“Life is pleasant. Death is peaceful. It’s the transition that is troublesome.”

~ Isaac Asimov

Does an Educational Intervention Change Knowledge and Attitudes Towards Advanced Directives and the Completion of the Maryland Life Sustaining Treatment Options Form in Patients in Nursing Homes?

Capstone Proposal

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Advanced Directives in the Nursing Home

Background

Background

- U.S. population of adult's age 65 years will comprise 20% of the total U.S. population, by the year 2030
- Nursing homes are becoming the place where Americans choose to live their final stages of life
- Ideas that guide decision-making have changed over the years
- Two goals of care, traditionally
  - Cure disease and prolong life
  - Provide comfort care

Reference: Morrison, R. S. (2008). Palliative care. *The New England Journal of Medicine*, 1-9.

Advanced Directives in the Nursing Home

Significance

Significance

- Consumer Rights Movement
- Patient/Resident Bill of Rights
- Court cases
  - Karen Quinlan
  - Nancy Cruzan

Significance

- Patient Self-Determination Act (PSDA) of 1991
  - A mandate for written information regarding legal rights
    - Participate in medical decisions, including the right to accept or refuse treatment
    - Formalize treatment wishes by completing an advanced directive

Significance

- In 2004, 3 of every 10 U.S. Nursing home residents did not have documentation of advance care plans (Resnick, 2009)
- Approximately 20% of all U.S. deaths occur in the Nursing home (Touhy, 2005)
- Only 15-20% of the overall population had completed advanced directives (Maxfield, 2003)
- Traditional approach of notifying families at the time of admission about advanced directives is not effective (Bradley 1998)

PICO/Research Question

- P- Nursing Home patients with decisional capacity
- I- Educational intervention utilizing the End of Life Nursing Education Consortium (ELNEC) Module 4, with focus on the ethical and legal issues of advanced directives
- C- The study group will be there own control group, as pre/post test will be used
- O- Feasibility of the study; Measurement of the change in knowledge and attitudes regarding advanced directives, as well as the rate of completion of the Maryland Life Sustaining Treatment Options form

Research Question

- Does an Educational Intervention Change the Knowledge and Attitudes towards Advanced Directives and Completion of the Maryland Life-Sustaining Treatment Options form in Patients in the Nursing Home?

Purpose of the Study

- 1) assess the feasibility of an educational intervention on advanced directives in the Nursing Home setting
- 2) evaluate if the education improves knowledge and attitudes about advanced directives
- 3) determine if the attendees complete the Maryland Life-Sustaining treatment Options (LST) form after the education

Advanced Directives in the Nursing Home

Theoretical Support

Theoretical Framework

- The Advanced Directive Decision-Making (ADDM) Model
  - Developed to assist both the patient and the provider
  - Increase patient autonomy
  - Increase compliance with PSDA of 1991

Reference: Goodwin, Z. J., Kiehl, E. M., & Peterson, J.Z. (2002). King's theory as foundation for an advanced directive decision-making model. *Nursing Science Quarterly*, 15 (3), 237-241.

ADDM Model

Personal Systems

Perception	---------- Holistic—more than a sum of its parts, client autonomous with right of self-determination, RN/NP desiring mutual goal attainment.
Time	----------Continuous - flowing to the future with ↓ in health related to ↑ in age/illness/trauma.

