A PIECE OF MY MIND

Responding to Suffering

Ronald M. Epstein, MD
Departments of Family Medicine, Psychiatry, and Oncology, University of Rochester School of Medicine and Dentistry, Rochester, New York.

Anthony L. Back, MD
Department of Medicine, Division of Oncology, University of Washington, Seattle.

Supplemental content at jama.com

Patients suffer. Yet clinical care has moved away from addressing suffering. Suffering—"severe distress that threatens the integrity of the person"[1]—spans physical, emotional, social, spiritual, existential, and financial domains, and as a whole-person problem it doesn't fit neatly within current biomedical paradigms. Suffering occurs in many clinical contexts, not only at the end of life, and calls on us as physicians to address our patients as whole persons, particularly challenging in our age of specialization and atomization in medicine.

Karen

Karen Volk (a pseudonym) first presented to her primary care physician with a long history of joint pains, depression, insomnia, and interstitial cystitis. Her physical functioning and mobility were worsening beyond what would be expected from fibromyalgia, yet physical examinations and imaging studies showed no signs of inflammation, and extensive rheumatologic and infectious workups were negative. Karen was frustrated by her pain and functional decline; she felt that she was being blamed for her illness. She had recently weaned herself off the opioids upon which she had become dependent for unrelieved chronic pain. Her physicians were frustrated by their inability to provide a clear diagnosis.

After several years of symptoms and multiple workups, an ankle x-ray film showed inflammatory changes. Inflammatory arthritis eventually affected all her large joints—a "real" illness to her and her physicians. Her joint destruction was painful and debilitating, requiring joint replacements of both knees and her left hip, surgery on both wrists and elbows, and long recoveries from surgical complications. Disease-modifying agents were started, but because of serious infections and a painful nonhealing leg ulceration, they were discontinued. Despite state-of-the-art medical treatments, physical therapy, meditation, antidepressants, and psychotherapy, Karen continued to decline physically and emotionally. She reluctantly restarted opioids and again required high doses to control her pain. She felt despondent and hopeless; her marriage crumbled. Despite extensive workups she still did not have a diagnosis. She was driving home from the office after debridement of her ulceration when the site started bleeding. Returning to the office in tears, she told her physician, "I can't take this anymore."

Then things began to change. Over the next two years, with consistent attention to the multiple domains of her suffering, Karen began to improve. Her leg ulcerations healed; a right hip replacement enabled her to walk without a limp; she lost the 30 pounds she had gained while she was immobile. She tapered her opioids. These biomedical improvements were matched by transformations in her personal life. She left her husband and felt stronger having done so. She started to work again. She began to find meaning in a life previously consumed by illness. She was able to smile and was again her radiant self, yet was under no illusions about her illness. This prompted us to wonder: What did her physicians do?

Diagnosing and Treating

Patients like Karen are humbling. Karen went years without a diagnosis, and no one understood why she seemed to get every possible complication from her treatments. It was difficult to untangle the degree to which the causes of her disability and suffering were physical, psychological, or social.

As physicians, we are trained to identify and characterize problems and to propose treatments to restore health and normal functioning—whether considering biomedical issues or psychosocial domains. Within Karen's long and complex history, there were moments when astute physicians recognized opportunities to use surgery, medications, psychotherapy, and other medical treatments. While these interventions were helpful, they were not enough.

Recognizing that *diagnosing and treating* could address only a portion of human suffering, we combed the medical literature in search of other approaches (see literature search strategies and results in the Supplement). We found only six empirical studies that pertained to physicians. From the remaining 69 citations, mostly case reports and essays published in journals rarely read by clinicians, we synthesized two clinical approaches to suffering to complement the familiar *diagnosing and treating* approach, which we named *turning toward* and *refocusing and reclaiming*.

Turning Toward

Karen's journey illustrates how suffering can persist in patients who live with chronic illnesses and how persistent suffering can make physicians feel helpless. Too often when feeling helpless, we withdraw—by referring to another specialist, scheduling the next follow-up appointment in the distant future, or blaming the patient.[2]

Rather than withdrawing, Karen's physicians turned toward her suffering and inspired others caring for her to do the same. *Turning toward* means recognizing suffering, becoming curious about the patient's experience, and intentionally becoming more present and engaged. Recognizing suffering may not be straightforward; suffering often manifests as indirect emotional expressions, inconsistencies in patients' narratives, or discomfort within clinicians themselves—a momentary awareness that something is not quite right even before they can characterize why. *Turning toward* requires us to cultivate a permeability to the patient's experience and to pay attention to our own experience as we enter the patient's world.

When turning toward Karen's suffering, her physicians accompanied her—by listening to her, looking at her,

Corresponding Author: Ronald M. Epstein, MD (ronald_epstein@urmc.rochester.edu).

Section Editor: Roxanne K. Young, Associate Senior Editor.

and walking with her from the examination room to the reception desk; they not only diagnosed her suffering, they saw it directly. Although looking at the face of suffering is uncomfortable for us, our own discomfort can be useful, a wake-up call. When patients have difficulty finding words or are constrained by stigma or shame, physicians can create environments that encourage patients to pull their thoughts together and express them,[3] perhaps by asking, "What's the worst part of this for you?"

