ABSTRACT. This essay is composed of five stories written by practicing physicians about their patients. Each clinical story describes a challenging ethical condition—potential abuse of medical power, gravely ill and probably over-treated newborns, iatrogenic narcotic addiction, deceived dying people. Rather than singling out one ethical conflict to resolve or adjudicate, the authors attempt, through literary methods, to grasp the singular experiences of their patients and to act according to the deep structures of their patients' lives. Examining these five stories with simple literary tools—attention to narrative frames, time, plot, and desire—reveals the mechanisms through which acts of writing and reading contribute to clinical clarity and ethical actions.

Key Words: literature, narrative ethics, reading, writing

I. INTRODUCTION

Rita Charon

The sub-discipline of literary studies called literature and medicine has introduced new methods of thought and action to medical practice and to traditional bioethics. More salient perhaps to ethical medicine than to medical ethics, literary methods help doctors and patients to achieve contextual understandings of singular human experiences, supporting the recognition of multiple contra-
dictory meanings of complex events. In turn, this recognition allows protagonists, despite moral ambiguity and interpretive tension, to act (Nussbaum, 1990, pp. 3–53).

How does literature actually work in helping doctors to practice ethical medicine? Rather than soft impressions or emotive feeling-states, literary methods can command sharp discriminations in the face of illnesses' murky conflicts. First, the narratives of medicine – from the illness itself, to patients' verbal utterances in medical interviews, to hospital chart entries – must be recognized. Using skill and seriousness, doctors recognize them by listening to them, reading them, or writing them down. Once recognized, the narrative must be inspected for the universal features present in any other story: narrative frame, time, plot, and desire. (Obviously, many other features of narrative – character, intention, genre, or diction, for example – could have been singled out. I present here four of the more clinically pertinent features.) These four elements, although never present in isolation, together build the narrative contract between teller and listener that allows a story to be told and received. By systematically exposing the frames, times, plots, and desires of their clinical narratives, doctors will begin to fathom the insides of the stories patients tell them, the conflicts imbedded in the stories doctors tell one another, the sources of clashes on the health care team, and the meanings of the sadness and guilt and rage that can overwhelm them and prevent them from doing their best. With the narrative knowledge about disease, patients, colleagues, and themselves that is available through rigorous and replicable literary methods, doctors can attain the balance and accuracy and sense of proportion needed for ethical practice.

Let me first briefly define my terms. Narrative frames enclose teller and listener in a relation. Barbara Herrnstein Smith defines narrative discourse as "someone telling someone else that something happened" (1981, p. 228). In clinical terms, narrative framing takes account of the relative power and knowledge of the doctor and patient, whether the discourse is a verbal interchange in a clinic, a referral letter sent to a specialist, or a so-called discharge summary dictated on the death of a patient. Time is the essential ingredient of any narrative, and medical narratives are, by their nature, obsessed with time, as in, for example, the oncological penchant for 5-year survival data. "Time," writes Paul Ricoeur, "becomes human to the extent that it is articulated in a narrative mode, and narrative attains its full meaning when it becomes a
condition of temporal existence” (1984, p. 52). Plot, according to Peter Brooks, “is the design and intention of narrative, what shapes a story and gives it a certain direction or intent of meaning” (1985, p. xi). Not the events themselves but how the events are configured confers plot on an otherwise meaningless set of occurrences. Critically speaking, differential diagnosis is an exercise in seeking the “best plot” for the available findings. And, finally, reading and writing are acts marked by irreducible desire. The writer experiences the hunger to tell, often finding in poetic diction the means of expressing that which otherwise remains unsaid and therefore unknown. The reader, too, is carried forward in a text by a thirst for meaning, a desire for knowledge, and a need to find out the ending (Barthes, 1989).

Frame, time, plot, and desire can now be examined in the doctors’ stories that follow. The five stories collected in this essay are evidence of the narrative work that underlies ethical medicine. Five practicing physicians – a psychiatrist, a pediatrician, a family doctor, an orthopaedic surgeon, and a cardiologist – write about individual patients under their care. Western-trained and appointed in U.S. University centers, they use all the power and logic of contemporary empirically-based scientific medicine. And yet here, they write not in technical diction but in common, resonant language. These doctors are practicing ordinary medicine, adopting methods that any doctor could use. They have each found, individually, that adopting literary methods helped them to practice in a wide range of ethical conditions – ambiguous frames, asymmetric temporalities, competing plots, and conflicting desires. With the help of their literary methods, they do not solve ethical problems so much as they prosper, with their patients, in challenging ethical climates.

They write and they read: one doctor reads the poems written by a patient’s mother. Another reads his patient’s description of the future. Works of fiction guide two doctors toward a knowledge that otherwise eludes them, knowledge for which they need a language. And they all approach the events befalling their patients as serious interpretive readers of signs.

Richard Martinez seeks to frame his therapeutic work with the patient whose initials are R.N. Where, he asks himself, are the boundaries between his patient the teller and himself the listener, between his work and his play, between the doctor he is and the person he is? Itself a narrative act, the framing of his clinical actions raises ethical questions about over-involvement, objectivity, and
personal gain. That Dr. Martinez confirms his eventual decision by recourse to a short story is doubly compelling: the story “Toenails,” also written by a doctor about crossing boundaries with a patient, furnishes an “answer” in its plot. More fundamentally, these two doctors, by inspecting the narrative frames of their medical actions, find ethically appropriate solutions to their clinical dilemmas.

