G. Jay Westbrook, M.S., R.N., CHPN - Clinical Director

Compassionate Journey:
An End-of-Life Clinical & Education Service
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Language of the Heart:
Empowering Dying Patients & Grieving Families

(University of Kentucky Summer Series on Aging - 6/5/2012)

BIO

Jay Westbrook is a multiple award-winning clinician, Visiting Faculty Scholar at Harvard Medical School's Palliative Care Department, and a specialist in End-of-Life care & education.

He created and was Clinical Director of the first Palliative Care & Bereavement Service in a California community hospital, and created American Society on Aging's End-of-Life Issues Committee. Westbrook has a Master of Science degree in Gerontology from USC, is a certified Grief Recovery Specialist, a Registered Nurse, and a Certified Hospice and Palliative Nurse.

He is nationally recognized as an expert on the constellation of issues surrounding End-of-Life, and is highly skilled in working with the spiritual, emotional, physical, and intellectual suffering of people approaching the end of their lives, and their families and caregivers.

He lectures & consults nationally, at both the keynote and breakout levels, on Pain Management, Emotional and Spiritual Suffering, Compassion Fatigue and Burnout, Quality-of-Life at the End-of-Life, Clinical Gerontology, Palliative Care, Nutrition and Hydration at the End-of-Life, Working With Dying Patients & Grieving Families, and the powerful Grief Recovery technique. **Westbrook is an informative, entertaining, and inspiring speaker who presents powerfully on the transformative aspects of suffering and on using suffering to awaken compassion.**

Organizations for which he has served as a consultant or educator include, but are not limited to:

Alzheimer's Association
California Assisted Living Association (CALA)
City of Hope National Cancer Center
Kaiser Permanente Hospitals of Southern California
Los Angeles County/USC Medical Center
Penn State University School of Medicine
U.S. Department of Defense
USC Keck School of Medicine
American College of Physicians
California Hospice Foundation
Connecticut Children's Medical Center
LAMP Mental Health Outreach Program
Multiple Los Angeles Schools of Nursing
St. Jude Medical Center
U.S.A.F. Keesler AFB Medical Center
Veteran's Administration Medical Centers

"Your stories & grace have haunted my thoughts & helped me tremendously." - E. Richardson, M.D.

"Your heart is so beautiful – your courage endless. Thank you for sharing." - C. Downey, M.D.

"Extraordinary care & teaching & modeling, Jay … You did an amazing job." - S. Block, M.D.

Statistics

	-127,750	350	15	1 q 4 min	U.S. kids
-6B	108M/year	296K/day	12,333/hour	205.5/minute	people

-"Graying" of **...**

-with fewer & more distanced family caregivers

-prisons

Concerns:

1. **where will I die? (7**5-80% vs. 20-25% = 50-60% failure)
2. **will I die alone?**
3. **will I die in agony/will I suffer?**
4. **will my mother/father … starve?**
5. **will I be a burden to my family/to others?**
6. **will I lose my dignity?**
7. **what will happen to my _____?**
8. **spiritual/existential issues**
9. **psychosocial issues**
10. **financial issues**

Prognosis

Medicine/Medical. a forecasting of the probable course and outcome of a disease, esp. of the chances of recovery.

-*Prognostic Disclosure to Patients With Cancer Near the End of Life*
Lamont & Christakis Study - Ann Intern Med 2001; 134: 1096-1105
96.5% able, 37% truth, 23% not tell, 40% diff (70%+/30%-)
formulated vs. communicated

-Most common reason for not telling Pt the truth is "not wanting to take away hope."

-Ask why the patient and family want to know

(-"Mommy, where did I come from?")

-"I hope to be at my daughter's graduation in June"

-**tell the truth and maintain hope** - legacy building

Evolution of Hope/Reframing Hope
(J Hospice & Palliative Nursing 2004; 6(4): 239)

Event	Hope
New diagnosis of CA	Diagnosis is wrong
Reconfirmed diagnosis	DZ responds to chemo
Several chemos, but persistent DZ	Perhaps NCC or CoH have experimental …
No experimental protocol available	We can get you on hospice
Enrolled in hospice	Grandchildren would visit
Few days B4 death; it was raining	Sun would shine tomorrow

-*Prognosis Communication in Serious Illness: Perceptions of Older Patients, Caregivers, and Clinicians* - Fried, Bradley, & O'Leary - J Am Geriatr Soc 2003; 51: 1398-1403

