

# 1: The ethicality of narrative medicine

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Sickness calls forth stories. Whether in the patient's "chief complaint", the intern's case presentation, the family member's saga of surgery, or the coroner's death note, patients and health professionals recognise problems, gauge progress, and lament defeat, in part, through telling about illness and having others listen. Medical ethics is no different from other aspects of clinical practice in having been found to have deep and consequential narrative roots. Those who assist individual patients to navigate the moral channels of illness have discovered that training in health law and knowledge of moral principles do not suffice to fulfil ethical duties toward the sick. They are learning that they also must equip themselves with sophisticated skills in absorbing and interpreting complex narratives of illness – the better to hear their patients, to accompany them on their journeys, and to honour what has befallen them. And, true to transformative form, narrative theory and practice have renewed and redefined the very enterprise of what used to be called bioethics.

The contemporary field of medical ethics arose in the mid-1960s in response to wrong-doing and potential wrong-doing by health professionals. Harvard anaesthesiologist Henry Beecher blew the whistle on biomedical scientists who were experimenting on patients without their consent.<sup>1</sup> Around the same time, medicine's growing technological ability to prolong life in the face of organ failure, starting with renal dialysis, triggered the public's anxious realisation that doctors might be in a position to decide which of us would live and which would die. From Beecher's 1966 essay in the *New England Journal of Medicine*, bioethics was conceptualised as a means to protect the patient from the doctor/scientist.<sup>1</sup> The bioethicist arose to intervene on the side of the patient in an adversarial relationship between doctor and patient. Hence, the early concerns of medical ethics – informed consent, safeguarding patients' autonomy, and resource allocation – arose from the formulation that doctors, left to their own devices, will exploit patients or in some way harm them and that patients need defence against them.

The assumption that the doctor–patient relationship is an adversarial one has governed the development of bioethics' agenda,

training, professionalisation, and world view, in North America at least. The extreme focus on patient autonomy, for example, can only be understood if the doctor is seen as poised to take advantage of a patient for unscrupulous reasons. The middlemen and middlewomen who populate the bioethical field between doctor and patient have tended until recently to be adversarially trained in either law or juridically inflected moral philosophy. David Rothman's "strangers at the bedside" have not only been "strange" to medicine: they have been downright hostile.<sup>2</sup>

Once the doctor–patient dyad was conceived as an adversarial one, contractual safeguards emerged to protect the one from the other. Ethical care became governed by negotiated instruments – advance directives, Institutional Review Board protocols, informed consent processes, conflict of interest disclosures. Bioethicists joined licensing boards, insurance company functionaries, and hospital admissions privilege overseers in building a tort-based, law-enshrining enterprise for controlling doctors and protecting patients. Now, many of these protections were needed to control the abuse of power and the avarice of some within medicine and bioscience, and medicine as a whole is safer than it otherwise would be. Nonetheless, thinking of medicine as an adversarial enterprise has hurt us all deeply in unrecognised ways.

Bioethics suffered a perilous restriction of its vision and influence once it accepted – often implicitly and seemingly unconsciously – the assumption that patients must be protected from their doctors. In some ways, bioethics achieved a caricature of its own mission. Again, the example of autonomy is most telling. In their zeal to protect patients' autonomy, bioethicists designated as paternalism any expression of personal opinion or clinical counsel on the part of health professionals. So as not to manipulate patients, some doctors have ended up withholding their own viewpoints from confused patients, leaving patients and families to make their treatment choices alone. Protecting patients' autonomy, in the extreme, constitutes abandonment.

But doctor–patient relationships are *not*, or at least need not be, adversarial ones. Certainly, there can be disagreement or disappointment or defeat within these dyads. There can be misunderstandings that lead to such polarised points of view that doctor and patient see different realities. There can be, and very usually are, lapses in generosity and failures to be attuned to all of a patient's concerns. There is, more often than we realise, greed. There is sometimes, we hope rarely, sadism. And there are always differences of opinion on what, clinically, to do about any medical situation. But, with exceptions, the doctor–patient dyad is not hostile and exploitative, and to treat it as such limits tremendously its growth toward true caring.

