Enriching the Doctor-Patient Relationship by Inviting the Patient’s Perspective

Thomas L. Delbanco, MD

Doctors and patients alike are saddened and angered by the distance that increasingly interferes with their interactions. Two complementary strategies may enhance the human quality of clinical care and improve outcomes. First, the doctor and patient can undertake a systematic “patient’s review” that addresses seven dimensions of care: 1) respect for patient's values, preferences, and expressed needs; 2) communication and education; 3) coordination and integration of care; 4) physical comfort; 5) emotional support and alleviation of fears and anxieties; 6) involvement of family and friends; and 7) continuity and transition. Incorporating the “review” into the clinical encounter encourages both patient and doctor to confront individual preferences and values and offers patients an explicit framework for participating actively in their care. Second, using survey instruments designed to solicit focused reports from patients that address each dimension of care, doctors can gather aggregate feedback about their practices. Such reports move beyond anecdote and can serve as screening tests that uncover areas in doctors’ practices that merit improvement. In addition, patients can join doctors in developing solutions to problems uncovered by patients’ reports.


From the Beth Israel Hospital, Boston, Massachusetts. For the current author address, see end of text.

A doctor’s job would be so much more interesting and satisfying if he would occasionally let himself plunge into the patient, if he could lose his own fear of falling.—Anatole Broyard (1)

Doctors and patients find themselves drifting apart. As smaller and smaller players in ever growing systems, both we who offer care and those who seek it too often keep a distance from one another. We doctors are told repeatedly how arrogant we appear, even as we ponder what is happening to the human side of care that attracted so many of us to medicine. Our patients too are sending a clear message, as more and more question our motives and the quality of our care.

How can we draw closer to those we serve? For the past 4 years, I have been involved in a project that seeks to evaluate and improve health services by focusing on the needs and concerns of patients as they themselves define them (2). In this article, I draw on that ongoing inquiry but write primarily from my experience as a practitioner and teacher. I am convinced that two complementary strategies could help sustain and enrich the doctor-patient relationship.

First, doctors can incorporate into their clinical encounters an organized and systematic consideration of each patient as a unique individual. Based on ideas suggested by Matthews and Feinstein (3) and Baron (4), a “Patient’s Review” that specifically addresses the preferences, values, and needs of each patient can serve as a complement to the organ-specific review of systems we learned in medical school.

Second, doctors can move beyond their individual patients and use questionnaires that invite patients to report collectively about clinically important experiences, thereby providing valid and reliable feedback about aspects of their individual practices. Patient surveys designed to evaluate systematically how doctors are doing from the patient’s perspective can help us both improve our practices and teach us about the clinical epidemiology of patients’ experiences regionally and nationally.

Characterizing the Patient’s Perspective

In 1988, my colleagues and I set out to learn more about what matters to patients, above and beyond the primarily biomedical aspects of their clinical management. Beginning with a review of the literature, we compiled a preliminary list of those features of care that patients could evaluate and that they judged to be most important. To ensure that the items identified were those most salient, we next convened eight focus groups of patients who had been recently discharged from medical and surgical services in hospitals, as well as groups of family members of patients, nurses, physicians, social workers, health administrators and policy specialists, and lay persons (2).

What did we learn? Patients do not focus on prettier waiting rooms, better hospital food, or problems with parking. Rather, they are concerned about issues of clinical significance that have nothing to do with what we think of as the doctor’s “image” or the hospital’s “atmosphere.” They want to be able to trust the competence and efficiency of their caregivers. They want to be able to negotiate the health care system effectively and to be treated with dignity and respect. Patients want to understand how their sickness or treatment will affect their lives, and they often fear that their doctors are not telling them everything they know. Patients worry about and want to learn how to care for themselves away from the clinical setting. They want us to focus on their pain, physical discomfort, and functional disabilities. They want to discuss the effect their illness will have on their family, friends, and finances. And they worry about the future.