-46% P/C & 34% CG/C pairs, C rpts saying P could die, and P/CG rpt 0 discussion

-23% P/C & 30% CG/C pairs, C rpts discussing life expectancy, and P/CG rpt 0 talk

-40% of those P reporting 0 conversation, state they do not want such a conversation

(where P = Patients, CG = Caregivers, and C=Clinicians)

Of those Patients who believed they generally knew their prognosis, desire for specific discussion increased inversely to life expectancy:
83% w < 1 yr, 79% w 1-2 yrs, 53% w 2-5 yrs, and 50% w > 5 yrs

-Blackhall '95 JAMA study of 800 elderly people in L.A.:
90% Whites & AfroAs, 55% KoreanAs, & 35% MexicanAs prefer straight prognosis

Ask, Ask, Ask:

Find out what the patient and family know

Find out what the patient and family want to know, and to whom that news should be delivered

Find out who the desired decision-maker is, and who should not be making decisions

Approach:

"Prognosis deals with the course and outcome of a disease. As we've previously discussed, in your case, this disease will take your life, so the question of prognosis comes down to when it will take your life, or in other words, how much time you have left.

Well, we report prognosis in terms of hours, days, weeks, months, or years. And while I'm wrong more often than I'm right, I'm seldom wrong by more than one category, i.e., if I say weeks, it might be days, weeks, or months, but it's not likely to be hours or years.

I wish I had better news to give you, but in your case, I think we're looking at _____.

Does this news surprise you?

Our **next step** is to _____ (get you comfortable, enroll you in hospice, have you speak with a social worker about your _____, etc.).

affirm your availability, set the next meeting, reframe hope

ask if there's anything else you might do or provide

last ?: with previous difficulties, where have you sought support and how did you come through them – what tools or techniques did you use?

Eol Communication:

Mechanics

1) source – with the intent of being understood
2) message
3) channel
4) target – who is paying attention and has an intent of understanding
5) feedback

Blocks to Communication:

1) using words that have different meanings to different individuals

-abstract words: hope, faith, commitment, strength

-with teenagers: few, early, dope, strawberry, etc.

-healthcare: crack, grave, positive

2) not acknowledge feelings before delivering facts or engaging in factual conversations

"I can't imagine how _____ this must be for you."

recognizes both magnitude of feeling and uniqueness of feeling

3) defensive reactions - can be minimized by:

-stating the positive first:

-"you're wonderful at expressing your feelings, but we need to hear from some of the other family members as well"

-using defense lowering statements:

-"I might be wrong, but is it possible …" -

-"You get to do whatever you want; I have a concern … "

Reframing:

Hospice Care

-speaking with patients and families - the ABCs of Hospice

-intro

-what it is - and what it isn't

-where it's delivered

-how it's delivered

-who delivers it

-what else is included

-eligibility criteria (3)

-diagnosis

-prognosis

-philosophy

Issues Impacting Hospice

-changing hospice statistics

-medicalization of hospice

-corporatization of hospice

-nursing shortage

Grief:

-the normal and natural reaction to loss

-completely unique in its length, intensity, process, style, and presentation

-Frank and Betty

-Gene and Dana

-mitigated by "completion" of the relationship, so, speak to families about:

-hearing

-delivering previously undelivered significant emotional statements

-permission

Self-Care

- create sanctuary – daily quiet & still time-even a little
    - uninterrupted by tech – turn it off for x minutes

- create closure rituals meaningful to you, e.g.
    - write a brief thank-you note to each patient who has died, identifying the gifts they provided to you, and then burn the note outside and watch the smoke float towards the sky, as you say goodbye

- cut the energy chords
    - with gentle karate chops over your throat, heart, abdomen, and groin

- work with Spirit – wash patients feet and use/live the Set Aside Prayer

- know & go to your true sources of support
    - don't go to Foot Locker for pastrami on rye

- don't discount difficulties in your life by comparing them with your patients

- avoid hurting yourself or others with your wounds

Nutrition & Hydration:

Ah-Breath:

Beverly:

Case Study:

-Hispanic family of mother, father, and 5 daughters

-19 month old dau drowns, brought to ER, intubated, and placed on vent in PICU

-Palliative Care works with family – and staff

-children visiting in PICU?

-inservices with staff

-how do you stay with a near hysterical, crying, screaming, grieving mom?

-disconnected emotional family - who do you approach 1st & what do you say?

-"how do you get a parent to give up the body of their dead baby or child when they've held it too long?"

