

## EDITORIALS

## Patients' Stories and Clinical Care

### Uniting the Unique and the Universal?

*The treatment of a disease may be entirely impersonal; the care of a patient must be completely personal.*

—Francis W. Peabody, "The Care of the Patient"

A decade ago, when I first walked onto the hospital wards to interview a patient, a series of events unfolded that in hindsight seems, by turns, sad and funny and symbolic. You may readily imagine the scene: a nervous freshman medical student, I entered the room of a middle-aged man, whom I recall as remarkably relaxed, lying propped up in bed, waiting for a cardiac transplant, dying by degrees of congestive heart failure. After some polite introductions, envision next the startling—indeed alarming—absence of a chair in the room. Caught between the unfriendly option of looming at the bedside and the undignified position of sitting on the floor, I desperately chose the middle ground and proceeded to kneel at the foot of the bed. And there I stayed throughout the entire interview, like a devoted supplicant before a wise man, as he told me stories about his illness—stories through which, directly and indirectly, he told me what he was thinking and feeling, what scared him and gave him hope.

Though time has since brought encounters with countless other patients, I recall that first pilgrimage to the bedside not simply with amusement but also respect. As an inexperienced student, I was keen to learn the universal principles of disease diagnosis and management. Subsequently, I have come to know much more about cardiomyopathy (and the merits of fetching a chair from the hallway), yet I have learned nothing further about that unique first patient of mine than what he told me while I knelt before him.

This anecdote, in my mind, has come to symbolize how clinicians struggle with a central tension in modern medicine—a tension between the pursuit of scientific knowledge about generalizable facts (which I so desired at the time) and commitment to a humanistic understanding of idiosyncratic individuals (which is what his stories offered).<sup>1</sup> The best clinicians work this tension between the universal and the unique creatively. Using current medical information and technology thoughtfully, engaging in empathic relationships with their patients skillfully, they ultimately synthesize these two approaches in good clinical judgment and quality care.

None of these thoughts, of course, is new, yet the daunting challenge of providing excellent, "completely personal" care has not exactly grown old. A topic for our times, the pursuit of high-quality health care presents difficulties that stem not only from too much information, too

little time, and too much paperwork, but also at a deep level from this tension between universal knowledge and unique understanding. This tension becomes especially conspicuous when thinking through the value of patients' stories in clinical care and (in a more general but allied sense) the role of qualitative research in medicine, a subject that recently has received much attention on the pages of this journal as well as others.<sup>2-12</sup>

Take, for example, the perceptive qualitative study by Ritholz and Jacobson presented in this issue.<sup>13</sup> Wanting to learn more about the patient's perspective of living with hypoglycemia, they adopted the methods of interviews and narrative analysis. After recruiting 20 young adults, white and highly educated, who had had type 1 diabetes for at least 10 years but as yet suffered no major complications, Ritholz (a psychologist) interviewed each one separately for about an hour, asking some prepared questions and then allowing the conversation to go where it would. At the start of the interview, Ritholz told the patients that she "wanted to hear their 'stories of hypoglycemia'," then encouraged them to tell their experiences of hypoglycemia and the ways these experiences affect their everyday lives.

After close scrutiny of the transcribed interviews, Ritholz and Jacobson (trained as a psychiatrist with an extensive background in diabetic mental health) identified several common concerns about living with "low blood sugar." Hypoglycemia undermined the patients' sense of personal autonomy, threatened their sense of control over their bodies and their behaviors, and damaged the integrity of their personal identity as responsible, capable, and self-controlled individuals. Often, with this heightened sense of vulnerability or failure, came feelings of shame and isolation. These concerns played themselves out in four recurring themes. Patients described how their hypoglycemia had led to conflict between themselves and a loved one, either over accepting help while hypoglycemic or about how to prevent reactions; how hypoglycemia created discrepancy between "their sense of self as a socialized, polite person and as a more irritable and hostile hypoglycemic self"; how "they rarely talked about hypoglycemia with anyone" and, when they tried to do so, found it difficult to convey the experience accurately; and how their doctors generally were not engaged in this subjective, experiential area of their lives, a state of affairs these patients accepted without apparent qualms.