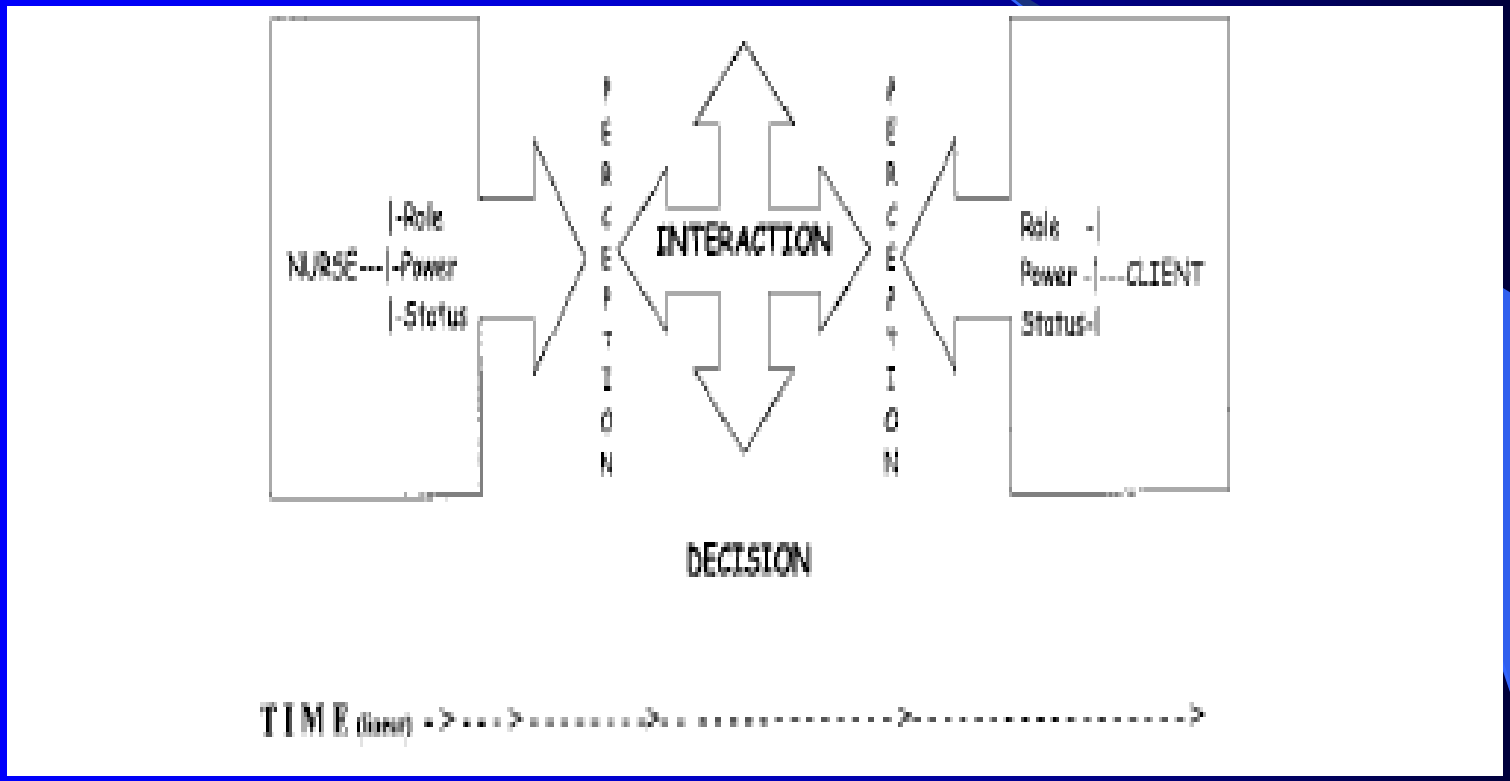
Interpersonal Systems

Interaction	----------Two-way communication with non-verbal cues considered and confidentiality maintained.
Role	----------RN/NP as facilitator (not enforcer, not evaluator); client as mutual partner for goal attainment.

Social Systems

Power	----------Client controlled, goal directed utilizing knowledge, skill and expertise of the RN/NP to support the client.
Status	----------Client perceived as having duty, power and authority to make decisions RN/NP stratified as competent, assistive, and knowledgeable.
Decision Making	----------A process, client selecting one action from alternatives, RN/NP advocating for client self-determination.

