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REVIEW ARTICLE

HARD CASES REALLY AREN'T THAT IMPORTANT: REFLECTIONS ON LISA BELKIN'S *FIRST, DO NO HARM*

SIMON & SCHUSTER, NEW YORK: N.Y., 1993, 270pp., $23.00 (HARDBOUND)

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First, Do No Harm chronicles events in Hermann Hospital, Houston, Texas, between May and October 1988. Belkin's title for these events expresses, of course, the familiar *minimal* moral duty of health care: if nothing else, do not leave the patient in a worsened condition. In regards to her "patients" — the practices of contemporary health care and the field of healthcare ethics — Belkin can be said to have satisfied this minimal duty. In her book, touted by the publisher as "[t]he dramatic story of real doctors and patients making impossible choices at a big-city hospital," Belkin has not harmed the cause of health care, nor the cause of healthcare ethics. Whether she has done them any good is, however, another matter. The other moral duty of healthcare to "do good" is much more difficult to satisfy.

The reflections I have to offer on *First, Do No Harm* are, accordingly, both positive and negative. The praise I have to offer relates largely to the insights the book offers to laypersons and healthcare professionals about each other. The criticism relates to the cultural attitude or "mind-set" about health care and ethics in which the book operates and which the book reinforces, perhaps unintentionally.

The book is based upon three years of remarkably intimate access to a hospital's inter-workings by a *New York Times* reporter. The result is a chronicle of cases, most of which involve relatively unusual healthcare developments and relatively dramatic moral decisions.

For example, the book begins and ends with the story of Patrick Dismuke, a fifteen-year-old suffering from Hirschsprung Disease. Patrick has defied the odds by surviving fifteen years on IV nutrients and by battling in his later years the constant threat of infections associated with the central line that feeds nutrients directly into his heart. The extraordinary

medical history that his case represents is matched by the highly emotional decision finally to stop treating his infections and to stop forcing into his worn-out body the tubes needed to "feed" him.

Then there are the Poarch twins, born four month premature, each weighing less than two pounds. While Jake dies within twenty-four hours, Taylor somehow manages to survive for two months in Hermann's neonatal intensive care unit. This case becomes a remarkable story about parents, nurses, and physicians struggling with almost daily crises in the life of an infant too small to live.

Armando Dimas may be the most extraordinary of the patients we encounter in Belkin's journeys through Hermann's wards. Armando is brought to Hermann from a small, rural hospital, with a gunshot wound to the back of his neck. The bullet has created a C-1 vertebra break, leaving Armando paralyzed from the jaw down. He arrives at Hermann as an expected organ donor and surprises everyone — except his mother, who is surprised only by the fact that he never does regain his ability to walk — by surviving to be discharged to a residential care facility, suited to his extensive and special needs.

As the book nears its end and the cases of Patrick, Taylor, and Armando and others begin to reach some closure, Belkin challenges her readers with just one more tragic tale. The Sparks are a Texas working class couple who have desperately wanted a child and who have finally managed to conceive, thanks to the powers of contemporary health care. Now the Sparks again have to rely on these same powers to help their three-month premature infant, born with a severe case of spina bifida. Landon Sparks survives and becomes the one obvious question mark in Belkin's "Epilogue," the concluding follow-up to some of the book's principal persons and cases. In Landon's case, Belkin does not seem totally convinced by the decision of parents, physicians, and Hermann's HEC to go forward with all possible treatment.

In all these cases, Belkin gives us a first-rate, newspaper-like, human interest story. The advantages of this approach — or genre — for the lay reader are obvious. The lay reader will find in Belkin's book the practices of health care presented as a *story* about people who have not only feelings but also doubts about what they are doing. The lay reader sees the physician, for example, as a person whose technical skills and scientific demeanor operate against a backdrop of all the usual human hopes, anxieties, fears, insecurities, and limitations. For members of the lay public who know physicians only as physicians, *First, Do No Harm* might very

well create a new perspective on the physician during that next office or hospital visit.

Belkin also provides the lay reader with another important service. She sneaks into her personal stories mostly accurate, but always nicely crafted, summaries of the history, politics, economics, and ethical debates that form the "big picture" of contemporary American health care. For example, Belkin first offers the lay reader the image of Patrick Dismuke having his picture taken next to his monstrous medical records (a stack of papers larger than he) and then uses the image as an opening to inform the lay reader about the management of healthcare information and about the separate culture created by the separate language of health care. Dry and lofty matters, more likely to appear in medical or academic writings, thus become an interesting piece of the patient's own story.

While *First, Do No Harm* is clearly written and marketed for the lay reader, it also carries insights for healthcare professionals. These are mainly about the way patients and, perhaps even more so, families react to the culture of contemporary hospitals. Some seem to be totally intimidated and simply avoid all but the minimally necessary amount of interaction with physicians, nurses, and administrators. This was apparently the approach taken by Patrick Dismuke's mother.