Our discussions with patients and clinicians suggest that most patients’ concerns fall into seven dimensions of care. Table 1 details the component parts of these
Table 1. Elements of the Patient's Review

<table>
<thead>
<tr>
<th>Dimension of Care</th>
<th>Focus of Patient's Review</th>
</tr>
</thead>
<tbody>
<tr>
<td>Respect for patients' values, preferences, and expressed needs</td>
<td>What are the patient's short-term and long-term goals? What level of involvement does the patient want in decision making? What does he need, want, or expect from the health care system? What are his feelings about an advance directive?</td>
</tr>
<tr>
<td>Coordination and integration of care</td>
<td>Is care delivered by the range of providers effectively coordinated? Does the patient get consistent information from different clinicians?</td>
</tr>
<tr>
<td>Communication and education</td>
<td>Does the patient have the information he wants about his clinical status, diagnostic tests, and treatment options? Do the patient and his family know what they need to know to manage on their own to the extent that they are able to do so?</td>
</tr>
<tr>
<td>Physical comfort</td>
<td>Is pain alleviated as much as possible? Does the patient have the help he needs with bathing, eating, household chores, or other activities of daily living? Have remediable deficits in functional status been adequately addressed?</td>
</tr>
<tr>
<td>Emotional support and alleviation of fears and anxieties</td>
<td>Is the patient worried about his or her illness or its effects on the ability to care for one's self or one's dependents? What are the principal stresses in the patient's life? Is he or she worried about paying medical bills or about lost income due to illness? Does the patient have access to appropriate support networks to help with these worries?</td>
</tr>
<tr>
<td>Involvement of family and friends</td>
<td>Are family and friends appropriately included in planning and providing care? Do they have the support they need?</td>
</tr>
<tr>
<td>Continuity and transition</td>
<td>Do the patient and family understand medications to take, treatment regimens to follow, activities to pursue or avoid, and danger signals to look out for? Are there clear plans for continuing care and treatment?</td>
</tr>
</tbody>
</table>

dimensions. The following comments by patients I recently interviewed bring each dimension into focus. The studies cited after each comment point to their clinical import, both in terms of the process and outcome of care.

1. Respect for patients’ values, preferences, and expressed needs (5-9)

   I feel very strongly that the patient has to participate. I mean, I have learned this. This is not a theoretical thing. I have learned that I have to be as involved in my care as the doctors.

2. Communication and education (5, 10-15)

   I ask for information when I don’t have it immediately. I mean, if they are going to go poking inside my body, I want to know what they expect to find; and then if they find it, what they are going to do about it. I need information. That is my basic food.

3. Coordination and integration of care (16-18)

   My experience so far has been that what I tell my doctor does not necessarily go anywhere else. One of the things that drives you crazy is every single person asking you the same questions over and over again.

4. Physical comfort (19-21)

   After a while, I began to get nauseated and I didn’t feel good and I just felt rotten and I was all upset. A very good friend of mine said, ‘Perhaps it’s the codeine.’ Well, I hadn’t been told—I wish I had—that codeine can upset your system. I didn’t realize it. As soon as I just took Extra Strength Tylenol, the pain was adequately controlled. Anyway, I didn’t want the codeine, so I made it adequate.

5. Emotional support and alleviation of fears and anxieties (22-24)

   If they had told me what I could do, that would have been helpful. I’ve felt so vulnerable that I think I’ve been a little timid to do things. There wasn’t much I could do, but I wasn’t told what I could do, and it might have been encouraging.

6. Involvement of family and friends (25-27)

   I have a very strong group of friends. It’s made a difference to me. They all tend to be rather inquisitive sorts, themselves. And if for some reason I space out, they will find the doctor and ask themselves, ‘Well, you’re going home. We have other sick people.’

7. Continuity and transition (28-30)

   It really just seems like, when it’s time for you to go home, they more or less push you aside and say, ‘Well, you’re going home. We have other sick people.’

Focusing on the Individual

How can we incorporate these elements of each patient’s unique perspective into our practices? We can discuss them using a format similar to the traditional review of systems (3). I find that incorporating the Patient’s Review into my interactions with patients encourages me to address the nontechnical aspects of care in a systematic way (see Table 1). For example, when discussing physical comfort, the patient and doctor review the different components of that dimension of care, just as the doctor has for years asked about certain symptoms when evaluating the cardiovascular system. However, in contrast to the traditional review of systems, which is orchestrated and conducted by the doctor, the Patient’s Review often results in a dialogue that promotes sharing of responsibility, an interchange that has been shown to affect clinical outcome favorably (14, 31-34).

Much as decision analysis teaches us to manage biomedical problems with greater intellectual rigor, the Patient’s Review helps to tailor care to the individual patient and forces us to make explicit what often has been implicit. All kinds of patients place their own stamp on the Review. Yes, I have always known that patients have their differences. I thought I could judge what they felt and wanted, but the issues that surface during systematic review never cease to amaze me (and them). How much do they really want to know? What do they want to decide? Would they rather leave decisions to me? What are the largest stresses in their lives,
their worries and fears? How well are they functioning? I can find out only if I ask (35-37).

