

# 3 INFORMATION IS NOT ENOUGH: THE PLACE OF STATISTICS IN THE DOCTOR-PATIENT RELATIONSHIP

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## INTRODUCTION

The hero of Leo Tolstoy's *The Death of Ivan Ilych* is a man of "incorruptible honesty," who prides himself on his work as an examining magistrate. "He never abused his power...."

but the consciousness of it and of the possibility of softening its effect supplied the chief interest and attraction of his office.... [H]e very soon acquired a method of eliminating all considerations irrelevant to the legal aspect of the case, and reducing even the most complicated case to a form in which it would be presented on paper only in its externals, completely excluding his personal opinion of the matter....<sup>1</sup>

This professional disinterest, a bureaucratic ideal after the 1861 Russian judicial reform, was a great improvement on the favoritism and bribery that preceded it, and Ivan Ilych polishes detachment to an art, devoting his career to its perfection. His goal is

to exclude everything fresh and vital, which always disturbs the regular course of official business, and to admit only official relations with people, and then only on official grounds.... Ivan Ilych possessed this capacity to separate his real life from the official side of affairs ... in the highest degree and by long practice and natural aptitude had brought it to such a pitch that sometimes, in

the manner of a virtuoso, he would even allow himself to let the human and official relations mingle. He let himself do this just because he felt that he could at any time he chose resume the strictly official attitude again and drop the human relation. And he did it all easily, pleasantly, correctly, and even artistically.<sup>2</sup>

When Ivan Ilych seeks advice from a physician about a persistent pain in his side, he encounters a professional with a demeanor very like his own:

There was the usual waiting and the important air assumed by the doctor, with which he was so familiar...and the questions which called for answers that were foregone conclusions and were evidently unnecessary.... To Ivan Ilych, only one question was important: was his case serious or not? But the doctor ignored that inappropriate question. From his point of view it was not the one under consideration; the real question was to decide between a floating kidney, chronic catarrh, or appendicitis. It was not a question of Ivan Ilych's life or death, but one between a floating kidney and appendicitis. And that question the doctor solved brilliantly....<sup>3</sup>

Not entirely daunted, Ivan Ilych presses the matter:

He...rose, placed the doctor's fee on the table, and remarked with a sigh: "We sick people probably often put inappropriate questions. But tell me, in general, is this complaint dangerous, or not?"

The doctor looked at him sternly over his spectacles with one eye, as if to say: "Prisoner, if you will not keep to the questions put to you, I shall be obliged to have you removed from the court."

"I have already told you what I consider necessary and proper. The analysis may show something more." And the doctor bowed.<sup>4</sup>

A century and a quarter later, medical care differs in many crucial ways, but every patient's most important question is still, like Ivan Ilych's, a question about life and death. As Nicholas Christakis has documented, when the outlook is grim, physicians too often shrink from offering a prognosis.<sup>5</sup> Their patients' burning question may not be as rudely deflected as it was by Ivan Ilych's physician, but in contemporary practice the answer is avoided and statistics offered in its place.

The patient's cancer, let's say, has a 5-year disease-free survival rate of 75%. Good odds, as things go. What should the physician say to the patient? How much information does the patient need? And what part should statistics play in the answer?

### WHAT DO PATIENTS WANT?

Physicians know that patients want to know about their diagnosis, but research shows they underestimate how much. Peter Angelos's study of the quality and quantity of information provided to patients with breast, colon, and pancreatic cancer suggests that two in thirteen patients receive too little information and that they want physicians to supply more detail than physicians themselves are comfortable offering.<sup>6</sup> Not only do some patients want more information than physicians think they do, the concept of "enough" differs substantially among patients.

This mismatch of expectation can have benign sources. Physicians who are confident of the therapy they offer want to prevent worry, preserve hope, and insure that needed procedures are done in a timely fashion. They are reluctant to disturb the patient, delay treatment while fears are allayed, or diminish the patient's trust and thus perhaps lessen any placebo effect that might speed recovery. Yet D. D. Kerrigan and colleagues found that patients awaiting elective hernia repair experienced no increase in presurgical anxiety following a very detailed account of what might go wrong during the procedure. They argue that full disclosure would reduce the potential for malpractice claims without adverse consequences for patients.<sup>7</sup>

