

Personal Illness Narratives: Using Reflective Writing to Teach Empathy

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ABSTRACT

Reflective writing is one established method for teaching medical students empathetic interactions with patients. Most such exercises rely on students' reflecting upon clinical experiences. To effectively elicit, interpret, and translate the patient's story, however, a reflective practitioner must also be self-aware, personally and professionally. Race, gender, and other embodied sources of identity of practitioners and patients have been shown to influence the nature of clinical communication. Yet, although medical practice is dedicated to examining, diagnosing, and treating bodies, the relationship of physicians to their own physicality is vexed. Medical training creates a dichotomy whereby patients are identified by their bodies while physicians' bodies are secondary to physicians' minds. As a result, little opportunity is afforded to physicians to deal with personal illness experiences, be they their own or those of loved ones.

This article describes a reflective writing exercise conducted in a second-year medical student humanities seminar. The "personal illness narrative" exercise created a medium for students to elicit, interpret, and translate their personal illness experiences while witnessing their colleagues' stories. Qualitative analysis of students' evaluation comments indicated that the exercise, although emotionally challenging, was well received and highly recommended for other students and residents. The reflective writing exercise may be incorporated into medical curricula aimed at increasing trainees' empathy. Affording students and residents an opportunity to describe and share their illness experiences may counteract the traditional distancing of physicians' minds from their bodies and lead to more empathic and self-aware practice.

Acad Med. 2004;79:351–356.

TEACHING EMPATHY THROUGH REFLECTION

Among the most difficult tasks of medical educators is teaching students the nuances of effective, empathic interactions with patients. Although a goal of many medical curricula, teaching empathy remains an elusive objective, both for the lack of consensual definitions of empathy and for the lack of effective pedagogic methods to teach it. Coulehan et al.¹ describe empathy as consisting of three distinct components: a cognitive component in which the clinician "enters" the perspective of the patient, an emotional component in which the

clinician puts himself or herself in the place of the patient, and finally, an action component in which the clinician communicates understanding by checking back with the patient. Methods of teaching empathy usually focus on one or more of these components and include teaching communication strategies,¹ reading literature,² and writing reflective narratives.^{3–5}

Narrative scholars posit that the key to empathetic communication is the ability to elicit, interpret, and translate the patient's illness story. Arthur Kleinman calls this model of clinical care "empathetic witnessing."⁶ Rather than technical adherence to any strict format of history taking, empathetic witnessing involves "the existential commitment to be with the sick person and to facilitate his or her building of an illness narrative that will make sense of and give value to the experience."⁶ Indeed, as others have posited, the physician is not only the witness to the patient's story but also oftentimes an agent within the story and even a co-creator of the patient's story.^{7–10}

This article describes a unique exercise that builds empathy through reflective narrative writing. Reflection is a "pro-

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cess of internally examining and exploring an issue of concern, triggered by an experience, which creates and clarifies meaning in terms of self, and which results in a changed conceptual perspective.”¹¹ Narrative medicine scholars have observed that the connections between reflection and empathy are bidirectional (i.e., they affect both caregiver and patient) and mutually nourishing. When doctors or medical trainees reflect on their own lives in medicine and when they inspect the memories and associations triggered by their care of the sick, they become all the more available and useful to their patients. Their explicit awareness of their own feelings and experiences deepens their capacity to respond empathically to patients while their generosity toward patients can prompt them to be more generous toward themselves.^{12,13}

Reflective writing exercises have been used in the education of medical trainees in myriad ways. Critical incident reports¹⁴ and clinical journal writing or clinically based reflection^{15,16} qualify as “reflection in practice”¹² in that the student–writer is asked to describe clinical scenarios in which he or she is on the doctor side of the doctor–patient relationship. Other writing exercises rely upon the student–physician to make an empathetic shift in perspective. For instance, exercises in which students compose letters to patients met in early physical diagnosis courses or write autobiographical sketches of their gross anatomy cadavers rely upon the students’ ability to step beyond the solely medical perspective.^{4,5} Exercises in writing a clinical story from the patient’s point of view or rewriting a patient’s narrative from a first-person perspective^{3,17} encourage students to reduce the emotional distance between self and patient. In the case of first-person narratives, this reduction in distance is accomplished through a signifier change from “him/her” to “I/me” and also through students’ imagination of the patients’ stories and “insertion of narrative interpretations peculiar to their own culturally and morally defined worlds.”¹⁷

