

## *One Cheer for Bioethics: Engaging the Moral Experiences of Patients and Practitioners Beyond the Big Decisions*

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*I have also learned, much to my continued disappointment, that ethical theories and ethicists are rarely helpful in decision-making at the bedside or for the individual.*

John Freeman

*When someone philosophizes, it shows he doesn't understand.*

Anton Chekhov

We will argue here that after more than 30 years of talk, theory, and clinical practice, we bioethicists still know far too little about what patients, subjects, and healthcare professionals are up to, morally.<sup>1</sup> Bioethics is still near the beginning in grasping what it means to understand, much less to honor fully, the moral power and perspicacity of those bioethics is designed to serve. This is, of course, a serious charge, but one we will endeavor to show has merit. However, we want to be clear from the start that we do not gainsay the important work that has been done in and through the influence of bioethics, both as a field of practical engagement and as a cultural movement, in improving how healthcare is delivered and how human subjects are treated. Thirty or 40 years—depending on how one marks the beginning point—is a very short time, and it is hard to imagine that wholesale changes, all of them in the right direction, could be the outcome for a field this young.<sup>2</sup> Hence, we do not intend the title, “One Cheer for Bioethics,” as a wholesale indictment, but as an indication that there is a great deal of work yet to be done, and that following the currently dominant direction of the field is not likely to get us there. Our aim is to indicate just where future work should be focused, and to do so we will need to be critical of some of the preoccupations of the last three decades.

Further, we will argue that it is not just on the fringes or in the places where bioethics hasn't made inroads into medical practice that the moral perspectives of patients and practitioners elude us. It is, arguably and to the contrary, right where bioethics has made its most dramatic impacts on institutional policy and practice that a different approach is needed: in appreciating and understanding issues involved in death and dying and in policies and procedures designed to establish and safeguard informed consent. We will examine each of these areas in detail. Our aim here is to note and describe just where it is that patients and

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subjects and healthcare providers reflect, decide, and act in ways that bioethicists do not expect and too seldom appreciate. In the short space of this article we can do little more than draw a sketch, but we hope it is one sufficiently clear that the outline for a different approach to bioethics will be evident.

One clue as to why bioethics is sometimes, perhaps often, unhelpful lies in the observation that many people are morally wise though not ethically learned. By “not ethically learned,” we mean that they don’t have formal training in ethics; they know nothing of Kant and Mill, Kohlberg and Gilligan, or Beauchamp and Childress, much less possess Ph.D. training in ethics. Their moral wisdom often shows up in hospitals and clinics as people become patients or research subjects and face major decisions about their care or the care of family members. What is this sort of moral wisdom? How do we account for it? We are confident that many of our readers have observed this very thing, though without, perhaps, giving it its due weight. There is a great deal to learn from these persons—persons who are “ordinary” only in the sense that they lack the training and credentials of a professional expert, but who are not, to be sure, ordinary in other ways.

To put it another way, we have found that the things that make ethical decisions challenging are not attributable to the difficulties in mastering the writings of moral experts. When dialogue goes sour or decisions go wrong, it seems it is *not* because ethics as an activity requires highly specialized knowledge or recondite theories available only to a select few. Ethical problems that are chronic, particularly vexing, or that seem insoluble may signal that we have not paid enough attention to the groundwork of moral encounter—and that what is needed is practical wisdom, not more and better theories. And here our patients may be far more reliable guides than we have yet realized.

We will proceed in the following way: We first focus closely on two sets of examples to establish our minimum contention. Following that, we sketch alternative approaches drawing from a wide range of philosophical, literary, and ethnographic literature to elucidate the phenomenon of patient and practitioner perceptions of moral significance that elude the customary approach. As we close the essay we suggest that attending to what we call “common moral wisdom” would go a long way toward countering the hegemony of outmoded Enlightenment understandings of human persons as rational decision-makers and as moral beings.

### **Bioethical Approaches to Death and Dying: Defining and Redefining the Issues**

A few years ago one of us (LRC) joined an interdisciplinary group to make a film about end-of-life decisions.<sup>3</sup> The aim was to help families who serve as surrogates for a decisional incompetent relative. For example, spouses routinely have to make or approve medical choices for their incapacitated partner, and children are sometimes pressed into service to select or confirm treatment options for one or both parents. Such decisions can span a wide range, but are typically focused on how aggressive to be in seeking an improvement in the patient’s condition in the face of uncertainty and less than fully effective treatments. Whether to enroll the patient in a clinical trial that might offer some hope for improvement, whether to readmit the patient to the Intensive Care

Unit (ICU), whether to write a DNR (Do Not Resuscitate) order, or whether to place or remove a feeding tube or a respirator are typical examples.

Making such decisions for others can be a daunting responsibility, especially when the patient is severely or terminally ill. There is, of course, a substantial bioethics and legal literature on how this should be done, but our aim was different. Rather than consulting the professional experts, we were seeking to make a film that would provide some guidance and support from the experiential experts—people who had been in these situations as families rather than as professionals. Our tentative working title was *Families Helping Families*, and the overall design was to ask family members who had recently acted as surrogate decisionmakers for their relatives to speak on film about how they had approached the problems they faced and what resources they drew from and, in general, to share their experiences with those who are currently burdened with this task.

