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“But How *Can* We Choose?”

Richard M. Zaner

Richard M. Zaner, PhD, is Ann Geddes Stahlman Professor Emeritus of Medical Ethics and Philosophy of Medicine at Vanderbilt University Medical Center in Nashville, Tennessee, rzaner@houston.rr.com. © 2005, *The Journal of Clinical Ethics*. All rights reserved.

I had been at Vanderbilt only a short time when I was asked by one of the physicians in the Maternal-Fetal Unit to consult on what was said to be an “abortion” problem — a consult that has stayed with me for many years.¹ A 22-year-old married woman, I was told, a Mrs. Judy Nelson, had been referred by her own obstetrician (OB) for evaluation and management of her first pregnancy, which was thought to be problematic because of an ultrasound (US), although the obstetrician was unsure precisely how to read the several USs she had performed. Mrs. Nelson’s pregnancy was thought to be about 22 ± 2 weeks gestational age.

Physicians and specialists in our Maternal-Fetal Unit confirmed the estimated fetal age. They also noted a myelomeningocele, however, along with possible ventricular dilatation — “spina bifida” with patent spinal lesion and protrusion. Presumably, Mrs. Nelson’s OB had actually seen something, enough to refer her to our unit, although uncertainty made her reluctant to tell her patient very much.

Informed of these results, the woman was also told that the radiologists couldn’t be “completely certain” of many aspects of that diagnosis; for greater accuracy, serial USs — several taken over a week or so — would be needed to determine whether, beyond the spinal protrusion, the apparent hydrocephalus was growing worse with time.

In any event and in light of their diagnosis, Mrs. Nelson was told, by the maternal-fetal specialist who had taken on her case, that she faced several options. On the one hand, she could “continue with the pregnancy,” but that, if developing hydrocephalus were to become clear, there was a “real chance” that she would likely have to undergo a c-section. When she asked why that might happen, she was told that the fetal head size might preclude vaginal delivery.

Clearly stunned by this news, she was immediately informed that there was another option: “abortion,” described as a “therapeutic option.”

“What do you mean, ‘abortion’?” she demanded.

A bit taken aback by her tone and demeanor, the physician — he told me how he felt, later when he asked for the consult — tried to point out, “Well, you see, if what is described as . . .”

“‘Described as?’ what in the world does *that* mean?”

“Well, you see, if you’ll just give me a chance to say it, . . .” As he said to me, he was at once confused by her insistent questions, and beginning to get a bit nervous over what she was really trying to say to him. It seemed pretty evident to him, he told me, that she was already quite upset, and she seemed to be getting ever more angry.

“So, say it, then: what is this all about? I mean, there I was, all happy and warm and, my baby on the way,

and then I'm told to just come here and see what's going on, and I don't know what that's all about. . . ."

"What it's all about is that our ultrasound techs have seen what they believe is spina bifida, and I understand that they talked with you about what that is, what it means, and so on."

"Sure," she said, "they talked about that, and they mentioned that other thing, that hydro thing. . . ."

"Hydrocephalus."

"Right, that, and, well, then, you come along and talk about 'described as,' and 'there's a chance,' and then talk about abortion. . . ."

As the physician continued on, more carefully, more gently, so he told me, to tell her about why there may be a need to abort, and that the gestational age of her fetus was rapidly approaching the "cut-off" date, she only grew more and more agitated. As he saw it, he told me, when he pointed out that "state law prohibits abortions after 24-weeks gestation" — without, he added, a documented threat to her own life — she just "exploded."

"What exactly made you think she was 'exploding'?" I asked when we first discussed the consult.

"I don't know what else you'd call it," he explained. "I mean, she grew red in the face, her voice escalated way up the scale, and she, well, she just exploded — no other word for it."

She was of course rapidly approaching that cut-off date; in fact, if serial ultrasounds were performed, she might well go beyond the date before "developing hydrocephalus" could be confirmed or disconfirmed. It was, I should add, at just this point that the physician had backed off from what he took to be "real anger" at him, telling her that he would get "someone" to talk with her. So, there she sat, by herself in the so-called "quiet room," waiting for "someone" to explain everything — hopefully, it was clear to me, also to help her calm down.

One other thing was mentioned just as I was about to take off to see her.

"I also pointed out," he said, "that an alpha-fetoprotein test might be helpful, with results known within a day or so — still well within the time left before the cut-off date."

"Was it done?"

"Well, sure, of course, we had to do it, you know?"

"So, okay, then, but what results?"

"Don't know yet, but they should be back today sometime."

The test had been done, and she was at this moment awaiting both me and the results. So I had to be sure not to get ahead of the tests, but still, I had to begin to address what needed attention.

In fact, when I got to her room, someone, a nurse as I recall, was already there, and she and Mrs. Nelson were already talking about the alpha-fetoprotein (AFP) test results. I waited in the hall for a few moments, until the nurse came out. The nurse saw me and told me that she had informed Mrs. Nelson that the AFP was positive for a neural-tube defect. She also pointed out that she made a point of telling Mrs. Nelson that results from these tests were not 100 percent certain. Indeed, the nurse had emphasized that test results show a "statistically significant" number of false positives (as well as false negatives).