Turning toward is about being authentic, emotionally available, and engaged. This is a practice of presence—intentionally attending to the immediacy of the patient's experience even when the suffering is horrific and troubling; not objectifying, reorienting, or recategorizing it. The physician offers being-with, bearing witness, compassionate solidarity, and humility[4]—learning about suffering *from* the patient, avoiding the presumptuous "I understand" in favor of "I can only begin to imagine …" Here, loyalty, honesty, shared humanness, nonabandonment—and even love—are expressed through small caring actions: the extra minute at the bedside, the call to a worried relative, the choice of words and gestures.

Refocusing and Reclaiming

Refocusing and reclaiming applies when physicians enable patients to connect with what is important, meaningful, and generative in their lives. This is not the exclusive domain of physicians, yet we should be attuned to such opportunities. Given the right personal and social circumstances, patients like Karen can move toward adaptation, a sense of confidence, clear decisions based on their values and aspirations, and deeper and more meaningful connections with family and friends. Karen was not merely coping; she redefined her agenda, recognizing that her prior state of health was no longer possible. Karen experienced a sense of wholeness and gratitude. She wished that no one else should have to walk a similar journey alone.

Refocusing and reclaiming involves posttraumatic growth—making sense of and learning from an illness experience, feeling a sense of spirituality, connection, transcendence, and healing. Karen's growth was manifest in the ways she reclaimed her personal life—separating from her husband, re-establishing a professional identity, and—most importantly—seeing herself as a complete human being and not as someone who was intrinsically flawed. Her physician helped in this process first by noticing that Karen was still suffering, then by gently supporting her efforts to be the person she aspired to be—and not to be constrained by dependence on medications or by the expectations of family and medical personnel.

Refocusing and reclaiming is a shared project. Listening deeply, recognizing ambiguity, incompleteness, and contradictions, physicians can gently challenge patients' self-perceptions and nudge patients toward considering alternative views.[5] Physicians can provide the hope that patients seek by showing that some of what really matters might be achievable, if only to a limited degree. They can support patients to find new relationships and move from dependent passivity to active engagement in care. Physicians can honor patients' wishes to be generative and move from feeling victimized by illness to feeling enabled to adapt and thrive despite adversity.[3] All of these were elements of Karen's care.

However, we offer the refocusing and reclaiming approach with a note of caution.[3,6] While other authors have suggested describing this approach as "transforming suffering," we have consciously avoided the notion of transforming because it is fraught with expectation. Physicians may unwittingly impose expectations—for example, being a fighter, accepting the illness, or growing spiritually—implying that patients had failed if they hadn't found meaning or experienced gratitude. Patients' illness accounts often contain contradictions and paradoxes that physicians can easily oversimplify or interpret prematurely in ways that expunge the patient's voice.[5] Yet attentive physicians can avoid these traps through "treat[ing] the patient's experience as testimony"[4] and legitimating the truth of each chapter in a patient's story. *Refocusing and reclaiming* can be momentary or incomplete, yet still can be profound. Even though Karen's joint symptoms will likely return, she and her physicians have established a collaborative project in her well-being that goes beyond her problem list.

The Physician's Role

Physicians can play a pivotal role in addressing suffering if they can expand how they work with patients. Some physicians use these approaches instinctively, yet most need training in responding to suffering. This kind of training is painfully lacking in medical education. Having a lexicon and guideposts can help physicians incorporate into practice a wider range of approaches to the relief of suffering.

For physicians to address suffering explicitly and routinely use these approaches would be a radical departure from the way medicine is practiced now. These three approaches ask us as physicians to engage ourselves as whole persons in order to address our patients as whole persons. While this is a tall order, it strikes us as more feasible than ever because of evidence that programs promoting mindfulness, emotional intelligence, and self-regulation make a difference; physicians can learn to be more attentive to suffering, act with compassion, and develop more fulfilling relationships with patients.[7] Turning toward suffering and helping patients refocus and reclaim their lives can also help physicians to reconnect with a deeper sense of purpose and meaning in their own work.

Funding/Support: The Arnold P. Gold Foundation Research Institute.

Additional Contributions: We thank Lorraine Porcello and Emma Pollock for conducting literature searches and Deborah Fox and Mahala Ruppel for copyediting.

Conflict of Interest Disclosures: The authors have completed and submitted the ICMJE Form for the Disclosure of Potential Conflicts of Interest and none were reported.

1. Cassel EJ. The nature of suffering and the goals of medicine. *N Engl J Med*. 1982;306(11):639-645.

2. 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(1):26-30.

3. Candib LM. Working with suffering. *Patient Educ Couns*. 2002;48(1):43-50.

4. Coulehan J. Compassionate solidarity: suffering, poetry, and medicine. *Perspect Biol Med*. 2009;52(4):585-603.

5. Garden R. Expanding clinical empathy: an activist perspective. *J Gen Intern Med*. 2009;24(1):122-125.

6. Shapiro J. Illness narratives: reliability, authenticity and the empathic witness. *Med Humanit*. 2011;37(2):68-72.

7. Beckman HB, Wendland M, Mooney C, et al. The impact of a program in mindful communication on primary care physicians. *Acad Med*. 2012;87(6):815-819.