Suffering in Medicine Drs. Melissa Bender, Kuang-Ning Huang, & Jeanne Cawse-Lucas

You see a new patient in clinic, a woman in her 40s recently diagnosed with systemic lupus. The exam room feels somber. She briefly makes eye contact with you to share that she is feeling hopeless. She isn't sure exactly why, but she has lost friends after becoming ill. You try a few more minutes to engage her in conversation, but she doesn't say much. When you see the patient on the schedule for a follow-up appointment, you dread the visit because you don't think you can help her.

Existential Suffering, defined as "severe distress that threatens the integrity of the person," may be a part of this patient's illness experience.[1] Diagnosing and treating a specific disease does not always relieve suffering because suffering often also involves other components- feelings of isolation, regret, fear of dying, loss of purpose, spiritual and cultural narratives.[2,3] The same structural factors that contribute to health inequities- such as poverty, racism, access to health care and education - can also contribute to suffering as a part of patients' illness experience.[4,5]

Spiritual Suffering is a type of existential suffering defined as "distress due to spiritual or religious concerns."[2] Spirituality often has very different meanings for different people. Some people may find spiritual meaning in experiencing suffering. This can be in the form of feeling closer to a higher power, having compassion for other people, or in a belief in necessary or redemptive suffering.[6] Some peoples' experience of suffering may call into question their spiritual beliefs. For others, they may see suffering as unnecessary and feel motivated to relieve the suffering.

In one survey, medical students reported they experienced suffering from isolation, stoicism, confusion about their identity/role as medical students, and witnessing suffering in patients, families, and colleagues.[7] Our experiences with suffering influences how we respond to patients who are suffering. Experiencing suffering may make it challenging to engage but also has the potential to enhance engagement with others who are suffering.

How can we recognize suffering in patients? We can recognize suffering when we are curious about the patient's experience and aware of their verbal and nonverbal cues. Patients who are suffering may be unable to express themselves (appear withdrawn or flat or stoic) or have other indirect emotional expressions (they may strongly feel one emotion, such as sadness over the news of their poor prognosis, but express another, like anger about something else) or they may express a sense of meaningless or loss of identity.[1,3]

If we are uncomfortable in the presence of a patient, it might be a clue that a patient is suffering. This discomfort may manifest itself as feeling helpless. It is common for clinicians to respond to feelings of helplessness by being hypo-engaged or hyper-engaged. This distances us from the patient and is a barrier to connecting with the patient in their suffering.[8] It is helpful to

recognize feelings of helplessness, allow yourself to experience the discomfort, take care of yourself, and determine how to constructively engage with the patient with the intention of alleviating suffering.[1,8]

***How can we engage with patients who are suffering*?** Approaches to constructively engage with the patient who is suffering include using reflective listening skills taught in motivational Interviewing, being curious about the patient's experience, using NURSE statements to respond to emotion, being present, authentic and emotionally available, and treating the patient as a whole person by also paying attention to the existential, spiritual, and psychosocial domains that influence patient suffering.[1,3,8,9]

Encourage patients to share their experiences. Helpful questions and statements include:[1,3]

"Are you suffering?"

"Are you at peace?" "What keeps you from being at peace?"

"How are you doing in everyday life?"

"What is the most difficult aspect of your illness?"

"What concerns you the most about your illness?"

"What should I know about you as a person to take the best care of you that I can?"

"I can only imagine how scary this must feel for you. I sometimes wonder how anyone can make sense of this."

"It sounds like you are trying to make sense of how this could happen."

"You said you've felt very apart from your family and your faith community since this began. Can you tell me more about that?"

Narrative Humility

While it is often helpful to encourage patients to share their experiences, this should be approached with narrative humility. We can never fully understand a patient's story and why they make certain decisions, "our patients' stories are not objects that we can comprehend or master, but rather dynamic entities."[4] Narrative humility also involves being aware of "our own role in the story, our expectations of the story, our responsibilities to the story, and our identifications with the story."[4]

Conclusions:

The physician-patient relationship provides a type of community in which the patient can feel safe to share burdens and receive support. It also becomes a source from which the patient can be connected to other supportive communities, e.g., spiritual communities or support groups. Interacting with suffering means accepting the limits of medicine and

developing a level of comfort with ambiguity. Patients don't expect you to fix everything, but they do expect to have their struggle appreciated. A positive aspect of being a family physician is that, through continuity, you can accompany a patient on their journey, providing a supportive relationship as the patient goes through changes.[9] Supporting patients through their struggles all the way to their deaths can be at times trying, but also can be personally and professionally very affirming and rewarding.[10]

Suggested Reading on Suffering:

1. "Responding to Suffering." Epstein RM, Back AL. JAMA 2015.
2. "A Heavy Burden." Dr. Amanda Kost. Family Medicine, 2017.
3. "Living Every Minute." Dr. Stuart Farber. Journal of Pain and Symptom Management, 2015.

References

1. Epstein RM, Back AL. Responding to Suffering. *JAMA*. 2015;314:2623-24.
2. Grech T and Marks A. Palliative Care Network of Wisconsin Fast Facts and Concepts #319 and #320, Existential Suffering Part 1: Definition and Diagnosis and Part 2: Clinical Response and Management.
3. Egnew TR. A Narrative Approach to Healing Chronic Illness. *Ann Fam Med. 2*018; 16(2):160-165.
4. Narrative Humility, Structural Competency, and Engaged Pedagogy. Academic Medicine 2015;90(11):1462-5.
5. Smedley BD. The lived experience of race and its health consequences. American Journal of Public Health. 2012;102(5):933-5.
6. Vitillo RJ. Discerning the Meaning of Human Suffering Through the Discourse of Judeo-Christian Scriptures and Other Faith Teachings. J Pain Symptom Manage. 2014 Nov;48(5):1004-8. doi: 10.1016/j.jpainsymman.2014.06.018. Epub 2014 Aug 19.
7. Egnew TR, Lewis PR, Meyers KR, Phillips WR. The Suffering Medical Students Attribute to Their Undergraduate Medical Education. Fam Med. 2018 Apr;50(4):296-299.
8. Back AL, Rushton CH, Kaszniak AW, Halifax JS. "Why are we doing this?": clinician helplessness in the face of suffering. *J Palliat Med*. 2015;18:26-30.
9. Egnew TR. Suffering, meaning and healing: challenges of contemporary medicine. *Ann Fam Med. 2*009;7:170-175.
10. Farber SJ, Egnew TR, Herman-Bertsch JL. Defining effective clinician roles in end-of-life care. *J Fam Pract.* 2002;51:153-158.