

# ADDRESSING THE END OF LIFE

What about the Staff and Family?


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# OBJECTIVES

- Identify barriers which preclude Intensive Care Unit nurses from delivering optimal terminal care.
- Recognize factors associated with the development of Post-Traumatic Stress Disorder (PTSD) related symptoms by family members of patients in the ICU.







# FAMILY FEUD

Name the top 3 barriers which preclude ICU nurses from delivering optimal terminal care

	1
	2
	3

Bockstrand, 2005; Downey, 2006; Bockstrand, 2006; Hansen, 2009; Espinosa, 2010

Name the top 6 factors associated with the Development of PTSD related symptoms by family members of ICU patients

	1		4
	2		5
	3		6

PTSD: Up to Dew 2014; Abouley 2009; McAdam 2009; Jones 2012; McAdam 2012; Netzer 2013; Netzer 2014

# Why?

Name the two things YOU can do to keep family members of ICU patients from experiencing PTSD

- 1
- 2

Azoulay, 2005, McAdam, 2009, Jones, 2012, McAdam, 2012, Netzer, 2013, Netzer, 2014

Name one thing that has been shown to decrease severity and length of PTSD for patients and their family members

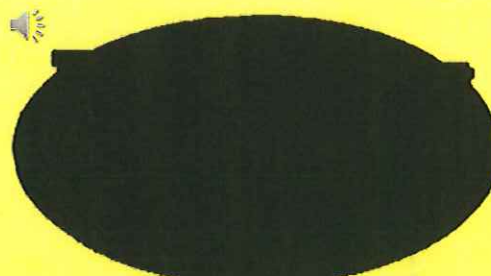
- 1

Jones, 2012; Jacobson, 2010; Garrouste-Orgeas, 2012

Factors associated with PTSD-related symptoms by family members in the ICU include which of the following?

- 1
- 2
- 3
- 4

Learning Assessment Question



Thanks

## Bibliography


## Bibliography


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**Slide 2**

When I was asked to do this talk I could not figure out how I was going to trim all the research out there on the barriers that nurses and families face with end of life care into 20 minutes or less session, little less make it fun and interesting.

End of life care discussions are generally depressing and not what ICU clinicians like to discuss amongst themselves little less with patients and their families. So how to make this fun? I did what I do best, I procrastinated.... Then as I was flipping channels on the TV I came across Jeopardy. Boy did I learn a lot in 20 minutes. So I thought why not make this session a game....

So you are about to play a version of....

**Slide 3**

I will ask you a question and I need you to think about, or write down your responses to the following questions.

**Slide 4**

Over 1500 ICU RN's (the majority of them we obtained from a random survey of AACN members) were surveyed by Beckstrand, Downey, Hanson and Espinosa regarding their most frequently perceived barriers to delivering End of Life Care in the ICU. The top 3 answers are on the board.

Survey Says..... Nurses

**A. Education—**

- a. Less than 20% of nursing schools have formalized EOL training (Ferrell) raise your hand if you are a nurse... leave it up if you had a formal class in school on EOL care?
- b. Leave school with minimal knowledge of pain and symptom management at end of life
- c. Where to go to obtain education
  - i. ELNEC end of life nursing education consortium Promoting Palliative Care in Critical Care google ELNEC—Dallas County AACN puts on an ELNEC class every year for a nominal fee, find information on the class at DallasAACN.org
  - ii. AACN website Clinical Practice tab free quiz/education you can take to assess your skills or you can purchase access for 6 months to earn a 3.5 hour CE course on Palliative and EOL care where you perform clinical interventions and conversations with your virtual patient and their family. \$50.00
- d. Nurses who are most comfortable with EOL care are nurses that have been nursing for a long time a lot of nursing is learned on the job. (Beckstrand)

**B. Communication**

- a. SBAR is what is learned in school.
  - i. Situation—your loved one is dying
  - ii. Background—they have stage IV lung cancer with mets to bone, brain, liver, kidneys due to 50 years of smoking 3 packs per day
  - iii. Assessment—renal failure—CRRT, respiratory failure—on ventilator Peep 15, FiO2 100%, TV 300, Rate 35 Po2 40% Peak pressures 45. DIC HGB 6 Platelets 15K, Vasopressin .04, Levophed 20, Dopamine 20 HR 48, BP 88/50 (62)
  - iv. Recommendation—allow your loved one to die remove vent, crrt, transfusions,
- b. Whose place is it to say a patient is dying?
- c. What communication tools are out there to help clinician at breaking bad news SPIKES (ELNEC)

