



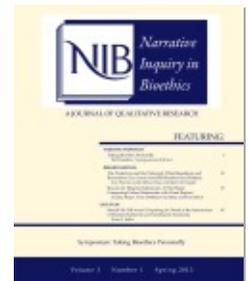
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Commentary

What the Experience of Illness Teaches

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Abstract. When invited to describe what the experience of illness taught them, a select group of bioethicists took eagerly to the task. This commentary culls three themes from their reflections: responsiveness to vulnerability, love as the proper motive for care, and reflective practice. U.S. bioethics was slow to appreciate the importance of recognizing and responding to human vulnerability. These essays describe its central importance for those suffering illness and make educating a more empathic and responsive generation of caregivers a priority. Descriptions of how family and friendship bonds with an ill person created a unique sense of their inherent dignity and needs clearly raises the question of whether or not love is a necessary motive for professional caregivers. Will our professional care always fall short if not motivated by genuine human love? Finally, each essay teaches anew the importance of the life lessons human experience can teach if we value reflection and seek to experience, understand and learn from our experience.

Key Words. Vulnerability, reflective practice, narrative, professional care

When I learned that my father was undergoing surgery for an “almost ruptured” abdominal aneurysm, I was a licensed professional nurse for two years and had happily begun to feel competent about my nursing practice. In the week I spent in the hospital, first in the surgical waiting room and then at his bedside, I learned so much more about the type of care that matters to patients and their loved ones. I can still remember the nurse who kept us informed about what was happening in the operating room (OR). Each time she came out to talk with us she crouched on her haunches to be on eye level with us. It was my first lesson about the importance of equalizing the power differentials in the hospital—and it stuck. In the intervening years it has often

been the illness of a friend or family member that has continued to challenge the adequacy of my practice. So I was eager to read these narratives written by bioethicists about the experience of their own illness or that of a loved one. I read as a family member and friend of the seriously ill and dying, as a nurse, as an ethicist, and as an educator of health care professionals. My first quick read of the narratives produced an almost overwhelming sense of despair. I know all too well that health care isn't perfect, but most of the essays described in some exquisite detail colossal failures of health professionals or mundane failures with sometimes, profound results. How long will it take us to “get it right?” Are our now long and serious efforts to produce the next generation of humane healers

bearing any fruit? Watson describes hospitals as “health factories” with a gravitational pull toward efficiency. “Patients quickly pick up the usually unspoken message that they will get the best ‘care’ precisely to the extent that they facilitate and do not impede the flow of the workplace.” Is all the current talk about patient-centered care just that, talk? Even more confounding was Rebecca Dresser’s essay about both wanting and not wanting the truth when it was a hard truth. If patients don’t know what they want, how can health professionals know how to respond. But as I sat with the essays my innate hopefulness bloomed anew as I realized the treasure trove of insights in these narratives. Each has lessons for anyone who is open to learning more about the myriad ways we influence one another—for better or for worse. Hope is the virtue that allows us to envision a future and to work to bring it into being. These essays are then hope-filled guides to what that better future might be.

There are many themes that might be culled from these narratives. Clearly present is the clarifying role illness and dying prompt. Sheila Crow writes: “When we are dying everything superfluous falls away, leaving what truly important.” Katherine Taylor echoes this sentiment, “Never take life for granted.” I chose, however, to address just three themes: responsiveness to vulnerability, love as the proper motive for care, and reflective practice.

Responsiveness to Vulnerability

When Beauchamp and Childress articulated the principles of U.S. bioethics the health care community was struggling to address the abuses of paternalistic medicine and reeling from disclosures about abuses in the research of human subjects. No surprise then that the principle of respect for autonomy gathered great support even more than the principles of beneficence, nonmaleficence, and justice. When the European principles of bioethics and biolaw were articulated a number of years later, vulnerability joined autonomy, integrity, and dignity as core principles, revealing a different emphasis. As one who has studied care ethics I have always

believed that the failure to address vulnerability in a more substantial way was an early failure of U.S. bioethics. Respect for autonomy is great so long as the recipients of health care are autonomous or have effective surrogates. Less fortunate are the many who have impaired or deficient autonomy and who have ineffective or no surrogates at all.

Katherine Taylor writing about her own experiences with cancer shares, “My greatest lesson was that patient vulnerability is a much larger factor in the physician-patient relationship than I had realized. While this point was brought home to me repeatedly in my clinical practicum long ago, I did not truly understand what that vulnerability meant until I became ill: how it feels to be debilitated and passive, how it affects the ability of patients to take in information, to ask questions, to make informed decisions. When that vulnerability is not recognized, when physicians treat patients as simply consumers of a service rather than as persons in need of a trusting and caring relationship, then physicians are excused from making a real effort to inform and care for their patients.”