To select the families for the film and to help us better understand the issues, we held three focus group meetings with persons who had had a death in their family within the past year and who had served in a surrogate decisionmaking role. A local hospice helped to identify many, but not all, of the focus group participants. By contacting the majority of focus group participants through hospice we reasoned that we would engage families that had already thought through some of the tough issues about aggressive treatments and had weighed these in comparison with the hospice focus on symptom management, patient and family control, and emotional/spiritual needs. We were also mindful of the results of the recently released SUPPORT study, which showed how difficult it can be to resist aggressive interventions in tertiary care hospitals.<sup>4</sup>

We held the focus groups on successive Saturday mornings. We anticipated that we would learn new content from these families, but we were very clear in our assumption about the kinds of issues that would frame our discussion. And we did learn, but in a more radical way than we had imagined. What the first focus group revealed, and which persisted throughout each of the Saturday morning discussions, is that the issues were not what we had thought. What we considered the main problems in fact were remote and tangential to the central themes of the family members' comments and stories. The big issues, from their perspective, were not whether to withdraw the feeding tube or to readmit to the ICU or have the risky surgery. The big questions were things like: "How can Mom be reconciled with her estranged stepdaughter?" Or "Has Dad made his peace with God, is he 'ready' to die?" One participant, speaking of her late husband, said: "I knew what he wanted; my problem was getting the children to accept it." These types of considerations formed the core of their surrogate decisionmaking experiences. Of course they were concerned with doing what was appropriate medically, but it was clear that they did not couch this responsibility in terms of medical or bioethical idioms. Their primary language was personal, familial, existential, and sometimes spiritual.

The focus of the film-making process shifted entirely following these focus groups, as we began to understand that the critical issues were ones of how families become reconciled, construct a meaningful narrative, do the spiritual work of care, and provide appropriate rituals of exit. Medical decisions and bioethical quandaries were all secondary to the larger issues of how to make meaningful choices in the face of uncertainty, suffering, and loss. Ethics at the edges of life, insofar as it involves surrogate decisionmaking, has to do pri-

marily with whether to call the sister in California for a possible bedside reunion or the church pastor for a final communion, or if, when, and how to tell one's father a final story of gratitude, or give one's dying mother permission to leave. Readmission to the ICU or placement of the feeding tube may well ride on whether it facilitates or prohibits such ritual enactments. This consideration is often of more importance than the medical focus on the patient's electrolytes or APACHE score, or the usual bioethical focus on the many ways to calculate "good" or "best" for another person. Indeed, the theoretical soundness of surrogate decisions regarding medical interventions was remote to the concerns we heard expressed and should be recognized as a bioethical priority, but not a patient or family concern.

### **Bioethical Approaches to Death and Dying: The Story of Two Deaths**

In one of those curious turns we invoke fate to "explain," one of us (DS) recently was present in an ER as decisions about end-of-life care were being made for his father-in-law, in circumstances that were eerily similar to the ones involving his father at another hospital nearly 35 years ago. This rather startling coincidence provides a view of "death and dying issues" before and after the advent of bioethics as practice and institution. It shows one of the greater impacts of bioethics on medical culture—and yet it also shows, we believe, that this impact has not yet penetrated to the most significant level of moral experience for patients and families. We will change the narrating voice to first person at this juncture to give the story its full sway.

Let's begin with a quick sketch of the relevant facts: Both men, my father and father-in-law, had been transported from their homes by ambulance after cerebral hemorrhages. Both men were treated initially in the ER of their respective hospitals. Both men were accompanied to the hospital by their spouses, and both had at least one child present. In both cases, the "decision" to be made was whether to put the patient on a ventilator or not. And here the similarities end.

When my father went into the ER in 1970, he was 43 years old, and no papers had been prepared ahead of time—no living will, no DNR, no healthcare power-of-attorney. For my 73-year-old father-in-law in 2004, all the papers had been prepared. In 1970 my father died, after failed surgical intervention, alone in a small room in one of the back and out-of-the-way wings of the upper floors of the community hospital. In 2004 my father-in-law died in the same room in the ER he had initially come in to, surrounded by family—his wife, youngest daughter, a grandson, and myself.

In 1970, the two neurosurgeons came out of the OR to speak with my mother and me who were awaiting news. They had come out only 20 minutes after going in—clearly the news would be bad. One of the neurosurgeons was a local physician who had been on call that night at the hospital. There had been a horrible bus accident, and he had been up all night working on patient after patient. The other neurosurgeon was my father's cousin and a nationally acclaimed leader in his specialty. He had driven over very early that morning from a nearby and very prestigious university teaching hospital. Outside the OR, standing in the hall with many people walking by, the local doctor said: "There is nothing we could do. His brain is completely destroyed. I don't think

he'll ever recover—but we can't be sure. So you have to decide about a ventilator." The visiting doctor gasped in horror and hurriedly asked if there weren't a more private place we could talk. The local doctor found us a dressing room used by residents, little more than a closet, and left us there with our kinsman. He explained things more fully and more carefully, and left us to make our "decision." Even for a stunned 18-year-old son and a 40-year-old wife in total shock, the "decision" took no time at all—no vent.