"You know, she is really upset, that Mrs. Nelson," the nurse told me.

"What do you mean?"

"I mean she is upset; I'm not even sure she understood what I told her."

So, I stepped into her room, noted her husband was also there, and introduced myself to them. I was met with both glares and tears. Clearly agitated, they nevertheless seemed quite willing to talk with me.

"Anything," she said straight off, "anything that can help clear up this mess."

"Mess?"

"I don't know what else you'd call it," she said. "I mean, what is this, can't anybody be straight about this? I thought that coming here and seeing all these specialists, so-called, I'd get some answers. But all I get is 'maybe this' and 'maybe that,' and 'perhaps,' and, my lord, nothing straight, all these dodges, all this 'we're not sure' and. . . ."

"Whoa," I broke in. "Maybe, Mr. and Mrs. Nelson, we'd better try and see what's been going on, what you've been told, why you're so angry."

Talking with the couple, I noted she was obviously agitated, anxious, and angry, as was he, although not as much. But not at the doctor. I first told them that my role was to help them to think carefully about their situation in light of their own beliefs, and for that I had to listen to what they had to say.

They obviously understood matters quite well. They knew, for instance, that if the pregnancy continued, and hydrocephalus were severe, there was a "good chance" that labor might have to be induced before full term, probably by cesarean section (because of fetal head size), with neonatal care thereafter: shunting the hydrocephalus, surgery to close the spinal lesion, ventilator assistance, et cetera.

"You rarely find such clarity or intelligence," I thought to myself. Still, there was something else bothering them. She asked, "How in the world can we decide what to do? The doctor just doesn't understand what it's like for us. It's not that we are opposed to abortion, but what if the tests are wrong, and there is nothing wrong with our baby? But if the tests are right, and we don't abort, that's not right, either; it's just not right to bring a baby into the world with all that going against it! Put yourself in our shoes: we know we've got to decide, but it's just not fair to ask this when things are not clear!"

The "problem" was clearly not "abortion," for them or for the physician. As evident as it was compelling, the issue posed a harsh dilemma for them. Any decision they could make would be irreversible (even not deciding would soon be set in stone, with the 24-week date coming up so soon), yet could only be based on information that was at once uncertain and not a little confusing.

"How," Mr. Nelson blurted out, "can anybody be asked to make such a decision when the tests could be wrong?"

His wife asked, "But how can we decide to continue with the pregnancy if the tests are right? I know they're only trying to do their best," she continued plaintively, "but the way they talk, we don't know what to think. Once we've decided, we can't 'undecide,' and the basis for it is just not certain enough for that kind of decision. For that, you ought to be able to be more certain!"

My observation, given as gently and sincerely as I could, went something like this: "Isn't moral life like that? Most often very critical matters have to be decided when we're not entirely sure either of the basis or the consequences." My opening remark was received, I must say, with understanding, but anguish as well. We also probed the options if the pregnancy were continued and the baby did have patent spina bifida, as well as the other possibilities if it did not, or if the spinal lesion were minor (an almost normal baby). The important thing was for them to be very clear that they really had thought about each of the possibilities as thoroughly as they could at this time, so that in the aftermath of no matter what decision they made, they would be less likely to berate themselves with thoughts of "if only we had . . ." — that is, experience subsequent guilt, anger, and resentment.

"You mean," Mrs. Nelson responded, "that all we can do is just decide, even if it turns out we're wrong?"

"No," I said, "perhaps it means that you have to try and figure out just what they're telling you about the US and the AFP test: they said there is a 'statistically significant chance' that the AFP was a 'false positive,' and that the radiologists were '75 percent confident' of their interpretation."

"But what does all that mean?" Mr. Nelson asked.

"Well," I responded, "if 'statistically significant' is translated, it means something like, oh, maybe 3 to 5 percent."

"What?" she broke in, "doesn't that mean that there is a 95 percent to 97 percent chance the test is *right*?"

"Not only that," I responded. "The radiologists think their reading is very likely correct — three out of four chances. Put that together with the AFP test: both are more likely correct than not."

I have obviously shortened the actual conversation. I should mention, too, that an equally key part of this consult focused on the physicians (and nurses). It was important, after all, to stress how the couple had interpreted the statistical formulation of uncertainty, and to be very clear about the basic moral issue they faced.

This situation involved a relationship among different persons, each with their own experiences and interpretations. The sense of that relationship became apparent contextually. Although textured by their

different feelings and thoughts, each of the individuals felt caught up in a kind of perilous adventure. Their respective involvements had the sense of uncertain and forbidding paths and eventualities, of a troubling trial or test. To listen to the wife's words, for instance, was to be immediately alerted to hazards faced by her baby and by them; alerted as well to their sense of alarming inability to know what to do. Implicit in the equally passionate words of the doctor about their "anger" was also an alert — "Watch out when you're dealing with this couple, for they are given to anger" — and a clear warning that, since abortion was the presumed "problem," one needed to be on guard for the well-known controversies that abortion always provokes.

