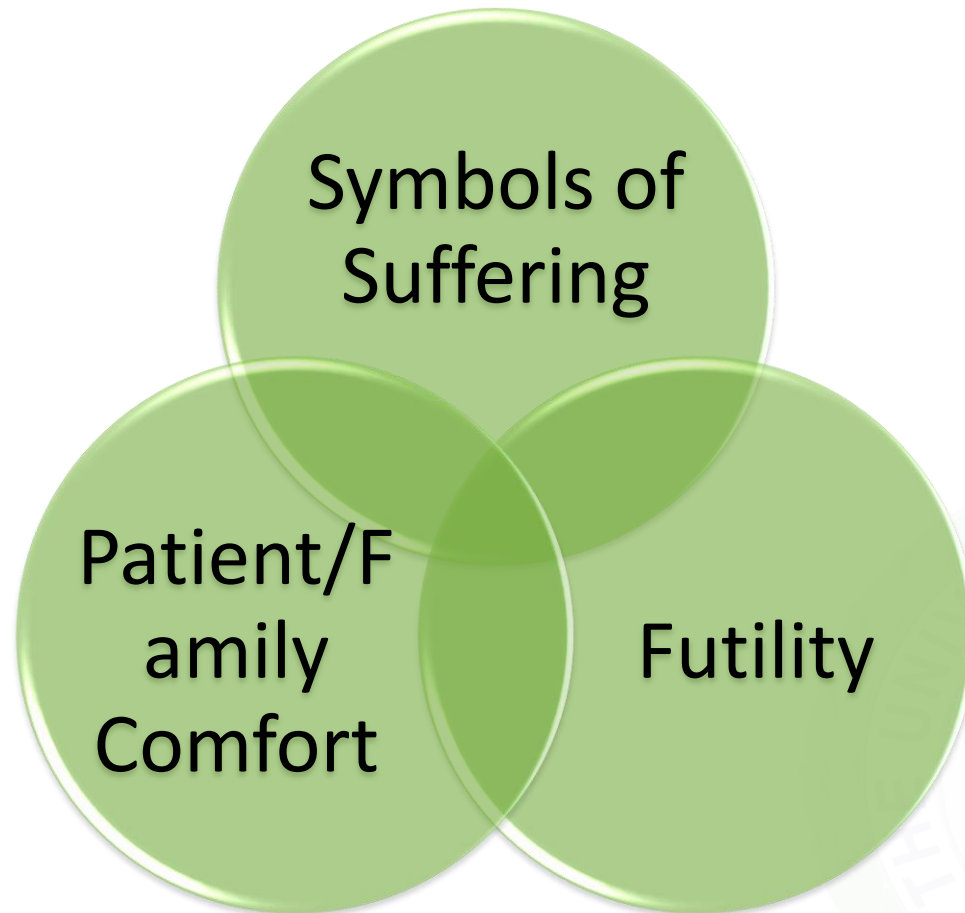
“No subject provokes greater distress and uncertainty—among both families and health professionals—than issues surrounding the use of artificial nutrition and hydration in the dying person.”

Qualitative - Results

- Scenario
 - Q1-Daughters concerns re: pain, discomfort, suffering for their father
 - Q2/3-Advantages/disadvantages ANH
 - Q4-Recommendations by nurse
 - Q5-What would they (RNs) do?
- Focus Groups
 - Themes: Pt/family comfort; futility; symbols of suffering



The Triad of Suffering: Suffering in Late Stage Dementia



Exemplars of Nurses' Statements

Patient/Family Comfort

- “The perception is if you don’t give them something to eat or drink then they’re suffering or they’re starving.”
- “I think sometimes it just makes the family feel better.”
- “It kinda sets up this false hope for the family too of waiting each day to see if they’ve [the pt] has gotten better because of the feeding.”



