Lights, Camera, Action: Improving Advance Care Planning

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“Care across the Continuum”

Objectives
1. Discuss the response to the Federal Law “Patient Self Determination Act” passed in 1991
2. Define the role and application of drama to enhance learning

1950s...dying was largely a private affair

- Ethical shortcomings 1970s-1980s provoked EOL
  - 1970s Karen Ann Quinlan case
  - 1983 Nancy Beth Cruzan
  - 1990 Terry Shivo case
  - 1990 Patient-Self Determination Act (PSDA)
  - December 1, 1991 Federal Law
Karen Ann Quinlan
- Karen Ann Quinlan and NJ supreme court, 1976
- remove from ventilator due to persistent vegetative state
- Family “allow to die with dignity”
- Court agreed and removed and lived for another 10 years

Nancy Cruzan
- Nancy Cruzan – critically injured, 1983
- Vegetative state, rendered irreversibly incompetent
- Family: Remove nutrition and hydration
- Made statements to her friends
- Missouri – common law doctrine of informed consent "right of competent individual to refuse medical treatment" and proxy or agent would have same right
- Supreme Court ruled her statement met standard
- Supreme Court – each state would be able to decide the right-to-die issues

Terri Schiavo
- Terri Schiavo, 1990
- Vegetative state receiving enteral nutrition
- Family and husband disagreed in Terri wishes for EOL care
- Feeding tube removed, 2005
- Terri died 13 days later
PDSA, 42 C.F.R. and 489.102

- Amendment to Title XVIII of the Social Security Act (Medicare)
- Federal Law December 1, 1991
- Patient right to Natural Death
- Health care facilities: provide AD education to staff, patients, & community
- Intent: protect unnecessary care and suffering, inappropriate use of financial resources

Gap Between Law and Intent
Support study (RWJ)
N = 9000

- 46% DNR order written two days prior to death
- Most ADs never made it into EMR; 14% that did gave little instruction
- 50% of patients had moderate to severe pain in final days

STATE OF MICHIGAN
/Public Act 312 of 1990/

- Legal document: Durable Power of Attorney for Health Care (DPOA-HC) – name someone to make decisions about your health care
- Appoint “Patient Advocate” that honors your best interest – takes effect when individual no longer can communicate health care decisions
SMML Policy 301

“Advance Directive and Patient Code Status”

a) Recognized person has a right to refuse or limit treatment options
b) Upheld when patient can no longer speak for themselves unless contrary to Catholic teaching
c) Hospital will make information available to patients
d) Provide community education

Gap Between SMML Policy 301 & Intent

- 2007-2011 – 240 patients requested information on ADs among 41,000 annual visits to the ED
- 15,000 admissions
- AD completion rates undetermined
- Not uncommon in ED for patients not to have an AD written

CODE BLUE: THE PATIENT SELF-DETERMINATION ACT HAS LOST ITS PULSE
Dying in America Report

- Most people are unable to make their own decisions about care when they're nearing the end of life.
- Conversation before a crisis
- Conversation not a one-time event.


Organizational Commitment Statements

- Trinity Health Statement Trinity Health’s commitment to improving end-of-life care goes far beyond the written words in our mission statement and core values
- Participate in the work of the Patient Quality of Life Coalition in advocating for federal and state policy improvements to palliative and end-of-life care.
Findings—Public Education and Engagement

- Need for public education and engagement is manifest at the societal, community/family, and individual levels.
- Most Americans lack knowledge about EOL care choices, and the health community and other leaders have not fully utilized strategies to make that knowledge available, meaningful, and relevant across diverse groups.
- Efforts are needed to normalize conversations about death and dying.
- Several social trends suggest that the time is right for a national dialogue on this issue.

How can the PSDA/Policy 301 be resuscitated?

Drama

- Use & application in nursing education not new
- Help assimilate theoretical knowledge into practice
- Drama techniques allows learners to describe, rehearse, explore, investigate experiences
- Engage in both real and fictional contexts at same time “metaxis”
Reader’s Theatre

- Reading of existing text
- Drama created by vignettes; audience interactive
- Help examine their own feelings about death and dying
- Allows reflection
- Raise awareness around EOL and benefits of having conversation

SPEAK UP!
WWW.NHDD.ORG

The Secret
What can happen if you keep it a Secret...

