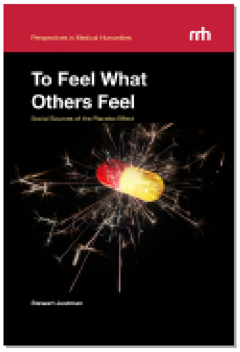
Epilogue



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Epilogue
Being Medically Unique

In a remarkable passage, Montaigne, the prince of skeptics, tells of a blind man who plays tennis:

> I saw a gentleman of a good family, born blind, or at least blind from an age such that he did not know what vision is; he understands so little what he lacks, that he uses and employs words proper to vision as we do and applies them in a way that is entirely his own and idiosyncratic. He was presented with a child to whom he was godfather. Taking it in his arms he said: "Oh, lord! What a lovely child! How beautiful it looks!" . . . There is more: since hunting, tennis, and shooting are our sports, and he has heard this said, he takes a liking to them, and busies himself with them, and believes he has the same part in them that we do. . . . He takes a tennis ball in his left hand and hits it with his racket; he shoots with his musket at random, and is satisfied when his people tell him he is too high or at the side.[1]

Though he "understands so little" that he appears to have convinced himself that he sees, it is not clear to me that the blind man should be dismissed as a fool. It could be said that finding himself in the Rome of the sighted, he simply does as the Romans do—takes part in human life as best he can.

Deriving the testimony of his senses from the reports of others ("How beautiful it looks!"), the sociable blind man resembles all who model their bodily experiences on those of others—who feel as others feel, according to the sociology of the placebo effect. We tend after all to experience what those like us do, or what we suppose they do, as when study subjects report less pain when it seems that others feel less,[2] or respond to the crafty prompt that the treatment they have been given has been shown to help others. The case has been made that because the information presented to a patient "potentially influences the experience of treatment outcomes,"[3] doctors need to be mindful of the placebo and nocebo effects that may spring from the very discussion of risks and benefits, which is another way of saying that reports of others' outcomes have an effect on our own.

While other factors, among them conditioning, may contribute to the placebo effect, it is largely as social animals that we enjoy its benefits, just as it is theorized to have evolved from social behavior such as mutual grooming among apes. By the same token, however, if we should lose the feeling that our case resembles others' and that we can be helped just as they have been, the entire edifice of hope and trust may break down, as I have learned from experience as a cancer patient. I don't mean to say the placebo effect has much to offer the cancer patient; the survival benefits for women with breast cancer who had "supportive-expressive group therapy" could not be replicated. I mean simply that my case has clarified for me the placebo effect's social sources. To be without the sense that one's case is like others is to play tennis at random, with no way of knowing whether a shot is in or out.

It all began conventionally enough when, like millions of others, I had a PSA test without the slightest idea of what I might be getting into. One test led to another and then to biopsies, one after another, my PSA rising all the while, until cancer was finally confirmed. Of the treatment options brachytherapy—the embedding of radioactive pellets or "seeds"—seemed the least bad, so that is what I chose. As it turned out, during the procedure the urologist was unable for some reason to get one string of seeds into place, but that didn't matter, we were told. Naturally I assumed the treatment was successful. But successful in doing what? As I became aware, belatedly, of the overdiagnosis of prostate cancer, I began to wonder if I had not unthinkingly sought treatment for an innocuous condition at the behest of medical activism.

But if mine was an innocuous condition it was also a stubborn one. Following the procedure my PSA dropped, but not enough, and as it resumed its upward course I became a patient in a medical center a thousand miles away, where a team of brisk, self-assured, not to say conceited doctors took over my case. "The patient who journeys to a famous clinic or physician is as ready to be helped as the pilgrim at a religious shrine,"[4] and in this case the first thing the priests did was form an idea about what was wrong with the pilgrim. Over time, and not without much theory-testing and diagnostic travail, I passed into the category of patients who have failed brachytherapy. Because radiation complicates surgical removal of the prostate if it should fail (as no one had explained to me), the best option at this point seemed to be a second procedure of the same kind, but more precisely targeted. My local doctor had left a “cold spot” that would now be correctly irradiated—this was the message. Five years after the original implant, a second was done.

In short order, however, the same sequence took place all over again—rising PSA, more biopsies with more samples (as many as 24 in one instance), imaging that yielded nothing, conferences, contradictions, delays, exploration and finally dismissal of the innocent possibility of PSA “bounce.” Somewhere in the middle of this burlesque, the radiation oncologist threatened to cancel a brachytherapy unless I met with him beforehand—as it turned out, only so that he could demonstrate his mastery of my case to his residents. At another point, as I sat in the waiting room thumbing through a lifestyle magazine, I came across a feature about my own urologist’s villa-like residence. In due course I became the only patient in his considerable experience, and I suspect one of the few to his knowledge, to have had not two but three brachytherapies. Three times I had to notify students that if any were pregnant they should not sit too close. With something like 150 spent radioactive pellets arrayed like chevrons in my prostate, meticulously placed but useless, I have gone from being one of countless men treated for prostate cancer—a rite of passage in the PSA era—to a data set of one.