There are also practical obstacles to providing more information. Time pressure shortens conversations, and when physicians do attempt to inform patients more fully, there is no

guarantee that information given today will be recalled tomorrow. It is not uncommon for a physician to explain a diagnosis, outline the prognosis, and describe the treatment choices, only to have the patient later seem never to have been told much at all. When cancer is the diagnosis, there is the added burden, one that never entirely disappears, of delivering truly bad news. Although only a handful of patients—far fewer than in the past—want *not* to know, no one really wants to hear that he or she has cancer. Even if the cure rate were 100%, the treatment is still severe and life-altering, and the social meaning of the disease remains complicated and dire. It cannot be easy to be the agent of a patient's painful discovery of an altered body, limited potential, or a shortened life. Thus, it is not surprising that even the most experienced clinicians often recoil from this repetitive duty to inform, especially since—despite its value in the patient-physician relationship—it seems to many to have been imposed on that relationship by lawyers and bioethicists.<sup>8</sup> Physicians understandably move to spare their patients—and spare themselves in the bargain. Even a subtle reluctance is likely to affect the time and attention they give the task and the amount and character of the information transmitted.

## INFORMATION AND REASSURANCE

A failure to provide enough information may also be fueled by the physician's sense that patients and their families are asking for more than information, a perspective on mortality that physicians may not be prepared to provide. Sick people facing prolonged treatment need reassurance, especially when the treatment is painful and life-threatening or toxic in itself. Most reassuring would be prognostic certainty, the confidence that treatment will work and the patient will be cured and restored to normal life. A great many patients and their families look to science for this reassurance, as our culture has taught us to do. Gathering information about their disease and the treatment choices is an attempt to hold on to a sense of predictability in the world. If life eludes control, at least we can understand how it has gone awry and how best to restore normality.

But scientific information is only part of what patients need, even those "intellectualizers" who are hungry for the facts. Data must be interpreted, evidence pieced together, and information

sorted for its relevance to one particular patient. Just as most physicians have found a wide middle ground between lying to patients and “truth-dumping,”<sup>9</sup> so it is possible to find a way between the stonewalling “trust me” (with a pamphlet at best) and launching into a short course in pathophysiology with a brief excursus into cell and molecular biology. The middle ground is large enough for every physician to find a comfortable position for almost every patient. What is less clear is whether the numbers—the statistical results of clinical studies required by evidence-based medicine—should be a part of the information that is offered to patients.

### IN PLACE OF CERTAINTY

A cancer diagnosis heightens the question of the role statistics should play in good patient care.

If the prognosis is at all hopeful, there is no certainty. Except near the end of life, patients and physicians are stuck with the odds. Facts are helpful for both decision-making and for a sense of control, but the limits of biomedical information are nowhere more pointed and painful than in the use—and almost unavoidable abuse—of statistics.

In their need for certainty, patients ask for scientific answers. What they get—or find on the Internet—is probabilities. Chance. The numbers are, after all, “the facts”—or their most nearly accurate representation. Yet, especially for prognosis, statistics are profoundly unsatisfying. In part this is because they are perceived so variously and so subjectively. In the 1970s Daniel Kahneman and Amos Tversky studied the psychology of risk assessment and the wide range of attitudes to risk that influence behavior. They described how the way a statement of probability is framed influences its effect and how common decision strategies, themselves based on probabilities, lead people to do such things as overestimate the importance of very low and very high percentages.<sup>10</sup> Education and experience do not alter this subjectivity.

When one of us (KKM) began to teach in a medical school, she kept a folder of articles and stories labeled “Sick Docs,” and the best was by a physician at Johns Hopkins, who after his treatment

for cancer became obsessed with the insidious threat of recurrence. His prognosis was good: the chance of disease-free survival for his diagnosis was solidly above 90%. He understood the statistics as well as anyone, but the number was no help. After weeks of debilitating anxiety, he realized that to get on with his life he had to come to terms with his lifelong record of ranking in the very top percentiles. He had been assuming he would be in that last decile this time, too.

Should he not have been told that percentage? Should he have been discouraged from investigating the studies on his own? It's hard to think such restraint would have been successful, even before the Internet. Survival statistics, especially the facts about recurrence, long ago entered the consciousness of the average citizen without a medical degree. These days, patients regularly ask physicians whether they will recover from their disease knowing that clinical studies offer the best available data. They expect to hear the numbers that pertain to them and their diagnosis. It's science, after all. The beauty of statistics is that they provide a scientific answer; they seem to represent a sometimes difficult but desirable honesty. They sum up the most, the best that is presently known about a disease and its stages. Statistics are the best science can do. Surely they should answer the patient's most pressing question.