ADDM Model


NURSE
Role
Power
Status
PERCEPTION
INTERACTION
PERCEPTION
Role
Power
Status
CLIENT
DECISION
TIME (linear)

Advanced Directives in the Nursing Home

Literature Search

Review of the Literature

Literature Search

- Databases
  - CINAHL
    - Boolean/Phrase
    - EBSCOhost interface
  - MEDLINE
    - MESH terms
- Other sources
  - Secondary hand searches
  - Google scholar search

Literature Search

- Inclusion criteria
  - 1997- present
  - Older Adults
  - Nursing home or LTC facilities, community-based dwellings
  - Advanced directives
  - Decision-making
  - Educational Strategies
  - Attitudes toward advanced directives
  - English language
  - United States
- Exclusion criteria
  - Hospital-based programs
  - Hospice programs
  - Persons less than 65 years

Strength and Quality of the Evidence

- Level I- A
  - 1 article
  - Experimental pilot study by Mercer (1997)
  - Instruments for this project adapted with permission from this study and author
- Level II- B
  - 2 articles
  - Quasi-experimental/non-experimental
- Level III-B
  - 6 articles
  - Mix of evidence ranging from qualitative to retrospective cohort study
- Level IV-B
  - 7 articles
  - Mix of evidence ranging from qualitative to expert opinion
- Level V- B
  - 11 articles
  - Expert opinion/literature review

Literature Review

- Barriers to the Completion of Advanced Directives
- Attitudes Towards Advanced Directives
- Program Interventions and Educational Strategies
- Physician Orders for Life-Sustaining Treatments
- Economic Considerations Related to Decision-Making at End-of Life

Barriers to the Completion of Advanced Directives

- Race and Ethnicity
  - African-Americans 27% completion
  - Whites 63.6%
  - African-Americans wanting more aggressive treatments

  (Troyer, 2006; Resnick, 2009)

- Failed communication practices
  - Physicians' rarely discuss patient values
  - 1/3 of the conversation was by the patient
  - 95% of patients want to have a discussion about advanced directives

  (Tulskey, 1998)

Attitudes Towards Advanced Directives

- Limited articles meeting all criteria
- Non-experimental study by Holley (1992), surveyed 43 in-patient hemodialysis patients
  - 17% had discussed advanced directives with health professional compared to 77% had discussed with family
  - 21% had completed advanced directive
- DPOAs attitudes much different from patient view
- Qualitative study (Deep 2007), surveyed 55 medical residents
  - Prior experience with death and decision-making at time of death will influence attitude
  - Poor communication techniques

Program Interventions and Educational Strategies

- Little literature regarding education and the patient and/or family
- Comparatively, many demonstrating education as an effective intervention for learning with nursing home staff
- Robert Wood Johnson Foundation projects
  - Key features include:
    - Regular communication
    - Documented advanced care planning
    - Patient and family education

    (Byock, et al., 2006)

Program Interventions and Educational Strategies cont'd

- Better completion rates in non-crisis situations (Basile, 2002; Dipko, et al., 2003)
- Retrospective cohort study by Dipko, et al. (2003) best strategies for older adults include group education
- Persistence and encouragement of discussion through education will improve completion rates (Basile, 2002)

Physician Orders for Life-Sustaining Treatments (POLST)

- State of Oregon 1991
- Patient wishes not being honored despite advanced directives
- Developed by the Center for Ethics in Health Care at Oregon Health and Science University
- Over 1 million POLST forms distributed, to date
- Standard of Care in State of Oregon
- Utilized by all Hospices and over 95% of Nursing homes in the State of Oregon

POLST cont'd

- Difficulties to national implementation of Program
  - State requirements for out-of-hospital DNR orders incompatible with requirements of POLST form
  - Witnessing requirements
  - Medical pre-conditions
  - Default surrogate provisions

  (Hickman, 2008)

- State of Maryland
  - Unsuccessful
    - Default surrogate provision
    - Consent limits
      - Terminal condition
      - Persistent vegetative state
      - End-stage condition