What impresses clinicians is the tremendous range of what, most fundamentally, to do during office hours. I saw a middle-aged woman two days ago in my internal medicine practice.<sup>ii</sup> She was relatively new to me: profoundly depressed, non-English-speaking, with a discouraging list of ailments including atrial fibrillation with its attendant need for chronic anticoagulation, and disabling back pain unresponsive to conservative management. She lived alone in an apartment in the city with no income except a little public assistance, poverty-level rent forgiveness, and state-program coverage for her medical care. In the interval since her last visit to me, I had succeeded in appointing her to a Spanish-speaking psychiatrist – no easy task in an overburdened clinic system! – to replace the prior clinic that had treated her so demeaningly that she felt the worse for going and had lapsed from treatment. With the interpreter sitting with us in the office, we set about our work. Was I ever tempted to start right in on the anticoagulant and the clotting time and leave it at that! The woman's dense depression was so menacing, so overpowering, that I had to *force* myself to dwell in her presence. I had to quite literally sit on my hands so as not to busy myself checking her latest coagulation test results on the computer or scanning the pill bottles for their prescription renewal dates.

She did not need me to do those mechanical things, at least not at the start of our visit. She needed me to bear witness to her despair. Although there was another doctor responsible for treating her depression, I had to acknowledge the reality of her life – its painful and suffusing darkness. I knew from a previous visit that she had recently been to Latin America for the funeral of her mother. I learned on this visit that a young cousin had just died of the complications of diabetes, raising great fears in the patient that she, too, had diabetes. As a corollary, I discovered that fears of illness, realistic and not, added tremendously to the patient's burden of depression. I also learned that she liked the new psychiatrist and that attending the twice-weekly therapy group helped her.

So I began to find some solid ground for myself in relation to her, some ground, that is to say, upon which to stand that would not cave in and drop me defenceless into the morass of her depression. I could appreciate with her our success in finding a new psychiatry clinic that seemed an improvement over the last one. I could ask her straightforwardly about her mood, the acknowledgement of her depression now possible without eliciting my panicky helplessness because we had done something practical to address it. I could listen as she mourned the deaths that seemed to have occurred all around her. I could offer, quickly and with great optimism, a blood test to prove she did not have diabetes. At the same time, I could behold the tremendous courage she demonstrated by living in the face of her punishing depression. Despite the depression, she got dressed in the

morning, she left the apartment, she kept her appointments, she took her medicines. What a commitment to life she demonstrated. I tried to voice my awe at her strength during our conversation.

And only then could I turn the corner toward the management of her heart disease and back pain, having not sought refuge in the body from the terror of the soul. As it turned out, our conversation about the blood tests, electrocardiographs and pills was much more brisk and efficient by virtue of our having started with her life and her mood and her fears. In effect, our medical business, by being informed by her overwhelming fears about illness and death, could proceed more effectively because I now knew how desperately she feared illness, and I could offer some aspects of her on-going treatment as a talisman for keeping well. More important in developing an effective therapeutic alliance than any technical skill was, I believe, my ability to tolerate Mrs M's profound depression and not to flee from it *because, of course, to flee from her feelings is to flee from her.*

In retrospect, as I collected myself in private in preparation for the next patient, I realised with a great sense of satisfaction that I had not abandoned her, however strong had been the temptation to do so. I had found a way to *be* with her – despite not speaking her language and despite my own experiences with depression that she forced me, briefly, to relive – so as to fulfil the duties I incurred by virtue of having heard her (or even more simply and instrumentally, the duties I incurred by virtue of having been assigned as her physician by the Medicaid bureaucracy). The satisfaction I felt was the satisfaction of an *internist* – not of an ethicist and not of a narratologist, although I am those things too – in my having found a way, today anyway, to be her doctor.

I think this picture of my office hours helps to convey what I mean to say about the doctor–patient dyad. I mean to draw attention to the tremendous benevolence available to us to do every day, the acts of goodness we can choose to perform or to omit in our clinical transactions. Not mere kindnesses, these acts contribute directly to our clinical effectiveness, and omitting them risks clinical failure. *These* are the acts of ethical medicine – not only signing the advance directive or talking about futility in the Intensive Care Unit – but these private acts that require courage and clinical common sense. What a privilege for me that, in the course of an ordinary day in practice, I am offered the chance to give this woman what I believe she needs clinically, to do so at some minor cost to myself (the sinking reminder of impending doom that surrounds us all), and to emerge from our visit feeling better than I did before it.