Sheila Crow writes, “I wanted my physician to listen to my story of suffering, to recognize my plight and to engage with me on a deep emotional level. If I had to stand on the precipice of death, then I wanted a physician who had the courage, and as Albert Camus might say, the ‘common decency,’ to stand there with me. This kind of care is what mattered most to me.” Today, even some in the palliative care community, which was founded on the central importance of journeying with the seriously ill and dying, are looking to replace presence and journeying with pharmacologic remedies. I am not suggesting that the relief of distressing symptoms should not be a priority—just that there needs to be more in our repertoire of skills than magic pharmacologic or technologic bullets. Equally as distressing as physiologic symptoms, and sometimes more distressing, are the loneliness and deep existential questions about our meaning and worth.

Several of these reflections reminded me of a note a friend with cancer wrote.

“ . . . Here is the hardest thing I know: I am alone. The kind of alone that even having such good and

plentiful friends can't fix. Ultimately alone. When they said, "You have cancer" they did not mean "You and your friends have cancer" or just "You and your family have cancer." They meant "You, Jean, have cancer." Well. Shit. I don't have much practice doing things alone. I don't have any desire either. I'm a team player. . . . Where's my 'You have cancer' team? I looked around. The room was empty. They meant just me. . . . They say there is a pill for making the sad more tolerable. I'll take that pill, but I'll keep wishing for the one that makes being alone less lonely."

The questions these narratives pose for me, is must those of us on the frontlines of providing care become ill ourselves to "get" the importance of recognizing and responding to vulnerability? As I talked about these narratives with my husband, a physician ethicist, he said, "I think I was a good physician, but no patient or family member ever told me in what ways I could be better or more helpful" (personal communication, March, 2013). Even in today's world of performance reviews ad nauseam, I don't think many professional caregivers get to hear the stories and distress of their patients and families who experience what seems to be cold indifference to their basic humanity and to their at times, exquisite vulnerabilities.

Physician Frances Peabody (1927) has educated generations of medical students to understand that the treatment of a disease may be entirely impersonal, but the care of a patient must be completely personal. "The secret of the care of the patient is in caring for the patient" (p. 882). Today, Abraham Verghese understands this truth and speaks it for today's generation. "I've gotten into some trouble in Silicon Valley for saying that the patient in the bed has almost become an icon for the real patient who is in the computer. I've actually coined a term for that entity in the computer. I call it the iPatient. The iPatient is getting wonderful care all across America. The real patient often wonders, where is everyone? When are they going to come by and explain things to me? Who's in charge? There's a real disjunction between the patient's perception and our own perceptions as physicians of the best medical care" (2011).

These essays reminded me to reflect on how we can form the next generation of professional caregivers to walk in the shoes of the vulnerable sufficiently to understand what their care needs to look like. Philosopher Alisa Carse writes that human vulnerability can lead to human flourishing if our vulnerability is accepted and then met with support and sustenance engendered by empathy, compassion and solidarity. If we refuse to accept our vulnerability and if we become the objects of indifference or hatred and bigotry, and we experience a lack of responsiveness, mutual respect and concern, we become isolated and fail to thrive (2006). These narratives beg for our renewed attention to the vulnerabilities illness engenders.

Love as a Necessary Motive for Care

I have to confess to a particular resonance with and affection for the narratives where it was the author's love of someone, which sensitized them to when health care professionals were behaving well or badly, helpfully or not. There is a particular poignancy in K. Jane Lee's description of perception. Lee is a pediatric critical care physician and a bioethicist with a six-year old daughter diagnosed with encephalopathy. She describes the gradual transition from seeing her daughter, Josephine, with a physician's eyes to also seeing her through a mother's eyes. Lee relates that as a physician she saw only the disabilities and fearful of these she was certain that Josephine's life would be horrible and that the entire family would be doomed to a life of misery. Now she sees Josephine's potential and believes in her child. She sees a child who has reasonable cognitive function, a multifaceted personality and marvelous potential. Her longer description of Josephine is not to be missed. Similarly, Monique Lanoix learns first hand about the importance of how we encounter and care for individuals who are cognitively impaired when a close family member is in a serious head-on car accident and suffers permanent neurological damage. "I have to ask myself whether I defend Paul's right to be treated as a full member of society because I have a personal bond with him and I am able