What should we, as critical readers, make of this study of patients' stories—or indeed, of any similar qualitative study? Much of the current debate over the value of qualitative research has framed the core issues as whether the investigation examines objective data or subjective experience and meanings, or whether knowledge is acquired through positivist, naturalist, or other paradigms. Though intrigued by elements in this debate, as a clinician I frankly worry much more about whether my knowledge is reliable and of potential benefit to a specific patient. Although some authors have lamented the lack of explicit guidelines for evaluating these aspects of qualitative studies,<sup>11</sup> the medical literature does contain a number of outlines.<sup>14–17</sup> Joined together and augmented by extensive work in the humanities and social sciences,<sup>18–24</sup> these outlines provide a reasonable set of steps and standards to guide our approach (Table 1).

First, Ritholz and Jacobson clearly asked an important question. Hypoglycemia, a common complication of all insulin therapy, is especially troublesome for the strategy of tight control studied in the Diabetes Control and Complications Trial,<sup>25</sup> which found a threefold increase in risk of hypoglycemia requiring assistance or involving coma or seizures among subjects under tight control.<sup>26</sup> For any clinician who helps patients with diabetes to choose and pursue a desired level of control, and then to live with the consequences, how people experience hypoglycemia and how they believe it affects their lives are certainly pertinent questions.

Second, as the authors themselves point out, the study's sampling and recruitment procedures limit broad

generalizations (as was also true of the Diabetes Control and Complications Trial). Because the subjects were mostly college-educated, middle-class young adults (with their acculturated values about self-control and autonomy and the particular responsibilities of their job and home life) who were willing to talk about their experiences of hypoglycemia, extrapolating the experiences and concerns of this homogeneous group to other kinds of diabetic people would need to be done with extreme care.

Third, the authors used a cross-sectional, semistructured interview technique, an appropriate choice for this study, delving as it does into a broad experiential realm that thus far has not been much investigated. Asking open-ended questions—even one so broad as “tell me a story about your experiences with hypoglycemia”—and thoughtfully using the answers to follow up certain evolving issues with more individualized questions can generate rich, suggestive material. Rather than assuming (in a potentially biased manner) that the meanings of these accounts of hypoglycemic reactions were obvious and unambiguous, Ritholz encouraged the patients not only to tell their stories, but also to comment on what the stories meant, their significance in the larger framework of the patients' lives.

Fourth, assessing the validity or “trustworthiness” of their results, at an internal level Ritholz and Jacobson specify that the interviews were tape-recorded and then transcribed, and that they then used narrative analysis techniques (referenced but not actually described) to identify recurrent themes and topics, which were defined—arbitrarily but sensibly—as those appearing in 40% of the interviews. In addition, they quote amply from the transcripts, enriching their findings and enabling skeptical readers to form their own judgments. Moving outward to assess the trustworthiness at an external level (sometimes referred to as “triangulation”), the authors point to historical work that I have done, which entailed the review of 101 patient records (many of which contained numerous letters written by patients) at the Joslin Diabetes Center from the period between 1898 and the 1960s. Similarly interested in the patient's perspective on living with what is now known as type 1 diabetes, I also found that many patients expressed concerns over control, autonomy, responsibility, and identity over many years as the disease itself was transmuted from an acute to a chronic illness.<sup>27–29</sup>

Looking further afield, other studies that explored the experience of living with diabetes and other chronic illnesses generally corroborate the themes identified by Ritholz and Jacobson.<sup>30,31</sup> Another step would have been to have the study subjects themselves review the findings, a technique called “member checks” that further strengthens the trustworthiness of research.

Finally, having decided that this is a worthy question addressed by a suitable study that yielded limited but fairly trustworthy results (which is to say, like some of the better quantitative studies), we can ponder whether the results will lead to some change—in other words, whether the study is fertile and useful, either prompting further

**Table 1. Steps to Evaluate Qualitative Research**

Research question
Clearly stated?
Important to the care of patients?
Sampling and recruitment
Methods thoughtful and clearly explained?
Limits imposed on generalizability?
Study design
Appropriate given research question?
Design implemented well?
Were researchers' personal biases minimized?
Trustworthiness of results
Internal validity
Methods described thoroughly?
Clear presentation of evidence?
Convincing conclusions?
External validity
Corroborated by other information sources?
Member checks performed?
Fertility and usefulness of results
Will they spur or spawn further research?
Can they be extrapolated to my patient?
Will they change my clinical practice?
By direct application?
By adoption of analogous qualitative learning methods?

and better research, or improving the care we provide patients. For practitioners, this can be rephrased as a clinically relevant question: Given these results, what if anything should we do differently?

