Discussion Guide: An introduction to *The Healing Muse** **for readers** and educators

ANDREA ASPRELLI

Editorial Assistant, *The Healing Muse*, Center for Bioethics and Humanities, SUNY Upstate Medical University, 618 Irving Ave., Syracuse, NY 13210. (315) 464-5404. www.thehealingmuse.org

The Healing Muse creates a unique starting point for discussion about illness, medicine, and the body by contextualizing these themes in narrative through short stories and poetry. This approach can help people who are experiencing illness, as well as their friends, family, and health care providers, to understand the personal, social, professional, and institutional complexities of healing. To help both readers and educators become better acquainted with the insights offered in the ninth volume of *The Healing Muse*, we offer this Discussion Guide for use in classrooms, book clubs, support groups, or simply for your own exploration. This guide focuses on questions in aging and dementia, the changing body, nursing in health care, empathy, health care institutions, and the social context of illness.

AGING AND DEMENTIA

"Un-Aged" by Jennifer Lynn Alessi (p. 16)

- 1. Alessi portrays the process of aging and dementia as a journey back through the former phases of life: "retracing her steps / through the thicket of her life / gathering blooms of affection and wonder / she'd missed along the way." In what ways does the mother's behavior reflect a role-reversal between herself and her care-giving adult child? In what ways would characterizing her behavior as child-like be considered demeaning or oversimplifying?
- 2. Why does the speaker ask if the mother has become "an abominable / jest at our sense of decency and order"? What does this line say about our society's ability and willingness to accept and cater to the needs of our aging elders?

"A Daughter's Dilemma" by Cynthia Carmichael (p. 20)

3. As the daughter in Carmichael's piece struggles with her mother's compromised state, she is forced to think about future decisions she will have to make one day about her own end-of-life care. What kinds of issues, both practical and emotional, is she concerned with? What would you want if you were in either the mother's or the daughter's situation?

THE CHANGING BODY

"Accidental Therapists" by Sallie Naatz Bailey (p. 31)

4. In her piece, Bailey contrasts the way her physicians talked about her stroke with the way she experienced it. Explain the reasoning behind the clinician's viewpoint and Bailey's viewpoint in the following quotes:

^{*} Neilen D, Garden R, eds. The Healing Muse. Volume 9. Syracuse, NY: SUNY Upstate Medical University, 2009.

- o "My good luck! I was 'lucky' that it wasn't closer because the neurologist informed me that my side would have been paralyzed."
- o "...in medical parlance strokes are called 'events,' which conjures something like ski competitions at the Olympics."
- 5. Disability activists often argue that the capability of people with physical impairments is severely underestimated by the able-bodied. Bailey comments that her inability to draw "wasn't a physical problem, but rather—a mental one." How do you think certain societal norms could have influenced her beliefs about her own ability after her stroke?

"Hip Precautions" by Johanna Shapiro (p. 6)

- 6. Shapiro frames the presently aging generation in light of their earlier days, when they demonstrated against Vietnam, created the Earth Day movement, and marched for civil rights, women's rights, and reproductive rights. What is the poem exhorting them to do? How should clinicians understand these aging citizens?
- 7. In her poem, Shapiro is talking directly to the post-WWII "baby-boomers." As this generation ages, the segment of our population that is over age 65 is growing faster than the population as a whole. What kind of long-term effects will this temporary expansion of the country's older population have on health care services, programs like Medicare, and the practice of medicine?

NURSING IN HEALTH CARE

"Dying Mother" by Paul David Adkins (p.18)

8. In Adkins' poem, he brings to light the importance of caring health professionals, and specifically the ways in which nurses have served as comforters at the start and at the end of life. Describe how important it is, both to the speaker and his mother, to have "someone / flesh and bone to hold her hand" as a component of comprehensive, compassionate health care.