Robert Nelson’s patient Emily and her family exist in a time different from the split-second decisions of the NICU. The pediatrician is caught between the therapeutic chronology of his technical decisions (Shall we start ECMO?) and the faith-rooted communal time of the religious family members. The retarded “developmental level” of the infant means little to the mother and grandmother, no matter how ominous the failure of the infant to measure up to her chronological age appears to the pediatrician. Admitting the mysteriousness of the family’s values and decisions, the pediatrician reconciles his own personal opposition to treating this impaired baby with the family’s wishes by opening himself to the transforming experience of their eternal narrative of hope.

Howard Brody and his patient are caught in competing plots. The same events – serious back injuries, unresponsiveness to treatment, probable narcotic addiction – are configured into clashing meanings. Such clashes have been figured by some branches of medical ethics as individual decisions upon which patient and doctor disagree, requiring mediation, arbitration, or adjudication. However, a literary or narrative ethic conceptualizes the differences as far more deeply imbedded in the entire apparatus that constitutes meaning – the ground substance that coheres a life. Once Brody recognizes the incommensurability of his plot with the patient’s, he has the sense to ask the patient to write his personal story. In the writing, the patient is able to tell his fantasies, his great confidence in a future without pain, and his refusal to abandon his plans for an active life. Having given the patient the power to dictate the narrative, the doctor can take on the role of friendly critic instead of omniscient narrator. This therapeutic writing is an astonishing example of the healing potential of words: Brody’s patient reclaimed a power of choice that had been denied him throughout a long illness. He ultimately did well, perhaps in no small part as a result of the narrative power his doctor granted him.

Mary Clark helps us to see the two faces of desire in narrative. Through her own writing, Clark fulfills her desires to come to
terms with her complex feelings about her mother’s illness and the clinical predicaments of her young patients. The mother of Clark’s infant patient, in turn, reveals her desires – from pre-natal fantasies of a perfect child to the dark desire for punishment or revenge – in the poems that she shares with her son’s doctors. Both mother and doctor find that poetry can articulate that which prose cannot, attaining through metaphorical language not sequential steps in logical understanding but the radiance and reconciliation of contradictory meanings. Through their poetry, writer and reader satisfy their desires to capture and behold the confusion of fact and feelings, ultimately helping them make the best possible choices.

In a story that relies on all four elements of narrative, Dwight Davis finds himself caring for a terminally ill patient whose family insists she not be told that she is dying. Framed by strangerliness and “kind” deception, doctor and patient have neither personal familiarity nor open discourse to help them make decisions. The story itself centers on competing plots – the family’s hopeful expectations of a heart transplant and a return to normality and the doctor’s clinical recognition of an elderly woman with multiple organ system dysfunctions that, together, preclude curative intervention. The conflict centers on the time course of this woman’s life – the doctor must deny her the future that the family assumes is hers. As one catastrophe after another befalls the patient in rapid succession, it becomes too late to talk, to allow the patient to make her own choices, or to help her come to terms with dying. Awakened by Tolstoy’s fiction, Davis’s thirst for honesty and genuineness allowed him, in retrospect, to realize what was wrong with the care of Mrs. R.L. These lessons, in turn, led to programmatic changes on the heart failure service to satisfy the imperatives of both doctors and patients to tell the truth and to act in its presence.

Literary contributions to ethical medicine, in the end, are not rules or policies or even processes. Rather, they are practices, learned from acts of reading and writing, through which doctors can attain, in Dr. Nelson’s words, the “synthesis that expresses shared understanding and produces common action” (p. 264). Examining the frame, time, plot, and desire of clinical narratives may not always provide an answer to specific ethical conflicts, but makes possible ways of being with a sick person and means of respecting that sick person’s language and story that can lead, ultimately, to fitting actions and knowing care.
II. TAKING ONE'S LIFE BACK FROM PAIN

Howard Brody

L.W., 23 years old, suffered from chronic back pain as a result of auto accidents in 1988 and 1989. The care he received from four previous physicians had been sporadic and disconnected. He was taking a narcotic and a muscle relaxant, and a neurosurgeon was considering further rhizotomies, even though six previous procedures had produced no improvement. Formerly a construction worker, L.W. was now in 1991 taking classes in a community college, though his pain was aggravated by prolonged sitting.

This three-year history suggested a pattern of chronic pain which had taken on a life of its own, independent of the original cause. Accordingly, I spent little time going over old history, reviewing x-rays, or discussing previous surgeries. Instead I resorted to a treatment approach that is a fairly typical primary care strategy. I sought to test L.W.’s willingness to commit himself to a very different therapeutic relationship, based on certain agreed assumptions: that I would be his family physician and remain responsible for his care no matter which treatments were working or not working, and that it was very unlikely he would ever be truly free of pain, though – with time and effort – he could live a productive and fulfilling life. To deal with his pain in this way it was critically important that both he and I understand just what the pain meant to him (Morris, 1991). Though somewhat skeptical, L.W. eagerly embraced the idea of a more continuous therapeutic relationship. We concluded this first visit by refilling his current medications, referring him for physical therapy, and arranging for him to visit a newly opened pain clinic.