The Review pushes me also to expand my horizons. It encourages both patient and doctor to confront and express individual preferences and values while offering patients a structured opportunity to participate actively in their care. It forces us to confront our own attitudes and the range of options we offer or control. When patients choose acupuncture, massage, guided imagery, folk healing or homeopathy, how do we respond if our experiences or values conflict? Patients who are encouraged and invited to do so can tell us more about “non-traditional” therapies they may embrace. In turn, we can care for them in a less judgmental way as we learn how they understand and approach their own health and disease.

What will it take for us to lose our “fear of falling” and adopt a more patient-centered approach? The current debate over the value of doctors’ time highlights an immediate obstacle: It takes time. I do not suggest that we launch into a detailed Patient’s Review during emergent, episodic care; after all, we omit the traditional review of systems during such encounters. However, the additional minutes spent on the Review when we are establishing or strengthening a relationship with a patient pay off in the longer run. It need not be completed during a single encounter. I consciously weave bits and pieces of the Review into my interactions. Similarly, the more extended dialogue I now remind myself to initiate before a patient’s discharge from the hospital often seems to improve both the process and the subsequent outcome of care. Anecdote, however, will not suffice. Like other innovations in clinical practice, we shall need to document the effect of incorporating a Patient’s Review.

When and how should doctors learn to use the Patient’s Review? I believe we should incorporate it into the early years of the medical school curriculum, just as we now teach the traditional review of systems to our students. The Patient’s Review could serve as a framework for teaching and learning how to address these highly personal and individualized dimensions of health care. It provides structure: Students learn how to ask questions, to engage patients in dialogue, to educate patients, and to establish a constructive doctor-patient relationship. Moreover, in our clinical teaching, just as we query students and residents routinely about physical signs and symptoms, we can ask them about their patients’ values, preferences, knowledge, and support systems. We can also take the next step: We can ask patients themselves for feedback about students’ performances (38, 39).

What about patients? Why not adapt the Patient’s Review for their use and teach them early on to use it in their encounters with doctors? We are now beginning to model health-promoting behavior and social strategies in primary and secondary school. So, too, could we begin to teach young people to use the health care system more effectively by incorporating the framework of the Patient’s Review into their thinking. They could learn to understand and articulate their own values and preferences and address them squarely in their interactions with health care professionals. Why not distribute an adapted Patient’s Review in doctors’ offices and hospitals, much as many hospitals now circulate a “patient’s bill of rights” (40)? Why not incorporate elements of it into the history forms many patients complete before seeing the doctor? This could both promote shared responsibility and add to the efficiency of its use.

As doctors and patients increasingly use this approach to care, the biggest obstacle the Review faces may erode: the hesitancy of both patient and doctor to be frank. Is there a common language we can learn to use in our discussions? At the moment, we are often divided by the clinical language of the practitioner and the patient’s language of subjective feeling. Today, we are witnessing many exciting efforts to bridge that gap (41-48). A common, systematic framework should vastly improve the prospects for open communication and shared understanding. As one of my patients stated: “I don’t think it should be totally up to the patient to ask questions. The patient doesn’t know enough to ask the questions. I think it’s up to the caregiver, whoever it is, to lead the patient, draw it out of the patient: ‘What are your concerns? What would you like to know?’.”

Soliciting Patients’ Reports

Just as we can use the Patient’s Review in our approach to individual patients, so too can we gather from patients aggregate feedback about our practices, using survey instruments designed to solicit their explicit reports. By asking patients selected at random from our practices to answer questions about the component parts of the dimensions outlined in Table 1, we can generate data that will help us improve the quality of our care.

Ernest Avery Codman (49) made the radical suggestion early in this century that we pursue our patients to learn from them the outcomes of their treatment. Avedis Donabedian (50) took a next step by suggesting that patients (and, I would add, their friends and families) are in an unique position to assess important aspects of the quality of the care we deliver. Consider, for example, the reflections of one patient on the time he spent in the hospital: “I didn’t have a whole lot to occupy my mind sitting in the hospital. I really didn’t. So I sort of watched, and I watched real hard. And I observed phenomenal differences across the board, just in the way they treat individuals.”