The Cast Members
Kathy Dattolo, Senior ER Social Worker
Deacon Jenny Ritter
Chaplain Diane McDonald
Jean Borin, Home Instead Senior Care
Glenna Yaroch, Home Instead Senior Care, Owner
General Hospital

Dr. Kim
Mrs. Miller
Michelle (daughter)

Social worker
Hospice

Shhhhh...

It's a Secret

Have you had the talk?
Even if your hands are shaking
And your faith is broken
Even as the eyes are closing
Do it with your heart wide open
Say what you need to say

Star Light
Star Bright
Using a nursery rhythm to outline the 5 wishes Advance Care Planning document
**Star Light, Star Bright**
*By Anonymous*

Star light, star bright,  
First star I see tonight,  
I wish I may, I wish I might,  
Have this wish I wish tonight

FIRST WISH: Tonight, my wish is to have _____ to speak in my behalf “to be my voice” when I can no longer make decisions for myself

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1. Did you have and AD prior to attending today?

<table>
<thead>
<tr>
<th></th>
<th>Yes</th>
<th>No</th>
<th>Totals</th>
</tr>
</thead>
<tbody>
<tr>
<td>Count</td>
<td>50</td>
<td>81</td>
<td>131</td>
</tr>
<tr>
<td>Percent</td>
<td>38%</td>
<td>62%</td>
<td></td>
</tr>
</tbody>
</table>

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2. Select your main reason for attending this event (Multiple Choice)

- I currently am involved with an EOL situation (28%)
- I want to be prepared (22%)
- I am concerned about the availability of quality EOL care in community (16%)
- I thought it sounded interesting (13%)
- I was told I had to attend (4%)

3. What was your overall impression of the information provided today?

- I learned many new things that will be useful to me (43%)
- I learned a few new things (42%)
- I learned new things (11%)
- I did not learn anything new (2%)
- I did not learn anything new and was disappointed (2%)

4. After attending this event, which of the following are you likely to do within the next month or two? Multiple responses

- More thinking/reading about this topic (23%)
- Talk to family members (12%)
- Talk to my doctor about my own wishes (12%)
- Talk to a leader or someone in my faith community (11%)
- Complete an AD form or 5 wishes document (10%)
- Update my AD or 5 wishes (9%)
- Help someone I know to complete an AD or 5 wishes (8%)
- Get involved in efforts to improve EOL care in community (5%)
- Other (4%)
5. Following tonight’s presentation are you more likely to complete an AD?

Yes, 62%
No, 11%
Maybe, 27%

6. If there were dates set up to complete an advanced directive would you sign up?

Yes, 46%
No, 22%
Maybe, 32%

7. Please provide the Following Demographic Information

Male 54%
Female 46%
Total 100%
8. Please provide this information

<table>
<thead>
<tr>
<th>Healthcare professional</th>
<th>Non-Healthcare professional</th>
</tr>
</thead>
<tbody>
<tr>
<td>38%</td>
<td>62%</td>
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</table>

9. Your age?

<table>
<thead>
<tr>
<th>Age Group</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>50-64 years</td>
<td>22%</td>
</tr>
<tr>
<td>36-50 years</td>
<td>21%</td>
</tr>
<tr>
<td>55 and older</td>
<td>31%</td>
</tr>
<tr>
<td>65 and older</td>
<td>30%</td>
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</tbody>
</table>

Conclusion

- Nurses’ voices are essential to advocate for each patient’s right to self-determination.
- “Patient centric approach” through drama is another option to provoke meaningful EOL discussions to inspire change.
- “Never forget that a small group of thoughtful committed people can change the world; indeed it is often the only thing that ever has.” Margaret Mead
THE FUTURE DEPENDS ON WHAT WE DO IN THE PRESENT

MAHATMA GANDI

NOW is the Right Time!

Resources

http://www.ninetoninymovie.com/
http://theconversationproject.org/
http://theconversationproject.org/resources/
- WWW.CARINGINFO.ORG
- WWW.NHDD.ORG
- WWW.ENGAGEWITHGRACE.ORG
- HTTP://RESPECTINGCHOICES.ORG
- WWW.AGINGWITHDIGNITY.ORG

My Health Care Wish App

http://www.americanbar.org/groups/law_aging/MyHealthCareWishesApp.html

http://www.americanbar.org/content/dam/aba/images/law_aging/app_walletcard.pdf
- The link to the Rock Center with Brian Williams video clip of GLHS.
References


References