This new clinic, however, seemed to adopt a purely mechanical approach, giving him a course of injections which provided only temporary relief. At this point I realized that the therapeutic relationship would have to become the primary treatment strategy. And interpretation of the problem was basic to this strategy. Finding that L.W.’s classes required essays, I suggested that he write a series of essays discussing the meaning of his pain. L.W. agreed readily, and I began seeing him every three weeks as he became more involved in this task.

The five or six brief essays he wrote on topics that I specified revealed several major themes. He had great difficulty writing about a future in which he continued to experience pain, but was
easily able to imagine himself five years hence pain-free. The future he pictured involved picking up his former life and returning to construction work. At present he felt little control over any aspect of his life, and a fair amount of anger surfaced in his essays. They also revealed considerable ambivalence on two major issues: he wanted to be "normal" and not have to think about his pain but he saw the value of taking action to reduce the pain (though this required having to think about it daily), also he wanted to get off narcotics to avoid the stigma of addiction although he saw that continuing narcotics enabled him to function better. An important finding from these essays was the relation of L.W.'s past, pain-free way of life (and his fantasies about a pain-free future) to his family of origin. His parents owned the construction firm for which L.W. and his twin brother worked. The brothers – for whom the term "identical twins" would be an understatement – used to work alongside each other. Since L.W.'s first accident, his brother had married and now had small children of his own. L.W., it emerged, was grieving the loss of his relationship with his twin, whose new family obligations made him seem less accessible. In the next stage of treatment, as I tried to help L.W. identify small areas of his life where he could assume more control, I suggested that he request some time alone with his brother to discuss these feelings.

About five months into treatment, the idea of his writing essays and our discussing them seemed to be paying off. I saw reason for cautious optimism. L.W. came regularly for his appointments, rarely called our office otherwise, and generally showed no signs of manipulative or drug-seeking behavior. He was cooperating actively in the program agreed upon, and was beginning to see the connection between reduced disability from pain and his enhanced sense of control. I found myself with two overriding ethical goals and with an agenda. My goals were to wean L.W. gradually off narcotics as he felt better through increased psychosocial support and physical therapy, and to preserve him from unnecessary, possibly harmful surgery. My agenda was based on my version of the next chapter in L.W.'s narrative. I saw him accepting his inability to work at construction, finding ways to relate positively to his family outside the workplace, and using the undoubted intelligence revealed in his essays to complete college training and obtain a job which was not physically demanding.

But visits over the next several months showed that L.W. was developing a better sense of how his own story should turn out –
a version quite different from mine. He eagerly accepted temporary jobs with the construction firm. Soon he was working up to 80 hours a week, driving a truck as well as helping to unload it, despite his increased pain. He returned to me ambivalent once again: proud of his earnings and his ability to function physically, yet distressed by his need for additional narcotics. L.W. made it increasingly clear that his sense of control over his life did not mean giving up his goals and going to school; it meant pursuing his goals as part of the W. construction firm. While he continued to express dismay at the dosages he needed, he began to see a clear relation between how much narcotic he took and how functional he was in his daily life and work. I was aware of the legal and moral arguments against continuing such high dosages, and even wondered if I might be the victim of an elaborate con job, as had actually happened in my practice twice before. But L.W. experienced no drug-induced euphoria, and when he was not at work loading trucks 12 hours a day, he reduced his narcotic dose to nearly nothing. His family and co-workers confirmed that he was a highly reliable and productive worker, and showed no work-related risk or disability from narcotic use. These supporting narratives gave me courage to continue my prescriptions. In the end, I had to trust my medical judgment, and I based this judgment on L.W.'s unfolding story. I was confident that it was not the story of an addict seeking drugs. I found out some time later that L.W. closely fit the pattern of a small percentage of chronic pain patients who actually do better while remaining on high-dose narcotics (Portenoy, 1990).

One might ask: Would I not have achieved the same therapeutic outcome had I simply spent more time with the patient, taking a careful family and occupational history? Time is limited in the typical primary care office visit, with patients scheduled for 15-minute slots. L.W.'s "homework" allowed me to raise a theme with him, have him ponder its significance several times during the intervening three weeks, and then return to discuss it—in effect doubling or tripling our interaction. Moreover, control was a key issue in L.W.'s treatment. He needed to replace feeling controlled by his pain with the feeling that he could accomplish goals despite the pain. These essays represented real and tangible accomplishments of which L.W. was quite proud.

Today, L.W. is married and continues to do construction work. He is looking forward to getting his license to operate heavy con-
struction equipment: this will mean less need to lift on the job and also – for the first time in years – reliable health insurance. He has benefited from an exercise program, and after two further surgical consultations no longer considers surgery a good option. A consult with a pain specialist confirmed the need in his case to continue narcotics. He has consulted other physicians, as I sought additional medical opinions on his care as well as reassurance that he was not becoming unduly dependent upon me personally. I am uneasy when L.W. expresses his gratitude in terms such as “you have given me back my life.” But I felt honored when he recently gave me what seemed the highest gift he could bestow – a cap emblazoned with the logo of the W. construction company.