These narrative writing exercises require students to reflect upon clinical experiences from either the perspective of themselves as clinicians or from the perspective of the “other” who is the patient or cadaver. Although they all rely on students to draw from personal experiences and life stories, they do not explicitly explore the realities of the trainees’ own bodies. As such, they may reflect the medical establishment’s reluctance to confront the bodily experiences of its practitioners.

PHYSICIANS’ STORIES, PHYSICIANS’ BODIES: REFLECTION AS SELF-AWARENESS

Reflective clinical practice requires self-examination.^{11,12,18,19} The “self” in question is necessarily both the professional and the personal self because clinical practice is informed by both

medical and personal experience. Few medical educators writing about empathetic witnessing or narrative medicine, however, make note of the impact that a physician’s personal identity—including personal and familial illness history, ethnicity, gender, sexuality, class—may have upon their ability to hear, interpret, and translate patients’ stories. Yet, analyses of physician–patient dialogues reveal that the physician’s subject position (i.e., the physician’s personally, culturally, and emotionally situated self) does influence interactions with patients. For instance, the gender and race of both patients and physicians have clearly been shown to affect clinical interactions.²⁰ Narrative medicine as a discipline has reintroduced the “Voice of the Physician”^{6,10} into a profession that traditionally “den[ies] or bur[ies] the personal voice.”²¹ And yet, physicians’ own bodies, and very personal experiences that arise from their bodily identities, have yet to be introduced as an important element of learning professional empathy. Although the field of medicine is dedicated to the examination, diagnosis, and treatment of bodies, the relationship of physicians to their own physicality is poorly understood, if not willfully ignored. In part, their disassociation stems globally from the Cartesian dualism and the ensuing traditions of Western science, psychology, and civilization that privilege mind over body. The distancing of physicians from their bodies, however, exceeds a Western predisposition to dualism. The separation is undoubtedly widened by the fundamental differentiation of physicianhood from patienthood.

As early in medical training as anatomy class, students learn that patients are predominantly defined by their bodies whereas physicians are defined by their scientific minds. It is also in the training process that such attitudes as professional detachment are learned. In gross anatomy, for instance, such distancing mechanisms as the use of scientific language, graveyard humor, and the treatment of body parts as inanimate objects⁵ enable students to disengage their emotions from patients’ bodies and, perhaps, from bodies in general. In later stages, rituals of medical education mandate the trainee’s disembodiment. A classic example is call schedules requiring over 24 hours of duty without rest during which the basic bodily needs of eating, sleeping, bathing, and using the bathroom are made secondary to medical responsibilities.

It can be argued, therefore, that traditional medical training teaches students that what lies below their white coats is irrelevant to their physicianhood. Further, a doctor whose body becomes relevant may risk losing his or her identity as a physician. In the case, for instance, of doctors who are themselves struggling with illness, “the dichotomy of being both a doctor and patient threatens the integrity of the club. To this fraternity of healers, being ill is tantamount to treachery.”²² Physicians’ literature is rife with descriptions of doctors continuing to perform medicine while ill themselves.

For example, a physician experiencing a miscarriage herself describes feeling that she should be at a patients' delivery rather than taking care of her own hemorrhaging: "But my patient is about to deliver," she writes, "I need to be there!"²³ Little space is made for physicians' bodies to experience even normal phenomena like pregnancy. Writer and pediatrician Perri Klass²⁴ writes about her experience of being pregnant in medical school as one in which she "rebelled" against the medical "worldview" of "emergency and intervention."

