Family Narratives, Culture, and Patient-centered Medicine

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Background and Objectives: As part of our family medicine clerkship seminar on the patient-physician relationship, third-year students write about an illness episode within their own families. Methods: Using a grounded research approach, we examined 260 student narratives to extract the most significant meanings. Results: Significant themes that emerged include the role of family members in illness episodes, specific influences resulting from the family's ethnicity or religion, experiences with socially unacceptable illnesses, experiences with death, appreciation of the moral trajectory of illness, and situations that display the fallibility and limitations of medicine. Conclusions: Writing exercises can help students recognize the centrality of narrative and of cultural values in medicine so they are better able to understand their patients and provide more patient-centered medical care.

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Since 1997, our family medicine clerkship has emphasized patient-centered medicine. Recognizing that writing can encourage students and practitioners to reflect on and enhance empathy in patient care, we assign writing exercises in which students identify multiple dimensions of illness with patients during clinical encounters and write about an illness episode within their own families.

The overall purpose of the writing exercises is to improve the students' appreciation of patient explanatory models, cross-cultural issues, the central role of narrative in patient care, and, ultimately, to improve patient-doctor relationships.

Methods

Our medical school is a minority institution, with 25% Pacific Islanders and 61% Asians among its students. Between April 1997 and June 2002, 260 medical students have participated in the writing assignments. The assignments are part of a four-session seminar on the patient-physician relationship conducted in our family medicine clerkship.

Writing Assignments

Students are instructed to portray their family dynamics, outline their families' beliefs about illness, note the influence of those beliefs on the course of the illness or treatment, and delineate the influence of their families' values on their views of the practice of medicine. The writing assignments range from two to five pages in length. The students then present their narratives in a small-group session of family practice clerks, led by the authors (a PhD faculty and Buddhist priest, two MD/MPH clinicians, and a cultural anthropologist who has attended sessions as a participant-observer).

Analysis

Using a grounded research approach, all four authors met monthly over a period of 6 months to discuss themes that emerged as important from a medical education standpoint. Between the meetings, we reflected again on the contents of the narratives, applying a hermeneutical method of interpretation, moving from part to whole and back, to extract the most significant
meanings from the students’ essays. Disagreements in interpretation or emphasis among the authors were resolved through discussion.

Results

Seven themes were found to be most expressive in terms of increasing self-awareness and most relevant to improved patient-doctor relations. To protect the confidentiality of our students and their families, we do not focus on the actual illness episodes. Rather, we convey their conclusions and reflections on what they have learned, as they reported such in their essays. To maximize the number of voices heard in this paper, each quote comes from a different student, each of whom has consented to being quoted.

(1) Roles of Family Members in Illness Episodes

Illnesses often unfold within a preestablished family context, so that roles played by family members often reflect premorbid family functions, while communicative styles within families continue to shape interactions.

"Illness in my family is private. Disease is private... perhaps the reason that sickness is guarded is that we perceive it as a character flaw."

Other narratives note changes in family roles as a result of a member’s illness, particularly when an illness is serious.

"For me it was one of the most upside down feelings because it was forcing a necessary change in the dynamics of our family. The person that had always been the leader and the helper and the caregiver now needed care and help from us. It was uncomfortable giving him help, and he was uncomfortable receiving it."

(2) Ethnic-specific Influences

Students perceive various aspects of their family responses to illness as deriving from their family’s ethnicity, although a noteworthy response was for students to insist on the unique cultural configuration to be found within their own family.

"Some Japanese families believe that being sick is punishment resulting from some wrong committed by the individual or bachi [Japanese: divine punishment]. My family does not share this view."

"We have not tried even the most common alternative or Chinese modes of treatments."

Other students, however, noted ethnically specific values and practices in their families’ responses to illness, as when one ill Hawaiian-Portuguese grandmother insisted on her granddaughter going to a family reunion, wanting her to develop an appreciation of her grandmother’s life experience. In another narrative, the death of an elderly Hawaiian grandparent becomes a celebration, with the entire family engaged in music and feasting. Students with Asian heritage frequently reported a strong respect for the elderly, maintained despite debility or disability, along with a strong value of family unity. However, valuing respect highly could also inhibit open communication within the family, as one student noted:

"Directly asking any of my uncles and aunts, let alone my mother and grandfather, how they were feeling would also be inappropriate in that it would show a lack of observing the proper roles within a family."