Hinges:

-presence

-vulnerability, privilege, invitation, attentiveness

-mercy, compassion, respect, and silence

walking with a soft belly, open heart, and a posture of exploration

Questions and Answers
Developmental Stages of Childhood Vis-à-Vis Understanding Death

1) birth – 2 years

a) development of sensory coordination
b) object constancy, i.e., an object exists separate from the child's sensory manipulation and/or perception
c) begin to understand being and non-being (peek-a-boo)

2) 2 – 7 years

a) partial mastery separating animate from inanimate
b) egocentric self-centeredness - child as center of universe
c) magical thinking
    i) thoughts, actions, & wishes drive reality
        ("step on a crack, break your mama's back")
d) little understanding of causality
e) thinking death can be evaded
f) death indistinguishable from sleep or separation (closer to age 2 than 7)
g) kids are very vulnerable at ages 5-7, because:
    i) they understand some of the permanence of death
    ii) they have very little in the way of coping skills

3) 7 – 11 years

a) understand death as lacking the biological aspects of life
b) may still view death as a punishment
c) understand the finality, inevitability, & irreversibility of death
    i) closer to age 11
d) transition from magical to literal/concrete thinking
    i) world as good/bad, black/white, either/or
    (choose words carefully 'cause kids this age take everything literally)

4) over 11 years

a) reality-based view of death
b) abstract reasoning
c) mastery of the 7 concepts necessary to an adult understanding of death:
    -object constancy -time, including forever
    -transformations -causality
    -universality -inevitability -irreversibility

Age	Developmental Stage	Concept of Death	Grief Response	Signs of Distress	Possible Interventions
2-4	Child believes the world centers around him/her because in the narcissistic stage of development. Hard to understand rational thinking because things are always in relation to "me". Child does not understand or grasp concepts.	"It may be my fault." "Did you know my daddy died-when will he be back?" Death seen as abandonment or separation. Seen as reversible not permanent.	Any separation may cause anxiety. Child is most aware of changes in daily patterns of care/structure. Responses are intense and brief.	May fear being left alone. May regress to "younger" behaviors. Eating & sleeping problem. Bed-wetting.	Child needs consistency more than anything else. Frequent repetition. Accept regressive behavior. Reassure child that he/she will be cared for. Short interactions work best.
4-7	Child begins building his/her language skills. These kids often fear that their wishes, fantasies, and thoughts create the world around them, which often leads them to feelings of guilt. Children at this "stage" become more independent.	Death still seen as reversible. Child often feels responsible for death b/c of thoughts or wishes they had. "It's my fault; I was mad at her and wished she'd die." May believe he/she can escape by being good, trying hard. May see death as a monster, person, or spirit.	Child often asks same questions over and over again. They want the answers to stay the same. May play dead or play funeral.	May regress to "younger" behaviors. Nightmares and sleeping/eating disturbances. Violent play. May act like person who died or take on their role.	Artwork: drawings. Symbolic play and stories. Allow and encourage expression of feelings/energy. Accept repetitive questioning by remaining patient and continuing to answer in the same way each time. TALK ABOUT IT!
7-11	Children become less self-centered and their cognitive abilities greatly improve. Now children are able to understand death as permanent, irreversible, inevitable as well as universal. This <u>begins</u> to open them to understanding their own mortality.	Children may have vivid ideas about what happens after death. Some children have concerns about consequences after death and that death may be a punishment.	Lots of questioning and need for details: coping by becoming an expert. Concerned with how "others" are responding: "What is right? How should I be responding?" Child starts to have the ability to mourn and understand mourning/grief.	Regressive behavior is common. Acting out: problems in school, withdrawal from friends. Emotions may be withheld or expressed. Eating/sleeping disturbances. Great concern with their body. Suicidal thoughts (want to join the deceased).	ANSWER QUESTIONS and acknowledge when you do not know the answers! Encourage expression of range of emotions. Support their coping style. Acknowledge the importance of peer relationships. Help with goodbyes. Symbolic play. DO NOT require child to be brave, grown-up, in-control, or to comfort others.
11-18	Thinking becomes more logical. Child fully understands own mortality. Child has ability to understand abstract ideas/thinking.	"Adult" approach. Able to conceptualize death.	Increased reliance on peers. More often willing to talk to people outside of family. Depression, denial, and/or repression. Mourning.	Depression and/or anger. Noncompliance, acting-out. Role confusion.	"I'm here if you need me." Recognize importance of peers. Recognize the adolescents need to work through independently. Also be available to child. Encourage verbalization, and self-motivation. Listen.