III. SMALL BOY, LARGE LIMBS, LARGER PROBLEMS
Mary Williams Clark

Can poetry influence the way physicians recognize and deal with the ethical issues that arise in patient care? For me, a pediatric orthopedic surgeon who has recently begun writing poetry, the answer is definitely yes. I discovered I could write when it became apparent that my eighty-seven year old mother could no longer live alone due to newly-diagnosed Alzheimer’s disease. This journey of hers and mine became a poem of almost epic length (into which I put my feelings about watching her change, about our old and new relationships, and about her wish to die). Then I began to write about my patients. I see patients who are literally unforgettable: the images and details of their situations remain in my mind for years. Writing poetry is for me a way to preserve these images, these “clinical moments” in my practice – to record experiences, to come to insights, and to share these with patients’ families and medical colleagues. Writing – and reading – poetry help sensitize me to all aspects, including ethical ones, of my patients’ medical situations.

I became aware of this when the mother of a severely deformed child named Dylan gave me a set of poems that she had written about her and her family’s experience with this child. Dylan has Klippel-Trenaunay-Weber syndrome, a vascular and lymphatic malformation. He was born by emergency Caesarean section, bleeding and in heart failure, due to shunting through the vessels in his hypertrophied left leg, his right foot, and in his abdomen. Surpri-
sing everyone, after three weeks in the neonatal ICU he was ready to go home. His heart failure responded to medication; his legs responded to compressive dressings. Multiple conferences shared information; multiple studies established that his abnormal vessel formation was extensive and in most areas unresectable. His major orthopedic problems were a significant (8–10 cm) leg length discrepancy and an almost flail foot on the long side. Early on, the team felt amputation would probably be necessary, but challenging. Twenty months old now, his immediate condition is felt to be stable. His long-term prognosis is less easily determined. Several of the team members predict his life expectancy is limited, possibly very short, due to the extensive intra-abdominal lesions, which will grow, and which will be difficult or impossible to remove.

Several ethical issues emerge in such a case. One is the challenge of honest and sensitive communication with the parents about a complex medical situation with an uncertain prognosis. I am convinced that the pursuit of good communication among patient, family, and medical team is an ethical issue: medical people have a responsibility not only to be sure that their words and their meanings are clear to the patient and family, but also to be sure they clearly understand patient and family concerns. And this can be complicated: a child like Dylan acquires (and requires) a large team: in this case, a pediatrician, three pediatric surgeons, two plastic surgeons, an orthopedic surgeon, urologist, physical therapist, and prosthetists, as well as another team at a large K-T-W consulting clinic in another state.

Another ethical issue is the question of whether or not to pursue “aggressive” care for a patient with a poor prognosis. How does one assess risks and benefits related to possible operations? Whose assessments, and whose choice? Good communication among patient, family and healthcare team is essential to our ability to deal with these questions. Traditional medicine has emphasized a primarily one-way communication model, the physician asking questions, the family answering, and the physician then providing “the” advice, often significantly censoring the information given. Many now see a need (and a right for families) for two-way communication, in which physicians not only ask for information, but also solicit their patients’ questions and opinions.

It was Dylan’s mother, through her poetry, who helped me realize how important communication is to clinical decisions that involve ethical issues. She began writing poems to Dylan during
her pregnancy, continuing to do so after he was born. The series, which came to number thirty poems, begins with her pre-natal intuitions and subsequently details the family’s experience as they work to come to terms with his condition. She gave copies to his healthcare team when he was about six months old.

These poems greatly facilitated my knowledge of the family’s situation. They helped me better to know the details of the challenge an unusual child presents – the complexities of the parents’ emotional responses and the draining day-to-day care – and they helped me assess the family’s capacity to deal with this challenge. I learned things from these poems that I think his mother could have communicated in no other way: for example, the dinosaur image that occurs in many of the poems gave me insight into the way the family was dealing with Dylan’s deformity. This image occurs in the first poem, written before he was born; with his birth it becomes a terrible reality. But within the first month, the negative turns to a positive: “We tell your brothers you’re part T-Rex/They think it’s tremendously cool/to have a brother with purple dinosaur legs/and feet from a sci-fi movie.”

The ambiguity expressed in the image of the dinosaur surfaces in other ways. Another poem describes the mother’s guilt about constantly extolling Dylan’s beautiful face, while selecting his clothing with care to conceal his lower body. Parental guilt about babies’ problems is common, often unspoken, and almost always unjustified. Dylan’s mother can acknowledge this guilt, recognizing that feeling guilty “will neither mend you nor lessen your pain.” She sees it as the parents’ task to foster their son’s independence, thus moving beyond the initial guilt of “failing” to produce a perfect child, “by encouraging risk-taking, by offering empathy but never pity, and by loving you for you.” Other emotions expressed in these poems include rage, sorrow, joy, despair, frustration, grief, a feeling of being overwhelmed, anger, and “a desperate need to place blame.” The anger recurs in several poems, is clearly real, multidirected, and undoubtedly includes anger at the medical team.

Such candid expressions of feeling can alienate team members, but draw the reader into the intimacy of the family’s life. This experience of imaginative involvement can be revelatory for clinicians, whose exposure to such a family may otherwise be limited to a few minutes at a time in the clinic. Not only does such sharing of experience and feeling facilitate genuine communication, but it also fosters trust. This mutual trust has proved essential to Dylan’s
care: it allowed me to facilitate communication with the team, with the consultation clinic, and to speak positively about amputating Dylan’s oversize foot; it also facilitated the parents’ acceptance of this frightening, if necessary, procedure.