Economic Considerations Related to Decision-Making at End-of-Life

- Cost at end-of-life estimated 10-12% of all total health care spending (Raphael, 2001)
- In final year of life, medical treatment options and life-sustaining interventions expensive, and often not helpful
- People living longer with more chronic illness, disability, and dependence (ELNEC, 2008)
- Four out of top five leading causes of death- chronic illnesses
  - Heart disease
  - Cancer
  - Stroke
  - Cardiopulmonary disease (Raphael, 2001)

Economic Considerations cont'd

- Increased freedom to make decisions about medical care and treatments
- Less paternalistic provider-patient relationship
- More choices available due to rapid technologies
- Expectations have changed
- Maintain control and take responsibility

Summary of the Literature

- Definite barriers- race, ethnicity, communication practices
- Little known about attitudes in this population and setting
- Educational interventions do work- with the Nursing Home staff, not a lot of support known about patients
- Interactive group discussions are effective teaching strategies with the older adult
- Use of decision-making tools, such as the POLST are effective

Advanced Directives in the Nursing Home

Methodology

Design

- Feasibility study
- Quasi-experimental
- Pre-test/Post-test
- Voluntary convenience sample
- Stella Maris Nursing Home patients with decisional capacity
- IRB approval obtained-dealing with human subjects
- ELNEC Module on ethics and advanced directives used
- Taught by sub-investigator, ELNEC trainer
  - Three sessions offered
  - 1.5 hours in length/each
  - Participants attended one session of choice

Sample

- Inclusion criteria:
  - 55 years or older
  - Decisional capacity as determined by PCP
  - Read and speak English language
  - No advanced directive or LST form, OR
  - Not revised in past three years
  - Resides at the Stella Maris Nursing Home
- Decisional capacity is defined as an individual who can make medical decisions for themselves
- Fifteen identified patients eligible for study

Sample-Setting

- Stella Maris Nursing Home
  - Founded in 1953
  - Located North of Baltimore city
  - Part of Mercy Medical Health Services
  - Catholic-based facility
  - 10 units, 448 beds

Instruments

- Informed Consent
  - IRB approved
  - 7th grade level
  - Outlines all aspects of the study
  - Approximately 10 minutes
- Participant Intake form – adapted (Mercer 1975)
  - General demographic and medical information and preliminary advanced directive questions
  - 13- items
  - Approximately 5 minutes

Instruments cont'd

- Advanced Directive Attitude Assessment Survey (Mercer 1997)
  - Assess agreement with statements regarding advanced directives
  - Pre-test/Post-test
  - 13- item
  - 4-point Likert scale, higher number response more favorable attitude
  - Tested with Cronbach alpha .80
  - Approximately 10 minutes/each

- Advanced Directive Knowledge Assessment Form (Mercer 1997)
  - –Questions the participants' familiarity with the concepts of advanced directives
  - –Pre-test/Post-test
  - –10- item
  - –True/False statements
  - –Tested with Cronbach alpha .79
  - –Approximately 10 minutes/each

Instruments cont'd

- Maryland Life-Sustaining Treatment Options (LST) form
  - Created by Maryland Office of the Attorney General
  - COMAR Regulations 02.06.03
  - Adopted by State of Maryland October 2007
  - Required for use in all Maryland Nursing homes at time of admission and each change of condition (Schwartz, 2007)
  - Purpose to establish goals of care and instructions for life-sustaining treatment options

Instruments cont'd

- Follow-up Interview tool
  - Subjective
  - 3- items
  - Face-to-face or telephone; minimum of three attempts to reach study participant
  - Answers recorded in pen and paper style by sub-investigator
  - Approximately 15 minutes

Educational Intervention

- Module 4: Goals of Care & Ethical Issues at the End of Life (ELNEC 2008)- Geriatric Curriculum
  - Non-licensed nursing home staff
  - Reads at 6th grade level
  - Power Point presentation
  - Adult-learning strategies: case studies, handouts, group discussion
- ELNEC established February 2000
- American Association of College of Nursing (AACN), City of Hope National Medical Center
- National education program
- Designed for nurses to improve end-of-life care

