The Many-Voiced Cultural Story Line of a Case of Diabetes Mellitus

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An ethnographic approach is used to conduct and describe my research into a case of chronic illness and to assist the family physician's interventions. What at first appeared to be a frustrating, difficult-to-control case of diabetes mellitus was later revealed to be an intricate drama involving multiple voices and issues: marital, life stage, family, religious, occupational, regional, economic, and physician family-of-origin. Questions such as who has the disease?, what is the disease?, what keeps the disease going?, who is the patient?, and who is the clinician? are explored in the context of this case. The case was "solved" when the loss and sadness of aging was discovered and accepted during a cathartic session involving the diabetic patient, her husband, their family physician, and myself, a consultant.

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At grand rounds, case conferences, hospital morning report, and other medical meetings, the medical staff routinely begins its discussion of a case with a stylized statement such as, "The patient is a 54-year-old married white female who presented to the emergency room/clinic with symptoms of . . ." Even such simple clinical rituals have a historical background and cultural context. Some contexts are perceived as more clinically relevant than others and thus receive more time and thoroughness. In medicine, organ systems, differential diagnosis, laboratory data, and procedures tend to be the most highly valued. Irrespective of our ritualized clinical recitations and our desire to get on to the best, most challenging part—the biomedical detective's search for elusive diseases (called "zebras")—we know that, whatever else a case might be, it is also an emerging *sequence* of events. Etiology and pathophysiology generally come first; treatment is often squeezed in last. There is a preferred order to biomedical reasoning and to the meetings in which it is conducted. A "difficult" case, therefore, may vex, disrupt that order.

No single case could ever constitute the clinical or any other cultural universe. But it can intimate it, and in so doing, compel us to rethink many of our conceptual and clinical categories. The case presented here is unusual only in that it makes explicit what most other medical discussions keep implicit. It asks such questions as: Where is disease located? Is it contained only within the symptom bearer? What perpetuates the disease or makes it worse? The many voices in a clinical story are allowed to emerge and be heard when questions such as these are asked.

The single case can also challenge us to think about the very texture of our culture, specifically, its relation to disease and healing. In this case of a woman with insulin-dependent diabetes mellitus, we traced the interconnections, together with their clinical implications, between (1) marriage, family, and individual life cycles; (2) religious values, expectations, roles; (3) sick role and pastoral/preacher's wife roles; (4) religion, family, and occupation (here, religion is the occupation); (5) the inner meaning of the physician-patient-family relationship for the physician (particularly with patients whom the physician knows outside the medical context); and (6) aging and culture.

If one were to assign the case as it emerged, it would have "belonged" culturally to such diverse American professional health care entities or disciplines as family medicine, family systems medicine, endocrinology, internal medicine, psychiatry, cultural medicine, geriatric medicine, occupational medicine, marriage and family therapy, even a Balint group. I shall argue, by contrast, that a naturalistic, ethnographic approach was required, one that was open to the many voices that constitute and narrate the clinical story, voices often unknown and unknowable at the outset. There can be no proprietary ownership of such patient

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stories (though there are powerful political, ideological, and economic claims to exclusive possession); there can be only responsibility taken for the tolerance of the anxiety and ambiguity that allows them to emerge.

Within a qualitative, ethnographic framework,[1–8] a single case may serve as a database for building theory. In their practice, physicians use ethnographic methods (usually without labeling them as such) every day to understand patients and their illnesses and to do patient care. Ethnography constitutes "real" research. It is something many physicians do meticulously, unselfconsciously, and quite ordinarily in patient care.

The case study method has a long esteemed history in medicine. It is often said that physicians, like most members of Western society, believe in numbers; that is, they accept as valid only an argument presented in statistical form. Yet physicians conduct much of their work one patient, one illness episode, one case, one examination room at a time. It is from the careful, controlled comparisons of these individual encounters that much medical theory and practice can be advanced. Good physicians know from experience that no patient's history is ever really "taken," that no one arrives packaged as a "case." Rather, histories and cases are constructed and reconstructed and the emergent stories sculpted.[9–11]

Further, even a single case study does not occur in a vacuum. It is sometimes part of a carefully formulated line of inquiry, or sometimes follows an implicit, unconsciously driven agenda. Even when we are unaware of it, our choice of cases (especially "interesting cases," as if the interest were an inherent property of the thing rather than of the clinician/observer) is often based on some prototype we have experienced or one we think we are discovering as a template. We expect it to speak to and for many others, like Herman Melville's novel *Moby Dick* or Robert Frost's poem "Mending Wall." A case gropes toward being a seed crystal. It is an exemplar of something we are often unaware of. Solving one mystery immediately conjures others, to us, and to other practitioners ("I once had a case like that where . . .").