Much of the ethical aspects of clinical decision-making is intuitive: we physicians are not trained in formal ethics. The knowledge I gained from these poems strengthened my intuitive support of the parents’ search for treatment options and their eventual decision to proceed with amputation. The decision to surgically intervene in such cases is determined by the degree to which it may enhance the child’s quality of life. In this case I felt confident that the family would provide appropriate stimulation for Dylan’s development, maximizing the benefits of the operation, and encouraging him to progress. The language of the poems also acknowledges that the parents realize his life is still precarious and that we must guard against unrealistic expectations.

I believe that moral guidance for treatment decisions comes from thorough discussion of the individual situations, and is very case-specific; and I believe that poetry, written by parent, patient, physician, or published poet, can foster the all-important connecting that is essential to true communication. Tess Gallagher observes that poems are useful as “reservoirs of grief:” “as in no other function for which we use language, [poems] are able to carry the density of the complex synthesis of...psychic, spiritual, intellectual, emotional, and intuitional perceptions through which we move.” Poems, she continues, are “the best and oldest forms we have for attending and absolving grief, for bringing it into a useful relationship to those things we are about to do toward a future” (1986, p. 117). Poetry continues to perform that function for Dylan’s family. Dylan has already benefited from his amputation, moving rapidly from his previous belly-crawl to toddler walking. As his treatment progresses, involving further therapy as possible for frequent bleeding, and reconstruction of the other foot, his mother has begun another series of poems.

IV. LESSONS ABOUT PATIENT DECEPTION
Dwight Davis

Much of a physician’s time is spent in continuing medical education. Literature offers an important, though unconventional, source for
Five Cases From Common Practice

this ongoing learning. One work of literature that has made a lasting impression on me is “The Death of Ivan Ilych” by Leo Tolstoy (1960). The heart of this story is what Tolstoy calls “the deception, the lie,” the lie that all the central characters, including Ivan, his family, and his doctors accept, that he is not dying, but simply ill. As the story unfolds, it becomes clear that this medical lie is the theme for a larger fallacy: Ivan becomes aware that, in a sense, his entire life has been a lie. This is a story that I have often reflected on while caring for critically ill or terminal patients.

Several months before reading “The Death of Ivan Ilych,” I cared for Mrs. R.L., a 58 year old female who was transferred to our facility with severely compromised heart function and refractory myocardial ischemia for consideration of cardiac transplantation. She had a number of other significant medical problems, including insulin dependent diabetes mellitus, long-standing hypertension, moderate obesity, chronic obstructive pulmonary disease, and significant peripheral vascular disease. Despite these problems, she remained an active homemaker for her husband as well as helping with the care of three grandchildren until she experienced an extensive myocardial infarction one month prior to transfer.

It became clear on arrival that Mrs. R.L. and her family were having a difficult time coping with her month-long illness and hospitalization. They came with high expectations of receiving a heart transplant. The preliminary evaluation indicated that she was an appropriate candidate for neither bypass surgery nor cardiac transplantation. So shortly after her arrival I had the unpleasant initial task of informing this family that neither transplantation nor bypass surgery were viable options. Cardiology tests the next day demonstrated that one of the three diseased coronary arteries was primarily responsible for her clinical symptoms. Following lengthy discussions with the patient, her husband, and her two daughters, we decided to attempt a high-risk vascular procedure to open one of the blocked coronary arteries. I reviewed with them the complications associated with the procedure, including the possibility of death. The patient explained that with so many terrible things in her recent life, including an unexpected and frightening heart attack, her prolonged hospitalization, and the fear that she might not be able to resume her active life, she wanted to “think positive,” and consented.

The following day an intra-aortic balloon device was placed prior to coronary angioplasty for protection of ventricular function
and to assist in coronary perfusion. The vascular procedure succeeded in reducing the stenosis from 95% to 30%. However, the following morning she developed a severe systemic infection, presumably from the vascular insertion site of the balloon device. This event started a progressive deterioration in her clinical status over the following 10 days. She developed hemodynamic and respiratory instability from sepsis and required placement on a ventilator. Subsequently, she also developed renal failure and massive upper gastrointestinal bleeding despite prophylactic antiulcer therapy.

The family felt strongly that the patient would not be able psychologically to handle knowing the severity of her illness. Although I stressed the importance of discussing Mrs. R.L.'s condition with her, the family was insistent. Unfortunately, she had never expressed her wishes regarding length and extent of artificial support. On admission – probably at a time when she did not give much thought to the possibility of serious illness or death – she had signed an advance medical directive form consenting to maximum support if she became incompetent. The family argued that, considering all that she had endured over the past month, realistic discussion about her condition would be psychologically devastating. It was an extremely difficult situation for me, especially since I had only known Mrs. R.L. and her family for a few days. The referring physician, who did know her well, indicated his agreement with the family’s assessment of the patient’s mental status.

Although we were able to wean Mrs. R.L. from the respirator, her overall clinical status continued to decline as a result of progressive heart and kidney failure. It shortly became obvious to her family, to me, and probably to Mrs. R.L. that she would not survive this hospitalization. At the continued insistence of the family, we developed a daily ritual of meeting secretly to discuss her lack of progress before collectively meeting with the patient. Just as in “The Death of Ivan Ilych,” our evening gatherings at the bedside became orchestrated attempts to keep her spirits up – or more bluntly, a lie. Noticing Mrs. R.L.’s increasing withdrawal, I again strongly recommended that we should try to create an atmosphere in which she and we could speak candidly of her condition and prognosis. The family continued to insist on avoiding any such discussion.