But, of course, they do not. Even as patients want more information than they presently receive—including statistics—those facts are only a stand-in for the reassurance patients need. Statistical information not only does not provide this reassurance but is often counter-productive. A wise oncologist once said he uses statistics all the time in making clinical decisions but seldom mentions them to his patients. When, as often happens, they arrive in his office armed with printouts hot off the National Cancer Institute Web site, he suggests they not put too much stock in them: "You don't want to be like the man with his head in the oven and his feet in the refrigerator," he tells them. "His head was hot, his feet were cold, but on average he was just fine." Not that the information they find is wrong, but it may not apply usefully to their circumstances. And even when it does, who's to say what their particular fate will be? There is no certainty. If physicians are to provide support and honest reassurance, they must use something more than numbers.

Besides, once known, the numbers deceive. Statistics, however helpful, are inevitably limited and misleading. “Does it look bad for *me*?” Statistics don’t say. No one survives 82%. Survivors survive entirely; those who die are completely dead. Nor does the number predict the disease-free interval. Although it can happen, a person with an 82% chance of surviving 5 years without a recurrence is unlikely to find the disease recurring a month and a half into the fifth year, when only 18% of the 5 years remains. No matter how promising the numbers, there is no certainty that this particular patient will do well. And worse, as Alvan Feinstein argued in his last dozen years, medicine’s reliance on imported mathematical models—including Bayesian inference and evidence-based medicine—eliminates the very clinical details that may be useful for discriminating among cases.<sup>11</sup> Not only do statistics fail to answer the patient’s life-or-death question, they may exacerbate the uncertainty while making it painfully real. What then should a physician tell a patient?

### STATISTICS AND TREATMENT CHOICE

The prognostic numbers are non-specific gamblers’ odds that apply uncertainly to a particular patient. But when it comes to treatment choice, the statistical results of clinical studies can be quite useful. Patients are not then in search of certainty—though it would be welcome—but rather some guidance in choosing the therapy that will shape their lives for at least the coming months. They need to be told as much as they want to know about the available regimens, their side effects, and how they can be lessened: therapy for the therapies. When treatment options are evenly weighted or when a loss, temporary or permanent, will be the consequence of disease or its treatment, every scrap of data helps many people to make the necessary decisions. Once the decisions are made, study results enable patients to understand and follow their treatment plans. They make sense of tests, justify adjuvant chemotherapy, and restore a sense of choice that can ease the disaster of having cancer. Data may even offer hope, sustaining patients through bad times. No wonder many patients want the most minute detail.

Conveying this avalanche of information is difficult. Some recommend that patients bring a family member to the appointment,

or a tape recorder, or both. Sidney Bogardus and colleagues suggest that physicians use a variety of formats—qualitative, quantitative, graphic—to communicate information about risk: numbers, words, and charts.<sup>12</sup> Numbers alone, they argue, are inadequate. All this is good advice. But what is most important, we believe, is the physician's time and attention to the task. A cancer diagnosis sends patients down the rabbit hole into a confusing new world of tests, specialists, specialized vocabulary, trials, treatments, side effects, side-effect medications, and support organizations. Patients who want help in making the decisions about their treatment need a guide and educator, not just a pamphlet or a Web site or a tape recording of one of the worst times in their life.<sup>13</sup>

When one of us (EKH-B) was diagnosed with breast cancer in the mid-1990s, she was sent to a surgeon who enjoyed explaining the details of breast-cancer surgery and staging to her and her husband. Both appreciated this help in becoming competent in the details of her illness. When it was time for chemotherapy, she searched for and found an oncologist who was willing to meet her need for information, provide context for studies, and lay out her treatment options in a way that was usefully clear and complete. Her first oncology appointment, after surgery, took up the allotted time in a busy clinic without coming to closure on a treatment choice. The physician had a lecture to deliver, but suggested the patient and her husband return in an hour to finish the discussion.