Exemplars of Nurses' Statements

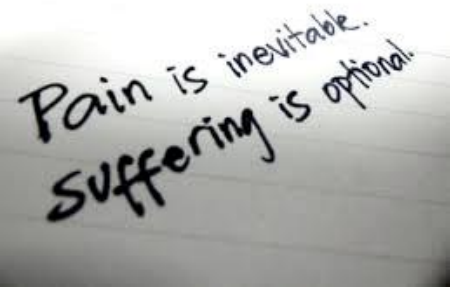
Futility



- “I just think it’s the helplessness; that’s what you do feel because you can’t fix it. You just want to fix it.”
- “Making it impossible for the body to die.”
- “It was just frustrating because you know what you are doing is not what should be done.”



Exemplars of Nurses' Statements

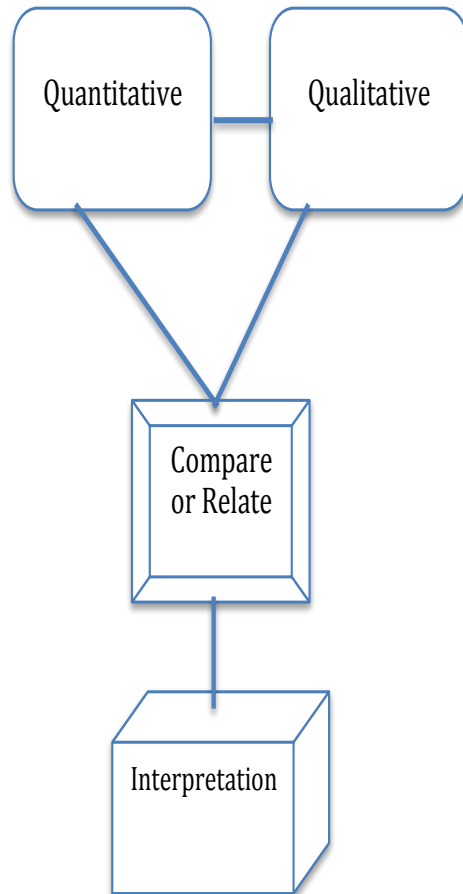


Symbols of Suffering

- “To me I guess, generally, would be any type of pain, hardship, distress, be that mental, emotional, or physical.”
- “When they have a moment of lucidity, they cry and they want to be normal.”
- “They come in [to the ED], they’re screaming, they’re crying. They don’t know where they are. They’re sick, infected, have bed ulcers; they’re scared, fighting. That’s when I go into ‘I pray these people don’t know what’s happening to them.’”



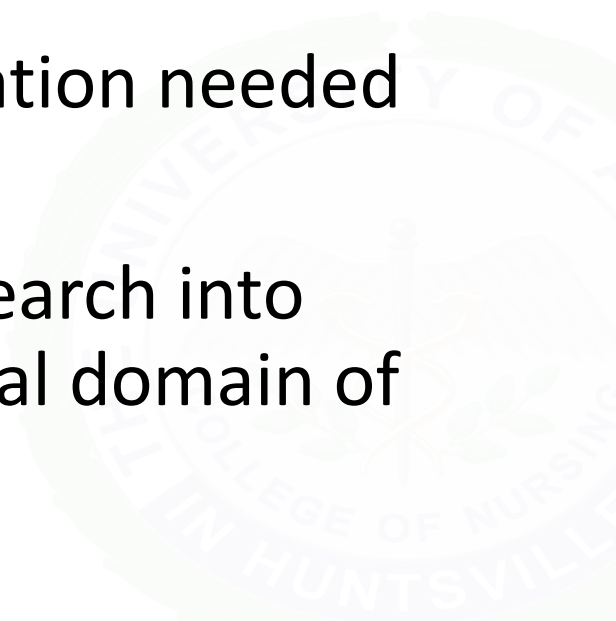
Parallel Convergent Design Results



- Themes support quantitative data
- ANH beneficial for pt comfort but also futile, leading to inaccurate information given to pts and families
- Conflict among nurses regarding prolonging life
- Contradictions from scenario questions with questionnaire statements
- Design supported assumption that knowledge, beliefs/perceptions influence their counseling of pts and families regarding decision-making

Conclusions and Further Considerations

- Home health nurses lack EBP knowledge
- Other domains of suffering in people with LSD
- More education needed
- Further research into psychological domain of suffering





Available upon request