What would happen to bioethics if the doctor–patient dyad were to be conceptualised as an occasion for such clinically relevant goodness; if it were seen not as a contractually governed hostile relationship of exploitation but as an intersubjective personal relationship of

vulnerability and trust? How would one practise bioethics if medical practice were understood as an enterprise in which one subject enters relation with another subject, both participants in the intersubjectivity illuminating one another's goals, hopes, desires, and fears, and contributing regard, trust, and courage?

Over the past decade, conventional bioethics has struggled to find its way among its chosen principles and has found itself too thin to really address actual values conflicts that arise in illness.<sup>3</sup> Although so-called principlist bioethics might be equipped to adjudicate appropriate surrogacy for the incapacitated terminally ill patient or to assess the risk to human subjects of a clinical research trial, it is ill equipped to guide an internist in caring for a depressed woman with heart disease or to help a paediatrician to tell parents the meaning of their 2-year-old boy's autism. Because, in part, principlist bioethics arose to deal with oppositional clinical relationships, it cannot be expected to support or to augment caring relationships.

Any number of alternative approaches to addressing the ethical problems in health care – feminist ethics, communitarian ethics, liberation ethics, phenomenological ethics, casuistry, and virtue ethics – have altered the conceptual geography of bioethics. With their foundations not in law and Anglo/continental moral philosophy but in the particularities of individuals, the singularity of beliefs, the perspectival nature of truth, and the duties of intersubjectivity, these complexly differing approaches share a commitment to narrative truth and to the power of telling and listening. They share a realisation that meaning in human life emerges not from rules given but from lived, thick experience and that determinations of right and good by necessity arise from context, plot, time, and character. These approaches do not start with an assumption that patients must be protected from their doctors. Instead, they all, in somewhat different ways, locate patients and their families *near* to those who care for them. Rather than emphasising – and therefore intensifying – the divides between patients and health professionals, these methods seek congress among human beings limited by mortality, identified by culture, revealed in language, and marked by suffering. It is not the case that some are sick and some are well but that all will die.

Although these approaches emerged quite spontaneously and simultaneously, around the mid-1980s, from such traditions as feminist studies, post-colonial studies, phenomenology, and liberation theology, they can be seen from this historical vantage point to constitute a family of narrative ethics. Indeed, the system that has ended up being called narrative ethics has borrowed tremendously from all these efforts, finding in their commonalities a core for practice.<sup>4,5</sup> What characterises these approaches as “narrative” is that they take as given that each sick person enters sickness singularly, that

each disease signifies differently, and that each death connotes the end of its life particularly. It is the ethos of narrative ethics that one must tell of what one undergoes in order to understand it and that, as a consequence, the health professionals who accompany one through illness have a responsibility to hear one out. Among the tenets of narrative ethics are the requirements to hear all sides, to contextualise all events, to honour all voices, and to bear witness to all who suffer. Training for such practice, it follows, is textual and interior – developing the skills of close reading, reflective discernment, self-knowledge, and absorptive and accurately interpretive listening. Deriving from narrative theory as it is articulated in literary studies, phenomenology, anthropology, psychoanalysis, and qualitative social sciences, these notions join bioethics to many seemingly unrelated human enterprises like the practice of law, the profession of faith, and the understanding of human psychology. These fields, too, have been inflected by the knowledge of how stories are built and what happens when one tells or listens to them.<sup>6,7,8</sup>

Bioethics has been the lucky recipient of narrative dividends from intellectual and clinical developments far afield itself. Independently from any developments in bioethics, new knowledge from narrative theory and practice has made its way into medicine. Narrative studies have gradually found welcome readers and adherents among doctors, nurses, social workers, patients, and those who study medical care (indeed, this book that you are holding in your hands is one testament to the major influence narrative ways of knowing have had of late on health care).<sup>9,10</sup> Narrative contributions to medicine have influenced bioethics, if only by having equipped some clinicians with narrative methods of making sense of their clinical and ethical duties toward patients, methods that turn out to be more helpful than those available from principlist or legalistic bioethics. Bioethics, then, is doubly informed by narrative theory: through the developing narrative competence of its “bio” sphere (the practice of medicine) and the increasing narrative commitments of its “ethics” sphere (the practice of ethics).