Over ice-cream cones, the patient and her husband organized the information they had been hearing into a rough five-column chart, one column for each of five treatment options (Fig. 1). "Oh, great!" said the oncologist when they showed it to her, and began filling in the blanks, explaining as she went and adding more rows for side effects. They left the appointment having heard a great deal about breast-cancer treatment in general and with a tool for not only recalling that information but for deciding which treatment choice was right for them. The multi-celled page reflected their own plans and worries, the importance they placed on various side effects, and their level of comfort with new therapies.



TREATMENT OPTIONS →	DO NOTHING / FOLLOWER	CMF + B	AC + T	TRIAL	
EFFECTS & SIDE EFFECTS				AKU	AKU
effect on metastatic recurrence	(25% chance)	36% reduction	36% reduction	? better than 36% better	? even better
heart damage	—	0%	<1%	UNKNOWN → increase in risk <5%	
leukemia	.002%	<1%	<1%	~1%	~1%
risk to fertility	—	EQUIVALENT		UNKNOWN	
Genetics					
SYMPTOMS	—	3 <sup>RD</sup> BEST	BEST	2 <sup>ND</sup> BEST	WORST
hair loss	—	BEST (thinning +10-15% chance)	EQUIVALENT AND TOTAL		
weight gain	—	WORST +10-15 lbs	BEST	UNKNOWN	
neutropenic infections PER. HOSP.	—	5% (<1%)	5% (<1%)	HIGHER	
length of illness system depression	—	6 mo	3 mo	4.5 mo	4.5 mo

Fig. 1. Treatment options for a young woman with early breast cancer (1995)

The main elements of this exemplary patient encounter were first, that the physician was willing and able to give them her attention and time, and second, the personalized chart that captured the information they needed. Keys to the chart's success as a tool were that it was created during the appointment, guided by and guiding the discussion among patient, spouse, and physician; that the physician provided explanations as she filled in the cells, making sure they understood them; and that the chart was customized to cover their available therapy choices alone. While a skeleton chart could be made up in advance, filling in the boxes—and sketching in new, relevant ones—was a far better way of introducing a patient to the complexities of adjuvant therapy for breast cancer than giving out a pre-printed handout covering the same information.

### **BEYOND THE NUMBERS**

The yawning chasm between the probable facts and the need for certainty is not unique to cancer care. Given that there is little certainty in other aspects of life—even aspects equally governed by the laws of science (think of flying, cooking, meteorology)—why should it exist in medicine? Reassurance, however, is less about certainty than the concerns that lie behind the patient's quest for certainty. Will the physician do his or her best? Will the patient not be abandoned in making important decisions about treatment or if treatment fails? Physicians can offer reassurance even in the most inauspicious circumstances: that their patients will be well taken care of; that they will make the best possible decisions in their case; that they will not lie to them. Farther along, there can be reassurances about the relief of pain and about not deserting them. Such assurances are not the manifestation of biomedical facts but the manifestation of medical attention, clinical judgment, and a physician's wisdom and fidelity. These things, too, provide human beings with a sense of control in their lives.

There are barriers to providing such non-statistical reassurance. In the United States, the fragmented delivery of health care and the division of clinical labor by subspecialties constitute two of them. A third barrier, however, is more personal and well within an individual physician's power to remove. It is the failure to acknowledge the patient's life-or-death question and the temptation

to avoid it altogether. Knowing that the science of medicine cannot provide anything like the certain answers the patient seeks, some physicians may become cynical about that desire and ignore it, thereby missing an opportunity to offer a different but ultimately more valuable kind of reassurance.

How best to live one's life is the central moral question for every human being, well or ill. A life-defining illness only sharpens the need for an answer. Providing such answers may not be the duty of the surgeon or even the oncologist; but if they are not to be mere technicians, they at least must recognize the existence of the question. This and some advice about ways to address the day-to-day aspects of life-threatening illness are part of the physician's work. Such advice may be as simple as pointing out that medicine cannot do the whole work of recovery: even when it cures the disease, the patient will have to work at recovering from the illness and, with cancer, from its treatment. Unless physicians are to become mere biotechnicians, it is never true that they have "nothing more to offer." There are referrals, Hospice, simple presence. Chronic and degenerative diseases impose an even stronger duty. Dewitt Stettin, Jr's plea to alter subspecialty practice is still as useful as the day he wrote it. After his macular degeneration was diagnosed, the best physicians in the country, some of them his colleagues, said they "could do nothing more for him." His *New England Journal of Medicine* article is a damning enumeration of all the conveniences—a talking watch, the Kurzweil reader, Talking Books—that he was left to discover on his own.<sup>14</sup>

