

Book Review

Travels With the Wolf: A Story of Chronic Illness
By Melissa Anne Goldstein
Ohio State University Press, Columbus, 2000

Reviewed by Jack Coulehan, MD, MPH

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In *Travels with the Wolf*, a young woman develops a persistent and unexplained illness during her first year at college. Her doctors consider various diagnoses, including atypical appendicitis, for which surgery is performed, but the patient continues to suffer from aching, fatigue and low-grade fever. Eventually she acquires the diagnosis of lupus, the wolf, but simply naming the beast fails to tame it. For the next ten years, Melissa Anne Goldstein experiences exacerbations and remissions, including lupus myelopathy, which leaves her too weak to walk. In the world of chronic illness, Melissa encounters numerous doctors who hold the reins of authority, yet live in a different world. Some fail to listen, others betray and abandon her. Only a few are willing to trust Melissa and walk with her.

Goldstein's well-written account of these events belongs to the relatively new literary genre called pathography, biography of illness. However, *Travels with the Wolf* is also an account of Melissa's quest for self-awareness. She converts her personal experience into the more general investigation of narrative in healing, both through creative writing – Melissa's illness experience is illustrated by her fine poems – and her professional work in the field of literature and medicine.

Toward the end of the book, the author asks, "Why, I wondered, do physicians harbor such strong feelings about lupus?" I have to admit that long before page 247, I struggled with those strong feelings. At a few points, I wanted to take Melissa by the shoulders and yell, "Come on, stop whining! Surely, it couldn't have been that bad!" I'm ashamed to admit this, but such feelings show how I am vulnerable to the same disheartening conflict that Melissa describes. Physicians often have difficulty empathizing with patients who threaten the comfortable belief that "objective" categories and numbers accurately reflect patient experience. While this empathy-gap is especially prominent in lupus and other autoimmune disorders, it may occur in all forms of chronic or recurrent illness. The culture of medicine tells us that we must trust the dictates of textbooks and machines. When patient experience comes into conflict with these dictates, we tend to cock our eyebrows in skepticism. Should we believe the patient whose reports, after all, are only "subjective," or put our faith in the more "objective" data, which, incidentally, is under our control? We often solve this quandary by attributing the patient's discomfort to mysterious psychological factors, rather than clear-cut disease.

Melissa finds herself plagued by distrust, defensiveness and betrayal. In 1988 when she questioned Dr. Smith's conclusion that her disability was caused by "excessive anxiety, not disease," the doctor "stood up, pulled the door open, then spat out, 'Our time is up.'" Two years later, Dr. Kostos, her

second rheumatologist, responded to Melissa's persistent weakness after she completed a course of pulse steroids with a curt command, "Out of bed. On your feet." He attributed Melissa's symptoms to a stress reaction, but offered no help. Later still, Dr. Fields, a neurologist with whom she had had a good relationship for several years, diagnosed Melissa's fits as "pseudoseizures," yet never informed her of that diagnosis. Moreover, when questioned by other specialists, Dr. Fields insisted, "she's fooled us before" and refused to evaluate the seizures. When her rehab physicians sought a further work-up, Dr. Fields responded by discharging Melissa from her service, again without explanation or acknowledgment.

Yet the news is not all bad. Other physicians emerge from these pages as sympathetic characters. How do these doctors differ from the betrayers? First, they are respectful of Melissa and willing to listen to her. Second, they enlist the patient as a partner in working toward a satisfactory result. Finally, they seem to be more concerned with doing whatever it takes to get Melissa back on her feet, than they are with defending medical theory or authority. In other words, these doctors are willing to enter the world of chronic illness as sympathetic helpers, rather than authoritarian policemen.

Travels with the Wolf also contains an interesting aside on the popular cultural belief in the mind's power to heal the body. This belief, which in its extreme form might be called "Bernie Siegelism," holds that "If you heal your life by improving your attitude, resolving conflicts, and letting go of anger and bitterness, then you can heal your body." The problem with the gospel of positive attitude lies in the implication that chronic illness is the sick person's fault. One could even attribute the etiology of a poorly understood disease like lupus to "bad thinking" that generates self-destruction. In any case, if you adopt the positive attitude described in Siegel's *Love, Medicine and Miracles*, you ought to get better. It is easy to see how a confirmed Siegelist might actually blame Melissa for continuing to be sick. She just isn't positive, or holistic, or spiritual enough to get well! Unfortunately, at the core of much of our popular New Age healing lies this unspoken fillip of guilt.

Melissa Anne Goldstein is a fine writer. Readers who suffer from chronic illness themselves will likely cheer the very features of her story that made me, as a physician, uncomfortable. Yet it is precisely to experience this discomfort – and to reflect thoughtfully upon it – that I recommend *Travels with the Wolf* to physicians and other health professionals. □

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