Narrative influences from outside bioethics have amplified voices within bioethics that have respected stories all along. The work of religious scholar Stanley Hauerwas, for example, took on new authority once the narrativist turn was noted elsewhere in the academy.<sup>11</sup> Richard Zaner’s phenomenology has become saturated with a respect for and insistence on narrative methods and interests.<sup>12</sup> Lawyer-ethicist George Annas has turned to writing plays. Inspired by such seminal texts as Alasdair MacIntyre’s *After Virtue* and Bernard Williams’ *Moral Luck*, philosophical bioethics has been challenged to grasp the storied elements of moral thought and the irreducibility of human plights.<sup>13,14</sup> Although principlist bioethics is still distantly taken up with autonomy, incapacity, and informed consent, its local

practitioners have realised that they are *not* judges but listeners, *not* measuring capacity or next-of-kinhood but measuring the depth of loss.

The place of narrative in medicine and in ethics can be illuminated by recognising the place of narrative in life (and, *pari passu*, this move helps us to recognise how medicine and ethics are but instances of life). In writing about the Iranian Islamic revolution and its attendant losses of freedom, especially by Iranian women, literary scholar Azar Nafisi explains how fiction sustained her and her students through ordeals of repression.<sup>15</sup> Nafisi kept alive empathy, the imagination, and courage by teaching such works as *Pride and Prejudice* and “Daisy Miller,” works that require their readers to inhabit alien spheres and to adopt and respect contradictory points of view, works whose protagonists develop the courage to choose freedom. Fiction’s critical and irreplaceable consequences are to force readers to recognise the storied shape of reality, to understand in the most basic way that there is no meaning outside of the plots into which one weaves the fragments of life, and that one *must* choose one’s plots. We make it up; in the most primal and primitive and primary way, we make it up. We do not “capture” the truth that exists around us through scientific measurements or through controlled experiments. We do not represent that which is external to us detachedly and objectively and replicably. No. Instead, we incorporate our sensations and perceptions and desires and ideas into a form which we first tell to ourselves and then might tell to others.<sup>16,17,18</sup> Identity itself – one’s sense of being a self – arises from the crib narratives we tell as infants, the entries we hide in our adolescent diaries, the associations we voice to our analysts, and the accounts we give of ourselves when befriended, when ill, when accused, when reflecting, or when imagining.<sup>19,20</sup> These stories we tell merge with those we hear – in fiction, in fairy tales, in family legends, in sacred texts – in great banks of plot, great plots of grounds for knowing, for rooting, for cultivating the self.<sup>21,22</sup> Telling and listening to stories are as organically necessary as are the circulation of blood or the respiration of oxygen to establish and maintain a self by metabolising into it that which is non-self and then contributing products of the self back into that alien domain, thereby making it home.

I have written elsewhere about what I consider to be the most salient contributions of narrative theory to medical practice – the means to probe, honour, represent, and live in the face of temporality, singularity, intersubjectivity, causality/contingency, and ethicality.<sup>23</sup> What is lacking in medicine – and, I suggest here, in bioethics too – is precisely the mode of vision made possible through sophisticated narrative practice, especially in relation to these five broad areas. It is with narrative temporality that we mark the passage of time, providing those who live amid illness with the urgency and the

patience to claim our numbered days and to see forward and backward toward their meaning.<sup>24</sup> It is with the narrative tools of description and dialogue and trope that we can render – and therefore recognise and admire – singular individuals and situations, not as instances of general phenomena but as irreducible and therefore invaluable particulars.<sup>25</sup> It is only with narrative effort that we achieve first the subject position and then, with luck, the intersubjective bond between ourselves and others, thereby inaugurating the therapeutic relationship.<sup>26</sup> It is with narrative emplotment that we attempt – often against all odds – to make causal sense of random events or humbly acknowledge the contingent nature of events that have no cause, enabling us both to diagnose disease and to tolerate the uncertainty that saturates illness.<sup>27</sup> Finally, it is with narrative acts and skills that we recognise and live up to the ethical duties incurred by having heard one another out and the indebtedness we sustain by having been heard by another.<sup>28</sup>