Yet, there is an alternate literature of physicians' transformations through personal illness, including Oliver Sacks's *A Leg To Stand On*²⁵ and Ed Rosenbaum's *A Taste of My Own Medicine*,²⁶ upon which the film *The Doctor* was based. The transformations that these doctors experienced were not only due to the physical reality of illness itself but also to the role-reversal that forcibly thrust the hitherto mind-defined physicians into their very real bodies. Their experiences were not without shock or resistance. Sacks writes about the horror of being the patient of an insensitive physician, while in *The Doctor*, the character played by William Hurt struggles to maintain his identity as a surgeon even as his colleagues suggest that an ill physician is a liability to their practice. In the process of witnessing, interpreting, and translating their own illness experiences, these physicians become better able to listen empathically for the stories of their patients.

A HUMANITIES AND MEDICINE SEMINAR: REFLECTIVE WRITING IN MOTION

In the spring of 2002 and again in the spring of 2003, one of the authors (SD) piloted a reflective writing exercise in a second-year medical students' humanities seminar at the Columbia University College of Physicians and Surgeons, "Reading the Body, Writing the Body: Women's Illness Narratives." The six-week seminar was designed to enable both male and female students to gain an empathic understanding of women patients by reading patients' narratives while simultaneously developing some understanding of their own personal relationships with illness through the writing exercise. The seminar was part of a larger humanities and medicine series during which all second-year medical students are required to select from among 12 to 14 concurrent seminars. Other seminars offered include film studies, philosophy of death, figure drawing, and the writing of fiction. In both the 2002 and 2003 seminars, only female students chose to enroll in this seminar. A separate article describes the gendered implications of the seminar.²⁷

The reflective writing exercise was designed to allow students to explore deeply their personal experiences of illness. In the initial assignment, participants wrote about either a personal illness experience or that of a family

List 1

Reflective Writing Assignments for a Second-Year Elective Humanities Seminar on Narrative Medicine, Columbia University College of Physicians and Surgeons, 2002–03

2002

- Week 1: Bring to class an idea for your illness narrative, which you will begin writing in class.
- Week 2: Try writing your narrative from the point of view of the ill person's body.
- Week 3: Try writing your narrative in a different form—prose, poetry, or dramatic dialogue.
- Week 4: Try writing about the familial, cultural, or ethnic context of your narrative's ill body.
- Week 5: Write about how the ill person's body is perceived or represented by others—consider writing from the physician's point of view (if there is one in your narrative).
- Week 6: Address the issue of bodily integration into self.

2003

- Week 1: Bring to class an idea for your illness narrative, which you will begin writing in class.
- Week 2: First narrative due.
- Week 3: Try writing your narrative from the point of view of the ill person's body.
- Week 5: Consider writing your narrative in a different form—prose, poetry, or dramatic dialogue.

member or friend. If they chose to write about the illness experience of a close loved one, however, they were expected to write personally (i.e., describing how that illness affected their own lives). Each week, the instructor guided the students to rewrite their text by changing narrative aspects of their essays—changing, for example, the genre, the temporal dimension, or the voice (see List 1). The instructor further asked that the essays in some way react or respond to that week's topic or assigned readings. Each week, a few students read aloud from their work, and these readings along with the weekly texts generated class discussions.

The first year the seminar was offered, each student wrote a total of five essays, based on guidance from the course instructor. The following year, responding to feedback from the first set of students, the instructor condensed the assignment to a total of three essays. Both years, a number of students expanded their illness narratives into longer essays for honors credit.

The writing of the "personal illness narrative" allowed participants to benefit from reflective writing in a new way. Rather than maintaining a clinician's point of view, or adopting the point of view of an "other," this exercise allowed medical students to explore subjective experiences of

illness. Such experiences may critically inform the nature of students' professional caregiving. These illness experiences may be central motivations behind a student's decision to become a doctor; they may limit a student's openness to hearing particular kinds of clinical stories; or they may render some patients' stories difficult to hear because they get "confuse[d] with their own."²⁸ In addition, the process of writing and sharing personal stories may clarify hitherto unexplored challenges or biases—vulnerabilities each physician carries with him or her throughout professional life.

