Confessions of a Reluctant Caregiver
Palliative Educational Program

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Merri Biechler, playwright
biechler@ohiou.edu
Tracy Marx, DO, CMD, OUCOM
marx@ohiou.edu
Overview

- Collaboration to use theatre to teach palliative care and end-of-life issues to preclinical medical students
- 90 minute stage reading of the play
- 60 minute debriefing “talkback” session with actors and palliative care physician
- Attitudinal post-survey & focus groups
Background

- Summer 2005 – met to discuss Merri’s story, created list of difficult issues to weave in, scheduled first reading for summer of 2007

- Why? story to tell, “limited” view points, difficult subjects, shades of gray

- Premise - Exposure to ethical dilemmas may translate to more empathetic responses
Research Components

- Two stage readings
  - one for medical students and invited faculty
  - additional one for healthcare educators, hospice caregivers, community members

- Immediate Post Survey based on “Wit” Educational Project
  - 12 questions plus demographics

- Focus groups conducted within 1-2 weeks
  - Students
  - Healthcare educators, caregivers
Video Clip from Confessions

- Hospital scene with mom, dad, and daughter
Purpose of Pilot Study

- Evaluate a new program designed to educate about ethical issues surrounding caregiving and end-of-life care

- Data analysis completed in three phases
  - Reliability analysis of survey data
  - Item analysis of survey data
  - Qualitative analysis of focus group data
Reliability Analysis of Survey

- Based on Wit Film Project although no documentation regarding reliability and validity of the instrument
- Examine the scale’s internal consistency so that all sub items are consistently measure the same construct
Reliability - Item 3
(Perception of Accuracy)

- 7 sub items each scaled as a 5 point Likert scale (entirely real – not at all real)
- In your opinion, how accurately did the play portray:
  - Emotions that terminally ill patients feel
  - Medical treatments that terminally ill receive
  - Way that doctors communicate with dying pts
  - Way that nurses communicate with dying pts
  - Caregiver experience
  - Hospice as an option for end of life
  - Impact of illness on family members
- Cronbach’s alpha for this scale was .845 (ideal > .7)
Reliability - Item 6 (Degree of Reflection)

- 6 sub items scaled as 5 point Likert scale (very much so – not much at all)

- To what degree did the play make you think about the care that you will give to dying patients with regard to
  - How we give bad news to patients
  - How we give bad news to family members
  - How we talk with patients about prognosis
  - Emotional & spiritual suffering that dying pts go thru
  - How we talk with pts about their end of life wishes
  - How to introduce hospice as an option for end of life care

- Cronbach’s alpha for this scale was .917
Survey can be expected to provide a reliable measure of feedback regarding viewer’s perceptions of the play’s accuracy and reflective power related to end-of-life issues.
Item Analysis of Survey

- 80 surveys returned
  - 29 (36.3%) medical students
  - 51 (63.8%) non-med students
- “Before participating... how comfortable were you with discussing EOL issues?”
  - 3 (10.3%) med students very/extremely comf.
  - 24 (48%) community very/extremely comf.
- “After participating... how comfortable were you with discussing EOL issues?”
  - 10 (34.5%) med students very/extremely comf.
  - 37 (72.6%) community very/extremely comf.
# Item Analysis – Perception of Accuracy

aggregate “entirely/very real”

- Emotions term. ill patients feel 73 (92.4%)
- Medical treatments pts. Receive 68 (86.1%)
- Way that doctors communicate 52 (65.8%)
- Way that nurses communicate 54 (67.5%)
- Caregiver experience 73 (92.4%)
- Hospice as an option for end of life 71 (93.4%)
- Impact of illness on family members 74 (94.9%)
Item Analysis – Reflection
aggregate “very much/good amount”

- How we give bad news to patients 63 (78.8%)
- Give bad news to family members 59 (74.7%)
- Talk with patients about prognosis 58 (74.3%)
- Emotional & spiritual suffering 67 (83.8%)
- Talk with pts about their EOL wishes 60 (75.1%)
- Introduce hospice as an option 60 (75.1%)
Item Analysis – Med Students

“How did this learning experience compare to...” (5 point Likert plus don’t know)

- **Didactic lectures** - 24 (85.7%) much more/somewhat more useful
- **Journal article readings** - 24 (85.7%) much more/somewhat more useful
- **Bedside rounds** - 5 (17.9%) much more/somewhat more useful, 6 (21.4%) don’t know
Qualitative Analysis – Overview of Findings

- Engaged in the play throughout entire performance, described in positive terms
- Positive educational experience, excellent learning tool to teach EOL care
- Creative way to bring out many issues; approp for those with varied experiences
- Students – underlying themes of home and communication
- Community/providers – reflect on their experiences and see similarities and differences
Qualitative Analysis – Overview of Findings cont’d.

- Stressed importance of developing educational materials for use with play
- Excellent “starting point” for teaching others about EOL care
- Immediate debriefing was helpful, followed by one or more sessions after had time to process the play
- Thought a DVD packaged with educational materials as most convenient mode of delivery due to time/expense
Focus Group - “Identify Key Issues”

- EOL care is a family affair
- Caregiving is a life-changing experience with intense emotional/psychological burden and many emotional/personal conflicts
- Caregiving involves difficult ethical decisions
- Communication is a crucial part of EOL care
- Role of physician in EOL care is challenging and requires many ethical decisions
Focus Group – “Identify Purpose of Play”

- **Students** – “theme of hope” in EOL care
  - Patients find hope in search for a cure
  - Patients find hope in accepting death
  - Caregivers find hope that good can come from bad
  - Physicians find hope in realization that death is a part of life

- **Community** – specific and tangible
  - Stages of grief, unique experience
  - Family dynamics
  - Role of patient in EOL care
  - Difficulties navigating health care system
  - Role of hospice and related services
Our Next Steps from Lessons Learned

- Minimal survey revision (rearrange order)
- Additional readings to other healthcare students
- Creation of facilitator’s guide for small group debriefing
- Reading at statewide geriatric conference to wider audience
Moving Forward

- Compiling data for publication
- Obtain additional funding and/or national sponsorship to take the Program across the state and national
- Create a model for sustainability
- Commitment for full production – Brick Monkey Theater Ensemble
Thank you.... Questions?