



Living Fiercely in the Face of Death: The Unspoken Gift of Hospice

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In the delivery of quality hospice care, we often examine outcomes and measures, which though important, leave little room for the extraordinary personal narrative that can occur when patients, family members and clinicians walk together to face end of life.

Join us as we hear from Dianne Gray, President of the Elisabeth Kubler-Ross Foundation as she explores what it is like to live fiercely in the face of death and why hospice is paramount to living as fully as possible throughout the end of life and grief journey.

Helpful Research & Resources

1. Cite and describe four key resources for furthering the patient narrative

- a. Journal of Pain and Symptom Management, June 2008; "Pain intensity and sense of well-being were similar in all groups before and after treatment. Subgroup analyses showed that patients whose narratives had high emotional disclosure had significantly less pain and reported higher well-being scores than patients whose narratives were less emotional."

[https://www.jpmsjournal.com/article/S0885-3924\(08\)00060-2/abstract](https://www.jpmsjournal.com/article/S0885-3924(08)00060-2/abstract)

- b. American Journal of Hospice and Palliative Medicine, Aug. 2006; "This article discusses the process of meaning construction and highlights the use of narrative, the expressive arts, and ritual to create meaning and connection. All members of the palliative care team play an important role in helping patients and families tell the stories of their illness and their lives and find meaning and purpose at the end of life."

<http://journals.sagepub.com/doi/abs/10.1177/1049909106290246>

- c. EAPC, Palliative Medicine; June 2017 "This pilot trial suggests a focused narrative intervention in palliative care patients with moderate to severe depression can reduce depression scores more than usual care alone. Patients receiving intervention appeared to have longer survival. These results support the need for a fully powered trial." <http://journals.sagepub.com/doi/abs/10.1177/0269216317711322>

- d. Journal of Palliative Medicine, Feb. 2018; "Telephone-based narrative interventions hold promise in improving advanced cancer patients' wellbeing. Further testing of delivery and implementation strategies is warranted."
<https://www.liebertpub.com/doi/abs/10.1089/jpm.2017.0007>
 - e. The Oncologist, March, 2018. Approximately a quarter of bereaved families had a sense of abandonment, which was associated with a higher rate of complicated grief. Oncologists may reduce the sense of abandonment by reassuring that the patients received the best anticancer treatment, recommending hospices as a potential choice rather than as mandatory, and by not saying there is nothing that can be done for the patients. *Important: This self-reported questionnaire study investigated the prevalence of families' feelings of abandonment when they were referred to hospice care, focusing on the association of sense of abandonment and the behavior of their physicians. Nearly a quarter of families felt abandoned by the referral to hospice, and the behavior of some oncologists was associated with the sense of abandonment.
 - f. <http://theoncologist.alphamedpress.org/content/early/2018/03/22/theoncologist.2017-0547.short>
2. Describe to patients why facing death can help one to live more freely (POLST/ACD)
 - a. <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC2853806/>
 - b. <https://www.npr.org/sections/health-shots/2015/03/29/394087394/videos-on-end-of-life-choices-ease-tough-conversation>
 3. Describe and discuss the very difficult topic of end of life conversation and how a model of care can be enhanced by focusing on life (inc. Pain Management conversations):
 - a. Positive language re: benefits of pain management protocol (family participation, fun, family)
 - b. Expectation validated. Clearer communication
 4. List and describe three important ways families can grow to understand the need for bereavement care
 - a. Visual descriptors: Family tree; Generational healing;
 - b. Physical, emotional, intellectual, spiritual quadrants
 - c. Meaningfulness v happiness
 5. Describe three considerations / ways to help families post-loss become your hospice's strongest advocates
 - a. Amount of time post-loss
 - b. Ability to express empathy and compassion without sharing own personal story
 - c. Educational requirements