Language use and expression were other reminders of ethnic influences. Although uncommon, idioms resistant to translation do appear, reminding students that core values of another culture often defy simple translation and may elude a caregiver’s understanding. Likewise, many narratives include the use of healing techniques belonging to the family’s ethnic heritage, such as native Hawaiian medicine, Chinese herbs, tai chi, acupuncture, or Japanese spirit mediums.

(3) Religion

One of the most common themes, occurring in one out of five essays, was the importance of religion, prayer, and rituals within the family. Praying was sometimes recognized as a central part of therapy—that forgiveness or a miracle was needed for a cure:

"[My grandfather] believed that asking forgiveness to those that might be responsible was necessary before one would be able to heal oneself... My grandfather believed that it was the ho‘oponopono [Hawaiian: a sense of balance and rightness] that cured him and not the antibiotics."

Although Grandma previously considered herself a Buddhist, she accepted Christianity after her diagnosis [of cancer] and started visiting a religious friend for prayer. Grandma was told by her friend that she had to forgive those that have wronged her and to let go of any anger she had toward anyone before she could find peace.

The offense of ancestors was noted above as a specific ethnic theme, while illness as divine punishment is also found in some Christian traditions:

"During many of my childhood illnesses, I thought God might be punishing me for my sins and that if I could only have been a better Christian, then I would not be sick."
(4) Experiences With Socially Unacceptable Illnesses

Illness can have private, shameful aspects. Students recognized that relatives sometimes perceive illness as "moral failure" and consequently refuse to discuss their illness or to name the condition from which they suffer, preferring general terms such as "old age" over clinical designations such as "Alzheimer’s" and recognized that relatives tried to avoid diagnoses of mental disorders, substance abuse, or alcoholism in their families.

We don’t talk about Grandma’s illness, her degeneration, as a family. We haven’t named it, acknowledged it. We watched Grandma progress to the state she’s in now, even though she saw doctors who told her it was Alzheimer’s—that there was nothing they could do. So we did nothing. I guess that feeling of helplessness, fear, and impotence is part of what is holding us back now.

Besides being identified as a “weakness” or “fault,” Alzheimer’s disease was perceived in some cases as a dishonorable condition or as a “sinister force.” However, the most serious approbation was reserved for mental disorders, which Asian-American families appeared to find particularly difficult to accept:

Mental illness is a taboo subject, and it happens to others, not to our family . . . For example, my uncle did not receive help until his paranoia threatened others at work, while he had paranoia symptoms that threatened his family months prior.

Other students recognized that alcoholism and other forms of substance abuse were particularly difficult to accept as medical problems.

I never talked to my older brothers about my father’s illness. My understanding of his problem was just that: it was his problem. (italics in original)

(5) Experiences With Death

One third of the cases addressed the death of a relative, making this the most common type of episode about which students chose to write. Most often, the death of a grandparent was discussed, as would be expected from the age of medical students, but there were also narratives about the deaths of parents and siblings.

My grandmother was one of the great pillars of my family. She raised me and many times was my primary caregiver. She taught me many lessons in life. Unfortunately, none of those lessons involved teaching me how to cope and understand the death of my instructor, herself. It was not until after her death did I realize that I did not just lose her but also a part of myself.

The possibility that life-threatening illness may lead to irrational behavior by family members, a crucial lesson, was explored by one student:

In a desperate attempt to delay the inevitable, two educated, rational people grasped at whatever straws they could . . . Perhaps it wasn’t just a cure that my aunt and uncle searched for outside of Western medicine. I think they sought compassion, a listening ear, validation, and reassurance that were not found in oncology, gastroenterology, or radiation therapy. I think the thing they sought most was hope.

In a case involving an initial misdiagnosis and poor medical care resulting in a father’s death:

The experience has taught me the limits of medicine. I have also learned that even if end-of-life issues have already been discussed, it is still very hard for the family to carry out the desired wishes.