EVALUATION

All 16 students who completed the seminars were approached with an evaluation form consisting of seven questions. Eight students who took the seminar in 2002 were e-mailed the evaluation and reminded of it a week later. Three of the eight students responded. The eight students who took the seminar in 2003 were given the evaluation during the final class session. All eight of these students completed the evaluation. The 11 responses were analyzed together with no differentiation made for year the seminar was taken. Two readers (SD and RC) independently performed content analysis and thematic analysis using an iterative process and arrived at consensus regarding major thematic issues. A summary of the responses follows.

Question 1: How did you choose the topic for your personal illness narrative exercise? Was it about a personal illness or the illness of another? Out of the 11 respondents who answered this question, eight (73%) wrote about personal illnesses while three wrote about illnesses that physically affected another. Students chose their topics based primarily on temporality, narratability, and gravity of experience.

Question 2: Describe the process of writing. Did you consciously structure or edit your writing? How did you select subject, voice, point of view and temporal structure? All 11 respondents answered this question, and the majority of students described their writing process as stream of consciousness, not edited until after writing. As one student phrased it, "I wanted to get all my thoughts out before I get it confused with all the intellectualizing I'm prone to doing." Students also commented that they allowed themselves to be guided by the suggestions of the syllabus.

Question 3: How did you feel about writing your personal illness narrative? A total of 16 emotional states were explicitly described by the 11 students, eight deemed positive and eight deemed challenging. The positive reactions were pride, enlightenment, healing, accomplishment, relief, clarification, a wish to have more time to do such exercises, and growing confidence. The challenging reactions were vulnerability, embarrassment, detachment, exposure, confusion, re-

sentment, fear, and difficulty. "I felt vulnerable yet detached from the experience [of illness]," wrote one student, "I suppose the latter defense mechanism comes in handy when you realize that little separates you from your patients." Many students who described challenging emotions, however, also described overcoming these emotions with time. One student noted, "I felt embarrassed and sometimes resentful. However, I was proud of what I was able to write." Another commented, "It was frightening, enlightening, uncomfortable, and ultimately very healing." In the words of a third student the exercise was "therapeutic and scary."

Question 4a: How did you feel about reading from your personal illness narrative? Ten out of the 11 respondents answered this question, and the majority of responses were similar to the challenging emotions described in the previous question. Students predominantly described emotions of discomfort, including nervousness and a fear of being seen as arrogant or self-indulgent in reading about their illnesses. However, some students described the experience as cathartic as well. "I felt very uncomfortable sharing initially," wrote one student, "but after seeing how supportive our group was I found it helpful to say out loud what I had been thinking about for so long."

Question 4b: How did you feel about listening to your classmates read? Difficulties students faced in reading and writing their own work were not duplicated in the process of listening to their colleagues. The nine responses to this question were all positive. Students felt that hearing each other's narratives opened up new aspects of their classmates not otherwise seen in medical student life. "They opened up a new dimension to themselves that I didn't exactly get to see in anatomy lab," wrote a student. Another noted, "The women in our group were so outwardly strong so it was interesting to hear their vulnerabilities expressed in their pieces." And finally, "Each story touched me and changed the way I perceived the other women, myself, and sick patients."

Question 5: What did you know about your illness experience after writing about it and reading it that you didn't know before? The process of writing and reading allowed the 11 students to acknowledge, and thereby experience, the affective component of their personal experiences of illnesses, even recognizing a previous sense of emotional detachment. The process of writing about illness was, in this way, revelatory for many students. "It had more of an impact on me than I realize, and that there are still things to uncover," commented one. Another observed, "It has helped me clarify my issues, which I've also realized I need to deal with." The exercise gave students a feeling of commonality with others. One student wrote, "I knew before and after that my illness was shameful to me. However, I did learn that I was not alone and that writing could be a reflective experi-

ence.” Another explained, “Although unique, my problems were not uncommon, were not something to feel shameful about . . . by writing about my experiences and reading what others have written, I have been forced to face the pain, embarrassment, and uncertainty that seem common to all our experiences. . . . Although at times I wanted nothing more than to close my eyes, shut my ears and block out the uncomfortably stark reality of my own illness, I learned that a direct and open approach is healing to both the ill and the caregivers.”