In 2004, the ER physician carefully explained the symptoms first to my mother-in-law and then to me. He reviewed the patient's health and the history of the incident. He spoke of the virtual certainty of death within 24 hours. He then outlined three different levels of aggressiveness for possible interventions. And he made—clearly, but with deference—his own recommendation that the least possible intervention be done. Reference was made to the DNR order and the other legal documents. For the wife and daughter, there was no decision—it was simply a reality that death was now here. I communicated this succinctly to the ER doctor and he accepted it with a brief statement of condolence. After that nurses came in and out to see what was needed—but mostly we were left alone in the room for the next eight hours until the patient died. After the death, we remained in the room for about 30 minutes saying goodbye. The entire staff displayed a marked sensitivity, even tenderness, about the approaching death throughout our time in the hospital. There was a clear recognition, shared with and communicated to the family, that something immensely powerful, even sacred, was taking place here. It should also be noted that this dying took place in a small rural hospital in South Carolina—a measure of just how far-reaching the changes in medical culture surrounding dying have gone.

There is no doubt in my mind that the differences in care here owe much to the bioethical focus on end-of-life issues over the past 30 years. Just here is where the decisional considerations that ethicists have rightly focused on for so long have come, albeit indirectly, into play. The bioethical stress away from paternalism and toward shared decisionmaking, the use of advance directives, and the advent of greater skill and comfort in dealing with terminal illness have set the context for a different kind of medical management of death, as these two experiences vividly illustrate. And yet the "big decision," to vent or no, was made in both cases virtually instantly, with no recognizable "decision process." It was more a matter of recognition—almost of perception—than a matter of decision. This is death that is coming: Yes it is.

What distinguished the two cases had nothing to do with the "big decision"—it had everything to do with the shame and sense of failure around death and the unwillingness to be in the presence of the dying in 1970, and the relative openness to death and dying in 2004. And here bioethics has only scratched the surface.

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We, the authors, are aware, of course, that in many, many cases the "decision" that was hardly a decision in these two instances can loom very large indeed. And yet we would still argue that bioethicists would likely have, in both these cases, been looking almost exclusively at the "decision" and hence would have been looking at the moral feature of this situation that mattered least. Another way to put it would be: It is "quality-of-death concerns"—not

“end-of-life issues”—that are most significant to the dying and their families. The phrase “end-of-life issues” (and its assumption that this is fundamentally a phenomenon best understood as points for decisions) reflects the bias of the medical profession—one which bioethics, for the most part, continues to accept.

For both of us, many years of involvement with patients in hospital and hospice settings in varying capacities—including 10 years of volunteer hospice patient care (DS)—have reinforced this learning. Sometimes patients took no time at all to “decide” that they wanted nothing to do with a feeding tube—so quick that we needed to lean down into their faces to be sure that they knew what that refusal meant. Invariably, they did. They knew their death was at hand and they wanted to face it. Again, a matter of recognition, not decision. And there were the patients who were ready to go, but were held back by families who couldn’t face the death. And families who were ready for the relief of death, but were still caring for parents who hadn’t yet finished saying good-bye. There was the very pious man, not sure he was saved and afraid to die and face the Judgment, who hung on for weeks in a coma. There were those in the hospital who had to get home to die surrounded by family—and those in crowded rooms who had to wait for everyone present to leave to die in peaceful solitude. In all these instances, and scores more, it was the quality of the departure that was central.

To put our point another way, and echoing our thesis in the filmmaking scenario depicted above, what families need help with in many end-of-life situations is not a buffing up of their decisional capacities, but compassionate attention to how the events unfolding before them can be made meaningful or bearable. This is ethics, not on the decisional edge of big choices, but in the full human sense of how people get around their world and orient themselves in life-changing situations. If bioethics does not attend to this, it has missed a great deal.

### **Bioethical Approaches to Informed Consent: Experimental Maternal-Fetal Surgery**

During 2000–2001 12 couples were interviewed to better understand their reasons for seeking enrollment in a clinical trial and their comprehension of the trial’s design, risks, and potential for benefit. One of us was involved in the interviewing, and both of us have been involved in reading and interpreting the transcripts of these interviews.<sup>5</sup> The trial was a feasibility study of the safety and efficacy of prenatal closure of the back in fetuses diagnosed with spina bifida. The hope was that closing the lesion before birth, rather than postnatally, would lessen or reduce hydrocephaly and thereby reduce or eliminate the need for shunts. Shunts often become infected or occluded, requiring additional operative procedures to repair or replace them. Reducing or possibly even eliminating this problem, if it could be achieved, would be a significant gain.

Yet, since its inception, surgery that requires imposing risk on the woman for the possible benefit of the fetus has been controversial, and it has been justified mainly in situations in which the fetus had a lethal anomaly. By contrast, maternal-fetal surgery for spina bifida involves intervening for a nonlethal anomaly. It also incurs substantial risk to both the otherwise healthy and viable fetus and the woman, and therefore involves a different risk/benefit calculus.

The couples we interviewed had been referred to the academic medical center by their local physicians, and they typically arrived filled with apprehension and hope. They spent two days in educational and counseling sessions designed to inform them of the risks and potential benefits of the experimental procedure, as well as the developmental prognosis for spina bifida and the resources available for dealing with the medical and social problems that children with spina bifida typically encounter.

The local Institutional Review Board (IRB) and the Principal Investigator (PI) for this study requested an ethics monitoring process in an effort to ensure that these couples understood that the procedure was experimental, that they understood its risks and the potential benefits of participating, and also to ensure that a free and authentic informed consent was obtained. The ethics consultants formulated their task not only as consent monitors, but also as researchers and obtained IRB permission to record and analyze the taped interviews they conducted. Our comments below come directly from these interviews. Although our primary aim as IRB monitors was to ensure a valid consent, our primary research aim was to learn how these couples decided whether to participate in this prenatal research—that is, to map the moral contours of their decisions. Most of these couples were young, roughly mid- to late 20s, and, for most of them, the decision about enrolling in this clinical trial was one of the most momentous and complex decisions of their lives to date.