Our patients sit looking around our waiting rooms. They lie for hours watching how the wards work. They and their families are eyewitness to hundreds of human interactions, to time-honored “standard operating procedures.” Yet, few doctors have sought systematic feedback about their practices. Asking patients to join in the ongoing review of the components of care outlined above could teach us how well we address their needs and how we can improve their care.

Four years ago, my colleagues and I developed and piloted a survey instrument soliciting such feedback from patients who had recently been discharged from hospital. Telephone interviews with almost 6500 patients who had been hospitalized in a probability sample
of 62 hospitals nationwide yielded striking insights into patients’ experiences with care (2). Working with a task force of clinicians at the American College of Physicians, we are now developing a similar instrument to provide doctors with feedback about their practices from patients. Increasingly, evidence suggests that survey responses can be both valid and reliable, whether elicited through face-to-face or telephone interviews, or through paper-and-pencil or computerized questionnaires (51-53).

Using patients’ reports about their experience with discrete events in their health care will move us beyond anecdote and certainly beyond the documentation of clinical encounters typically found in the medical record. Moreover, discrete reports are more helpful than global measures of patient satisfaction, because they tell us in a concrete way what patients did and did not experience (51-53). I might be distressed to learn that 25% of my patients are dissatisfied with the care I give them, for example, but a survey that tells me, “Twenty-five per cent of your patients report that they were not told what they could or could not do at home after leaving your office,” helps me to take specific action. Annual surveys of 200 patients drawn at random from a doctor’s practice will send a clear message about the doctor’s determination to learn from their experiences and perceptions. Their reports will serve as useful screening tests, showing doctors the areas of care that they need to examine and improve.

Consider other potential benefits from gathering such systematic feedback. National and regional data documenting patients’ experiences would enable us to make comparisons and generate new insights. Who are the clinicians whose patients report first-class care? They could become the exemplars from whom we all might learn. Which patients receive outstanding care, and which do not? For example, our hospital survey found that the chronically ill may be at particular risk for poor communication (2). Might we find in our practices that we give haphazard attention to the values and preferences of certain groups of patients?

Looking Forward

As practices change to involve patients more actively and patients’ reports become integrated into ongoing measures of quality, patients themselves, along with their families and friends, could play a creative part in crafting solutions to problems. They are a varied lot; they bring broad experience and expertise. They also hold an extraordinary personal stake, and many would be eager not only to report on their experiences but also to join health personnel in addressing and solving problems. We could convene focus groups of patients to help examine varied aspects of our practice, ranging from the floor through our offices to the way we communicate. They could work with us, helping us to make choices and set priorities. What a creative activity this would be! What better way to draw closer to our patients!

Incorporating the Patient’s Review into our practices and collecting both patients’ perceptions and suggestions for change will address clinically significant aspects of the patient experience, foster the active involvement of patients in their care, and help assess and improve the quality of the care we deliver. Combining a systematic consideration of patients’ individual characteristics in clinical practice with the routine solicitation of their aggregate perceptions will engender a powerful synergism. It will help doctors draw closer to their patients and restore and strengthen public trust. It will both improve the quality of our care and add to the joy of being a doctor.

Acknowledgments: The author thanks his colleagues in the Picker/Commonwealth Patient-Centered Care Program; Paul Cleary, PhD, Jennifer Danziger Delbanco, MD; Susan Edgman-Levitan, PA; Margaret Gerteis, PhD; Thomas W. Moloney, Mare Roberts, PhD, and Janice Walker, RN, for their collaboration in conceptualizing this work; Frank Davidoff, MD, Lachlan Forrow, MD, and Christine Laine, MD, for their review of the manuscript; and Ms. Patricia Wilkinson for her assistance in preparing the manuscript.

Grant Support: By the Commonwealth Fund of New York City.

Requests for Reprints: Thomas L. Delbanco, MD, Division of General Medicine and Primary Care, Department of Medicine, Beth Israel Hospital, Boston, MA 02215.

Current Author Address: Dr. Delbanco: Division of General Medicine and Primary Care, Department of Medicine, Beth Israel Hospital, Boston, MA 02215.

References

19. Cheek WA. Results are better when patients control their own analgesia. JAMA 1982;247:945-7.
My life closed twice before its close—
It yet remains to see
If immortality unveil
A third event to me
So huge, so hopeless to conceive
As these that twice befell.
Parting is all we know of heaven,
And all we need of hell.

Emily Dickinson, #1732
The Complete Poems
Little, Brown, and Co., p. 702