Others seem to take on the culture as an obstacle to be conquered or as a reality to be mastered. This was apparently the approach of Taylor Poarch's parents, who mastered the medical facts of their daughter's care, the routines and practices of the neonatal intensive care unit, and finally the politics of patient-physician and physician-physician relationships. The result of this accomplishment was two laypersons who became better moral, if not healthcare, decisionmakers than Taylor's own physicians. It was the parents who knew when the time had come to stop treating this hopeless infant, and it was the parents who forced healthcare professionals into the same realization.

Finally, there are those who deal with the culture of contemporary healthcare as if it were not there. Armando Dimas's mother had her faith guiding her decisionmaking and nothing that scientific health care might do or say mattered. In one encounter, a completely frustrated and angered attending physician showed Mrs. Dimas the x-ray of Armando's head and neck to "prove" to her that Armando had no chance of recovery from his injuries. Her only response was to ask pointedly why the bullet was still in his head. The lessons for healthcare professionals from these stories are two-fold. The first lesson is that the lay public does not handle the culture

of contemporary healthcare in any single, or simple, or even coherent manner. It is best then not to assume too much about what patients and their families may or may not do in response to the events that typically occur in contemporary hospitals. The second lesson is that in some circumstances the wisdom of informed patients or family members may be greater than the wisdom of the most experienced healthcare professional. It is one of the more notable ironies of contemporary healthcare that physicians and nurses may sometimes be too close to a case *medically* speaking to have much perspective on it *morally* speaking. While Belkin does not have the copyright on either of these lessons, her stories function as skillfully written reminders of each. For this reason alone, the most hardened or sanguine healthcare providers would not waste their time reading *First, Do No Harm.* However, this recommendation needs to be qualified.

Of its flaws, the least serious is the way in which this book might mislead healthcare professionals, and perhaps even the lay public, regarding the history of and current consensus in healthcare ethics. For example, Belkin's "history" of the reaction against and aftermath of the famous Baby Doe regulations suggests that the demise of these regulations signaled the arrival of the HEC, which was now to make decisions formerly assigned to federal regulators. This, of course, is far from accurate. The resulting federal legislation, enabling regulations, and accompanying court cases did not simply put HECs in the place of "Baby Doe" federal regulators.

She also describes the famous Seattle dialysis committee of the early 1960's as being "completely about money," and then offers this "fact" as the reason why current HECs avoid the consideration. I am sure that the members of that Seattle committee would be *rightfully* shocked to read this characterization. I am also sure that if asked whether the Seattle committee's approach determined, by way of contract, their own, non-economic approach to addressing moral problems, most members of current HECs would respond by asking "What Seattle committee?"

Then there is the case of the ninety-year-old stroke victim for whom the HEC decides that a surgically implanted feeding tube is a moral necessity because "the law" requires it and because not to implant the tube would be, according to the HEC chairperson, *active euthanasia.* This "little" case is reported by Belkin almost in passing, without so much as a nod to the peculiar, almost unorthodox analysis offered by her friends at Hermann. It would be unfortunate if healthcare professionals were to take from this account the mis-impressions that some "law" prevents the forgoing of treatment for very old and very ill patients and that *active* euthanasia is

somehow about forgoing treatment with the intention of letting the patient die. Healthcare professionals would be wise to take with a grain of salt at least some of Belkin's accounts of current health law and policy.

These lapses, where Belkin misleads her readers, are relatively minor compared to the fundamentally flawed perspective that Belkin seems to embrace as the book's ruling assumption. This flawed perspective might be described in the following manner: The true nature of the healthcare arts, as well as the essence of healthcare ethics, is to be found in what happens and in what we do in hard or dramatic cases. These are the cases whose facts are truly extraordinary, or highly complicated, or exceptionally emotion-laden. The idea engendered by this perspective is that health care is at its best — is on its own true frontier — when it is dealing with hard or dramatic case: the brand new gene therapy that saves the child with ADA, the first-time-ever parent double-lung transplant that saves a young woman with cystic fibrosis, the made-for-TV life-saving medivac rescue and trauma center surgery of the accident victim no one expected to survive, etc. From this perspective, health care is about miracles, and the hard case gives health care the chance to be most miraculous.

The criticism of this perspective — relative to the overall structure of the healthcare professions and relative to the public and private policies that provide health care with direction and purpose — should be familiar. This perspective tends to make health care more curative than preventative. It tends to make it more high-tech than low-tech. It tends to make it a more specialized practice than a general practice.

We may not have considered, however, what this perspective does to our understanding of ethics in general and healthcare ethics in particular. Even more to the point, we may not have considered what this perspective does to our expectations of the HEC.

In the closing section of the book ("October"), Belkin offers this account of Hermann's HEC, itself one of the book's central characters:

> It had been a particularly long summer at Hermann Hospital. The Ethics Committee had seen its busiest stretch in memory: Patrick Dismuke; Taylor Poarch; Armando Dimas; Mr. Hardy; Mrs. Fence; Dexter Advani; an AIDS patient whose lover wanted treatment continued and whose mother did not (the ventilator was removed); a mentally retarded, severely handicapped girl who needed risky, expensive, experimental surgery (it was not done). In all,

> there were twelve hard cases in five long months. Everyone on the committee was tired (p. 212).