The case that here began as diabetes mellitus and noncompliance, ended up as a multivoiced drama involving many people's lives. It turned into an unsolved mystery about boundaries: what the disease was and where it was located, who had it, who the clinician was, who was father and mother, and who was son. For all its apparent complexity, it is, in fact, a quite ordinary case.

Case Description

Several years ago a family medicine resident discussed with me the case of a 54-year-old woman who had long been a fragile diabetic with high blood glucoses often in the 300 to 400 mg/dL range. I shall call the resident Dr James Marshall. He was becoming frustrated with his patient's treatment. No matter what he did medically to control her diabetes and no matter how hard she tried to abide by the prescribed regimen of insulin and diet, she remained "out of control." As he presented this background information to me, I wondered, "Why this patient? What keeps the disease going, prevents it from being medically controlled? What else do we need to know in order to diagnose and treat the diabetes and its context?" I also wondered what was special, or different, about this case for this resident. I had worked with him for more than a year and had found him to be a meticulous, responsible, compassionate physician.

The patient, Martha W., was the wife of Marshall's pastor, a Nazarene minister. Marshall confided that he felt uneasy dealing with personal, family, and religious matters involving his own pastor: "I'm young enough to be their son," Dr Marshall explained. "Sometimes I feel like I am. They see me both as a son and as a parent figure. And he's my pastor, which makes him a kind of father figure. How am I supposed to tell him and them what to do? Yet they do want me to counsel with them as well as to be Martha's medical doctor."

Marshall's own father, I already knew, was also a Nazarene minister, so there was, in this case, a potential double transference, including a displacement from the physician's own family of origin. I put in the back of my mind that the "presenting complaint" had in fact been made to me by the family physician, and that although he certainly was not a patient nor I his therapist, given the circumstances, the focus of my ethnographic and clinical attention must include all three of them.

Over the previous 21 months, Martha had two hospital admissions for insulin reactions, and 13 office visits with Marshall at the family medicine clinic. He had gone out of his way to have long office and hospital visits with her. Early, he had referred Martha to a hospital dietician for diet instruction. Although Marshall often recommended a split dose of insulin, she usually took only her morning dose (40 units NPH). She treated her foot ulcers with povidone-iodine wet-to-dry dressings twice a day. When she had hypoglycemic spells (feeling nervous and weak, usually occurring in the afternoon and at night), she would take sugar to compensate.

Marshall met with the patient and her husband at Reverend W.'s church office to review their Beck Depression inventories and to discuss life stresses with them on their own home ground. Marshall had suggested to Martha the idea of counseling with someone outside his clinic, but she adamantly ("sternly," to use his term) rejected the idea. She accepted counseling only with him.

When the couple met with Marshall in the clinic, he brought up the idea of meeting together with me in the family medicine clinic. They agreed to this.

Marshall had told the couple that I was a behavioral science consultant to the residency program, that I myself had a lot of interest in religion, and was respectful of people's beliefs, and that he needed help in their counseling since he found it difficult to be as direct with them as with other patients because he was also their parishioner. They were respectful of his wishes and accepted my presence. The physician had invited me to serve as a cotherapist. I agreed to listen to the interplay and to offer comments during the session, provided that Reverend and Mrs W. concurred with this arrangement as well. For the first half hour or so, I mostly observed the interaction between Marshall and the couple. Now and then he interrupted his visit with them to explain something to me, for instance, about Nazarene values, pastoral visitation, or medical indications.

Martha had been married for the past 35 years to Reverend W., a Nazarene minister. She had been an insulin-dependent diabetic for most of their married life. In recent years her condition had worsened considerably. She developed near-blindness in one eye and a number of small ulcers on her legs and feet. She did not have the energy she used to have. Yet she expected herself, and was expected by her husband and their church, to be early to and present at all church functions.

During the past few years she had experienced a series of stressful events. Martha's best friend had died from diabetic complications. Reverend W. had quit his unlucrative pulpit to go into a furniture business. This business had failed largely because of the depressed Great Plains economy (based on wheat, cattle, land, oil, and gas). He then had become the associate pastor in the Nazarene church in a rural Great Plains town. Their last child, a daughter, had abruptly left home and eloped unannounced. Martha complained to her family doctor that her husband was often gone from the house for long hours. He was either at church or making frequent pastoral calls to parishioners' homes. Sometimes she wondered whether he was having affairs. Moreover, it was virtually impossible for her to express her anger or resentments toward her husband. Both her husband and Marshall wondered whether she was paranoid. According to Martha, Nazarenes value generosity and kindliness and do not harbor, let alone show, anger. Thus, she should not have had these feelings in the first place if she were a truly devout Nazarene.

Moreover, Reverend and Mrs W. had also made loans of large sums of money to their children, who kept requesting more. The parents felt sad at having to turn their children down. They said it was difficult for them to be angry with their children for their constant demands.