One of the most striking findings from our interviews is that moral decision-making was seen as a search for overall coherence and integrity in life, not just a right action for this occasion. This is illustrated by the quote below from one of the women as she explained her overall approach to the decision: “I believe there’s a reason for everything, whether it’s a higher power, whether it’s me being stubborn and trying to be true to myself or to my beliefs. But something happens for a reason. Why does it happen to us? I don’t know. I truly don’t. But it’s my job to get through it the best I can and, you know, with Jim’s help, maintain our household, our lifestyle, and family and my sanity.” Other couples gave similar responses.

In the search for overall coherence, the couples looked for signs and signals to interpret both their situation and their choices in a wide range of places, many of them surprising and unpredictable. For example, one young woman gave the following account: “This may sound weird to you, but since my grandfather passed away, I’ve felt his presence like he’s watching over us, and in my heart and in my mind, I felt he’s going to be watching over me if I have this procedure done, and he’s not going to let anything happen.”

Another woman reflected on how her decision was grounded in her religious beliefs and indicated how something that would have otherwise been insignificant became a sign of how to proceed, thereby carrying special meaning. “Our first experience, this was really kind of interesting, I have no problem saying I am a Christian. I believe in the Bible. You know, that’s where we’re at. Friday when we found this out and we’re having all these horrible visions in our minds. . . . We’re questioning, ‘Gee, if we bring a child into the world with this horrible ailment, you know, life is going to be horrible.’ We were debating that. I will tell you that it was interesting to look in our mailbox. And I pull out my magazine—It’s *Decision Magazine*, it’s called *Decision Magazine*. And it says ‘Your strength in the storm,’ and this is our faith. And so when I got that, I

immediately felt ‘Whew. OK, all right. My faith, you know, this is why I have faith, for these types of situations.’”

Yet another couple was thrust into a deeply reflective mode when they discovered that their hotel near the medical center was located on “Mt. Moriah Church Road.” This connected in their sensibility to the story in Genesis and to the site on which Abraham is commanded to sacrifice his son Isaac, only to be reprieved at the last minute. Questions about responsibilities to children, born or unborn, figured very deeply into the decisions for all the couples. But who would have predicted that a road sign—or a magazine retrieved from the mail box—would provide a key for understanding a decisional process?

For all the couples, making *good* decisions meant fulfilling a role, playing a part well. Deciding what the role entailed was not a deliberative process, but seemed spontaneous, like an act of recognition. This is not to say it was unthinking or reactive, but it seemed to flow naturally out of what was already self-evident to them. One father, speaking about his rationale for participating in the trial, said: “It’s the way I was brought up with my parents. They did everything possible to help their kids. Their parents did the same thing. It’s just what you do.”

For these couples, the role that provided the proper perspective was clearly that of parent. From this vantage point, narrative lines were imaginatively cast into the future in terms of gauging a good or acceptable choice. For several couples, their story included an anticipated conversation 10 years in the future in which the couple is trying to explain to the child the reasons for the choice to accept or decline the prenatal surgery. A slight variation of this story line was the projection of the child’s future view of the decision in terms of parental motives. This is captured in the following: “I don’t want our child to grow up and say: ‘Well, Mom and Dad could have done something, but they didn’t want to risk their own selves [*sic*] to do it.’” The implication is that the good parent is the one willing to sacrifice a great deal, even risk one’s own life and health to benefit the child.

Some of the decision processes we observed strained the meaning of the term *decision*, at least as typically understood. Choosing well for these couples meant aligning their actions with their authentic selves and being faithful to their deepest perceptions about the situation. In this sense, the couples didn’t “decide,” but sought to discern their proper place in the scheme of things. Sometimes this discernment involved letting go of the sense that one has final authority or power to affect the outcomes through a decision. One couple put it this way: “Well, you know, regardless of what happens, if we decide not to have the surgery or to have the surgery, if we lose the baby, well, then that was God’s will. So we’re just going to have to stay with that.”

Of course, not all the couples expressed their convictions in frankly religious terms, although it is true that couples who took the time and energy to investigate the trial were couples who had already decided against terminating the pregnancy, and in that sense, might have been an atypically religious sample. But even with those couples for whom religion did not play an explicit role in their decision process, there was a sense that the higher wisdom may be in acknowledging limits on what one can control, and therefore the need to select a course and stay with it.

In sum, we think it is accurate to say that the decisional model most often endorsed by bioethics practitioners was not in evidence in the thoughts of these



couples. They did not follow any of the classic patterns of deliberating on the options, sorting out the values involved in each option in a logical way or deducing courses of actions from the interpretation of rules or principles. Nor were their decisions any worse for this deviation from the bioethical standard. Decisions were for them less “made” in the sense of constructed than “arrived at,” reached after a journey, and sometimes the path of the journey was seen as already mapped. The task was to find the path. Reaching resolution was less a matter of deciding than of following rituals and practices that would allow them to locate the right way for them, and by so doing, to reaffirm themselves as being certain kinds of people, viz., “good parents,” “Christians,” or, more simply, “responsible.”