I run the risk of ethereality. Let us descend to 6 Garden South, the hospital floor on which, some months ago, I was ward attending, caring with my residents and medical students for severely ill patients admitted to Presbyterian Hospital with terminal cancer, end-stage renal failure, heart failure, liver failure, failure to thrive. Throughout the month we came across and found ways to live with serious ethical conflicts.

Mrs M was admitted for terminal care of Stage 4 breast cancer.<sup>iii</sup> Only 48 years old, she wanted badly to live, and yet the oncologists had nothing left to try. The resident complained that the patient's unrealistic sons wanted "everything done". The sons' obdurate demands for intensive medical care inflamed the resident's searing guilt that there was nothing more to do, and so he was very angry at them. I gently suggested that he ask the social worker to convene a family meeting to clarify the goals of care. The very next day, the social worker sat with both sons, their wives, the resident, the intern, and the medical student caring for the patient. With the safety of the social worker's presence, my resident was able to put into words the hopelessness of continuing treatment. He emphasised his commitment to the patient's freedom from pain and discomfort. The sons, it almost goes without saying, were exquisitely aware that their mother was dying. Their insistence that the doctor "do everything" was just the only means available to them, up until then, to register their undying loyalty and unswerving commitment to the well-being of their mother. Once my resident asked them to join with him in acknowledging that the end was near, they could surrender their stance of hostility and blame and could begin their long road of mourning.

Mr A, a middle-aged man with a long history of alcoholism, was admitted to hospital in liver failure. Another resident and intern

adeptly deployed powerful diuretics, tapped fluid from the patient's abdomen, and replenished nutrients, often deficient in alcoholics. And yet the patient sank further and further into encephalopathy and coma. His mother was at his bedside, rocking and praying, even when the patient could no longer hear her. My resident and intern did not flinch, even in the face of the suspicion that their rather aggressive treatment had made matters worse, from consulting with the liver specialists, thinking through the deranged physiology involved in end-stage liver failure, and devising new approaches when the standard ones failed. What impressed me was that they did not give up. Every morning at rounds they meticulously reported all the patient's ins and outs, the results of his blood tests and scans. One morning, he woke up. He had been over a week in deep coma with all the earmarks of an irreversible vegetative state, and yet he rose. As I spoke with him that first morning, I said something in my little broken Spanish that I hoped translated to "Thank God you're alive!" And the patient winked. He winked! Imagine had we given up.

A woman was admitted as an emergency from a nearby dialysis centre with fever and evidence of bacterial sepsis, probably from an infected dialysis access graft. Another woman suffered complications from needed surgery, resulting in pulmonary and neurological compromise. These two cases made our team brood on the dangers of medicine as we know it. My young doctors were forced to ask themselves, "Are patients better off with us or without us?" When a complication occurs, however well understood and accepted its risk, one cannot help but feel responsible. The residents and interns caring for both these patients had to display enormous tact and professionalism to convey the clinical truth to the patients and their families while dealing with their own confusing calculus of benefit and risk.

What did my team learn about bioethics? We learned that the words one says – like "do everything" – can have multiple contradictory meanings and that ethical medicine requires an active intersubjective process, working against a gradient of complacency or convention or detachment, to discover the meaning of words. We learned about duty – duty in the face of self-inflicted disease, duty in the face of our own shortcomings, duty in the face of the inevitable complications of our yet-primitive medicine. Such duties are not prescribed by oversight committees or specialty boards but are discerned, over time, through a life lived humbly around illness and the consequences of trying to intervene in it. Surrendering neither to nihilism nor to deceit, my house officers fulfilled the ethical duties that accrue to their knowledge, to their loyalty toward their young science, and to their constancy in the care of individual patients.