Martha explained to the physician that a model wife is expected to be long-suffering and tolerant, not to get angry, not to make demands for herself, and not to be critical of her husband. How dare she, she asked herself and heard the church asking her as well, criticize her husband who was so devoted to his church? To do so would only reveal her selfishness and un-Christian attitude, and how would that look to the church and community (a conflict, I might add, familiar to many physicians' spouses)? It would reflect badly not only on her, but on her husband—and this was the only job he could find for now. The home and occupational (church) situation was compounded by her husband's relationship with his superior. The senior pastor appeared to Reverend W. as exacting, tyrannical, driving, and demanding; as someone who insisted his associate be at his beck and call as an obedient subordinate. Reverend W. characterized his boss as "a little Hitler." He was constantly sending him on errands and making new work for him. Reverend W. feared being fired by him and could not imagine refusing a request or setting limits.

Getting ready for church was an ordeal for Martha, and Reverend W.'s good nature was severely tested at these times. They often got into struggles for control, especially in recent months. She needed increasingly more time to have her orange juice, to adjust her insulin (months of visits to the family medicine clinic involved insulin adjustment that never quite seemed to work). At the same time, her husband needed to get ready for church and arrive there early.

Increasingly, Martha resented his pastoral demands. He, in turn, increasingly resented her disease and the demands and limitations it put on him. Finally, feeling at the breaking point, Martha said to him that if he must get to church early (pressured by his boss), he could go alone, even if the church congregation gossiped about it. She resolved she was not going to kill herself for the sake of his pastorate and the church. He could not accept her diabetes; she could not accept his church commitments and obligations. I asked them to try to recall the last time they had been happy together. For a moment a burst of sun entered their emotional storm. They answered: "When I [or he] was in the furniture business. I [or he] was able to be more independent." They said that at the time they had felt many years younger, too.

Early in our joint meeting, I was immediately struck by how aged, frail, and tired they both looked. But their words, their ostensible mood, and their posture told a different tale. For much of the first part of the session they bickered constantly, argued over virtually anything, sometimes inclining themselves away from one another and leaning toward Marshall or me, or grimacing angrily when facing each other. Much of the conversation was

acrimonious. It felt as if a monumental struggle for control was going on, not only between them, but for Marshall's acceptance and affection. I could feel the "sound and fury" of the pace that the pastor was trying to keep and that his wife was struggling both to keep up with and to resist.

I wondered whether this vying for vindication was an attempt to flee from the recognition that they both were aging, that they were not 20 or 30 years younger. It was as if each had projected aging, if not death, onto the other in order to sustain denial. I gently confronted them with a disparity I was seeing over and again played out between them. I said something like:

"I keep listening to your words, and hear your anger, resentments, even your rage. Yet as I look at you both I see also how aged and weary you both look. I wonder whether you might be fighting that realization in all your quarreling? I hear a great sadness and disappointment in your bitterness."

It was a cathartic, unexpected, powerful moment for all of us. Struggle melted into sadness and quiet tears. The couple realized they were trying strenuously to live as if they had no limits on their bodies or their aspirations, that tragedies could be undone. Each had made the other the enemy to avoid feeling his/her own sense of loss and grief. The remainder of the session was quieter, more serene, reflective. There were warm silences of mutual recognition.

During the session, I also carefully explored with them the "real" and "imagined" aspects of Reverend W.'s relationship with his chief minister, who was unable to set limits on himself or others. How real was Reverend W.'s fear that he could be fired at a whim? Was he utterly a victim of circumstance and had no choice?

During the latter part of the session, Reverend and Mrs W. began to express anger and disappointment, less about and toward each other than about themselves, their circumstances, and the unfulfilled hopes they had for their own lives. They began to grieve for their aging, for what they had not been or done. They realized they were not only bewildered and hurt by their last daughter's abrupt departure, but that it had been a kind of "last straw" that rudely reminded them of time and limitation.

Follow-Up

This joint session, and future individual or joint sessions, helped reduce projection and opened more emphatic communication between the couple, which they continued at home. Some weeks later, Reverend W. reported to Marshall that he had drawn the line with his senior pastor, while keeping the latter's respect and his own job. Gradually, too, Martha's diabetes came under better control. It was still quite "fragile," but the blood sugar swings were not as wide or as frequent.

In the months following the joint meeting between Marshall, Reverend and Mrs W., and myself, Martha's diabetic ulcers healed almost completely, and her blood sugars were brought down into the low 100s. She was on 35 units of NPH insulin in the morning. The couple courageously talked their situation over with church members, who purchased an Accu-Chek glucometer for them. Instead of feeling compelled to solve everything for themselves, in isolation, they found they could count on others in their church to help them. They both described their home situation as improved.