I suspect that many HEC chairpersons and members, throughout the country, will look enviously upon this HEC's labors. I suspect that many chairpersons and members will ask themselves why this HEC has been so successful and their own HEC not so. For this reason, I would like to propose and briefly explain a different reaction. I would like to propose that our response to this account should be that the Hermann HEC has gotten the idea of *ethics* all wrong and has thereby gotten itself exhausted by all the wrong sorts of cases and by otherwise misguided activity. In particular, the HEC's apparently single-minded devotion to hard or dramatic cases entails a misunderstanding of the true nature of moral decisionmaking and the true nature of moral character.

The way in which hard cases are not important moments of moral decisionmaking can be illustrated in reference to the now familiar principles of bioethics. It is fair to say that many, if not most, bioethicists think that the following precepts provide important moral guidance in the practice of healthcare: [1] that the autonomy of patients should be respected; [2] that healthcare professionals should do the patient no harm; [3] that healthcare professionals should benefit the patient or act in the patient's best interest; and [4] that patients should be cared for in a manner that is fair and equitable to all. These principles of autonomy, non-maleficence, beneficence, and justice constitute, for most, the broad conceptual framework for the moral navigation of healthcare. But imagine how this framework might look or operate if our understanding of these principles were based solely on hard cases.

Take, for example, the principle of patient autonomy. Suppose that a colleague asks: "What exactly does it mean to properly respect the patient's autonomy?" We might attempt to provide some practically useful meaning to this principle by presenting to our colleague a very complicated case involving a patient expressing very contrary wishes regarding treatment at different times in the course of her care, and all of this occurring in the context of possible duress and lapses in decisional competency. Such a case would not, however, provide any positive contribution to our colleague's understanding of this important moral principle. On the other hand, we might attempt to answer our colleague's question by presenting a clear and simple case involving a patient who has always been her own master, who remains in full command of her decisionmaking abilities, who is fully and

truly informed of her condition, and who is deciding on treatment (or not) in a way that is obviously within the boundaries of reasonable judgment. In this case, we have given our colleague the practical, factually-specific benchmark (or paradigm) needed to make use of this moral principle. That is, this clear and simple case establishes that the principle of autonomy, as a binding moral duty, is all about respecting the wishes of a patient in *this* kind of circumstance. Thus, in cases similar enough to this clear and simple case, we remain bound by this same duty, whereas in other cases not so similar to this clear and simple case we may not be so bound.

All general criteria for proper moral decisionmaking must be understood *first and foremost* in terms of clear and simple cases. The hard cases tell us only that at times, there can be reasonable disagreement among reasonable decisionmakers as to what is morally permitted or required. The hard cases tell us only that "at times, it's hard to tell what to do!" This, I would maintain, is no great moral insight. If we were to generalize this insight and apply it to all cases, we would be left with virtually no moral compass.

When Hermann's HEC met on Landon Sparks' case, the chairperson's remark about the difficulty of the case elicited from a physician-member the comment: "[e]thical questions by their very definition have no solutions" (p. 245). Here is obviously a moral decisionmaker raised only on hard cases. If these questions have no solutions, then why have an *ethics* committee? Or, if a HEC exists by force of bureaucratic habit, then why bother going to it for guidance in moral decisionmaking? My point is that ethical questions do have definite solutions in *some* instances at least. A HEC has to be well versed in the clear and simple cases in order to be able to offer any proper guidance in other instances. And HECs become well versed in the clear and simple cases — the benchmarks of moral reasoning — by paying close attention to the play of facts that make these cases *morally* clear and simple.

This brings me to the final misunderstanding operating as an assumption in Belkin's book. Just as hard cases are not necessarily important moments in moral decisionmaking, hard cases do not necessarily reveal or form moral character. Morality, as the good character of decent people, does not normally make for good drama. Accordingly, if you focus on the dramatic in the everyday life of any institution, you probably have missed the real workings of the moral life in that institution. Heroic figures might be found in dramatic events, but men and women of ordinary moral decency are found in everyday decisions. Belkin apparently wanted heroes

for her story and went looking for a heroic HEC in a series of hard cases and "impossible decisions."

Unfortunately, we never see the HEC do the little things that might help form its members, and others, into ordinarily decent healthcare professionals. For example, we never see the HEC engaged in sessions of self-education and moral reflection. We never see the HEC's members learning to have perspective, or learning to be sensitive to the right kind of facts, or learning to spot their own biases in the recounting of experiences, or learning to have confidence in their own fallible moral judgments, or learning to be a moral community. None of this is very dramatic. This aspect of moral life takes too long and develops in too subtle a manner to be dramatic. Thus, the hard cases of healthcare do not tell us much about the general moral well-being (or lack of moral well-being) in health care.

In *First, Do No Harm,* Lisa Belkin does not invent the tendency of our culture to expect the drama of an event to increase its moral significance. It is, however, our loss that she was not able to put her splendid talents as a reporter to the service of a better set of assumptions about what is important in health care and about what is central to healthcare ethics. It would itself be too dramatic to say that Belkin's failing harms the cause of health care and healthcare ethics. It is, however, fair to say that Belkin missed the opportunity of showing how all the clear and simple cases, as well as the little things in the everyday practices of healthcare, are what *really* make the moral difference.