**C. Internal Feelings of Conflict/Moral Distress**

- a. Once the decision is made to change our focus and efforts on keeping patient comfortable and treating the noxious symptoms associated with the dying process. You get the symptoms under control, then there is guilt am I giving too much medicine, am I hastening the patient's death? Multiple studies show pain and symptom management prolongs life.
- b. Last dose philosophy/ Double Effect Jennifer's story 85 YO Cabg/AVR patient did not want to have surgery... family talked her into it. Coded 3 times first time broke ribs
- c. Unable to communicate with patients to determine what their wishes are most are learned from other people (Beckstrand, Espinosa)

- D. Guilt
  - a. providing futile care
  - b. Sense of relief once focus is changed to allow a natural death— taught in school that disease can be cured when disease is not cured failure of caregiver.
  - c. When a patient is going to die, then want to provide a “good death” most of us believe a good death is not being hooked up to a ventilator, medicated and sedated, away from family members
- E. Processing of emotions... Compassion Fatigue or “Crusty RN” Coping Skills/ Complicated Grief
  - a. Snickers, coke
- F. RN feelings of abandonment
  - a. Not a part of the treatment team (example Dr. X and 86 YO woman with PNA advanced directive, stating no heroic measures used to extend her life if she is terminal or has an irreversible condition, intubation for pneumonia/sepsis pneumonia/sepsis is not incurable, or terminal (?))
  - b. Orders are received, up to RN to carry them out, even if they don’t agree with them
- G. Staffing
  - a. Time
    - i. Taking care of a dying patient and their family takes time to address the emotional and physical demands
    - ii. Sometimes your other patient who is going to live takes up too much of your time
    - iii. Should patients that are dying be made One on One ?
  - b. Assignment
    - i. Dying patient given to nurses that are floating, travelers, less clinically adept

Survey Says... Physicians

- A. Lack of formal training on end of life care in medical school curriculum
- B. Lack of knowledge about patient’s desired or even ordered code status (JAMA Support trial 40% MD’s not aware of patients code status)
- C. Medicine “culture has changed” lost the “Do no Harm” moved to Death is a failure (doing so we have changed peoples abilities to have a dignified or even quick death) (Mr. C roto prone x3 pneumothorax’s chest tubes, etc. still left with his underlying liver disease, esophageal varices, life style choices if he lives)
  - a. MD’s job is to save lives (used to be to alleviate suffering) now Death is viewed as a failure. We all know people are going to die; they just need to die when someone else is in charge of their care.
- D. There are too many of you on a case—each just looks at their own organ and moves on
- E. Evasive and avoid conversations with family members
- F. Prognostication
  - a. Ability to predict patients course of illness and survival status with 100% accuracy
- G. Don’t let patient’s die from their disease process anymore--Pneumonia
- H. It is easier and quicker to act than not act
  - a. 20 minutes you can line, intubate and “stabilize” a patient Make some Money
  - b. 60 minutes to talk with family and patient if they are well enough to have EOL discussions, focus medical efforts on noxious symptoms of death make less money.
  - c. I think that is a rip off you invest more physical and emotional effort to a patient and family and get paid less.

Survey says.....Families

- A. Multiple calls checking on patient as a opposed to contacting family spokesperson—calls interfered with patient care
- B. Don’t understand the term life saving measures and all of the implications that entails (keeping people alive sometimes has life-long complications that Christiane Perme and Dr. Davis mentioned yesterday families are not aware of this) Watch the Vanderbilt website about Delirium and see people say if they knew they would have been left with the health they have now they would have rather died)
- C. Denial the patient is dying
- D. Don’t know what surrogate decisions should be made
  - a. Surrogate has not had the “difficult” conversation prior to this event
  - b. Surrogate has not been chosen, paperwork has not been filled out
  - c. (Shalowitz, 2006) does surrogate really understand what patient wanted 32% chance they are making the wrong decision.
- E. Angry family members take up a lot of time to placate as opposed to delivering patient care
- F. Family requests life sustaining measures contrary to patient’s wishes



- G. Families not accepting poor patient prognosis
- H. Azouzy France 53% of families did not want to make the decision; they wanted the doctor to make the decision for them.

### Slide 5

Multiple Critical Care Research studies were surveyed; Top six answers are on the board.

Name 6 factors associated with the Development of PTSD related symptoms by family members of ICU patients.

Survey Says...Health

#### A. Health

- a. (Netzer, 2014 in the Annals of Thoracic Society March, 2014) stated significant Sleep deprivation affects 12-15 % family members/surrogates have cognition impairment that equals a blood alcohol level of .05-1% Would you ask a drunk to make end of life care decisions
- b. Poor eating/diet of family members
- c. Lack of exercise/sunlight/fresh air
- d. Are their pre-existing health problems family members are ignoring with stress of loved one in the ICU?