A few years ago a paper concluded, “The best management of the small number of brachytherapy patients encountering failure is unclear at this time,”[5] referring of course to patients who fail once, not to the still smaller—the vanishingly small—number who fail twice. Now, with my PSA resuming its dismal pattern, the third treatment seems to have failed as well. A friend and former officer of the American Urological Association, himself a patient, but whose cancer is more advanced, warns that with three doses of radiation I am already “challenging morbidity” and advises against further biopsies. Another medical acquaintance, whose name is well known but whose uncommon kindness is not, says apologetically that at this point there is nothing he can do for me. My urologist, however, proposes resuming the same old round of biopsy and imaging, to be followed by a fourth brachytherapy if necessary. I am considering dutasteride, a drug whose incautious use to inhibit prostate cancer I have argued against.[6] In the midst of all this, I learned on good authority that a member of my team has recanted his activism, though when I asked him about it he refused to answer. I have since run across a paper of his on the benefits of group morale for the prostate cancer patient.

Over recent years as I have become an enigma to myself and others, my belief that medicine knows how to treat my case, or even understands it, has crumbled. I doubt my doctors know whether my cancer, invariably identified as Gleason 6 (Intermediate)—yet wrongly entered in the medical records at several points as Gleason 7—was ever significant. They are as blind as I am, though they would have me believe it is definitely significant because otherwise their treatments are harming me for nothing. Of one thing am I sure: their complete indifference not only to the contradiction in their or my records but to the side effects I have encountered, and which once landed me in the ICU, since I began this journey by following others only to end up being interesting to medicine in my own right. "Yours is a unique story," I have been told; but it is so involved, protracted and bewildering that it verges on the untellable, and in any event this is a matter in which no one wants to be unique.

Though as patients we hope to be treated compassionately, too much compassion can give us the wrong idea, and we may also prefer to be treated somewhat impersonally, if only because professionalism is reassuring and tells us our problem can be managed. Those who say doctors ought to show confidence are on to something. We don't want a doctor to act in a way that suggests he or she has never seen our case before. But what if he or she actually hasn't?

Now that it is clear to me that my urologist has in fact never seen my case or anything quite like it, hope and trust—those good companions—have been replaced by gnawing doubt. The man's professionalism, which might once have assured me that he knows exactly what he is doing, now seems a mask. His few words, which formerly made him seem less talker than doer, are now the shield of one who will not confide, admit or affirm anything. As my case has grown ever stranger and more intractable, his manner has remained exactly the same—frozen. He acts as if there were no reason to think a treatment that has failed repeatedly will not fail again, or that side effects are of any concern. It wouldn't bother him to learn, either, that many of the ill effects of repeated treatments, beginning with fatigue, cunningly mimic the markers of depression. The ritual meeting of patient and doctor has degenerated into a ceremony of repetition. There is no "therapeutic alliance." I am like someone in the placebo group of a study who is told, "This pill has been shown to help others," but understands this clever equivocation for what it is.

The doctors may have written off my case as inexplicable, but to me it has confirmed one thing at least: the largely social nature of the placebo effect. It is because of our bonds with others, including others whose experience seems like our own, that we are able to find sources of encouragement even in illness. Recall Haygarth's experiment at the Bath General Hospital in 1799, where subjects were specifically told that a certain worthless instrument had cured the pains of others and would cure theirs. It is easy enough to laugh at these credulous souls who wittingly or not modeled their very sensations on those of others, but we too are social beings, attuned to others. "The placebo reminds us that we are not alone."[7] Not to be able to liken one's experience to others is to be lost. As my case went from ordinary to incomprehensible and my sense that my experience resembled anyone else's melted away, I became lost indeed—blind, pathless.

But even as I went through treatment after treatment and trust in my doctors eroded and then collapsed, many showed the humanity they did not—nurses, clerical staff, intake and pre-op specialists, other doctors (some of great kindness), entire teams in the emergency room and the ICU. Like Telemachus in the palace of Menelaus, I came to them in need and found them not only attentive but generous in ways impossible to imagine before the event. One nurse made me forget my own humiliation as completely as if I had consumed an Egyptian drug. To her I was not a case but a member of the human company. To me she herself was heartsease.