Editorial

Informed Consent: Who's Informed? Who's Consenting? And Other Questions

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Long before medicine became ensnared in controversies involving insurance companies, government regulations, and malpractice attorneys—indeed, long before "informed consent" was a term, much less an obsession—*good* medical practice was founded on a strong physician-patient relationship. The case described by Hartlaub and colleagues[1] (see page 383) emphasizes that informed consent is not "obtained" as if it were a technical procedure or bureaucratic goal. Rather, it is both an ongoing process and an ideal, mutually aspired to by patient and physician. Informed consent is not medical "fast food" to be manufactured on the health care assembly line by completing an impersonal protocol, or to be quickly disposed of by assigning the responsibility for obtaining a signed document to a medical student or a hospital admissions clerk. Informed consent occurs as a part of the ongoing, trusting relationship between physician and patient.

The case challenges us to rethink such questions as: Who is informed and who is consenting? Who seeks what kinds of information and why? What does respect for a patient's autonomy mean? How do we know when—or whether—shared decision-making based on mutual respect and understanding is taking place? When does the ritual between physician and patient serve only as a façade to avoid law suits? What are the physician's agendas and motivations? Does the very paperwork that ostensibly signifies a mutual decision instead protect those involved from each other and set them as adversaries?

Since the mid-1970s, Arthur Kleinman and his colleagues have demonstrated the role that "explanatory models"[2–4] play in regulating clinical relationships and health care outcomes. The case presented by Hartlaub et al[1] describes how the physician-patient dyad is complicated by an intricate web of others, eg, other physicians, the patient's nephew, hospital attorney, potential plaintiff attorney, insurance company manager, and more. All these produce a complicated array of expectations, and a host of opinions about informing and consenting. How crowded have examination rooms and hospital rooms become?

The unfolding of the case raises numerous questions that remain unanswered. What, for instance, are the perspectives and motivations of each participant in the case? First, let us consider Mr F., the patient. What were his understandings of and feelings about his "prostate problem"? In what context—the patient's life story—does this prostate problem occur? How did his agenda for his life compare with the residents' and attending physicians' expectations? I wish I knew more of the patient's life priorities and choices, and how his prostate problems fit into his 74 years. At some level, did he "know" or suspect that he had cancer? Might his insistence that only one prostate problem existed indicate that he did not wish to know the details and extent of his disease? Cancer, after all, has long been our most frightening disease until AIDS appeared. As Sontag writes, cancer is not only disease, but metaphor.[5,6] How did the patient perceive cancer? Why was he opposed to aggressive testing? Did his acquiescence to have the biopsy indicate that he was finally informed, or was this decision haunted by his (or his nephew's or physician's) emotional responses to cancer? Whose motivations, whose definitions should take precedence?

What do health care providers need for or wish for their patients to know? Did the residents view the patient's prostate problem differently from the attending physicians? What is the relationship between what physicians "need" to say and what patients "need" to hear? And how are these frequently different needs acknowledged and negotiated? Might, for example, the patient want to know more about his cerebrovascular accident

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because it would divert his attention from the more terrifying prospect of cancer? If that were the case, wanting to know would be intimately bound up with not wanting to know.

What was the patient's perceived time-line? How long did he expect or want to live? Within whose frameworks of rules are physicians willing to work? I wish the residents or authors had asked the patient what he feared most, both in life and about his illness. Was his worst fear a wasting death from cancer or death itself? Was it pain? Was it loss of bodily functions? Likewise, I wonder what were the residents' and authors' and nephew's greatest fears. For pain, loss of function, separation, and death raise intense emotions in patients, physicians, and family members alike. Whose anxiety, then, is confronted in the name and guise of informed consent?

The case is a lesson in vocabulary as well. Our words often reflect our assumptions rather than our knowledge. The residents concluded that the patient made an informed decision not to have his prostate evaluated for cancer, although he wanted to have all lifesaving measures taken if he needed to be resuscitated. Is this apparent disparity necessarily paradoxical? Or is it only paradoxical to physicians? Similarly, the seemingly descriptive term "informed refusal" is as value laden and pejorative as the term "noncompliance." If a patient acting within his definitions of life and health does not wish to have tests or treatment, does that necessarily indicate a *refusal* to accept biomedical advice? Must honest differences in perception of life and health be construed as an affront to a physician's power?

The case also illustrates a conflict that often arises between medical authority (to which physicians have traditionally expected and wanted the patient to defer) and the patient's inalienable right to experience life (which inevitably encompasses death) as he or she chooses. To whom, then, should the patient listen? Who is the expert in "informed consent," and what constitutes expertise in this area? The authors enlisted the patient's nephew to "reinforce" the need for the proposed biopsy. We might infer that influence exerted by the nephew reflects the authors' genuine wish to include the patient's family and significant others in decision-making. But we are not told why only the nephew was involved and not other family members or friends. This raises the concern that coercion occurred under the guise of inclusion. I worry that physicians can use "family" for leverage to obtain permission to do what they think is best for the patient.

Admirably, the authors moved informed consent from its usual context of medicolegal and medico-economic jargon into the reality of the clinical setting where physicians, patients, families, and others interact. Motivation for achieving informed consent should be based on concern for the patient, not on the regulations of an insurance company or fear of a lawsuit. Furthermore, both as a formal concept and an informal process, informed consent should not be limited to cases that involve a life-threatening illness. Ideally, all clinical communication should occur in the autonomous spirit of informed consent.

Many physician colleagues have cynically lamented to me that in these days of sophisticated biomedicine, the only person who even approaches having the competence to provide truly informed medical consent is another physician. Nevertheless, we must remember that all illness experience, even disease diagnosis, is *socially* constructed. Science is not immutable; today's definitive test might be tomorrow's anachronism. What a patient "has," be it a disease, condition, or syndrome, is more elusive than we often dare to admit. There can be no "informed consent" without an honest physician-patient relationship that includes a mutual acknowledgment of each other's limitations.[7,8] The physician-patient relationship, like any human relationship, is built not only on words but on shared moments of silence, unspoken commitments, and perseverance in times of adversity.

In the face of continuous change and uncertainty in medicine, a good physician-patient relationship is the only reliable foundation upon which "informed consent" can take place. It is the caring relationship between physician and patient that abides as the bridge between not knowing and knowing, between anxiety and trust.

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