Subsequently, Marshall and I began to understand the double transference, so to speak, that had ensnared him: the church family and his family of origin. Not only were Reverend and Martha W. father and mother figures, but his own parents were Nazarene minister and minister's wife. Marshall suddenly felt himself to be back in his childhood home again, and was, to a degree, paralyzed. The entire case, in fact, could be seen as a metaphor for the struggle between dependency and separation, both as wish and as fear. How could (or dare) he clinically achieve with parent surrogates (who are likewise endowed with the authority and service of God) what he must not do toward his own parents?

He explained that from his family's experience as well as his patients', there are few financially successful ministers and ministerial families in the Nazarene church. There are those individuals who become what he called "super preachers" with a big church and a large enough income to be able to squirrel away money for retirement. Reverend W., whose style and duties are more those of pastor than pulpit preacher, is one of those who are left with the "small stuff," that is, parishes that often barely make it financially. Marshall emphasized to me that in his church preachers are much like salesmen. That is, emphasis is placed on youth, dynamism, the "big sell" to parishioners: "You make it big, or you're out to pasture." In his experience, the more individualist Nazarene Church makes no provisions for caring for its pastoral elderly. They must fend for themselves. Financial independence is highly valued, but it is elusive. He wanted to help, not abandon, his ministerial surrogate "parents" who felt abandoned in many areas of their lives.

Discussion

Customarily, medical case presentations begin in the clinic or hospital emergency room with the patient's presenting complaint. Entering the clinic examining room, for instance, a physician might open with "What brings you here

today?" The patient might answer with a series of signs and symptoms. In the case under discussion, the presenting complaint was voiced by the physician to me: namely, his interpersonal difficulty in telling a pastoral couple what to do. The patient's diabetes, and her associated difficulties, medical and otherwise, were for the moment secondary. Thus, for me, the case began with the physician's conflicts over authority and role and reawakened Oedipal issues played out within the uncertain boundaries of religious and occupational responsibilities, which had caused a kind of paralysis in the physician's ability to fulfill his clinical role.

The unfolding of the case revealed the breadth, depth, and texture of human culture, present even in the tidy role-compartmentalizations of secular, postmodern society. Displacements, projections, condensations, reaction formations—the stuff of dreams and culture alike—gave texture to what at first seemed fragmentary. It became clear that, although the disease entity, diabetes mellitus, existed in Martha W., her own personality and its interweaving with marital, family, occupational, community, religious, and economic processes both sustained and exacerbated her disease. What was perceived initially as *her* disease was also a symptom of and metaphor for a much wider systems pathology. One facet of the treatment lay in defocusing (and in discovering the need to defocus) on her, and focusing temporarily on her husband, his own conflicts over authority and the religious/occupational and economic situations in which he and others in the Great Plains region were mired.

Yet another, and for me, the consultant, the most fundamental, facet of the treatment, was the family doctor's emotional response (countertransference) to the couple. The case actually enveloped the doctor-patient-couple-church relationship. My first task therefore was to help Marshall to identify and disentangle his emotional involvement in the case. Harold Searles[12] emphasizes how analysands (patients in psychoanalytic therapy) often stretch their analysts therapeutically to levels of integration previously absent.

Early on, I realized that the case resonated of my own life as well. I, too, have struggled with deep and turbulent religious currents streaming from my Jewish upbringing and family. How could I objectively tell either this physician or this pastoral couple the "right" thing to do! After all, rabbis, cantors, and two centuries of Hasidim (pious men originating from a religious movement in Poland) occupied my human pantheon. This case forced me to rework, to refeel, many of my own unfinished struggles with issues of separation-individuation, Oedipal strivings, and human authority in occupational settings. All four of us had our personhood contained within the case. I used my own emotional response to understand that of my colleague and thus helped him to help this couple in distress.

Conclusions

The case described in this paper epitomizes difficult, frustrating physician-patient-family relationships. It is unique in its details but not in its complexity. It reminds us that cases often have numerous voices that exist behind the disease process, and the knowledge of them is a crucial part of a more complete diagnosis and treatment plan. Moreover, it supports recognition and use of the ethnographic method in medical care, where each clinical case is itself a research project.

The case presented, based on the ethnographic clinical methodology, advocates that certain questions be generalized and applied to virtually all cases, but especially to cases involving chronic illnesses and "difficult" physician-patient situations. Such diagnostic questions include: Where else is the disease located? Is the patient a symptom bearer for a larger system such as his or her family? What keeps the disease going? What makes the disease worse?

Answers to these diagnostic questions usually cannot be offered directly. A good physician infers them as he or she, together with the patient, family members, and others, pieces the hidden puzzle together. Paradoxically, even in this expanded framework, effective treatment consists not only of arriving at the right diagnosis (specifically one that is both inclusively broad and deep enough) but also explaining it in an idiom that both the patient and family can translate into their own experience.

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