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The Patient's Voice in Medical Education: The Family Centered Experience Program

Arno K. Kumagai, MD

Within the intimacy of the patient-doctor relationship, there is a deceptively simple but profound interaction: one human being uses his or her training, knowledge, and skills to alleviate the suffering of another. Profound, but not simple. Misunderstandings and mistrust abound.

“He’s angry and noncompliant.”

“My doctor’s a quack.”

“She doesn’t seem to care what happens to her.”

“My doctor never listens to me.”

Difficult clinical interactions may arise in part from problems in communication, but that’s not the whole story. An even greater barrier to common understanding exists. Patients and doctors often see the same thing—the problem with which the patient is afflicted—from two very different perspectives. For doctors, it is a *disease*, a physiological disturbance that can be understood and treated through biomedical theories and their applications. For the patient, it is an *illness*, the subjective experience of being sick [1]. These two perspectives are frequently expressed in very different languages: the language of disease is dry, scientific, statistical, rational, and impersonal; the language of illness is intensely personal and individual and expresses itself in terms of discomfort, suffering, and loss. American essayist Susan Sontag—herself a breast cancer survivor who ultimately succumbed to lymphoma—once wrote:

Illness is the night-side of life, a more onerous citizenship. Everyone who is born holds dual citizenship, in the kingdom of the well and in the kingdom of the sick. Although we all prefer to use only the good passport, sooner or later each of us is obliged, at least for a spell, to identify ourselves as citizens of that other place [2].

Modern medicine has become increasingly focused on treatment of chronic illness. Providing this care effectively requires an ongoing collaboration between the patient and doctor to which each brings his or her expertise. The doctor’s expertise is conferred by years of study and training; the patient’s consists of the “lived expertise” of having a chronic medical condition. At the University of Michigan, we believe that an essential part of physician training is an understanding of, and

openness to, the patient's perspective, and through the Family Centered Experience (FCE) we hope to provide temporary entry to this "kingdom of the sick."

Family Centered Experience

Launched in the fall of 2003 as part of a new medical school curriculum, FCE is a required 2-year course in which pairs of first-year medical students are matched with volunteers in the community who have serious or chronic medical conditions [3-5]. Volunteers are not only diverse in their clinical conditions, but also in race, ethnicity, gender, sexual orientation, family structure, and educational and socioeconomic background. During the first 2 years of school, students visit the volunteers' homes for a series of conversations based on different themes pertaining to the experience of illness, such as the impact of illness on the self and family; the relationship between patients and doctors; receiving bad news; stigma and illness; and resources and obstacles in accessing and receiving health care. Following each visit, students meet in groups of 10 to 12 with a clinician-educator to discuss observations, thoughts, and insights from their visits. To foster and maintain a safe environment for discussions of highly personal or emotionally charged issues, the groups and their instructor remain the same throughout the 2-year course.

The basis of the FCE is the stories that individuals and families tell of illness and its care. Stories are arguably the most powerful means that human beings have for passing down wisdom gained through struggles, challenges, and experience, and the FCE wishes to harness this power to enhance empathy and transform perspectives of physicians-in-training toward more patient-centered, humanistic clinical practice [4]. We believe that the power of these stories derives from their ability to stimulate both affective and cognitive learning (to touch the heart and the head) and to link with fundamental social and psychological processes: self-reflection, perspective-taking, and identification with another individual who is different from oneself [4]. Studies of students in the program suggest that the knowledge they gain from their conversations with volunteers differs from that acquired through traditional lectures or textbooks; it is personal, highly individualized, and rooted in specific social and familial contexts [3, 6]. Students learn to treat patients as individuals and not merely as diagnoses and test results.

Among the several essential features of the FCE are (1) the establishment of a long-term relationship of trust and rapport between medical students and volunteers; (2) a place of safety and support in which students may discuss their thoughts and impressions with a small group of peers; and (3) the close relationship between students and clinician-educators who serve as advisors, mentors, and role models of humanistic care. In this learning environment, there is also a major shift in the roles of faculty and students from the traditional "top-down," expert/novice model to one that respects the personal beliefs, values, perspectives, and experiences each individual brings into the classroom. In essence, the small groups are engaged in truly collaborative learning—from their volunteers, instructors, and each other. Interestingly, the impact of these discussions on the instructors themselves has been profound. In one study, the FCE instructors described being continually inspired by

their students' idealism and reported that interactions with students had led to great personal and professional growth and development [7].

Despite the best intentions and effort, challenges still arise. Some students and volunteers have difficulty talking about suffering, death, and dying; some students are skeptical about learning such "soft" or "touchy-feely" subjects; other coursework and exams make competing demands; and the pace of medical school often discourages taking time for quiet thought and reflection. We encourage students to address these and other challenges in the small groups, where, instead of being passive recipients of knowledge, they become active agents in their own learning.

From FCE to Good Doctoring

How do these activities help train doctors to handle difficult clinical situations? We believe that by adopting a clinical approach that validates the patient's perspective and experiences and incorporates a critical regard for the assumptions one makes when encountering someone who is different from oneself, students learn to avoid some of the pitfalls and misunderstandings that arise between patients and doctors. Furthermore, by assimilating lessons learned about breaking bad news and the stigma of illness and by expressing compassion for the true experts—those living with illness—we may tailor our care to fit the specific interests and expectations of those in need. We may learn that the seemingly difficult patient may be reacting to a lifetime of mistreatment and humiliation; the noncompliant patient may not be taking medications due to a lack of clear explanation or insurance and financial means; and the apathetic patient may be distracted by other, equally important issues (e.g., losing a job or home, worries about safety in a violent relationship, concerns about keeping his or her children healthy) and cannot give sole attention to our recommendations and instructions. By listening, we learn. Through thoughtful reflection and empathic identification, we may both treat and heal.

Brazilian educator, Paulo Freire, has described teaching as the practice of freedom [8]. The purpose of the Family Centered Experience and similar programs is not to teach compassion or idealism. These are qualities that beginning medical students have in abundance. The purpose of these efforts is to use stories and conversations, as well as reflection and discussion, to allow each student to fashion his or her own way of working with human beings. At the heart of medicine lies the notion of justice: to treat patients as individuals with all of the richness and complexity that each possesses as a human being. By rehumanizing medicine, we may work with, rather than against, our patients in relieving suffering and providing care.

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Arno K. Kumagai, MD, is an associate professor of internal medicine and medical education and the director of the Family Centered Experience program and Longitudinal Case Studies course at the University of Michigan Medical School in Ann Arbor. He is also the director of the Intensive Insulin Therapy Clinic at the University of Michigan Diabetes Center and has clinical and research interests in management of type 1 diabetes, narrative medicine, multicultural education, and the patient-doctor relationship.

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