Stated in its positive form, decisional capacity for these couples emerged from a condition of being oriented, an ability to draw from one’s customary moral resources, and a demeanor of confidence in the face of uncertainty and ambiguity. One of the critical questions that confronts anyone who enters the foreign turf of a large academic medical center, especially one away from home, is how does one marshal resources to find one’s moral bearings in this strange, and often intimidating, place. The task for these couples could be fairly described as how to get grounded in a new place in a very short time and with strangers who are striving to be helpful, but may or may not share the same customs or values. Here it is important to acknowledge that bioethicists typically worry about *decisions* being grounded—about their quality, coherence, and consistency—whereas these couples were more worried about the prior task of *how they themselves can be grounded*. These are different phenomena.

Another way to put this is to say that these couples embodied a robust and deeply reflective ability to use the traditions in which they had lived to help them through the current crisis. In saying these couples were deeply reflective we do not mean that they were theoretical. They were not probing the adequacy of the moral standards they brought with them; rather they were seeking to work out the implications of their commitments in the current crisis. In doing this they displayed a kind of quiet confidence in themselves. They seemed to know somehow that their moral resources were adequate to the decision they faced. They were sometimes uncertain about what to do, but not intellectually puzzled about what would be the framework for a good choice. In this sense they were not bewildered or overwhelmed by what was happening to them. For example, couples with whom we worked were deeply saddened by the news that their child would have handicaps, they were often shocked and emotionally challenged by the prospects they faced, but they were not intellectually troubled over what standards they should use to decide what they should do. What they arrived at was less a *decision* and more a *response that “fit”* them and their lives; what they engaged in was less deliberation than reorientation. In this sense, H.R. Niebuhr seems to offer a better moral phenomenology than Aristotle, Kant, Mill, or others in the standard bioethics pantheon.<sup>6</sup> Of course, the couples we studied did come to decisions. But decisions here seemed to be ways of finding or affirming *meaning*, not solving a problem. A quotation from John Gardner serves to summarize this phenomenon well. “Meaning is not something you stumble across, like the answer to a riddle or the prize in a treasure hunt. Meaning is something you build into your life. You build it out of your own past . . . out of the things you believe in,

out of the things and people you love, out of the values for which you are willing to sacrifice something.”<sup>7</sup>

In sum, the parents we interviewed were like people who woke up one day to find themselves in a different world. The children they were soon to have were not the children they had hoped for or anticipated, and they soon realized that they were newcomers in an astonishingly complex world, in which healthcare and rehabilitation programs would be standard fixtures. Their decision for or against the prenatal surgery was part of what it was about to find their way in this new world, regaining a sense of what is possible, how to be who they are in the new environment—in essence, a recalibrating of self. Our main point is that the logic of this recalibration of selfhood follows a different dynamic than the rational, theory-driven approaches so often favored by bioethics.

### Toward Alternative Approaches

We have made allusions to the dominant model of bioethics without specifying its features. For our purposes, it is sufficient to highlight two major elements:

1. Ethics is primarily about making decisions.
2. Theoretical reflection is required for such decisions to be “sound.”

There is, of course, an immense literature raising questions about this dominant model, both within the field of ethics and the more restricted field of bioethics.<sup>8</sup>

Our purpose here is not to introduce yet another theoretical treatment of the limitations of theory, but to urge that the thickness of what is before us in our interactions with patients and healthcare providers *shows* us the inadequacies of the dominant model. The striking feature of our work with patients and subjects is the inability of the dominant view to capture *their* discernment of the issues they were dealing with and the complex ways they reached a resolution. Our work shows us, in other words, that decisions are most often *not* the primary stuff of bioethics—and that theory is *not* the only way reflection can be undertaken. And it bears repeating here that the dominant view can’t account for our own personal experiences, when we found ourselves to be patients or family members in crisis, any better than it can account for the experiences of those we interviewed.

As a result, we have become increasingly wary of the many subtle ways the dominant view—essentially an Enlightenment model for ethics—discredits the moral insights that patients and research subjects bring to their medical encounters. We are seeking to highlight this wisdom, which, because it defies exhaustive rational analysis and concise theoretical grounding, too often flies under the radar. Yet we are not claiming that our patients and subjects are necessarily “wise persons,” or that they always made the “best” choices, but only that, in these powerful circumstances, they display what most would recognize as wisdom—often the wisdom carried in their families, churches, or communities. Earlier we used the phrase “common moral wisdom” and we return to it at this juncture to highlight a kind of moral perceptiveness we believe is evident in the vignettes we have described. Such wisdom is “common”—not in the sense of “held in common,” as though there were some

set of views held by everyone—but “common” as used in the political tradition of “common sense” or in the everyday expression “the common cold.”

Likewise, and consistent with our whole approach, we deliberately offer no technical, theoretical, or philosophical definition of *wisdom* beyond its usage here, first, because, following Ludwig Wittgenstein, we find such inquiries to be fruitless and also beside the point, and, second, because our usage is, we believe, well within the common family of usages in ordinary life, as well as that in traditions of philosophical discourse.<sup>9</sup> Still and all, it is a strong word, a provocative word—and we have deliberately chosen it for *both* of those qualities.

When we say our patients and subjects display wisdom, we mean that they demonstrate an ability to get themselves oriented, and reoriented, in unfamiliar and challenging settings, in the face of the many new people and the new culture of the medical arena, in confronting huge life changes. This reorientation is certainly not made possible by theory, theoretical reflection, or expertise in bioethics. It is also our initial impression that this reorientation does not occur through narrative—at least not in any developed sense. Many who have been critical of the dominant model, as we are, have looked to narrative to frame an alternative account. But our experience is that patients and subjects tell short anecdotes, quote family members or a pastor or rabbi or priest, repeat truisms, muse philosophically, give homilies, recount web searches, recall poignant moments—and that they do these things in what would appear, from a theoretical perspective, to be little more than a jumble. But if we put the term *omnibus* here, we might say that this is a description of their method. They gather in what is to hand—what they can use to reconstruct their moral world in new settings, with new people, before new challenges. It’s “a little bit of this, a little bit of that.” Not narrative in any literary sense, or even in the more ordinary usages of the term. And certainly not argument.

