Understanding illness

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The Meaning of Illness: The Phenomenological Account of the Different Perspectives of Physician and Patient
By S. Kay Toombs
Dordrecht: Kluwer Academic, 1992
184pp. Clothbound, $64.

This is a wonderful, remarkable book, nothing less. I expected to read it rapidly as one does the book of a friend with a congenial point of view (and generous citations). Instead, I found myself learning in new depth things I mistakenly thought I already knew. I could not read more than about ten pages at a time because there was so much richness without a wasted word. In 119 pages of crystal-clear text (with plenty of footnotes), Toombs demonstrates the distinctiveness of the patient's perspective of illness and its fundamental importance to physicians in the care of the sick. Since this is a point of view that is not only familiar to many of us, but is the basis of our understanding of medicine, what has Kay Toombs written that is so important for us to read?

She starts by telling us that, "My interest in exploring the nature of the patient's and the physician's understanding of illness has grown out of my own experience as a multiple sclerosis patient." Subsequently, she only rarely refers to her multiple sclerosis. Her illness may have given her *entrée* to the patient's perspective but she has developed an understanding of it that transcends her experience as a patient with multiple sclerosis—and an understanding *vis-à-vis* the physician's perspective. Her multiple sclerosis remains important, obviously, but our knowledge of it does not remain central to her task in this book, a perfect example of the difference between experiencing and understanding. Because she has been a patient, she also has knowledge of physicians beyond what she might have learned from them as friends and by reading. Thus, Toombs also *understands* the physician's perspective—its origins, importance and driving forces—permitting the book to maintain a rare balance between the two.

An introduction describes the phenomenologist's task. In a recent essay, Richard Baron depicts the difficulties of teaching physicians the phenomenologist's method as a clinical tool. In her introduction, Toombs provides a characterization of phenomenology that not only makes it appealing but suggests the basis of a clinical technique. It is here that we begin to understand the importance of her contribution and the challenges it sets for our continuing exploration (which she does not meet):

> With its emphasis on firsthand or direct description, phenomenology provides the means to elucidate the domain of unreflective, taken-for-granted lived

> experience. To provide a detailed account of the manner in which we interpret the world of everyday life (the lifeworld). . . . phenomenology provides an explication of the fundamental and important distinction between lifeworld interpretation and scientific conceptualization.
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> . . . the different perspectives of physician and patient . . . [are] not simply a matter of different levels of knowledge (too often assumed to be the case) but [of a] difference in understanding [that] is much more profound. . . .The distinction is particularly important in the physician-patient relationship where the decisive gap between lived experience and the scientific account of such experience clash in a direct way with regard to the phenomenon of illness.

Having said that, she is required to show why the physician's understanding of the patient's lived experience is necessary to a fully developed medicine. She demonstrates, for example, that in the fundamental domains of time, space, and objects the patient inhabits a world of meanings different from that of the physician, introducing "a systematic distortion of meaning in the physician-patient relationship." The basis of all communication—*all* intersubjectivity—is put at risk by these differences. To the extent that a physician (in contemporary medicine) acts *qua* physician, intersubjectivity will be distorted. If, as is usually the case, the physician reaches out as a person, the action will be essentially untrained—with rare exception, not part of the physician's education.[1]

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Chapter 2, on illness, is a gem. One wants to quote long sections, to share the richness and multidimensionality of the author's account of illness. It has, to my knowledge, never been done better. She draws on her own experience, the autobiographical literature of the sick (including the extensive genre of sick doctors) and the contribution of phenomenologists. Don't expect to find just another description of what it is like to be sick—a sort of phenomenologist's Anatole Broyard—or a sophisticated appeal to treat the patient as if the patient was a person. (One thinks of Broyard's desire that his doctor talk to him, laugh with him, and appreciate him.) Kay Toombs is moving us beyond mere hope for a compassionate doctor. She is describing what the physician must *understand* about the ill in order to do more than a halfway job—going further than the inadequate model of acute diseases like pneumonia in order to make her points. Only a cloistered intensivist or a clinician with no patience for patients could come away from this chapter without knowing that here is a kind of knowledge that is essential to his or her work.

The next chapter, the longest, deals with the body. In its layer-by-layer dissection of the lived body, the distortions of function and their reflection in meaning and the unfolding process of the illness, it is wonderful. It might well be read alongside Drew Leder's recent essay exploring the distinction between the lived and the anatomical (structural) body.

When I had finished the book I asked myself: How are physicians to do what the author wants? How are doctors to attend simultaneously to two very different perspectives coming from different parts of themselves? How are they to gather from separate levels of the same patient the information required to make two distinct types of diagnoses, then integrate the disparate "diagnoses" to form a whole on which action can be based?

Despite working at it for years I do not know a systematic answer. But I have some clues. First, abandon the idea that a disease diagnosis is anything more than a shorthand name for a process. The structural meaning of the disease, despite its uses, holds back thinking in the terms of this book. Second, understand that what Toombs is telling us about the sick person and the illness is another process that interacts with the first—like two pinwheels forming a unique design in which their patterns overlap. Third, accept the fact that only another person, as a person, can discover the illness. Fourth, begin to develop the tools that will permit the doctor to do all these things. Finally, read Kay Toombs' book to learn how to go about steps two through four.

Notes

1. For a notable exception, see William Carlos Williams' "The Practice," in *The Autobiography of William Carlos Williams* (New York: New Directions, 1967).