Physicians' reluctance to offer non-statistical advice and reassurance is one of the side-effects of medicine's claim to be a science. The word "science" itself is noble, and the aspirations it evokes are praiseworthy, but the claim—and its eager acceptance by patients and society as a whole—has led to the expectation that medical knowledge is invariant, objective, replicable, and a basis for reliable prediction.<sup>15</sup> Yet medicine is not a science, however scientific its knowledge or technological its therapies. It is, as it has always been, the diagnosis and treatment of sick people. Although biology is now the frame for much of medical knowledge, and evidence-based practice draws upon aggregated analyses of clinical studies, *clinical* knowing is focused on the interpretation of what is happening over a course of time with a particular patient. Such

knowledge is still called an opinion; the skill used in arriving at that opinion is still called judgment. No one understands this better than surgeons.

In their case-based interpretive use of knowledge, physicians resemble judges and medical rationality resembles jurisprudence, the interpretive reasoning lawyers use to construct their cases. Both professions are engaged in practical reasoning, which, Aristotle observed, they also share with practitioners of navigation and moral reasoning.<sup>16</sup> In these practical realms, knowledge is particular, experiential, conventionally agreed upon, finely interpreted. Although the areas of agreement may be large, even international and transcultural, physicians (like lawyers, moral reasoners, and navigators) rely on skill and judgment that are taught and practiced, improved and clarified case by case. Biology grounds clinical knowledge and promotes valuable technological advance, but this simply means that medicine has both a body of basic scientific information and, like other practices, a fund of established practical wisdom. That double resource means that clinicians work more like naturalists or economists or archeologists than biochemists or physicists.

Medicine's double store of knowledge and experience is what patients call upon: not just scientific facts but also clinical judgment—including hunches and intuition. This is wisdom of a real-life, practical kind. Some patients may want scientific information; many more will want statistics; but all hunger for information about the world of illness they have entered. "Is it serious, doc?" What we all need to know, in one way or another, is whether we can live with our diseases. Biomedical science, millennial technology, and the advances of evidence-based medicine make this possible for many diagnoses to an extent (and for a length of time) unimaginable a short while ago. But to provide the reassurance patients need, physicians must be willing to go beyond the statistics.

## CONCLUSION

Good physicians have always sensed what patients need. If they cannot assure them of a cure for their disease, then they can speak about the manageability of the disease or, when death is in prospect,

offer reassurance about the relief of pain and their commitment not to abandon the patient. If these last tasks are not ones that a specialty like surgery usually assumes, then a promise to help the patient find a physician who can make these commitments ranks a close second. Such assistance may threaten a physician's long-standing wariness about making an empathic connection with patients, but to avoid offering this help risks the opposite danger: protective detachment can harden into an unfeeling shell that will impoverish a physician's daily experience. The chill professionalism of Ivan Ilych's day is a misplaced norm. Rita Charon has pointed out that "detached concern" was a description of practice observed by the sociologist Renée Fox and not a prescription for physicians' attitude to patients.<sup>17</sup> Instead, as William Branch and Anthony Suchman suggest, connection with the patient is for many physicians much less exhausting and painful than its avoidance.<sup>18</sup>

If contemporary practice provides no time for physicians to be more than a bare statistical informant, contemporary practice must be changed. The alternative is the loss of medicine's identity as a profession, its reduction to a technology or a business enterprise. In the short run—and at the very least—physicians who care for cancer patients need to recognize Ivan Ilych's burning question in whatever shape their patients ask it. "What are the chances of recovering?" Reliable factual information is needed for choosing treatment. But the best answer for prognosis is not statistics. Numbers are of little use in deciding how to live a life altered by disease and its treatment or one shortened altogether. The best answer to a patient's life-or-death question is an acknowledgment that the question is terrifyingly important. "Am I going to die of this?" Whatever the numbers, the answer—details of which the patient must ultimately supply—is how to live with whatever time we have.

#### NOTE

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9. This phrase has been in colloquial use for more than a decade, but there is no better illustration than Reynolds Price’s account of being told his cancer diagnosis in a busy hallway of the Duke University Hospital by two young specialists who then turned and rushed off to other, more important tasks; *A Whole New Life: An Illness and a Healing* (New York: Penguin/Plume, 1994).
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