Here we have at least two complementary options. One is to use the results directly to generate hypotheses, not for the purposes of scientific research but rather in the pursuit of improved understanding about individual patients. Clinicians cannot start from scratch with every new patient, with regard to either the science or the art of medicine. Just as good quantitative clinical trials supply necessary guidance about diagnosis and therapy, qualitative studies can provide an entry for the clinician into an informed appreciation of the unique world of a specific patient. An expedient leading question, for instance, when talking with a diabetic patient who has had a hypoglycemic reaction might be along the lines: "I know that for some people with diabetes, these hypoglycemic spells create conflict between themselves and people at home or at work. Is that true for you? Are these spells affecting your life in any other way?" This directive approach may allow us to cut to the clinical chase, but does less than one might hope to expand and deepen the therapeutic dialogue and agenda.

The other option for using the results of this and other qualitative studies, therefore, focuses less on the specific results and more on the method.<sup>32</sup> Here we return to that central tension and the choices it presents. In part, the goal in clinical care is to generalize: to abstract sufficiently so as to identify in the patient's particular symptoms and signs the pattern of a disease, or to categorize the patient in a group of similar patients who benefited from a certain treatment. As important, though, clinical care must also move in the opposite direction and (if you will) "particularize": to explore issues of physiologic impairment, functional disability, and societal handicap in the context of this particular patient. Many would endorse this drive to particularize as a move toward patient-centered or relationship-centered care.<sup>33-35</sup>

In this endeavor the clinician, whether caring for an individual patient or more generally a group of patients within a particular clinical setting, should ideally ascend a productive learning curve. Adopting certain aspects of qualitative research methods (which we might then call "qualitative learning methods" so as to differentiate them from the more rigorous research endeavor) can potentially steepen that curve.

For starters, promoting a similar process of "storytelling" and "exploring meaning"—and using it in a consciously reiterative manner so that each interview cycle of "ask-listen-think" ideally leads to a better subsequent cycle (which is a standard goal in qualitative research)—is one means to learn more about patients' experiences. Although only a thesis that needs further proof, storytelling quite possibly opens a door for patients and doctors alike.<sup>36-45</sup> As it invites entry into more private areas of our lives, giving patients the opportunity to tell a story provides a way for them to indirectly raise personal issues, a route to express

hard-to-articulate feelings or worries, a method of starting a dialogue over the meaning of events in their lives, a means to access the simple therapeutic qualities of asking and listening. Treating each patient as unique and being fully open to variations on typical patterns and perhaps surprising differences in beliefs or reactions, are two crucial qualities of qualitative research methods—and of good clinical care.<sup>46</sup>

Alternatively, one might adopt the focus group method.<sup>47,48</sup> For instance, all the diabetic patients in a clinic could be invited to join in a facilitated discussion about their experiences with hypoglycemia. Sharing stories with each other, for many patients, is a supportive activity. Furthermore, in a few hours a keen observer is likely to discover a remarkable amount about the problematic issues, key concerns, and shared values in that specific group of patients at a level of knowledge that is local, pertinent, and useful.<sup>49-52</sup>

The clinical goal, whether using individual or group qualitative learning methods, is to follow a curve of understanding as unique as the individual patient. For in medicine, we operate with instances, contingent and case-by-case, no matter how evidence-based our broader knowledge may be. With each patient encounter, we struggle—if not literally on bended knee, then figuratively so—to couple our evolving knowledge of general medical principles with our emerging understanding of individual patients. Good qualitative studies provide one means to tie these two pursuits together, while engaging in a thoughtful dialogue provides another, as we seek to unite the unique with the universal in the "completely personal" care of patients—**CHRIS FEUDTNER, MD, PHD**, *University of Washington, Seattle, Wash.*

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