Question 6: *Has writing and reflecting on your own illness influenced your understanding of or ability to care for patients?* Nine of the 11 students commented that writing and reflecting on personal illness experiences positively influenced their understanding of or ability to care for patients, while one was unsure if it did, and one student did not respond to the question. Specific comments, not surprisingly among this group of predominantly second-year students, focused on an increased sense of regard and empathy for patients. One student was struck by the “openness and honesty” of patients she encountered with her own illness, after the difficulty and shame she experienced writing about her own illness: “My writing experience and reflections about my own [illness] helped me to have great empathy as well as pride these patients fortitude.”

Question 7: *Should other students or residents participate in this exercise?* The illness narrative exercise was recommended by all ten students who responded to this question. “It makes you explore your own perspectives and biases as well as learn from other people’s perspectives,” commented one student. Another wrote, “I think it would be a wonderful and enlightening experience for all students and residents to have.” One respondent suggested it might be interesting to do in the third year, when students have closer contact with patients. Others commented about the specifics of the exercise, for instance that “the intimacy and safety of the setting was vital to making the experience worthwhile.” Ultimately, the role of this and other reflective narrative medicine exercises in overall training programs was noted: “Medical school desensitizes you to the point of numbness and we need this mode of expression to soften the edges created by our curriculum.”

LESSONS LEARNED

The personal illness narrative exercise described in this article was well perceived and highly recommended for other students and residents. The emotional difficulty that students described in reflecting on their illnesses represents what may be a lived detachment or disembodiment from their own bodily experiences that is reinforced, if not mandated, by

their inculcation into medical culture. This perception was articulated by the student who expressed surprise at her patients’ abilities to deal openly and honestly with an illness upon which she struggled to reflect. The students’ positive reactions to listening to their colleagues’ stories reflect the rarity of the opportunity in medical training to share emotional and physical vulnerability. Participants observed that their explicit awareness of and reflection on personal illness experiences brought them closer to the experiences of their patients. Because of small numbers of participants, however, we were unable to examine the differences between students’ writing about their own illnesses and students’ writing about the personal impact of the illnesses of close family members. This area requires further investigation.

Although we believe there was considerable interrater reliability in the qualitative analysis of these results, a potential bias emerges from the fact that both raters were involved in the course and construction of the exercise. In addition, the role of the teacher-facilitator in creating this positive experience was not examined. Further feedback from students can be elicited after other faculty members conduct the exercise. The exercise can also be conducted among more senior students and residents who have greater clinical contact and, necessarily, more years invested in medical training and culture.

Incorporating this emotionally revealing writing exercise into a medical school seminar is challenging and requires professional attention to safety and trust. Ground rules regarding strict confidentiality outside of the seminar, respect for others’ experiences, and support must be established early and articulated often. Small class size is important to foster an atmosphere of intimacy and mutual support. Although the exercise as described here was given to a self-selected group of female medical students, there is no need to presume that it could not be used in classes of both genders. Indeed, the method has been adopted successfully by one of the authors (SD) in seminars involving male and female trainees in health advocacy.

Ultimately, the personal illness narrative exercise enables medical students to articulate and examine feelings and thoughts about bodily realities of illness, health, and selfhood. Students are able to witness, interpret, and translate their own and each others’ experiences to gain a better understanding of themselves as practitioners and, in turn, of their patients. Indeed, the personal illness narrative allows the reader-writer to more fully enter the reality of the patient world by recognizing, describing, and integrating the similarities in her own personal experiences and those of the patient. This is, in essence, a manifestation of what medical sociologist Arthur Frank calls “thinking with stories.” In his words, “To think about a story is to reduce it to its content and then analyze that content. . . . To think with a story is to

experience it affecting one's own life and to find in that effect a certain truth of one's own life."⁸

"It takes a whole doctor to treat a whole patient,"²⁹ or so the saying goes. In the case of a narrative-based practice of empathetic witnessing, it also takes a whole (embodied) doctor to *hear* a whole patient. Such "wholeness" must involve a self-aware practice that incorporates both professional and personal realities. The personal illness narrative exercise is one means toward recognizing, acknowledging, and incorporating the physician's self-story into their clinical practice.

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