If this is what is before us when we look closely at what actually happens for patients and subjects, when we get outside how we as bioethicists expect them to behave and decide, where then do we look for resources for alternative approaches, alternative accounts—we who are ourselves soaked in, trained up in, and captivated by this model? How do we get a wedge in here, loosen the conceptual and linguistic cramps in our heads—and our hearts—so that we can see what is in front of us and learn from the patients, subjects, and healthcare providers we work with?

What we find when we look, actually, is that there is an immense richness of resources available to us—but a richness we have, collectively, as a field, largely ignored in our servitude to the dominant model. Within the analytical tradition of philosophy, there is Wittgenstein’s later work, which has provided a plethora of examples and insights for those wanting to escape the dominant model—and which has inspired so many probing critiques of the role of theory in the moral life.<sup>10</sup> In the Continental tradition of philosophy, the French have been offering for decades investigations of the limitations of theory and of the subject as a rational agent. We think, among others, of Merleau-Ponty, Deleuze, Foucault, Derrida.<sup>11</sup>

Likewise, literature offers much material for reflection. Anton Chekhov, himself a physician, comes first to mind. His stories of medicine, doctors, and patients display a much richer awareness of what we may call the “full-life context” of medical matters than most anything in bioethics. It is, we would

argue, this detail and attentiveness that has given Chekhov's work its widely respected moral authority and its reputation for wisdom.<sup>12</sup>

We have found anthropology to be most helpful in our own most recent reflections, and so will linger here a bit longer. One may think of anthropology as a whole discipline—like modern philosophy itself, theoretical and Enlightenment-grounded—that has steeped itself in non-Enlightenment, non-theoretical ways of thinking, being, and doing. There is much to learn from fieldworkers like Keith Basso and his investigations of the Apache notion that “wisdom sits in places,” as well as from theorists like Levi-Strauss and his notion of the *bricoleur*.

In his *Wisdom Sits in Places: Landscape and Language among the Western Apache*, Basso tells the story of a portion of his own education into wisdom as understood by the Apaches of the Cibecue region in Arizona.<sup>13</sup> He recounts his efforts to learn and to pronounce properly a vast array of place names—e.g., “Trail Goes Down Between Two Hills,” “Water Flows Down on a Succession of Flat Rocks,” “White Rocks Lie Above in a Compact Cluster.” Places of significance to the Apache have stories associated with their names as well, stories of the people of “long ago” that have clear moral punch to them. By exchanging the names of places, each of which is associated with well-known stories of what took place there—and with equally well-known moral lessons taught by the stories—the Apache conduct moral discussions, draw moral conclusions, and make moral judgments. There is no “theory” in any recognizable Western sense—but there is clearly reflection, thoughtfulness, and moral insight. And, Basso's teachers say, there is also the wisdom that comes from meditating for years and years on these place names and their stories and what they teach about human nature. “Wisdom sits in places. It's like water that never dries up. You need to drink water to stay alive, don't you? Well, you also need to drink from places. You must remember everything about them. You must learn their names. You must remember what happened at them long ago. You must think about it and keep on thinking about it. Then your mind will become smoother and smoother. Then you will see danger before it happens. You will walk a long way and live a long time. You will be wise.”<sup>14</sup>

The Cibecue Apache have a process for moral reflection, a method of discernment that is not theoretical and does not focus on decisions. And, although it depends on narrative, its force comes really from the assembling of a variety of names and narratives and moving them quickly among one another in dialogue.

Holding with this notion of assembly, we turn to Claude Levi-Strauss' presentation of the activity of the “*bricoleur*” in *The Savage Mind*:

The “*bricoleur*” is adept at performing a large number of diverse tasks; but, unlike the engineer, he does not subordinate each of them to the availability of raw materials and tools conceived and procured for the purpose of the project. His universe of instruments is closed and the rules of his game are always to make do with “whatever is at hand”, that is to say with a set of tools and materials which is always finite and is also heterogeneous because what it contains bears no relation to the current project, or indeed to any particular project, but is the contingent result of all the occasions there have been to renew or enrich the stock or to maintain it with the remains of previous constructions or destructions.<sup>15</sup>

Suppose that the process of getting oneself oriented in situations that require moral reflection and conducting that reflection once oriented is something like the *bricoleur's* work. Thinking this way we would find that the moral agent keeps a ready stock of resources useful for various moral puzzlements—old stories, memories, wisdom sayings, pithy maxims. These resources are made up of elements that have been useful in the past, either to the *bricoleur* himself/herself or to his or her people or community, to someone the *bricoleur* has known, to the old ones. They are “the contingent result of all the occasions there have been to renew or enrich the stock.” Thus when confronted with a new setting, new people, or a new conundrum, the moral agent rummages through the kit looking for what might be of use, a “little bit of this, little bit of that”—looking for what Levi-Strauss calls “operators”:

The set of the “*bricoleur's*” means cannot therefore be defined in terms of a project. . . . It is to be defined only by its potential use or, putting this another way and in the language of the “*bricoleur*” himself, because the elements are collected or retained on the principle that “they may always come in handy.” Such elements are specialized up to a point, sufficiently for the “*bricoleur*” not to need the equipment and knowledge of all trades and professions, but not enough for each of them to have only one definite and determinate use. They each represent a set of actual and possible relations; they are “operators” but they can be used for any operations of the same type.<sup>16</sup>

Once again there is a process of assembly—though this time less systematic than what Basso describes.<sup>17</sup> But Levi-Strauss is giving us a Weberian ideal type, and it is one that we can recognize as we look at the subjects, patients, and families that we have described in this essay: people reaching into their toolkits, their resource bags, and pulling out elements to assemble—or rather reassemble—their moral worlds in the face of medical culture and the huge issues of living and dying that that culture so often serves as custodian for in contemporary society.

But after going to and through all the immense richness of such resources, we come back as we always must, to this: The greatest richness is in our patients and subjects themselves. These encounters are our ultimate resource—yet they are the ones most often overlooked, caught as we tend to be, as a field and as practitioners, in the grip of the dominant model. We need to do more of our own “thick descriptions,” paying more careful attention to the wisdom that’s right in front of us.<sup>18</sup> We need to take Wittgenstein’s admonition to heart, and to work: “To repeat: don’t think, but look!”<sup>19</sup> In saying that these encounters are our ultimate resource we are not, to be sure, claiming that subjects, patients, or health-care professionals always arrive at the best or “right” decisions, nor would we claim that they are all wise persons. But we are saying that many of them carry a wisdom that sustains them through situations that might be deemed “impossible.”

The broader aim of ethics calls to us here, calls on us to get in touch with a profound place in ourselves, a deeper sense of who we are and what our lives are about, for both ourselves and others. Ethics is less a search for what is correct and more an effort to fathom what is deep, what is wise. It is our task to look for such places and moments and to find ways to train our physicians and caregivers, as well as our ethicists, to take their cue from the wisdom of our patients and subjects, and to live there as well.

## Notes

1. Both of the authors emerged from graduate school at the time bioethics was being established as a discipline. One of us has worked in medical settings ever since. The other has taught in liberal arts colleges and worked in a variety of nonprofit healthcare delivery organizations. Both of us wrote cautionary essays as the new field began to emerge. Schenck was the lead author for a review of the *Encyclopedia of Bioethics* with Charles Reynolds and Glenn Graber in the *Religious Studies Review* 1981;7(1):5-14. With his coauthors, he argued that, "Rather than utilizing the awareness reflected so scrupulously in the *Encyclopedia* of the diverse resources for reflection on ethical matters offered by, for example, religious traditions and the social sciences, ethicists continue to return to the unreconstructed canonical works of Kant and Mill time and time again." And further, "Another missed opportunity [in the *Encyclopedia* and in the field of bioethics] is the failure to grasp the intricate rootedness of values and principles in specific social contexts, e.g., the professional practice of medicine." Which led to the plea, "Can we learn in bioethics to be more sensitive to the context in which ethical decisions must be made, with particular attention to those who are deciding?" Churchill wrote about "The Ethicist as Stranger" [rather than moral expert] in *The Hastings Center Report* 1978;8(6):13-5; and "Bioethical Reductionism" in *Man and Medicine* 1980;5(4):229-2 in a similar vein, arguing that "standard problems of bioethical analysis will not lead us to insights about human beings if they are isolated from the moral sensibilities that first shaped them as problems. If the task of bioethics is compressed into the analysis of the goodness or rightness of actions at the decisional edge, the leverage it might have on the moral life of practitioners and patients will be forfeited."

Those concerns expressed in our early essays remain with us to this day—and have been dramatically amplified by our participation in, and observation of, 30 years of bioethical practice and reflection. In this way our experiences—though vastly different in other ways—share something with those of pediatric neurologist John Freeman. The quotation on the opening page of this essay is taken from Freeman J. On learning humility: A thirty-year journey. *The Hastings Center Report* 2004;34(3):16.

2. See Jonsen AR. *The Birth of Bioethics*. New York: Oxford University Press; 1998.
3. Churchill L, Doron M, Rothman E, Yarger L. *Those Who Stay Behind*. Fanlight Productions; 1999.
4. See, for example, The SUPPORT Principal Investigators. A controlled trial to improve care for seriously ill hospitalized patients. *JAMA* 1995;274:1591-8; Lynn J, Teno JM, Phillips RS, Wu AW, Desbiens N, Harrold J, et al. Perceptions by family members of the dying experience of older and seriously ill patients. *Annals of Internal Medicine* 1997;126:97-106.
5. A full accounting of the research on parental perceptions of maternal-fetal surgery for spina bifida from which we draw here can be found in Rothschild B, Estroff S, and Churchill L. The cultural calculus of consent. *Clinical Obstetrics and Gynecology* 2005;48(3): in press. Rothschild served as the principal investigator for the study, which was supported in part by the Greenwall Foundation.
6. See Niebuhr HR. *The Responsible Self*. New York: Harper and Row; 1963:47-68.
7. Gardner J. Personal renewal. *Western Journal of Medicine* 1992;157:457.
8. See G.E.M. Anscombe's "Modern Moral Philosophy," originally published in 1958 and reprinted in her *Ethics, Religion and Politics*. Minneapolis: University of Minnesota Press; 1981; see also Murdoch I. *The Sovereignty of Good*. London: Routledge; 1970; MacIntyre, A. *After Virtue*. Notre Dame, IN: University of Notre Dame Press; 1981; Pincoffs, E. *Quandaries and Virtues: Against Reductivism in Ethics*. Lawrence: University Press of Kansas; 1986. Among bioethicists, see Walker MU. Keeping moral spaces open. *The Hastings Center Report* 1993;23:33-40; Fins J. Commentary: From contract to covenant in advance care planning. *Journal of Law, Medicine and Ethics* 1999;27:46-51. Walker has characterized the "dominant modern view" of ethics as "the attempt to articulate and justify the right or best moral theory." While acknowledging that this model has many detractors in the history of philosophy, she also believes that it is "thoroughly embedded in medical ethics" (p. 33). In this view theories are important because they provide a way of justifying, in an impersonal way, the selection of some actions as preferable to others. Thus conceived, the person who can wield theory most successfully stands the best chance of being able to justify his or her choice. So Walker is appropriately worried about the way this model privileges a notion of moral expertise, favoring those who are facile with theory over others involved in patient care.

