

How to Message Brain Death

May 29, 2014

Kerry L. Holliday, B.S.W., M.S.W.





Working with Families of Critically Ill Patients

CONSISTENT MESSAGING

HEELP

Help

Earlier in parallel with the

Loss of a

Loved

Person

(Smulda, Hegedus, Mihaly, Szabo, & Fazakas, 2012).

Consistent Messages: Language

- Discuss expectations for outcomes even if they are uncertain
- Use language appropriate with grave prognosis and then death
- Timely & candid discussions are essential for emotional preparedness
- Incorporate empathetic statement

Consistent Messages: Language



“I am very concerned he is getting worse”

“We are not seeing the brain react”

“The machine is doing all the breathing for him”

“She is not on any sedation.”

Consistent Messages: Actions

- **Ask-Tell- Ask** as a rule of thumb
- Team huddles/shift change discussions regarding communication with family
- Family meetings
- Communication of prognosis to family

Consistent Message: Tools

- Share information during neurological checks
- Allow family to observe the clinical exam
- Show family pictures from the Blood Flow Study
- Show family EEG results

ATTEMPT to...

- Ensure non-contradictory information is being provided
- Prepare families for what they will see
- Establish referrals for additional services (i.e. Palliative Care, Spiritual Care).

Challenges: Hope

- To promote realistic expectations versus taking away hope.

How can we respond?

“Have you ever seen anyone recover from this type of injury?”

Pay **ATTENTION** to the...

- Emotional distress of the situation
- Inability to process information
- Search for control
- Need to establish and maintain trust



Challenges: Honesty

- To maintain our credibility and the credibility of our colleagues.

How can we respond?

“Nurse Jane told us that he is doing better. You give us nothing but bad news, we don’t want you to take care of our son anymore.”

EXPECT...

- Emotional swings
- Loss of hope coupled with unrealistic expectations of survival
- Fantasy of a coma as opposed to brain death
- Internal dialogue (recalling last conversation, memories, etc.)
- Anchoring

Challenges: Trust



- To maintain communication when trust is compromised.

How can we respond?

“We want to move him to another hospital, where they know what they are doing.”

AKNOWLEDGE the difficulty of...

- Being in a foreign environment
- Not being able to meet physical needs (i.e..
sleep, nutrition etc.)
- Sharing information with extended family &
friends
- Saying goodbye
- Making a decision about donation

Challenges: Power

- To set boundaries without engaging in a power struggle.

How can we respond?

“I am not leaving, I don’t care if it is shift change. It is my right to be here and we will have as many people in here as we want.”

Give TIME to..

- Realize the inevitability of death.
- Understand the cause of death.
- Discuss with other family members
- Seek reassurance for any concerns



QUESTIONS?

References

- Billings, J.A. (2011). The End-of-Life Family Meetings in Intensive Care Part I: Indications, Outcomes, and Family Needs. *Journal of Palliative Medicine*, 14 (9), pages 1042-1050
- Billings, J.A. (2011). Part II: Family-Centered Decision Making. *Journal of Palliative Medicine*, 14 (9), 1051-1057.
- Billings, J.A. (2011) Part III: A Guide for Structured Discussions. *Journal of Palliative Medicine*, 14 (9), 1058-1064.
- Hope, A. A., & Nelson, J. E. (2014). The Overlap of Palliative Care and Critical Illness. *Textbook of Post-ICU Medicine: the Legacy of Critical Care*, 50.
- Jacoby, L., & Jaccard, J. (2010). Perceived Support Among Families Deciding About Organ Donation for Their Loved Ones: Donor VS Nondonor Next of Kin. *American Association of Critical Care Nurses*, 19. Retrieved from <http://ajcc.aacnjournals.org/content/19/5/e52.full.pdf+html?sid=0ade18da-5802-4170-8640-adc0f98098d1>
- Kross, E.K., Engelburg, R.A., Gries, C.J., Nielson, E.L., Zatzick, D., & Curtis, J.R. (2011). ICU Care Associated With Symptoms of Depression and Posttraumatic Stress Disorder Among Family Members of Patients Who Die in the ICU. *CHEST*, 139 (4), pages 795–801.
- McAdam, J. L., Fontaine, D. K., White, D. B., Dracup, K. A., & Puntillo, K. A. (2012). Psychological symptoms of family members of high-risk Intensive care unit Patients. *American Journal of Critical Care*, 21(6), 386-394.
- Smudla, A., Hegedus, K., Mihaly, S., Szabo, G., & Fazakas, J. (2012). The HELLP Concept – Relatives of deceased donors need Help Earlier in parallel with the Loss of a Loved Person. *Annals of Transplantation*, 17 (2), pages 18–28.

Thank you for sharing in our mission, to save lives through organ and tissue donation and transplantation.