Crucially, students learned from the death of relatives the ultimate limits of medicine:

My father’s death was the single most important evidence of the limitations of modern medicine to me. We, as physicians, cannot cure everyone.

(6) Appreciation of the Moral Trajectory of Illness

From our perspective as medical educators, some of the most interesting essays were those demonstrating that students understood the ways in which illness plots its moral and aesthetic trajectory through entire families. This trajectory may have a serious influence on outcomes, as one student noted:

I believe my grandma’s outcome would have been very different with a very different family. Basically, a family can create, make, or break one’s illness. I will focus in the future on what role the family may play in my patients and alter treatment accordingly.

Another student observed that her grandmother’s refusal to name her progressive neurological condition appeared as part of an “almost delusional pursuit of normalcy.” In one family, where the father was a physician and the mother was a nurse, illness was nevertheless still something “we never really talked about.” Frustration and self-doubt are also part of the moral trajectory of an illness in the family:

I began to feel like my Mom was somehow hindering her progress by just laying in bed all day, what I interpreted as ‘weakness and focusing on the pain.’ We felt angry when she did not want to take the painkillers since
she claimed, ‘I don’t like to take medicines if I can still tolerate the pain, because all medicines have side effects.’ I began to question why I wanted to go to medical school when I was helpless in helping my own mother.

Finally, students recognized that the general lessons learned within their own family could be generalized to future patients:

Just as my parents’ past influences shape their views about illness, I realize that each patient will have his or her own set of life experiences that will determine his or her views and approaches to illness.

(7) Fallibility and Limitations of Medicine

Recognition of the limits of medicine sometimes developed into a critique of the present-day US health care system, when students reported on problems of access to medical care, the use of unfamiliar jargon by physicians, and conflicts with individual physicians. The cost of treatment was an important lesson:

Medicine has its price, which to some may be frightening.

Some noted cases involving misdiagnosis and mistakes in treatment, charting the painful learning process in such circumstances.

I don’t think any of us really realized that all care facilities are not made equally and that all nurses are not necessarily trained equally.

I was appalled at the complete incompetence of the entire hospital staff.

Another way in which the moral dimension of illness is manifest is in the interactions that the students have with physicians. While some of the doctors that they have encountered have earned their respect, more often students report wanting to improve over the physicians that they have met:

I was visiting my grandmother with some other relatives. A medical student and intern popped into the room to answer any of our questions. The medical student gave a complicated explanation full of medical jargon when my 16-year-old cousin asked a question. . . . I made a mental note not to follow this example in my future practice.

I watched these doctors out of hope that I would see something that I wanted to mimic, skills I could practice. Yet, the more I watched, the more disturbed I became. Not once did I see his doctors sit next to him, shake his hand, give him a hug, or ask about his two young children. Not once did they ask him how he felt or what it was he wanted.

Discussion

Davidoff notes: “Even at its scientific best, medicine is always a social act.” Biomedicine is itself a cultural system, with its peculiar set of norms, attitudes, and moral logic. Alternative models of organizing knowledge are generally not acknowledged in the medical setting and are even losing ground in the psychiatric setting. Caught between the lay world and the biomedical world, medical students learn to adopt a professional gaze during their education and subsequent training. By the time that they are third-year students, most medical students are heavily invested in the biomedical model. To counter this trend, we encourage students to develop their skill at listening to narrative. We seek to develop student self-awareness of the socialization process by which physicians in training adopt the biomedical paradigm and to change this transformation from an unconscious one to a conscious one.

All illness episodes are initially communicated as narrative, giving them an aesthetic quality. By having students narrate episodes of illness in their own families, students begin to appreciate the aesthetics of narrative. Significant themes that emerged from our examination of student narratives include the role of family members in illness episodes, specific influences resulting from the family’s ethnicity or religion, experiences with socially unacceptable illnesses, experiences with death, appreciation of the moral trajectory of illness, and situations that display the fallibility and limitations of medicine.

Putting such experiences into words may allow students to develop greater emotional capacity, with attendant benefits to the health of the narrator. To the degree that this exercise allows students to recognize the pain revealed by such episodes, we hope that their confidence in their ability to heal is strengthened. Future research will need to determine if exercises such as ours allow students to indeed develop such capacities.

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