Fins makes a similar case against the dominant view in a discussion of advance care planning and healthcare proxies. He argues that when he needs to rely on his own healthcare proxy he doubts very much whether she will engage in "an exercise in rationality." Fins

- contends that the chief capacity to be prized in a proxy decisionmaker is not clearheaded reasoning but a set of virtues—"fidelity, wisdom and love"—and a deeply attuned memory—"recalling our intertwined lives and the challenges we had faced together" (p. 46).
9. For example, under the entry "Wisdom" in the *Encyclopedia of Philosophy* (New York: Macmillan; 1967;8:322-4), Brand Blanshard discusses a wide range of views, including ancient "wisdom literature" that is concerned with sound judgment about the living of a good life, and what he terms "the Greek conception," including Plato, Aristotle, and the Stoics. Blanshard notes, relevant to our concerns here, that the Enlightenment period marks a turn away from wisdom traditions to more epistemological and technical metaphysical concerns in ethics. A related but distinct understanding of wisdom can be found in Western religious traditions, which could be roughly characterized as consisting of moral counsel in the form of exemplary stories, parables of moral discernment, fables of critical events, and collective sayings thought to be vital to the well-being of communities. See, for example, Crenshaw JL. Ethics in wisdom literature. In: Childress JF, Macquarrie J, eds. *The Westminster Dictionary of Christian Ethics*. Philadelphia: Westminster Press; 1967;662-3. Importantly, Crenshaw insists that wisdom literature is not insulated from reflective and critical interpretation and often contains reflexive agnostic and skeptic approaches to the wisdom literature itself.
  10. Yet the impact of Wittgenstein in bioethics has been marginal. To the best of our knowledge the only exploration of Wittgenstein's work for bioethical uses is Elliott C. ed., *Slow Cures and Bad Philosophers: Essays on Wittgenstein, Medicine and Bioethics*. Durham, N.C.: Duke University Press; 2001.
  11. For apposite remarks on the uses of these and other Continental thinkers, bioethicists should take a look at Zaner RM. *The Context of Self: A Phenomenological Inquiry Using Medicine as a Clue*. Athens: Ohio University Press; 1981; Schenck D. Operative dimensions of Zaner's *Context of Self*. *International Studies in Philosophy* 1985;16:59-64. To trace the genealogy of this inquiry in phenomenology, one should work back through Scheler and Schutz, and then move on to Merleau-Ponty, and finally on to Levinas, Deleuze, and Foucault. In roughly similar territory, we would note Wittgenstein's fascination with Fraser and Freud and his use of them and the literature that those inquiries have spawned—including certain strands of the work of Clifford Geertz, by way of his reading of Gilbert Ryle. And, from these starting points, it is but a short leap to the history and sociology of medicine and various other inquiries in the purview of the medical humanities.
  12. For instance, see Chekhov's "A medical case, Ward no. 6" and "A dreary story." The quotation at the beginning of this essay is from Chekhov A. A dreary story. In: Wilks R, ed., *The Steppe and Other Stories, 1887-1891*. London: Penguin; 2001:223. See the journal *Literature and Medicine* for hundreds of illustrations and elaborations of how narrative works as an instrument of moral discernment and critique.
  13. Basso, K. *Wisdom Sits in Places: Landscape and Language among the Western Apache*. Albuquerque: University of New Mexico Press; 1996.
  14. See note 13, Basso 1996:127.
  15. Levi-Strauss C. *The Savage Mind*. Chicago: University of Chicago Press; 1973;17. (*La Pensée sauvage*—"a wildly spectacularly untranslatable pun," as Clifford Geertz has it.)
  16. See note 15, Levi-Strauss 1973;17-8.
  17. To go further with assembly and on into "assemblages," all in senses relevant to our project here, work with Deleuze G. and Guattari, F. *One-Thousand Plateaus*. Massumi B. trans. Minneapolis: University of Minnesota Press; 1987:passim.
  18. Geertz, C. Thick description: Toward an interpretive theory of culture. *Interpretations of Cultures*. New York: Basic Books; 1973.
  19. Wittgenstein L. *Philosophical Investigations*, 3rd ed. Anscombe GEM. Trans. Oxford: Blackwell Publishers; 2001:27#66. The German is sharper than Anscombe interprets it: "*Wie gesagt: denk nicht, sondern schau!*". "To say it again: Think not, but look!"