Her final days were very much like Ivan’s. During her last three days she completely lost interest in my superficial updates on her condition. It became difficult for the family to carry on meaningful conversation with her, probably because of the silence regarding
the terminal nature of her illness. Her last two days were spent in a metabolic coma with the family almost constantly at her bedside. The family and I had decided not to attempt resuscitation since there was little chance of recovery. The terminal event was ventricular fibrillation. I was present with our chaplain and other members of the family who had been called in anticipation of her death.

There were many similarities between this patient's clinical history and the story of Ivan Ilych. For Mrs. R.L., as for Ivan Ilych, her final illness occurred at what felt like the wrong time. Despite some minor problems, life had been good for her and her family prior to the myocardial infarction. During this final month of life, like Ivan, they questioned many times – both themselves and me – why she had to endure this illness. Each time they found no rational answer. Again like Ivan, Mrs. R.L. and her family went through a time when their sole focus was on finding a cure for her illness. At the end, Mrs. R.L. had to face death alone, while her family and I went on refusing to acknowledge her impending death in her presence. The death of Mrs. R.L. had a devastating effect on me, as a person and as the responsible physician. I felt tremendous guilt for my participation in deceiving a patient about her condition and great frustration with my inability to facilitate thoughtful and empathetic acknowledgment and discussion of her impending death, while trying to accommodate the strongly held desires of a family that I did not know well. I feel I neglected my moral responsibility to my patient.

Reading "The Death of Ivan Ilych" helped me understand this difficult case at a deeper level. First, there was the closely similar relationship between the patient, physician, and family. Second, although Ivan was a participant in his own deception, he was also tremendously tormented by it: he needed his dying to be acknowledged, shared, and pitied. By describing the ordeal from the patient's perspective, Tolstoy provided me with a heightened sense of empathy that I would not have gained from other sources. I also understood more deeply the importance of meaningful involvement by family members with patients who are critically ill or terminal. Aside from attending to basic medical needs, the physician should play a key role in facilitating open and sensitive communication between the patient, family, and healthcare providers. Otherwise, the patient's experience can be agonizingly lonely and frightening. Of course, the physician must be sensitive to differences between patient and family units in handling illness.
and death. This role is easier when it is based on an established and long-standing relationship. But often – as in my case – this difficult task must be faced by specialists in tertiary care facilities who don’t know a patient well.

I was prompted by Tolstoy’s story not only to recognize this problem, but also to deal with it. Tolstoy goes beyond a description of the dying process to provide a judgment on the conditions surrounding dying. Reading his story led me to reassess how we handle communication with critically ill and dying patients in a tertiary care facility, and motivated me to make changes that should provide better overall support for patients and their families. On our heart failure service, we now incorporate focused discussions about the illness and potential consequences with patients and their families, starting with the first day of admission. All members of the healthcare team are actively involved in this process. Our goals are: first, to provide sensitive and honest responses to the question posed by Ivan Ilych – how serious is my illness? Second, to demonstrate and remind patients, as Ivan’s servant Gerasim did, that their care is not burdensome. And lastly, to assure patients that they will not be abandoned.

V. CROSSING BOUNDARIES
Richard Martinez

In my work as a psychiatrist I find literature invaluable in illuminating complex ethical issues. An example from my own practice is the case of R.N., in which a story by Richard Selzer helped me understand and validate a problematic decision I had reached intuitively. Though this understanding was retrospective, it has helped me clarify moral aspects of a psychiatrist’s (or any physician’s) relationship with his patients – a subject for which current ethical guidelines are inadequate.

R.N. is a 50-year-old male physician. He has been divorced once, and has raised two teenage children for ten years as a single parent after his former wife developed a psychiatric condition. He entered therapy after becoming depressed following the death of an old friend. R.N.’s history is notable for early childhood neglect: his mother was episodically depressed and withdrawn, his father was emotionally distant. Both parents and a younger sister are dead, and R.N., with few friends, is now quite isolated. His one pleasure
is fishing. Shortly after beginning therapy, he asked to bring his children to a session; he felt it would be useful if the entire family could talk together with my help. Family therapy was successful, and lasted two months, after which R.N. continued in individual therapy. To celebrate what therapy had accomplished and to have me see his home, R.N. asked me to a family dinner – a trout dinner.

R.N.’s invitation confronted me with a hard decision. My traditional psychoanalytically-oriented training discouraged such contact with patients. Such requests, I was told, should be explored for their “hidden meanings.” If he responds to such requests, the psychiatrist risks gratifying an unconscious wish that might better be explored in therapy rather than acted upon. Patients, one supervisor told me, don’t pay for friendship but for our expertise – as if these are mutually exclusive. From my own point of view I was being asked to give up an evening from my private life and continue working, without remuneration. On the other hand, I liked R.N. I respected his commitment to his children, his capacity for hard work, his courage and determination in the face of hardship and disappointment. I knew of his desire to decrease his isolation and to step back from work and develop a more balanced life.