Procedure

- Screening and Recruitment, prior to start of Program, with IRB approved media, included:
  - Flyer
  - Program Announcement
  - Staff and physician encouragement

Procedure cont'd

- Single- day Program
  - Informed consent
  - Participant Intake form
  - Pre-test Knowledge and Attitudes Assessment Instruments
  - ELNEC Ethics Module
  - Post-test Knowledge and Attitudes Assessment Instruments
  - LST form instructions

Procedure cont'd

- Follow-up Interview
  - Face-to-face in Nursing Home, OR
  - Telephone contact
  - Minimum 3 attempts
  - Occurred 7 days post-session

Data Analysis

- SPSS 17.0 version (Pallant 2009)
  - Manually entered by research assistant
- Participant Intake form- descriptive statistics/frequencies
- Pre-Post test comparison- Wilcoxin Signed Rank test
  - Statistical significance at the $p<.05$ level
- LST form- descriptive statistics and qualitative ‘themed’ discussion

Advanced Directives in the Nursing Home

Results

Results

- Participant Intake Form
  - N=6
  - Health Status
    - 5 (83.4%) very good-good
    - 1 poor (16.7%)
  - Education level
    - 4 (66.7%) high school
    - 2 (33.3%) college
  - Sex
    - 5 (83.3%) female
    - 1 (16.7%) male
  - Age
    - 76- 85 years (33.3%)
    - 86-95 years (66.7%)
  - Religion
    - 100% Catholic
  - Ethnicity
    - 100% Caucasian
  - Insurance
    - All insured
    - 5 (83.4%) Medicare-type plans
    - 1 (16.7%) Medical Assistance

Table 2. Participant Intake Form- Advanced Directives

Advanced Directives	Frequency (n) Total = 6	Percent (%) Total= 100%
Do you know about Living Wills?		
Yes	6	100.0
No	0	00.0
Have you completed a Living Will?		
Yes	5	83.3
No	1	16.7
Do you know about Durable Power of Attorney?		
Yes	3	50.0
No	3	50.0
Have you completed a Durable Power of Attorney?		
Yes	4	66.7
No	2	33.3
Do you know about Maryland LST form (LST)?		
Yes	0	00.0
No	6	100.0
Have you completed a LST form?		
Yes	0	00.0
No	6	100.0

Results cont'd

- Advanced Directive Attitudes Assessment Survey
  - Individual items showed improvement trends in all statements except Item 1 and Item 9
    - Not statistically significance, however
  - Item 1: Advanced directives will not deprive me of medical care (pre 2.8 and post 2.8)- no change
  - Item 9: Advanced directives are important to me because I like knowing that my end-of-life treatment decisions will be guided by my unique values and life goals (pre 3.1 and post 3.0)- decreased score

Table 4. Total Attitude Survey Scores* for Each Participant, Pre- and Post- Intervention.

	Pre-attitude Score	Post-attitude Score
Participant #1	39.0	38.0
Participant #2	29.0	35.0
Participant #3	31.0	37.0
Participant #4	36.0	44.0
Participant #5	44.0	46.0
Participant #6	35.0	36.0
Total Score	35.5	37.5

*Note: Total Possible Score Range, minimum 13- maximum 52, with the higher score indicating an overall more favorable attitude and belief in the statements.

