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Compassionate Journey:
An End-of-Life Clinical & Education Service
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Ethical Communication: **What Is It and How Do I Practice It**

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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, the Role of Forgiveness in Transforming Suffering, When Your Aging Client is a Substance Abuser, Ethical Communication, Symptom Control, Palliative Care, 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	American College of Physicians
California Assisted Living Association (CALA)	California Hospice Foundation
City of Hope National Cancer Center	Connecticut Children's Medical Center
Kaiser Permanente Hospitals of Southern California	LAMP Mental Health Outreach Program
Los Angeles County/USC Medical Center	Multiple Los Angeles Schools of Nursing
Penn State University School of Medicine	St. Jude Medical Center
U.S. Department of Defense	U.S.A.F. Keesler AFB Medical Center
USC Keck School of Medicine	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.

Introduction

- phones off/vibrate
- CD/DC
- Buddhists say ... one way we open ... connection ... communication
 - also say "You are all ...
- Concierge
- Knock Knock
- Stats: 7B 55M/yr 150K/day 6,300/h 105/min St. Peter
- Graying of ...
 - with fewer & more distanced families
 - prisons

Overarching Framework:

- 1) -Women of Calvary - Kindness – Clinical Competence – Non-Abandonment
- 2) how we do anything is how we do everything
- 3) speak through the ears of the listener/ write through the eyes of the reader
 - am I creating harmony or divisiveness?
 - am I shaming & limiting or empowering?
 - Bernadette Doyle
 - toothpaste – I wish you'd die
 - debulking ...

Communication:

Mechanics

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

Purpose

- to inform
- to instruct
- to inspire
- to correct
- to shame
- to show off
- to provide tools
- to empower
- to facilitate decision-making
- to assure
- to manipulate
- to deflect, distract, dismiss

Ethical Communication, at the least, is:

- non-manipulative
- understandable
- honest
- compassionate BYH
- empowering
- informative
- non-stigmatizing
- non-leading
- non-agendized
- reciprocal
- responsive
- based on an intent to be understood

Case Study #1 - normal & natural

Case Study #2 - murderer

Case Study #3 - no morphine - H2O

Prognosis

“How long do I have to live?”

-*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 truth is “not wanting to take away hope.”

-Ask why the patient and family want to know - “Mommy ...”

-“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

Culture

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

-other cultures – Hells Angels - Mistake Analysis

-physicians

-little black book

-speak through the ears of the listener

-write through the eyes of the reader

Blocks to Communication:

1) using words that have no meaning to listener - CA & EoL nutrition

2) using words that have different meanings to different individuals

-abstract words: hope, faith, commitment, strength

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

-healthcare: crack, grave, positive

3) not acknowledging feelings before engaging in factual conversations

“I can’t imagine how ___X___ this must be for you.”

`recognizes both magnitude and uniqueness of feeling

4) defensive reactions - can be minimized by:

-stating the positive first:

-“you’re wonderful at expressing your feelings, but we need to hear from the other family members as well”

-using defense lowering statements:

-“I might be wrong, but is it possible ...” -

-“You get to do what you want; I have a concern ... “

5) not presenting choices, not stating them in a normalizing way

-“many of my Pts A, while many others B; into which group do you fall?”

6) ignoring filters

-visual – show you

-auditory – tell you

-tactile – give you a feel for

7) ignoring directional focus

-moving towards or away from

8) misperception/assuming

-“my dad didn't trust me to handle the news of his terminal illness”

-when, in fact, he didn't trust himself to not fall apart

-“my mom sent me to boarding school because she didn't love me”

-in fact, she loved me enough to send me away to protect me

-bully

9) certainty

-convicted murderer – spiritual dilemma

10) manipulation

-life support vs. mechanical support

11) Nancy

-computer first

-interrupting

-finishing sentences

-answering different questions

- “you don’t need to know/worry about that
- “Hi, I’m Julie from Social Services – do you need/can I get you anything

12) Not Reframing:

-Sean Benedict

-is there another way to tell the story

Stray Tools

There is a courage required, in reaching for generosity, graciousness, & compassion, for in that reaching, we become vulnerable.

There is a risk associated with not reaching for generosity, graciousness, & compassion; it is the risk of hardening, separating, isolating, and disconnecting.

3rd partying

Ethical Communication filters:

- does this build harmony or divisiveness?
- is this shaming & limiting or empowering
- is this both true & balanced?
- does this need to be said?
- is there a kinder way to say this?
- is this a message of depth & weight?
- do these words reflect graciousness, humility, generosity, mercy & compassion?

If my X were listening, would I speak this way?

-where X = God, child, dog, mother, boss, spouse, etc.

Ask:

"Is there anything in my perspective, my words, my attitude, or my actions that is contributing to this problem?"

Greet Suffering with Compassion

suffering can look like tears, anger, contempt, “fine,” dismissiveness, sulking, bullying, isolation, etc. - SA

\$100 - Angola

Case Study:

- 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