I decided to go to dinner. The evening proved enjoyable. I saw R.N. with his children in his home, his own domain. He showed a relaxed side that I had suspected but which had never fully developed in my office. Likewise R.N. learned things about me that would not have been revealed in the usual therapy. The experience strengthened our relationship. In subsequent sessions we discussed the meaning for him of my coming to his home. He began a new process of grief, letting go of regret for the past and expressing new hope for the future. He talked with new intensity and openness, and a different kind of trust. Over the next year he began to date and slowly to make new friends. He left therapy transformed, able to manage periods of depression, hopeful about his future life.

What are the conceptual issues and principles that bear on such a decision? In psychiatry the concept of “boundaries” is used to analyze various clinical and ethical aspects of the patient-psychiatrist relationship (Gutheil and Gabbard, 1993). A broad use of the term would include sexual misconduct with patients at one end and accepting gifts from patients at the other. At the center of this spectrum is concern for patient exploitation and coercion. Many psychiatrists argue for developing strict ethical guidelines to assure
good patient care, while others fear that the profession has gone too far in distancing the patient, leading to neglect and injury. Boundary considerations are not simply matters of therapeutic strategy or clinical problems to be solved. At the heart of this debate are important moral concerns involving principles of medical ethics; virtues, such as respect and compassion; moral obligations and ideals, including the concept of supererogatory acts; and all those aspects of character and motivation involved in the physician's calling to medicine.

What light can literature – in contrast to the debate about principles – shed on a boundary-crossing act such as mine? I have been much impressed by a story by Richard Selzer called "Toenails" (Selzer, 1983). It tells of a surgeon who enjoys spending his afternoon off reading in the public library. He observes, with interest, the elderly people who sit at his side week by week. One morning an octogenarian he calls "Neckerchief" enters the library limping. On inquiring, the surgeon discovers that Neckerchief's toenails are painfully ingrown. They descend to the library's basement restroom, where the surgeon proceeds to clip the toenails of this new patient – or friend. At the story's end, the surgeon is kneeling Christ-like in the restroom, washing the feet and clipping the nails of the rest of this circle of the elderly and abandoned.

As it turned out, my decision to visit R.N. was the right one: I was able to help him in therapy. But one wants more than this pragmatic validation for such a problematic action. Rules about proper medical boundaries, the analysis of ethical principles, speculations about correct clinical intervention all provide some guidance. But they fail adequately to illuminate the often ambiguous and confusing terrain of the relationship between doctor and patient. Selzer's story does not debate principles. Instead, it presents a moral ideal of the virtuous physician. Selzer's surgeon-narrator is a human being first and a physician second. Neckerchief is not his patient, and this is no medical emergency. He could see him in his office the next day or he could refer him to a colleague. As they talk and Neckerchief tells of his past, his dead wife, his love of boxing, he ceases to be an anonymous elderly derelict and becomes a person for the reader as well as the surgeon. Just as my own feeling for R.N. evolved into a kind of affection, so we come to appreciate this elderly man, rich in memory, crusty and alive, through his encounter with the surgeon-narrator.
Lastly, I have found Selzer's story helpful in reflecting on cases like that of R.N. that involve supererogatory acts. In the age of managed care, where each "patient contact" is valued by whether it is billable, Selzer's image of the kneeling, Christ-like physician challenges our notion of what it means to be a physician. Selzer's surgeon is a healer at all times. He is not fragmented by contemporary notions of professionalism. Perhaps it is our duty to go beyond our duty. The story tells us what it means to care, and to be a human being first and a physician second. Selzer's surgeon explores and ventures across boundaries. Whether the situation is the rare invitation to a wedding, the decision to attend a funeral, the receiving of a holiday gift, the giving and receiving of a hug, or the psychiatrist who is invited to dinner, his story reminds us that the practice of medicine extends beyond the office and the defined hours of doctoring, sometimes requiring actions that are not only helpful for the patient but perhaps necessary for the physician who aspires to realize the full meaning of his calling.

VI. EMILY'S STORY
Robert M. Nelson

"Is severe birth asphyxia a reason not to do ECMO?" The other physician's voice sounded tentative. It reflected the ambivalence we both felt about escalating technology in treating an infant with life-threatening pulmonary hypertension. We reviewed the data, recognizing the difficulty of predicting neurological outcome in cases of severe birth asphyxia, yet admitting that we have not withheld ECMO from such an infant, despite our doubts.

The mother's response was very different. "Please save my baby!" As soon as her physician told me of this reaction we arranged for transfer. I was not surprised: the shock and subsequent denial of an infant's sudden illness, the impact of sedation after a cesarean section, the hopes fostered by nine months of dreams for the life of her child all contributed to an unrealistic and perhaps irrational hope that her infant would be fine. "If only she understood," I reflected. A few hours later I called her to discuss placing her infant on ECMO and to express my concern about her infant's neurological prognosis. She sounded tired and sedated, and I was unsure how much information she received. I did learn that the
infant’s grandmother was on her way to the hospital, though she would not arrive prior to the infant being placed on ECMO. So I described the procedure and obtained her “informed” consent. Our conversation ended with her parting words – “I want you to do everything you can.” Perhaps I would have better luck with the grandmother.

Her mother was unable to visit Emily – as she was now named – for a week after birth because of post-operative complications. But during this time I spoke repeatedly with both mother and grandmother about Emily’s condition. She developed an intracranial bleed on the third day of ECMO and was switched to a conventional ventilator. I again questioned the value of continued support. Despite a worsening neurological prognosis and the real risk of death, both mother and grandmother consistently wanted full support. Eventually Emily’s lungs recovered. She was unable to suck and swallow adequately and thus needed to be fed with a naso-gastric tube. She had a seizure disorder which required medication. Emily’s mother refused a gastrostomy tube to assist with feeding and learned to insert the naso-gastric tube. With this regimen, Emily was discharged for home.