"The Ironman" by Burson Richards (p. 93)

9. In Richards' story, the new doctor finds himself unprepared to maneuver the different health care barriers that go along with working in an impoverished, urban setting. In what ways did the socio-economic status of patients affect the concerns and duties of Star and the nursing staff? Contrast the role of the head nurse with the role of the physician in the dialysis clinic, and explain the dynamic of this relationship.

EMPATHY

"From the Heart" by Carol Scott-Conner (p. 25)

- 10. Carol Scott-Conner interplays the narrator's experience with serious illness with that of her patient Sharon, who is diagnosed and treated for breast cancer. In what ways does the narrator draw on her own experiences to develop understanding for Sharon's position?
- 11. Developing empathy for patients through narrative is an important part of clinical care, but empathy is not without its limitations. In debating how best to comfort Sharon, the narrator remembers "we are in Sharon's story, not mine," (p.27). Explain why you think the she chose not to divulge her own story, and instead to respond the way she did.

"Self-Exam" by Jane S. Attanucci, (p. 69)

- 12. In Attanucci's story "Self Exam," Marian Crowley is comforted by the warmth and kindness of the receptionist, Naomi, during her follow-up mammogram. What kind of social support network does Marian have? What clues do you think Naomi picked up on to deduce Marian's social situation and needs? Was it Naomi's job to do so?
- 13. The physical design of a space can encourage or discourage certain kinds of social behaviors. What characteristics of the waiting room and changing area could be considered isolating? Where is Marian when she learns the results of her mammogram? How would you improve the design of the clinic?

HEALTH CARE INSTITUTIONS

"And Then Something Familiar" by Adam Philip Stern (p. 64)

14. Stern's piece gives the reader a glimpse at the inner workings of a hospital, including the systemic and institutional barriers to care that come with it. What aspects of the hospital setting make it difficult to provide patients with optimal care? Could the student have done anything to help Mrs. Wiggington in light of these obstacles? What responsibility, if any, do health care professionals have in helping to establish more ethical systems of health care delivery?

"The Country of Illness" by Meryl Natchez (p. 46)

15. In Natchez' poem, she describes her journey to the "Country of Illness." Interestingly, the speaker is just as concerned with adjusting to life in the hospital as she is with her illness itself. Discuss features of the hospital that would make the environment stressful. What affect can these features have on health and recovery?

SOCIAL CONTEXT OF ILLNESS

"Band Aids" by Robin Reid (p. 2)

- 16. In Reid's story, Ms. White is characterized as a troublesome, "non-compliant" patient, whose medical visit is a draining experience for all involved. Despite receiving multiple consultations from a variety of specialists, Ms. White's condition remains unchanged, and the medical team appears reluctant to explore the situation further. Explain what they could have learned from asking Ms. White the following questions:
 - O Social Support. Do you have friends or relatives that you can call on for help? Do they live with you or close by?
 - o Life Control. Do you ever feel that you're not able to afford food, medications, medical expenses, etc?
 - o Literacy. Do you have trouble reading your medication bottles, instructions, or other patient information?†
- 17. The physician and nursing staff at the clinic see Ms. White as someone who is difficult to care for and whose illness is complicated to treat. How does a clinician handle an "unlikeable" patient?

[†] Green AR, Betancourt JR, Carrillo JE. Integrating social factors into cross-cultural medical education. 2002 Acad Med 77;3: 195.

Disappearing Act by Kayleen Wilkinson p. 116

- 18. In Wilkinson's story, the speaker's family plays an integral role in her recovery process. While she may have had a number of medical visits over the course of her illness, the medical community is largely absent from her narrative. The only instance that mentions the medical community is when "3 nurses, 1 doctor, and a handful of teachers" called her parents to express their concern for her health.
 - O Granted this narrative, what do you infer about the role of social support networks, such as family, in the context of illness and healing? Can physicians tap into these support networks to help their patients, while still maintaining patient confidentiality?
 - O How can the lives of close family and friends be affected when a loved one has an illness such as this one? What kind of support and resources can health care professionals offer them?