Results cont'd

- Advanced Directive Knowledge Assessment Form
  - Overall, no statistical significance in the improvement of knowledge and advanced directives, post-intervention, $z = -1.841$, $p < 0.066$
  - Median score on total knowledge increased from pre-intervention (Md= 16.1) to post-intervention (Md= 18.3)

Results cont'd

Item 1: The best time to draw up an advanced directive is when you first get sick and you think you may be admitted to the hospital; this will assure that your advanced directive is up to date. (false)

Item 1 showed statistical significance, $z = -2.000$, $p < 0.046$

Table 6. Total Knowledge Form Scores* for Each Participant, Pre- and Post- Intervention

	Pre-Knowledge Score	Post-Knowledge Score
Participant #1	19.0	19.0
Participant #2	14.0	17.0
Participant #3	14.0	16.0
Participant #4	16.0	18.0
Participant #5	20.0	20.0
Participant #6	14.0	20.0
Total Scores	16.1	18.3

***Note: Total Possible Score Range, minimum 10- maximum 20, with the lower score indicating an overall higher accuracy or knowledge gained .**

Table 7. Follow-up Interview Results

	Frequency (n)	Percent (%)
Have you completed any type of advanced directive since study?		
Yes	0	00.0
No	6	100.0
Total	6	100.0
Have you discussed information learned since study?		
Yes	5	80.0
No	1	20.0
Total	6	100.0
Do you plan to use the information learned in the future?		
Yes	6	100.0
No	0	00.0
Total	6	100.0

Advanced Directives in the Nursing Home

Discussion and Implications

Participant Intake Form- Sample and Setting

- Nursing Home
  - Catholic-based
  - Caucasian females
  - Educated more than high school level
- Sample size
  - Limitations, despite feasibility study
  - Random sample not feasible
  - Dependent on decisional capacity
- Education Sessions
  - Three separate offerings, varying times
  - Schedule conflicts
  - Room accommodations
- Marketing and Support
  - Study flyer
  - Announcement
  - Lack of staff ‘buy-in’

Attitudes Toward Advanced Directives

- Results suggest participation, alone had a positive effect on the participant's attitude
- Literature not available; thus this feasibility study can help to fill in the gaps
- The ADDM Model supports these results

Knowledge and Advanced Directives

- Statistical Significance in Item 1 is important to note; this is consistent with the literature
  - Karen Ann Quinlan
  - Nancy Cruzan
  - Non-crisis situations allow for better completion rates
- Two participants showed no gain of knowledge
  - Previously educated
  - Nothing else to learn
- Despite scores, all indicated they were interested in the content and engaged in the session

Knowledge and Advanced Directives cont'd

- Instruments
  - Advanced Directive Knowledge Assessment form
  - Borrowed from a previous pilot study
  - Inconsistency with the content provided
  - Content

Maryland LST form

- Responses to open-ended questions were positive, despite not completing the LST form post-Program
- Responses consistent with the literature
  - Three themes
    - 1) being unfamiliar with them
    - 2) feeling too healthy or too young to need one
    - 3) not having time to discuss with their provider/family

Reference: Morhaim 2010; Ott 2008)

Maryland LST form

- The ADDM Model
  - Time as a continuum
  - Allow for more than seven days fro completion of Follow-up Interview
- Handout of LST form
  - Briefly discussed

Recommendations

- A more diverse population of study participants
- Greater number of enrolled participants help for better generalizability
- More education regarding study details with the Nursing Home staff
- Optimize marketing materials
- Re-evaluation of Instruments used
- Inclusion of family members and/or DPOAS

Advanced Directives in the Nursing Home

Recommendations for Practice

Recommendations

- Partnerships
  - Academia, hospices, and nursing homes need to collaborate and determine best practices
- Education Programs
  - Formalized
  - Family, staff and residents
- Advanced Care Planning
  - Earlier and better defined choices
- Treatment Interventions
  - Within context of life choices- resuscitation, intubation, hospitalizations, etc.
- Research
  - Ongoing and more of it

Advanced Directives in the Nursing Home

Implication for the Doctorate of Nursing Practice Role

DNP role

- Essential I: Scientific Underpinnings for Practice
- Essential II: Organizational and Systems Leadership for Quality Improvement and Systems Thinking
- Essential VI: Inter-professional Collaboration for Improving Patient and Population Health Outcomes

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Questions???

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