Emily’s mother was optimistic about her infant’s chances for neurological recovery. The nurses were convinced either that I had not informed her of the medical facts and prognosis or that she was denying the reality of Emily’s condition. To address these concerns, I invited several nurses to meet with me and Emily’s mother. I began by asking whether she understood the extent of Emily’s neurological injury. Emily’s mother proceeded to describe her injury and, in the process, drew a simple though accurate rendition of the recent CAT scan. I then asked her what I had said about Emily’s expected outcome. Her response was: “You said that she would never walk, talk, or be able to feed herself.” Emily’s mother was obviously aware of the medical facts and of my estimate of Emily’s neurological outcome, however, she still hoped her child might lead a close to normal life.

Was this response denial, or faith, or both? When a parent disagrees with our conclusions, does this necessarily show ignorance or irrationality? Or do doctor and parent each choose to tell a different story? In counseling parents, focusing on the medical facts alone cannot reveal or resolve the complexities of moral choice. The simple fact of a severe intracranial hemorrhage on top of an asphyxic insult has little meaning unless placed within a coherent
narrative of what might happen to this particular patient. We cannot know what to do without some sense of what to expect. The initial story I told Emily’s mother was my story, shaped by my personal and professional values, guided by my hopes and fears, reflecting my sense of obligation as a physician and as a person to Emily and to her family. However, I was not the only narrator – or actor – in the story. The narrative her mother and grandmother constructed for Emily was shaped by their faith in God’s providence. Rather than an irrational act based on unrealistic expectations, their decision to continue treatment was their response to a new challenge as professing members of a community of faith. Thus the question that guided Emily’s mother was, “How should I respond to my infant’s illness in light of my faith in God?” Her decision cannot be understood by a string of adjectives fixing her character at a moment in time, but only through her story – a narrative shaped by a communal story – yet singularly her own.

Through our conversations, I began to appreciate the depth and quality of the mother’s and grandmother’s faith. Though I personally disagreed with their decision to continue life-sustaining treatment in view of Emily’s prognosis, I came to respect the integrity of their response to the challenge of her condition. Nevertheless, my story and their story for Emily’s future were – and perhaps remain – very different. Perhaps what was most unnerving was not the course Emily’s mother had selected but the fact that I was asked to be a player in her unfolding drama, a clear and coherent story to her mother but potentially a mystery to me.

Emily is now six months old. According to her grandmother, Emily is able to take a bottle and no longer needs tube feeding. She is gaining weight. Developmentally, she is able to hold her head up and occasionally pushes herself up to look around while in the prone position. She makes intermittent eye contact, follows faces and voices, and smiles while making appropriate noises. She requires seizure medication and is getting weekly physical therapy. Emily appears to be functioning at a three or four month old level.

I asked Emily’s grandmother to reflect on all the child had been through in her first weeks of life. Her first response: “Thank God we let her live.” And her assessment of my participation: “You stuck with it. She’s one of your hard projects.” My thoughts ranged back over our conversations about withdrawal of support. Was the decision to continue reasonable? I could not imagine Emily’s mother and grandmother making any other decision. In fact, they should
not have made any other decision. Would withdrawing support have been wrong? I believe not, given my best guess of the future at that time. A different family might have agreed to withdraw support, and that too would have been an appropriate decision. Will Emily’s mother and grandmother (or even Emily) regret the decision to continue support? Perhaps, although I doubt it. The grandmother’s parting words to me were: “I’ll be praying for you.”

I saw Emily and her mother in clinic the other day. Emily is thriving and well cared for, however, her neurological exam gives me pause. My estimate of a three or four month developmental level may be generous. More tests need to be done. As I examine Emily, I talk with her mother about my concerns for Emily’s vision and spasticity. Nevertheless, Emily’s mother is as sunny and optimistic as ever. As before, we see the same things, yet still respond differently.

The moral issue in this ongoing story is not the decision about treatment but the relationship of parent and physician. How am I to understand my role in her ongoing narrative? Did I simply defer to her mother’s decision? To interpret my actions as simply respecting her autonomy may distort our encounter in at least two ways. It narrows our focus to the particular decision at hand, and it values the context only as it illuminates that decision. As such, it fails to acknowledge that understanding another’s intentions requires an openness available only through engagement within a common narrative.

The concept of openness moves an ethic based on narrative beyond the appreciation of context on the part of the physician to an ethic involving the possibility of change for physician, patient, and family. “Taking a good history” becomes more than a technical exercise aimed at a better diagnostic or therapeutic intervention, rather, the physician engages in a process of interpretation that requires an openness to the truth of the patient’s narrative. The evolving story of the clinical encounter thus becomes a fusion, albeit partial, of the patient-authored and the physician-authored narratives. Both are in dialectical tension with the “fused” narrative, the synthesis that expresses shared understanding and produces common action. A narrative ethic thus involves more than a technical appreciation of context and point-of-view. It demands an openness to stories whose truth may differ from ours, a way of
understanding other persons that may modify our own stories and challenge our personal or professional point of view.

REFERENCES