Number 5

#### B. Surrogate

- a. Does patient have an advanced directive, is the family and staff following it? Does the surrogate decision maker have the mental fortitude to follow it?
- b. Does the surrogate even know what the patient wants? Shalowitz 2006 studied The accuracy of surrogate decision makers mentioned that patient-designated surrogates often incorrectly predict end-of-life treatment preferences) only 68% of patient and surrogate chose the same response in hypothetical situations
- c. Is the surrogate comfortable with following the patient's treatment preferences? (80 year old female came in with SOB, chest pain, did not want a heart cath, and had been talking about dying last few years to her family. Developed profound SOB, intubated, cardiologist wanted to take her to the cath lab st elevated MI, said if she does not she would die, in cath lab her ef was low she had multivessel disease, low ef, low bp, impella was placed. Cardiac surgeon was consulted, son did not want to be the one to say it was OK not to do surgery, even mom had been stating she was going to die soon, surgery was done, patient died anyway 8 days later in the ICU when entire family was at bedside and had to tell doctors their mom would not have wanted any of this done.) (Schenker 2012 J. Gen Internal Med.) (Hickman, Decisional Conflict and Regret, 2012, Applied Nursing Research)
- d. New Yorker Magazine, 2013 reported that surrogates choose treatments for the patient they would not want for themselves due to the stress of being the one to "choose" treatments.

Number 4

#### C. Resources

- a. Lower educational level more likely family PTSD will happen
  - i. Education periods stress = 3<sup>rd</sup> grade level most done at 12<sup>th</sup> grade (even if we think we are dumbing it down) (Dallas Morning News, 1998)
- b. Financial
- c. Emotional
  - i. How have they coped with stressful situations in the past
- d. Support

Number 3

#### D. Female

- a. Child of patient making decision it is very difficult especially if patient never discussed EOL decisions (Jennifer McAdam Psychological symptoms of family members of high risk Intensive Care unit patients, American Journal of Critical Care, 2012)

Number 2

#### E. Unplanned Admission

Top reason family members develop PTSD

#### F. Inconsistent information

- a. Multiple MD's and nurses each with a different goal of care, and thought process, few consult family or each other about the course of care. (or read progress notes prior to entering room)

### Slide 6 Why...

Is this information important to us as ICU clinicians?

1. It is important as (Beckstrand, 2005, reported that) 60-80%, of Americans who die, die in a hospital or medical facility. Even though, when surveyed, the majority state if they are going to die they want to die at home surrounded by family not in a facility surrounded by strangers. We must be skilled in providing end of life care at as that number accounts for about 2 million people. (That is around the size of Houston)

2. Dr. Netzer, 2014, reported that:

- a. Conflicts with families hurt us, and increase our burn out rate.

- b. Futile Care hurts patients

1. It takes up beds that could be used by patients that would have a better outcome if their ICU admission was not delayed due to inappropriate use of ICU resources

2. It hurts the patient who is receiving the care (ICU interventions are painful) (ELNEC)

3. PTSD level of severity is the same as those being admitted to inpatient psych wards for PTSD this can occur while the patient is still in the ICU.

4. Fumis, 2014 poster presentation—CCM conference in Brussels reported that

Family members suffer more than patients. If the patient survives or dies the end result is the family has more incidence of PTSD at the end of 90 days than the patient does

*184 pairs of patients*

7 % of patients suffered PTSD at 30 days resolved by end of 90 days

6.2% of family members suffered PTSD at 30 days and their numbers increased to 9% at 90 days

Science Daily 2008 published PTSD found in 35% of all family members at end of 6 months

46% family members loved one died in ICU had complicated grief...

Dr. Giora Netzer et al. in the Annals of Thoracic Surgery March, 2014 proposes a Family Intensive Care Unit Syndrome that mimics the PICU Patient Intensive Care Unit Syndrome. Decreased cognitive functioning, learned helplessness, depression, to name a few of the symptoms

Philosophy of "Fast vs. Slow" medicine

Family conferences have been shown to be effective ***IF Family*** gets to do the majority of the talking.

Like some of the previous lecturers I was not comfortable with just telling you the grim facts, but I wanted to give you some ideas to help keep our family members from experiencing PTSD.

Name things you can do to keep family members of ICU patients from experiencing PTSD? Top 2 answers are on the board

Cognizant

Remember your family members are tired, not thinking clearly, do not understand the terminology you are using, and do not know, as we have learned these last few days, that some of our patients that survive a critical illness NEVER regain a quality of life the patient would be happy with. It is sometimes more palatable to not consent to *Fast Medicine* if the outcome would not be what the patient would want. Find out if people have advanced directives, see if they philosophically believe in *Fast or Slow medicine*. Figure out what philosophy your family would like to be on and see if that is achievable by the healthcare team. If it is not achievable find out what goals of care would be agreeable to the patient, and family, and see if you can compromise on those for now. Have your family view the Family resources pages available on the SCCM website and the Vanderbilt Delirium website. Let them see "first hand" the good and the bad consequences of a critical illness in the ICU.

Be Consistent

Try to be on the same page as everyone else, and keep the healthcare team on the same page. Good luck!