Mr. and Mrs. Nelson's various conversational and physiognomic expressions were thus marked at the outset with harbingers of possible pitfalls and precarious risks. But there was more to it. Their poignant plea for help in understanding things and reaching a decision, for instance, made their sense of vulnerability quite prominent. Though *they* had to make the decision, they yet had to trust *others* — the doctor and the radiologists — for vital information without which no right, good, or just decision could be made. The doctor, on the other hand, was both cautious yet impatient — which may account for the Nelson's sense that he was trying to "push" them to abortion. Yet he was confident that the diagnosis was correct, and he was in fact somewhat disturbed that things were not immediately obvious to the couple.

That peculiar mixture of caution and impatience was, doubtless, communicated to the couple. It certainly became a permanent part of my own understanding of the complications implicit to clinical life. Too, it may well have been responsible for their reactions, which were seen by the doctor as "anger" toward him, and even for their sense that "the doctor just doesn't understand what it's like for us." This relationship thus turns out to be fundamental to apprehending the moral dimension of such encounters.

Of course, something inevitably falls out of this for any clinical ethics consultation. What Arthur Frank says, rightly I think, about illness narratives, or what he terms "telling-illness," is also true for those of us who tell stories, not about our own illness, but about those suffered by others.² To undergo illness is to undergo an uprooting of the natural attitude — that quiet, unquestioning acceptance of "things as they are," which Schutz insisted is fundamental to social life.³ In Frank's compelling words: "The loss of the taken-for-granted world — being wrenched out of the natural attitude and facing the fundamental anxiety of death — induces panic, in the mythic sense of unexpectedly encountering the terrifying god who screams in despair."⁴

The issue of every consultation, I am led to conclude, is extraordinary caution, for what illness always bodes — more in its serious forms, of course — is the shattering of the ill persons' world. It is also an appeal to others, the consultant in particular, to help in re-moralizing, in normalizing, what has been shattered. And this — I think Frank is right — means understanding, listening to those who are sick as they talk their way in and through their circumstances, thus recognizing the need to help "create conditions for [stories] to occur."⁵

Like many clinical encounters, this situation was remarkable for the range of passionate feelings (wishes, aims, hopes, et cetera.) that were variously expressed by the main characters. These feelings reveal remarkable significance. In the first place, the feelings that were manifested were evoked strictly by the fetus's condition (and to a lesser degree, the parents'), were directed to the fetus as "now presented," and were aimed at the range of possible future prospects (as efforts to "do something" for the fetus and the parents). In this complex sense, the feelings were *oriented* expressions of moral concern: efforts to do the right thing, to be good people, and to act fairly as regards everyone concerned. They were efforts to be responsive to the present (the now-presented and -diagnosed fetus) and responsible for the future (the fetus and themselves as parents, whether the aftermath was an abortion or an impaired infant).

In the second place, Mrs. Nelson at one point exclaimed: "The doctor just doesn't understand what it's like for us!" In almost the same breath, she seemed to plead with me: "Put yourself in our shoes: is it right to force a baby to be a hero just to stay alive . . . ?" Which was also meant for the doctor, of course: to understand "what it's like for us," he and I needed to put ourselves in the Nelson's shoes.

Not to belabor the obvious, Mrs. Nelson was urgently asking the doctor at once *to understand* and, more importantly, *to be understanding*. I'll never forget this sense as they conveyed it to me; how powerful it was, how heart rending, how difficult it was for them to face the irreversibility of what they knew was necessary

yet could hardly, if ever, be justified. Is an ethics that truly takes account of uncertainty possible? Can it be anything else?

For that matter, and more personally, I was left with a strong sense of my own vulnerability in the face of such uncertainty. I know I've often used the words, thinking I knew what they really meant: we've got to have an ethics that is responsive to the realities of genuine uncertainty, vagueness, not knowing what seems necessary in order to decide, much less to act. But do I understand? I know that the Nelsons brought home a sense that, in truth, I probably didn't understand, even while I know, too, that they were grateful for this chance to talk, to open up, to share their own vulnerability. And so, I'm left with this — what shall I call it? — this sense of my own not knowing, not really, just what is best, for them, or for me.

NOTES

1. All characteristics that might identify any person, except myself, in this narrative have been altered to protect privacy.

2. A. Frank, "Experiencing Illness through Storytelling," in *Handbook of Phenomenology and Medicine*, ed. S.K. Toombs (Dordrecht, the Netherlands: Kluwer, 2001), 241.

3. A. Schutz, "Symbol, Reality and Society," in *Alfred Schutz: Collected Papers I*, ed. M. Natanson (the Hague, the Netherlands: Martinus Nijhoff, 1971), 287-356.

4. See note 2 above.

5. *Ibid.*, 243.