Compassion & Humanism in Healthcare: The Lens of Language

Deborah Cook
Objective

Acknowledging the pervasive suffering in the ICU…..

To consider how stories may enhance humanism & foster compassion
<table>
<thead>
<tr>
<th>Clinician Response</th>
<th>Sympathy</th>
<th>Empathy</th>
<th>Compassion</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Ego-based</td>
<td>Emotional</td>
<td>Altruistic</td>
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<td>Attributes</td>
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<td></td>
<td>Verbal</td>
<td>Verbal</td>
<td>Virtuous</td>
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<td></td>
<td>Reactive</td>
<td>Affective</td>
<td>&amp; Action-oriented</td>
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<td>Regarding Suffering</td>
<td>Acknowledge</td>
<td>Acknowledge</td>
<td>Ameliorate</td>
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<td></td>
<td></td>
<td>understand &amp;</td>
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<td></td>
<td></td>
<td>resonate</td>
<td></td>
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<tr>
<td>Patient Response</td>
<td>Pitied &amp;</td>
<td>Heard &amp;</td>
<td>↓ Suffering</td>
</tr>
<tr>
<td></td>
<td>Patronized</td>
<td>validated</td>
<td>↑ Well-being</td>
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</tbody>
</table>

Adapted from Sinclair et al, 2016
FROM THE INSIDE

Ángela Alonso-Ovies
Gabriel Heras La Calle

ICU: a branch of hell?
Language is Dehumanizing

- ‘Bed 3’
- ‘The lady with sepsis’
- ‘That bad GI bleed’
- ‘The PRISMA guy’
- ‘She bought herself a tube’
Stories Are Dehumanizing

- Scripted case histories
- Abbreviations
- Template notes
- Digital documentation
- E-handovers

Silverman, JAMA Int Med 2017
Before meeting the actual person in the hospital or clinic, residents often get to know an electronic facsimile of a patient—an ‘iPatient’.

[Verghese, NEJM 2008]

Internal Medicine residents spend more time at the computer than they do providing direct patient care.

[Oxentenko, J Grad Med Educ 2012]
Do You Really Know Your i-Patient?
Humans communicate and interpret their experiences through stories

- 158 narratives May 2011-July 2013
  - JAMA (A Piece of My Mind)
  - NEJM (Perspectives)
  - AIM (On Being a Doctor)

Moniz, Lingard, Whating, JAMA 2017
5 Lessons
  – Practicing medicine is a privilege
  – Patients are vulnerable
  – Physicians are fallible
  – Humanity matters
  – The ‘system’ is flawed

6 Narrative Strategies
  – A rediscovery
  – A quest
  – A hero story
  – A testimony
  – An awakening
  – A lament

Moniz, Lingard, Whating, JAMA 2017
Stories Can.....

• Help us process angst
• Make meaning
• Connect the past and present
• Create or reshape our identities
• Build community with others

What about the role of stories at the end of life?
Overall Goal of The 3 Wishes Project

To improve the quality of the dying experience for patients and their families
Premise of the 3 Wishes Project

• Eliciting then implementing wishes in the hope of bringing peace to the final days or hours of a patient’s life, and ease the grief for those left behind

• Wishes may be those of
  – the patient
  – their family members
  – ICU clinicians
  – 3 Wishes team
Objectives

• For patients, to dignify their death and celebrate their life

• For family members, to humanize the dying process and create positive memories

• For ICU clinicians, to foster patient and family-centered care and inspire a deeper sense of our vocation
Wish of a Granddaughter for her Grandfather

Dear papa Lou,

You have always been an inspiration to me. I have always been inspired by your strength and attitude. Throughout my whole life, and even before then, you have been modelling true perseverance and strength to me, our family and anyone else who crosses your path. For years I have kept a picture of you and grandma Nell close to me, simply because I hope to be just like the two of you.
“Just keep this in mind. There will be good days. There will be bad days. There will be days when you wished that you never got married. But as long as the good days out-weigh the bad days, I reckon you are doing alright.”
Fig. 1. Proposed mechanisms to explain the beneficial mental health effects of storytelling.

Schencker, Palliative & Supportive Care, 2015
“...and they started to remember things about the patient and talk about significant things in his life and who he was and what these words represented, I just saw that somehow, it was calming for them...it gave them time to really sit and talk and remember.”
“Receiving a family framed cloud meant more to us than anything. It was wonderful...a keepsake in our mother’s honor.”
Narrative medicine and death in the ICU: word clouds as a visual legacy

• A model of humane care, whereby clinicians recognize, absorb, interpret, and are moved by patients’ stories

• Word clouds tell stories, forge and enrich relationships, and foster compassion

Vanstone, BMJ Supportive & Palliative Care 2016
Clinical Empirical Definition:

• a virtuous response that seeks to address the suffering and needs of a person through relational understanding and action
Narrative Medicine

“The ultimate goal of narrative medicine is affiliation’ – that is, a strong connection between human beings, or within the self.”

Charon, Narrative Medicine 2006
Summary

• Dehumanization in the ICU - physical, verbal & attitudinal can threaten compassion
• Compassion is more evolved than sympathy & empathy
• Sharing stories may
  – promote human connection
  – foster compassion
  – ease the grieving process