to make an easy link with his past self. If I cringe when people encounter him, and if I am afraid of the manner in which they will respond to him, is it because I have known him for a long time? Of course the answer is in part yes, but I also want to hold on to the intuition that a lack of agency should not automatically cancel a person's membership in the moral community." So is a familial or intimate friendship (read Sara Jordan's essay) bond of love the only thing that enables caregivers to see, and respect, the intrinsic dignity of an individual with disabilities? When my husband and I were visiting northern Italy we were proudly shown a carefully designed nursing home community—where I have to say love was palpable. We were introduced to numerous residents and shown many common rooms. The doctor and nurses also brought us to several rooms of residents with complex care needs. We repeatedly asked, "How do you provide such excellent care, day in and day out?" And we always received the same answer. "We do it because we love them." Our experience in a home for medically fragile children in lower Manhattan was similar. These children had complex care needs, which their families were unable to meet at home. As we toured the facility we were again in awe of the vibrant love we encountered in each of the four "neighborhoods." We talk much about professional care, but we don't write much outside the religious literature about the virtue of love. Is it reasonable to expect professional caregivers to do what we do well because we love our patients and residents? How is this love different from that of a parent, family member or friend? Is love *an* or *the* motivation for caring? Is it an ideal that sharpens our perception, directs our response, and sustains us when the burdens of care giving seem overwhelming? Or is it the *only* basis for respectful, compassionate care, especially for our most vulnerable? Speaking to a conference of nurse educators in Kyoto, Japan in the fall of 2011 I included a slide which stated, "Love, a sincere commitment to meet human vulnerability with exquisite human caring, seems to be in short supply and can no longer be presumed to be the primary motivation for nursing." Does this statement engender sadness or it simply a fact of

today's world. Katherine Taylor states, "It shouldn't be the patient's responsibility to earn respect." If individuals with serious disability lack family advocates, what is it reasonable for them to expect of all professional caregivers?

Reflective Practice

Reflective practice is "the capacity to reflect on action so as to engage in a process of continuous learning", which, according to the originator of the term, is "one of the defining characteristics of professional practice" (Schön, 1983). Sara Jordan thoughtfully reflects on what happened when her training partner needed health care in Hong Kong for a fractured humerus. "When Henry emerged from the hospital after 3 days, I was left with a lingering scar as well—could I consider myself to be an educated, culturally sensitive ethicist any longer, given that I had imagined the incompetence of the 'others' based upon the interactive effect of non-shared language and, by proxy, race." Sara perfectly demonstrates the goal of reflective practice: look at an event, understand it, and learn from it. Learning that "shared communicative capacity mattered more than [she] could have imagined for [her] ability to trust professionals of a different linguistic group and race," Sara reflects on whether there might be a role for clinical bioethicists as cross-cultural navigators and proposes culturally immersive internships that teach language and culture as a means. Less well articulated is whether and how this experience will transform Sara's human encounters in future situations where language barriers challenge comfort with and confidence in others. Other authors describe similar experiences where reflection led to changes in their self-understanding and practice. Chris Kaposy honestly shares his and his wife's responses to positive screening for Down's Syndrome. I learned that "autonomous choice is something that has to be won, and fought for, in spite of it all. . . . The choices we made during the process of prenatal testing challenged our values, buffeted our emotions, and we felt influenced on many sides. The main difficulties were not with

inadequate disclosure of information—. . . instead the main challenges we faced were with the influence of technology.” But the chief learning seemed to be to avoid being judgmental. As a clinical ethicist, Kaposy writes, “The need to reserve judgment is an ideal I try to live by (though I don’t always succeed). I find it important to keep an open mind and to list to all sides of a story when dealing with conflict.” Thomas Harter uses communication failures surrounding the births of his premature children to illustrate the effect this has had on how he communicates when doing an ethics consult. “My hope is that I continue to find new ways to use these two experiences as examples of the importance of information sharing in medicine, and that these two experiences continue to help my development as a clinical ethicist and father.” Katherine Taylor writes, “My experiences with dismissive physicians taught me the real value, and necessity, of respectful, compassionate communication with patients and their families. Gifted communication, including the skill of really listening, is hard to find in health care and should be better cultivated.”

Striking in the essays of all these ethicists who teach ethics to medical students is how their experience of illness changed their sense of what the outcomes of ethics education should be. Everyday ethical comportment, defined by Benner (1996) as the embodied, skilled know-how of relating to others in ways that are respectful, responsive and supportive of their concerns, assumed central importance.

Sheila Crow’s reflection on her experiences with her physicians made her question the adequacy of how she was teaching ethics to medical students. “I realized that I had been teaching students that ethical principles were like a handy tool, something they could use or not, as the clinical situation required, rather than focusing my attention on enhancing the moral character and professional identity of the individual student, or what I have since come to call, the everyday ethical practice of medicine. . . . I needed a physician who was compassionate, discerning, and trustworthy, in addition to being highly skilled and knowledgeable in the area of cervical cancer. It is this weaving of ethics

into the fabric of every encounter with a patient that matters most. This lesson, I thought, is what medical students need to learn.” Crow challenges all of us to reflect on how well we are teaching to this outcome.

I began by writing, “these essays, then, are hope-filled guides to what a better future might be.” I would like to conclude by quoting K. Jane Lee, who describes the striking contrast between the worlds of the family with a seriously or chronically ill member and the professional. “I carry this lesson into my work as well. I speak out now; I try to see both sides, and help each side to see the other perspective. It doesn’t always work of course. But I try. I know there are more lessons ahead of me; my education is not yet complete. In the meantime I try to take this wonderful education and use it to improve my work. I hope that you, too, will embrace these lessons without ever being a position to really know.” Will we use these narratives to teach us what our own poverty of experience cannot?

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