Over the course of the month, we became all the more able to behold the singular, the mystery, the marvel. Why did Mr A wake up?

We will never know. And yet, we can celebrate, as miracle, his resurrection. We can learn from his course how to do even better with the next case of end-stage liver failure, while we can let ourselves *wonder* what happened as he slowly awakened, from how far away he travelled to open his eyes and then to wink. "I had a guy," my intern will say years from now, "who was encephalopathic even longer than your guy but he woke up. Keep giving him lactulose; diurese him gently, don't give up." We all learned about the savage contingency implicit in our work – in the occurrence of aggressive breast cancer, in the success or failure of diuresing or tapping the alcoholic, in the ways that we and our patients responded to the sickness all around us. As they told me stories at attending rounds – "This is the fourth CPMC admission for this 54-year-old chronic alcoholic with a history of DTs, positive family history of alcoholism, and multiple failed attempts at detox" – making sense in our own little way of the events of others' lives, we understood the capricious nature of our emplotment, and we recognised the artificial process by which, for our sakes alone, we impose on the contingent our sense-making plots, realising full well that as new pathophysiological explanations replace the faulty ones we live with now, the stories which we tell of what befalls our patients will change along with them.

On 6 Garden South, we did not address the ethicality of our clinical situations separately from their temporality or causality or contingency or singularity or intersubjectivity. *It happens all at once*. The ethical dimension is one facet of a narratively competent medicine, or narrative medicine for short, that occurs *while* the intersubjectively linked participants (some well, some ill) behold the singularity of one another and their situations, while they fathom where in the arc from birth to death they might be now, while they search for causes amid the random and the unfair. What humans owe to one another is not excisable, as a discrete concern, from the whole texture of how they reach one another, how they place themselves in time, how they emplot the events that occur to them, how they tolerate ambiguity or uncertainty, or how they recognise the absolute uniqueness of one another (and, in reflection, of themselves too), how they hear one another out. As a result of all these things, they perform for one another acts of goodness, their benevolence the full enactment of their science, of their justice, of their art.

We begin, then, to contemplate the consequences of choosing a new plot within which to consider medicine and its ethics. If ethics recognises medicine not as an adversarial process but rather as an on-going intersubjective commitment in the face of vulnerability and trust, what becomes of its practice?

To practise such ethics requires that practitioners, be they health professionals to begin with or not, must be prepared to offer the self as a therapeutic instrument. The ethicist must enter the clinical

situation, willing to suffer in the process. If another kind of ethicist could fulfil his or her duty by hearing, in the safety of a conference room, the report of a patient's predicament and somehow making judgments from afar about the proper action to pursue, the narrative ethicist must sit by the patient, lean forward toward the person who suffers, and offer the self as an occasion for the other to tell and therefore comprehend the events of illness. This ethicist does his or her work by absorbing and containing the singular patient's plight, soliciting others' perspectives on the situation, being the flask in which these differing points of view can mingle toward equilibrium. Not all things dissolve, and so solutions are not the only end points craved by this ethics. Instead, we choose to live with the tensions of all things being said, all things being heard, sedimenting toward stillness. What the person practising narrative ethicality knows for sure is that he or she will be transformed by contributing benevolence and courage to another person's plight. Revolutionary, consequential narrative once again enacts its truth that nothing remains unchanged by story.

Let me close by reproducing for you a story written by Rose Susan Cohen, MD during her third year of medical school.<sup>iv</sup> We have learned that reflective writing is a powerful method for developing the textual and interior skills required of narrative ethicality. Years ago, I invented the Parallel Chart as a place where health professionals can write in non-technical language about critical aspects of their care for patients, aspects that cannot be written in the hospital chart. Clinicians and students write in the Parallel Chart about what they witness patients to endure in illness and what they themselves undergo in caring for the sick. This is an excerpt from Dr Cohen's Parallel Chart:

*Altagracia. I am obsessed with her first name ... I imbue her name with spiritual, romantic, and mysterious overtones.*

*"Yo se que yo voy a morir en el hospital." I know that I am going to die in the hospital. Clutching her wrinkled face, which droops on the left, with her tendinous, wasted hands with papery dry purple skin, she looked at me through her claw-like fingers. She's childlike, hidden.*

*Failure to thrive. She won't eat. She kicks, she hits, she clutches and bends your fingers. No, you can't open her eyes to shine a light, and you can't open her mouth. She's hiding from me, deep inside her body.*

*Slowly, she's dying ... Her brain is 79 years old, infarcted, probably demented, but I want to believe that there is a complicated, dignified sadness in her mind that she is sequestering from the world. She lies in bed lamenting, suffering, crouching on her side, mourning mysterious and not so mysterious losses of her life.*

*We all shuffle into her room and peer at her. "Hola, hola," I call softly. She swats her arms and covers her face. I keep thinking about her premonition, "Yo se que yo voy a morir en el hospital." Did I really hear her say that? Did I imagine that she could speak? The attending spoke. "We need to peg her and place her."*

*Altagracia, graceful and seemingly out of touch, pretends we aren't there.*

This beautiful, if doomed, clinical act of beholding the human mystery of this woman with humility and absorptive grace *means* something – for the student/writer and also, perhaps, for the patient. By writing this description of Altagracia, Dr Cohen takes the measure of her own awe, her loyalty to the patient, and her hopes for her own and her patient's futures. She exposes her own desires – to believe in the patient's dignity, to grant her her mystery, to distinguish herself from the insensitive attending physician, the only one in the story consigned to the past tense. The author's muscular imagination "fills in" that which dementia has erased, enabling her to treat her patient with reverence. By searching for (or by being open to) and choosing the words, the images, the time course, and the plot of this story, the author gives birth to a particular way of comprehending the events of this hospitalisation. This patient, whom the attending physician dismisses as a transfer to a nursing home once a stomach tube is placed, emerges by virtue of the writing as a mysterious, powerful, complicated woman whose difficult behaviour can be interpreted as complexly determined and connotative. She of the highest grace is the heroine and not the victim of her story, knowing that which others do not know, hiding in her wasted husk a life of great ambition. Only by having apprehended such a vision of the patient can the student care for her with benevolence and, therefore, effectiveness.

The ethics I have described in this chapter and that are teachable through narrative training are within-medicine ethicality, not without-medicine bioethics. This ethicality is not one that one can "contract out", that one can surrender to another to perform. Nor is it applied only when certain topics arise – futility of treatment, for example, or protection of human research subjects. Governing clinical actions at all times, narrative ethicality endows the practitioner with an eternal awareness of the vulnerability and the trust of self and other. A narrative ethicality saturates the doctor, nurse, social worker, or ethicist with the sensibility and the skill to recognise and to fulfil the duties incurred by intersubjective nearness, by mutual singularity, by knowledge of causes, and by the sense that time, by its nature, runs out. If sickness calls forth stories, then healing calls forth a benevolent willingness to be subject to them, subjects of them, and subjected to their transformative power.

## Endnotes

- i The term “bioethics” was coined around the same time by two persons. Sergeant Shriver came up with the word to denote the new ethics-for-medicine institute being established by the Kennedy family at Georgetown University. What Shriver meant by the term was the rather instrumental application of legal and philosophical principles to solve dilemmas in medical research and practice. Physician Van Rensselaer Potter also created the word, but in his hands it denoted a “science for survival”, that is, an environmentally inclusive effort to live, as humans, in concert with the universe with a recognition that the biological life interacts with the moral life. Evidently, the first definition ascended, although the second may be emerging from the cosmic shadows. See Martensen R. Thought styles among the medical humanities: past, present, and near-term future. In: Carson RA, Burns CR, Cole RG, eds. *Practicing the medical humanities: engaging physicians and patients*. Hagerstown, MD: University Publishing Group, 2003, pp 99–122.
- ii I have merged the descriptions of several patients I saw during one morning in practice to make my point, and so I have not elicited consent to publish this description, as it does not actually “belong” to any one of the several men and women who are part of this portrait.
- iii These patients are unrecognisable composites of many patients my team cared for over the month.
- iv Dr Cohen has consented, in writing, to my publishing this excerpt of her writing.

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